Practical and Ethical Issues Involved in Decisions About Life-Sustaining Treatments in Older Patients

Lesley Kenyon Bowker BM, MRCP

Doctor of Medicine

Faculty of Medicine

October 2001
Life-sustaining treatments such as cardiopulmonary resuscitation (CPR) have become widely available in the developed world in the last thirty years. The low success rate for these procedures as well as the burden on the patient, the family and the medical service has led to debate about the appropriate use of resuscitation. Further debate arises around who should be making such decisions and what criteria should be used.

Probability of a successful outcome is a major factor in CPR decisions. A retrospective study of a consecutive set of patients (n=264) undergoing CPR revealed that pre-arrest factors measured by three different morbidity scores can accurately predict a subset of patients for whom CPR attempts are futile. These morbidity scores have low sensitivity but high specificity.

Whilst there is widespread acceptance that the patient's views about CPR should be sought there is little evidence about patient’s opinions. Three different populations of elderly patients (mixed medical inpatients n=214, patients in the community following an admission with stroke n=100 and inpatients with acute stroke n=60) were interviewed to determine which life-sustaining treatments they would accept/refuse. Inclusion rates for the hospital-based studies were low (36%, 75%) because many inpatients were physically or mentally unable to participate in decisions about CPR. Patients had poor knowledge of techniques and success rates of CPR and following education around 10% refused CPR who had previously accepted it. The acceptance rate for CPR in the three groups was 60% to 82% for CPR, and 60% to 72% for artificial feeding. A significant number of patients had changed their minds about CPR between admission and follow-up at discharge from hospital (16%), or in the community (17%). Although competency rates were higher at follow-up this factor alone could not account for changes in view about CPR. There was no significant relationship found between age, sex, disability or quality of life and wish for CPR. Eight qualitative interviews were carried out which allowed a more detailed investigation of the influences and reasoning behind CPR decisions.

Advance directives are advocated as a means of improving patient involvement in CPR decisions. A questionnaire revealed that General Practitioners are often ignorant of their legal status. Only 70% of inpatients questioned following stroke were competent to complete an advance directive. During the qualitative interviews patients revealed several reasons why they were reluctant to complete advance directives.

The findings of this thesis are discussed in the context of the rapidly and continuously evolving fields of medical science, social values and the law.
List of Contents

Page
i Title page
ii Abstract
iii List of Contents
ix List of Tables and Figures
xiii Preface
xiv Acknowledgments
xvi List of Abbreviations
xvii List of Publications

Page Section Title
1 Chapter 1. Literature Review

2 1.1 The Scientific, Ethical and Legal Background of Medical Decisions about Life-sustaining Treatment

2 1.1.1 The Medical Science of Life-sustaining Treatment

5 1.1.2 Ethical Background

5 1.1.2.1 Ethics

6 1.1.2.2 Medical Ethics

11 1.1.3.3 Medical Ethics and the application of life-sustaining treatments

13 1.1.3 Historical and Currant Legal Situation Regarding Limitation of Treatment

13 1.1.3.1 The United Kingdom

20 1.1.3.2 Australia

20 1.1.3.3 The United States of America
<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>1.2</td>
<td>Survival after CPR and prediction of outcome</td>
</tr>
<tr>
<td>24</td>
<td>1.2.1</td>
<td>Outcome After Attempted CPR</td>
</tr>
<tr>
<td>24</td>
<td>1.2.1.1</td>
<td>Survival rates</td>
</tr>
<tr>
<td>27</td>
<td>1.2.1.2</td>
<td>Quality of survival</td>
</tr>
<tr>
<td>31</td>
<td>1.2.2</td>
<td>Factors That Predict Outcome after CPR and Morbidity Scores</td>
</tr>
<tr>
<td>31</td>
<td>1.2.2.1</td>
<td>Peri-arrest and post-arrest factors</td>
</tr>
<tr>
<td>33</td>
<td>1.2.2.2</td>
<td>Pre-arrest factors</td>
</tr>
<tr>
<td>36</td>
<td>1.2.2.3</td>
<td>Morbidity scores</td>
</tr>
<tr>
<td>42</td>
<td>1.3</td>
<td>Perceptions of Patients, Relatives and Health Care Workers Regarding the Appropriate Application of Life-Sustaining Treatments</td>
</tr>
<tr>
<td>43</td>
<td>1.3.1</td>
<td>Patients’ Perceptions</td>
</tr>
<tr>
<td>43</td>
<td>1.3.1.1</td>
<td>Wishes for resuscitation</td>
</tr>
<tr>
<td>49</td>
<td>1.2.1.2</td>
<td>Factors predicting patients’ wishes for CPR</td>
</tr>
<tr>
<td>52</td>
<td>1.3.1.3</td>
<td>Qualitative studies of patients’ views about CPR</td>
</tr>
<tr>
<td>58</td>
<td>1.3.1.4</td>
<td>Patients’ knowledge about CPR</td>
</tr>
<tr>
<td>59</td>
<td>1.3.1.5</td>
<td>Patients’ views on who should make decisions about resuscitation</td>
</tr>
<tr>
<td>63</td>
<td>1.3.1.6</td>
<td>Stability of patients’ views about CPR</td>
</tr>
<tr>
<td>65</td>
<td>1.3.2</td>
<td>Relatives’ Views on Resuscitation and Proxy Decision-Making</td>
</tr>
<tr>
<td>69</td>
<td>1.3.3</td>
<td>Health Care Professionals’ Views About CPR</td>
</tr>
<tr>
<td>71</td>
<td>1.3.4</td>
<td>How CPR Decisions Are Made in Practice</td>
</tr>
<tr>
<td>77</td>
<td>1.4</td>
<td>Advance Directives</td>
</tr>
<tr>
<td>78</td>
<td>1.4.1</td>
<td>Background</td>
</tr>
<tr>
<td>78</td>
<td>1.4.1.1</td>
<td>Definitions</td>
</tr>
<tr>
<td>81</td>
<td>1.4.1.2</td>
<td>Historical development of advance directives</td>
</tr>
<tr>
<td>82</td>
<td>1.4.1.3</td>
<td>Current legal status of advance directives in the UK, USA and Australia</td>
</tr>
<tr>
<td>86</td>
<td>1.4.2</td>
<td>Problems with Advance Directives</td>
</tr>
<tr>
<td>86</td>
<td>1.4.2.1</td>
<td>Availability of advance directives</td>
</tr>
<tr>
<td>86</td>
<td>1.4.2.2</td>
<td>The use of advance directives for rationing of resources</td>
</tr>
<tr>
<td>88</td>
<td>1.4.2.3</td>
<td>Stability of choice in advance decision-making</td>
</tr>
<tr>
<td>91</td>
<td>1.4.2.4</td>
<td>Competence to complete an advance directive</td>
</tr>
</tbody>
</table>
Chapter 2. What are the opinions of elderly inpatients’ about CPR?

- The Southampton Study

Chapter 3. Do morbidity scores predict outcome after CPR?

- The Winchester Study
<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>142</td>
<td>Chapter 4. Do General Practitioners in the UK know when living wills are legal?</td>
<td></td>
</tr>
<tr>
<td>143</td>
<td>4.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>145</td>
<td>4.2</td>
<td>Methods</td>
</tr>
<tr>
<td>146</td>
<td>4.3</td>
<td>Results</td>
</tr>
<tr>
<td>150</td>
<td>4.4</td>
<td>Conclusions</td>
</tr>
<tr>
<td>151</td>
<td>Chapter 5. What are the attitudes of patients following disabling stroke to life-sustaining treatments such as cardiopulmonary resuscitation (CPR)?</td>
<td></td>
</tr>
<tr>
<td>152</td>
<td>5.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>154</td>
<td>5.2</td>
<td>Methods</td>
</tr>
<tr>
<td>157</td>
<td>5.3</td>
<td>Results</td>
</tr>
<tr>
<td>157</td>
<td>5.3.1</td>
<td>Response rate and demographics</td>
</tr>
<tr>
<td>162</td>
<td>5.3.2</td>
<td>Wishes for life-sustaining treatment</td>
</tr>
<tr>
<td>162</td>
<td>5.3.3</td>
<td>Pre-education level of knowledge about CPR and affect of education on views</td>
</tr>
<tr>
<td>164</td>
<td>5.3.4</td>
<td>Determinants of CPR preference</td>
</tr>
<tr>
<td>165</td>
<td>5.3.5</td>
<td>Comparison of patients’ views with CPR status while in hospital</td>
</tr>
<tr>
<td>166</td>
<td>5.3.6</td>
<td>Views about relatives as witnesses to resuscitation</td>
</tr>
<tr>
<td>167</td>
<td>5.4</td>
<td>Conclusions</td>
</tr>
</tbody>
</table>
Chapter 6. In patients suffering an acute stroke, what is their level of competence to complete an advance directive and how stable are their decisions about life-sustaining treatment?

- The Australian Quantitative Study

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>171</td>
<td>6.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>174</td>
<td>6.2</td>
<td>Methods</td>
</tr>
<tr>
<td>177</td>
<td>6.3</td>
<td>Results</td>
</tr>
<tr>
<td>177</td>
<td>6.3.1</td>
<td>Proportion of stroke patients available for first interview</td>
</tr>
<tr>
<td>179</td>
<td>6.3.2</td>
<td>Views about life-sustaining treatment</td>
</tr>
<tr>
<td>180</td>
<td>6.3.3</td>
<td>Level of knowledge about life-sustaining treatment</td>
</tr>
<tr>
<td>182</td>
<td>6.3.4</td>
<td>Competency to complete an advance directives</td>
</tr>
<tr>
<td>185</td>
<td>6.3.5</td>
<td>Views and competency at follow up</td>
</tr>
<tr>
<td>192</td>
<td>6.4</td>
<td>Conclusions</td>
</tr>
</tbody>
</table>

Chapter 7. What factors influence patients’ opinions about CPR and end of life decisions?

- The Australian Qualitative Study

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>197</td>
<td>7.1</td>
<td>Introduction</td>
</tr>
<tr>
<td>199</td>
<td>7.2</td>
<td>Methods</td>
</tr>
<tr>
<td>201</td>
<td>7.3</td>
<td>Results</td>
</tr>
<tr>
<td>205</td>
<td>7.3.1</td>
<td>Informants’ views about resuscitation for themselves</td>
</tr>
<tr>
<td>206</td>
<td>7.3.2</td>
<td>Informants views about criteria for deciding about CPR</td>
</tr>
<tr>
<td>206</td>
<td>7.3.2.1</td>
<td>Quality of life</td>
</tr>
<tr>
<td>209</td>
<td>7.3.2.2</td>
<td>Age</td>
</tr>
<tr>
<td>211</td>
<td>7.3.2.3</td>
<td>Being a burden</td>
</tr>
<tr>
<td>212</td>
<td>7.3.2.4</td>
<td>Religion</td>
</tr>
<tr>
<td>212</td>
<td>7.3.2.5</td>
<td>Fate</td>
</tr>
<tr>
<td>213</td>
<td>7.3.2.6</td>
<td>Futility</td>
</tr>
<tr>
<td>213</td>
<td>7.3.2.7</td>
<td>The experience of illness</td>
</tr>
</tbody>
</table>
# List of Tables and Figures

<table>
<thead>
<tr>
<th>Item</th>
<th>Page</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a</td>
<td>Figure 8</td>
<td>The Hippocratic oath</td>
</tr>
<tr>
<td>1b</td>
<td>Table 18</td>
<td>Timetable of important events relating to limiting life-sustaining treatment in the UK</td>
</tr>
<tr>
<td>1c</td>
<td>Table 22</td>
<td>Legal framework for medical decision-making for incompetent adults in the United Kingdom and Australia</td>
</tr>
<tr>
<td>1d</td>
<td>Table 26</td>
<td>Survival rates after in-hospital CPR in the five major review papers</td>
</tr>
<tr>
<td>1e</td>
<td>Table 27</td>
<td>Summary of studies documenting brain damage following CPR</td>
</tr>
<tr>
<td>1f</td>
<td>Table 29</td>
<td>Summary of studies providing data on dependency and/or employment changes following successful CPR</td>
</tr>
<tr>
<td>1g</td>
<td>Table 38</td>
<td>The three morbidity scores</td>
</tr>
<tr>
<td>1h</td>
<td>Table 40</td>
<td>Clinical evaluations of morbidity scores</td>
</tr>
<tr>
<td>1i</td>
<td>Table 44</td>
<td>Surveys of patients’ willingness to undergo CPR in the UK</td>
</tr>
<tr>
<td>1j</td>
<td>Table 45/46</td>
<td>International surveys of patients’ willingness to undergo CPR</td>
</tr>
<tr>
<td>1k</td>
<td>Table 53</td>
<td>A comparison of qualitative and quantitative research techniques</td>
</tr>
<tr>
<td>1l</td>
<td>Table 61</td>
<td>Studies of patients’ views of who should decide about CPR – UK</td>
</tr>
<tr>
<td>1m</td>
<td>Table 62/63</td>
<td>International studies of patients’ views of who should decide about CPR</td>
</tr>
<tr>
<td>1n</td>
<td>Figure 79/80</td>
<td>An example of an advance directive</td>
</tr>
<tr>
<td>2a</td>
<td>Table 106</td>
<td>Diagnoses / reasons for admission for 214 patients interviewed</td>
</tr>
<tr>
<td>2b</td>
<td>Table 107</td>
<td>Answers to the three core questions</td>
</tr>
<tr>
<td>2c</td>
<td>Table 108</td>
<td>Comparison of preference for CPR for 118 patients at admission and discharge</td>
</tr>
<tr>
<td>2d</td>
<td>Table 109</td>
<td>Characteristics of patients 193 patients who expressed a preference for or against CPR</td>
</tr>
<tr>
<td>2e</td>
<td>Table 110</td>
<td>Decisive factors in subjects' CPR preferences</td>
</tr>
<tr>
<td>2f</td>
<td>Table 111</td>
<td>Characteristics of subjects favoring each type of decision</td>
</tr>
</tbody>
</table>
Definitions used for scoring morbidity scores
Details of 87 arrest calls excluded from the study
Structure of study
Age, sex and time to arrest for all patients and for survivors and non-survivors shown separately
Place of arrest and percentage of those who died who received CPR in different clinical areas of the hospital
Bar graph showing length of time to arrest for all patients divided into groups of those who survived and those who died after CPR
Mean morbidity scores for survivors and non-survivors
Histogram demonstrating PAM scores for survivors and those who died following CPR shown separately
Histogram demonstrating PAR scores for survivors and those who died following CPR shown separately
Histogram demonstrating MPI scores for survivors and those who died following CPR shown separately
Outcome for patients above and below the derived morbidity score 'cut offs'
Sensitivities of morbidity scores and combinations of scores in predicting death after CPR
Venn Diagram to demonstrate the overlap in patient groups correctly identified as having unsuccessful CPR using the three different morbidity scores
Shows the fate of the 28 patients who were discharged alive
Histogram showing length of survival for 28 patients who survived to discharge after in-hospital CPR
Morbidity scores, age and time to arrest for 28 survivors divided into short-lived and long-lived groups
Kaplan Meier survival curve for patients who survive to discharge after in-hospital CPR
<table>
<thead>
<tr>
<th>Item</th>
<th>Page</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>4a</td>
<td>Figure 149</td>
<td>Bar chart showing the proportion of correct answers for the 104 GP's who answered questions 2 to 7</td>
</tr>
<tr>
<td>5a</td>
<td>Figure 158</td>
<td>Demonstrating the recruitment of 100 stroke patients</td>
</tr>
<tr>
<td>5b</td>
<td>Table 159</td>
<td>Details of the 226 exclusions from study</td>
</tr>
<tr>
<td>5c</td>
<td>Table 160/161</td>
<td>Characteristics of the study population in relation to their wish for CPR</td>
</tr>
<tr>
<td>5d</td>
<td>Table 164</td>
<td>The influence of educational material on patients’ wishes for CPR</td>
</tr>
<tr>
<td>5e</td>
<td>Table 165</td>
<td>Patients’ estimate of how their stroke had influenced their preferences for CPR</td>
</tr>
<tr>
<td>5f</td>
<td>Table 165</td>
<td>Comparison of patients’ preferences for CPR with their resuscitation status as recorded in medical notes at time of discharge</td>
</tr>
<tr>
<td>6a</td>
<td>Table 175</td>
<td>Information collected for each patient</td>
</tr>
<tr>
<td>6b</td>
<td>Table 177</td>
<td>Proportion of patients recruited to study and reasons for exclusion from study</td>
</tr>
<tr>
<td>6c</td>
<td>Table 178</td>
<td>Demographics and medical characteristics of all 60 patients</td>
</tr>
<tr>
<td>6d</td>
<td>Table 179</td>
<td>Views about life-sustaining treatment for all 60 patients</td>
</tr>
<tr>
<td>6e</td>
<td>Table 180</td>
<td>Characteristics of study population in relation to their wish for CPR</td>
</tr>
<tr>
<td>6f</td>
<td>Table 181</td>
<td>The effect of education about CPR on patients’ views</td>
</tr>
<tr>
<td>6g</td>
<td>Table 182</td>
<td>The patients’ estimate of how stroke had changed their views about CPR</td>
</tr>
<tr>
<td>6h</td>
<td>Table 182</td>
<td>The mean, median and range scores shown for both scenarios separately and for the Total competency score</td>
</tr>
<tr>
<td>6i</td>
<td>Figure 183</td>
<td>Scatterplot to show correlation of competency scores for the two scenarios</td>
</tr>
<tr>
<td>Item</td>
<td>Page</td>
<td>Title</td>
</tr>
<tr>
<td>------</td>
<td>--------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>6j</td>
<td>Figure 183</td>
<td>Histogram showing competency scores for all 60 patients in the study</td>
</tr>
<tr>
<td>6k</td>
<td>Table 184</td>
<td>Comparison of the competent and incompetent groups of patients</td>
</tr>
<tr>
<td>6l</td>
<td>Table 186</td>
<td>The level of knowledge and degree of planning about CPR and other life-sustaining treatments compared for the 51 patients who were interviewed twice</td>
</tr>
<tr>
<td>6m</td>
<td>Table 187</td>
<td>Comparison of patients views about CPR at first and second interview</td>
</tr>
<tr>
<td>6n</td>
<td>Table 188</td>
<td>Change in competency scores in those who changed their minds about CPR between the two interviews</td>
</tr>
<tr>
<td>6o</td>
<td>Table 188</td>
<td>Table to show how views about artificial feeding changed between the first and second interviews</td>
</tr>
<tr>
<td>6p</td>
<td>Figure 191</td>
<td>Bar chart to show the change in competency scores between the first and follow-up interviews</td>
</tr>
<tr>
<td>6q</td>
<td>Table 191</td>
<td>Change in competency between first and follow up interview</td>
</tr>
<tr>
<td>7a</td>
<td>Table 202</td>
<td>Informant characteristics</td>
</tr>
<tr>
<td>7b</td>
<td>Figure 203</td>
<td>Coding tree</td>
</tr>
<tr>
<td>7c</td>
<td>Table 204</td>
<td>The coding system developed and employed during the analysis of the qualitative interviews</td>
</tr>
<tr>
<td>8a</td>
<td>Table 245/6</td>
<td>Learning outcomes from the thesis</td>
</tr>
<tr>
<td>8b</td>
<td>Figure 257</td>
<td>A media-fuelled scandal about a DNR order</td>
</tr>
<tr>
<td>8c</td>
<td>Figure 273</td>
<td>A story about advance directives</td>
</tr>
<tr>
<td>8d</td>
<td>Figure 274</td>
<td>A portrait of death over two decades</td>
</tr>
</tbody>
</table>
Preface

This thesis brings together several discreet but related research projects that the author has conducted throughout her postgraduate junior doctor career. All the work was undertaken alongside full time clinical commitments at senior house officer, registrar, senior registrar and finally senior lecturer levels. The site of the work has therefore followed training jobs in several different centres ranging from Winchester in Hampshire to Perth in Australia. The chapters are arranged in chronological order and the final two chapters have yet to be submitted for peer-reviewed publication.
Acknowledgements

I gratefully acknowledge the assistance of the following in the preparation of this thesis.

Dr Kevin Stewart, Dr Sebastian Fairweather and Professor Leon Flicker for their overall supervision and guidance during my earlier years of research.

Professor Roger Briggs and Dr Bee Wee and my father (Mr Michael Bowker) for their help and advice in the preparation of the final manuscript.

Professor Mildred Blaxter for her generous contribution to my re-writing of the qualitative methodology and qualitative analysis sections.

Finally I am grateful to all the patients who so willingly agreed to share their views with me and without whom this thesis could never have been written.

Chapter 2
Dr Helen Roberts and Dr Peter Bruce-Jones conceived the Southampton project and designed the initial draft of the questionnaire. Dr Peter Bruce-Jones in conjunction with a research nurse performed the interviews at Poole Hospital and Dr Veneta Cooney assisted by performing some of the interviews at Southampton. Data analysis was a combined effort between Dr Peter Bruce-Jones, Dr Veneta Cooney and myself. We thank the consultant Geriatricians at both Poole District Hospital and Southampton General Hospital for allowing us to interview their patients.

Chapter 3
Dr Kevin Stewart supervised this project and helped with the data analysis and interpretation. The medical records department were very helpful in retrieving all the medical notes. Dr Adrian Wagg gave helpful comments on the study.
Chapter 4
Dr Susie Hayes and Dr Mike Gill conducted the questionnaire study in the Newham district. Donations from several different drug companies allowed us to purchase the BMA booklet that we distributed to those GPs who completed the questionnaire.

Chapter 5
The original questionnaire was adapted from one devised but never employed by Dr Sebastian Fairweather. Dr Tony Hope and Dr Jenkinson gave helpful advice on the questionnaire at the design stage. Dr Simon Winner kindly allowed me to use information from the Oxford Stroke Register for recruiting patients. Ms Gillian Jacobson, acting as a research nurse, conducted some of the patient interviews.

Chapter 6
Thanks to Dr Graham Hankey and members of his multi-disciplinary stroke unit team for allowing me to interview their patients.

Chapter 7
Dr Saras Henderson tutored me in qualitative research and was present at all the interviews. She also assisted with the conceptual coding of the interviews. We thank our typist for transcribing the qualitative interviews.
**Abbreviations**

AD  Advance Directive  
ALS  Advanced Life Support  
APACHE  Acute Physiology and Chronic Health Evaluation  
BLS  Basic Life Support  
BMA  British Medical Association  
COOP  The Dartmouth Primary Care Cooperative (COOP) chart (Nelson et al 1990)  
CPR  Cardiopulmonary Resuscitation  
DNR  Do Not Resuscitate  
DNAR  Do Not Attempt Resuscitation  
DASCAD  Decisional Aid for Scoring Capacity to complete a Directive (Molloy et al 1999)  
GDS  Geriatric Depression Scale (Sheikh and Yesavage 1986)  
GP  General Practitioner  
HCAT  Hopkins Competency Assessment Test (Janofsky et al 1992)  
LACI  Lacunar Anterior Circulation Infarct (Bamford 1991)  
MI  Myocardial Infarction  
MMSE  Mini Mental State Examination (Folstein 1975)  
AMTS  Abbreviated Mental Test Score (Hodkinson 1972)  
MPI  Modified PAM Index (Dautzenberg et al 1996)  
PACI  Partial Anterior Circulation Infarct (Bamford et al 1991)  
PAM  Pre-Arrest Morbidity Score (George et al 1989)  
PAR  Prognosis After Resuscitation Score (Ebell et al 1992)  
POCI  Posterior Circulation Infarct (Bamford et al 1991)  
RCN  Royal College of Nursing  
SIACAD  Screening Instrument to Assess Capacity to Complete a Directive (Clarnette and Molloy 1989)  
SF 12  Short Form 12 (Ware et al 1998)  
SUPPORT  Study to Understand Prognoses and Preferences for Outcome and Risks of Treatment (Teno et al 1995 and 1997)  
TACI  Total Anterior Circulation Infarct (Bamford et al 1991)  
UK  United Kingdom  
USA  United States of America
Publications

The following is a list of publications arising from the research reported in this thesis.

ABSTRACTS

Bruce-Jones P, Roberts H, Bowker LK and Cooney V
Resuscitating the Elderly: what do patients want?
Age and Ageing 1994;23(S2):14 (abstract)

Bowker LK, Wagg A and Stewart KS.
Morbidity scores predict futile cardiopulmonary resuscitation
Age and Ageing 1997;26(S1):8 (abstract)

Bowker LK and Stewart KS
Is there a difference between morbidity scores’ ability to predict futile cardiopulmonary resuscitation?
Age and Ageing 1997;26(S3):62 (abstract)

Stewart K and Bowker L.
Is there a difference between individual morbidity scores’ ability to predict death after CPR?
Journal of American Geriatric Society sppl 1997;45(9):96.F34 (abstract)

Bowker L, Hayes S, Gill M and Stewart K
General Practitioners (GP’s) knowledge of the current legal status of advance directives (Living wills)
Age and Ageing 1997;26(S3):80 (abstract)

Bowker LK and Fairweather DS
Attitudes of patients after disabling stroke towards life sustaining treatments
Age and Ageing 1998;28(S1):61 (abstract)

Lesley K Bowker, Sebastian Fairweather and Leon Flicker
Resuscitation preference and capacity to complete an advance directive immediately after an acute stroke Summer 00 - Platform
Journal of Internal Medicine - a publication of the RACP (will be 2002) (abstract)

Bowker L, Henderson S, and Flicker L
Elderly Patients’ Views about Life-Sustaining Treatments: A Qualitative Study
Age and Ageing 2001;30(S1):35 (abstract)

Spice C, Bowker L, Holland M, Gill M and Stewart K
Long Term Survival Following Cardiopulmonary Resuscitation (CPR)
Age and Ageing 2001;30(S1):35 (abstract)

Bowker L, Maher S, Fairweather D and Flicker L
Resuscitation preference and capacity to complete an advance directive immediately after an acute stroke – Spring 2001
Age and Ageing (abstract)
Bowker L, Maher S, Fairweather D and Flicker
Age and Ageing (abstract)

ORIGINAL PAPERS

Bruce-Jones P, Roberts H, Bowker LK and Cooney V
Resuscitating the Elderly: what do patients want?
Journal of Medical Ethics 1996;22:154-159

Bowker L, Stewart K, Hayes S and Gill M
Do general practitioners know when living wills are legal?

Bowker L and Stewart K
Predicting Unsuccessful Cardiopulmonary Resuscitation (CPR): A comparison of three morbidity scores
Resuscitation 1999;40:89-95

Spice C, Bowker L and Stewart K
Long-term survival after In-hospital Cardiopulmonary Resuscitation (CPR)
Resuscitation 2001;49(2):207-208

The following two papers have been written and are awaiting submission;

Attitude of Stroke Survivors to Cardio-Pulmonary Resuscitation (CPR)
Lesley K Bowker and D Sebastian Fairweather

Competence to complete an advance directive and stability of decisions about life-sustaining treatment in a group of patients following stroke
Lesley Bowker, Sean Maher and Leon Flicker

REVIEWS

Stewart K and Bowker L
Advance Directives and Living Wills
Postgraduate Medical Journal 1998;74:151-156
LETTERS

Stewart K and Bowker L.
Resuscitation witnessed by relatives - Might lead to a breach of confidentiality.

British Medical Journal 1997;314:145

Stewart K, Bacon M and Bowker L.
Patients with untreatable cancer almost never survive cardiopulmonary resuscitation.

British Medical Journal 1998;316:1166

Bowker L and Bruce-Jones P.
Hospital admission and opinions of cardiopulmonary resuscitation.

Age and Ageing 1998;27:545-546

Stewart K, Bowker L, Hayes S and Gill M.
Only half of GP’s in study knew that advance directives could carry legal weight in the UK.

British Medical Journal 1999;318:123

Bacon M, Stewart K, Bowker L.
CPR decision-making by elderly patients.

Journal of Medical Ethics 1998;24(2):134

CHAPTERS IN BOOKS

Bowker L, Price C, Stewart K and Rai GS
Chapter 58: Ethical dilemmas in Elderly Care
In; Ratnaike RN: Practical Guide to Geriatric Medicine
Mcgraw-Hill 2001
Chapter 1.1

The Scientific, Ethical and Legal Background of Medical Decisions about Life-sustaining Treatment.

resuscitate, v. 1. *trans.* To restore (a person) to life (physical or spiritual) or to consciousness. 2. To revive, renew, restore (a thing). 3. *intr.* To revive, to come to life again. Hence

resuscitating *vbl.* *n.* and *ppl.* *a.*

1.1.1 The Medical Science of Life-sustaining Treatment

Although the art of medicine is ancient the development of techniques to support life beyond a stage where death would normally occur, and even to revive the recently dead, are very modern (De Bard 1980). It surprises most people that the first paper to describe cardiopulmonary resuscitation was written in 1960 (Kouwenhoven et al 1960).

Cardiopulmonary Resuscitation (CPR)

Mouth to mouth expired air ventilation was first described in the eighteenth century, but less effective manual methods of ventilation such as rocking the patient were popular until 1958 when mouth to mouth was proven to be the superior method. Although closed chest cardiac massage had been used successfully in animal experiments open chest massage, where the chest was opened and the heart compressed directly, was felt to be the only effective method until 1960.

Defibrillator machines were developed using funds supplied by an electricity company that were concerned by deaths due to electrocution in its linesmen. Human internal defibrillation was used in 1947 and external defibrillators began to be used in 1956. Four years later Kouwenhoven et al (1960), published his seminal paper in which he described the combination of external chest compression with mouth to nose respiration and defibrillation in 20 patients, 14 of whom survived.

Recent refinements to this technique include the introduction of drugs such as adrenaline, early intubation for artificial ventilation, a shift from alternating current to direct current defibrillation and changes to the rates and ratios of chest compression and respiration. Lignocaine, a membrane stabilising drug that was used extensively in the 1980s was largely abandoned in the late 1990s due to evidence that it actually increased mortality rates (McGowen et al 1999).

A distinction is drawn between basic life-support or BLS (which includes diagnosis of cardiac and or pulmonary arrest, mouth to mouth ventilation and chest compressions) and advanced life support (ALS). ALS includes basic life-support, electrocardiographic (ECG) monitoring, rhythm identification and restoration of haemodynamic stability through intubation, defibrillation and pharmacological therapy. Basic life-support maintains the flow of oxygenated blood to vital
organs. Sometimes it is successful in isolation but usually it just ‘buys time’ until definitive treatment (eg treatment of an arrhythmia) can be instituted (Thel et al 1999, European Resuscitation Council Guidelines 1998). Due to the requirement of special training and equipment ALS is only commonly available in hospitals and from certain ambulance crews. In contrast BLS can be provided in any environment by anyone with rudimentary training.

Resuscitation is now a well-established procedure in all hospitals. Between 10% to 57% of patients who die in hospital will have received CPR prior to death (Saklayen et al 1995, van Delden et al 1993). Assuming that death is inevitable following cardiac arrest without CPR, it has been calculated that CPR reduces hospital mortality by around 6% (DeBard et al 1981).

There are two major CPR councils (The European Resuscitation Council and The American Resuscitation Council) which coordinate research and produce and update protocols. There is also an International Liaison Committee on Resuscitation. In order to collect comparable data from different centers on outcome after CPR there is now a set of guidelines on uniform reporting called the ‘Utstein Style’ (European Resuscitation Council Guidelines 1998, Cummins et al 1997).

The science of CPR is still evolving mainly through animal research since studies on humans are rare because of consent and ethical problems (Thel et al 1999). The European Resuscitation Council Guidelines (1998) changed the rate of chest compression from 60/minute to 100/minute. More recently the advised ratio of breaths to chest compressions has changed from 1:5 to 2:15. Drug treatment is also constantly evolving.

Training in CPR
In 1982 the United Kingdom Resuscitation Council was formed to foster improved knowledge and practice of CPR (Tunstall-Pedoe et al 1992). There was concern that doctors performed CPR poorly and were inadequately trained (Chin et al 1997). Since then several strategies have been introduced. There are national guidelines on both BLS and ALS and nationally standardised courses are used to train and assess proficiency. Medical students are now trained in resuscitation and most junior doctors hold ALS certificates after passing the assessments during a two-day intensive training course. Practical testing of resuscitation skills is now included in the Membership of the Royal College of Physicians examination (Chin et al 1997) and many hospitals undertake regular training of all staff as part of their risk management strategy. Most
hospitals in the UK now employ a resuscitation training officer to coordinate training and promote excellence in CPR. There is one study, which provides some limited evidence that patient mortality may be influenced by such appointments (McGowen et al 1999).

In the last decade there has been an effort to train large cohorts of the public in basic life support in the UK and Australia although there is evidence that retention of techniques is poor. In one study only 12% of subjects tested six months after a training course were able to demonstrate effective CPR (Morgan et al 1996). It is likely that frequent retraining is required to maintain a good standard of CPR in both health care workers and general public volunteers (Morgan et al 1996, Chin et al 1997).

Other Life-Sustaining Treatment
The growing role of CPR has paralleled the growth in other areas of technological medicine such as haemodialysis, artificial ventilation and intensive care units. Artificial feeding methods which include nasogastric tubes and surgically placed gastrostomy tubes are also being used with increased frequency. Although a nasogastric tube is hardly 'high technology' it is still life-sustaining for patients whose poor nutritional status would previously have led indirectly or directly to their death.

More subtle changes in medicine and society include the increasing admission rate for the frail elderly to the hospital environment where they get skilled nursing and access to modern diagnostic and therapeutic interventions. Simple medical treatments such as intravenous antibiotics for pneumonia or surgical fixation of femoral fractures must have a large but unmeasured impact on mortality.

The Cost of CPR and Life-Sustaining Treatment
The provision of CPR services is not cheap. In America, where patient billing makes cost analysis easier, Berger and Kelly (1994) estimated that it costs $63,000 per life saved for in-hospital CPR. In their analysis of the ‘Economics of Dying’ Emanuel and Emanuel (1994) report that 27% -30% of Medicare payments each year are for the 5 – 6% of beneficiaries who die in that year. Payments for dying patients increase exponentially as death approaches and payments during the last month of life constitute 40% of payments during the last year of life. See section 1.4.2.2 for a discussion of the role of advance directives in cost-limitation.
1.1.2 Ethical Background

1.1.2.1 Ethics

Ethics may be defined as “the study of rational processes for determining the best course of action in the face of conflicting choices” (Royal Australian College of Physicians' Ethics Manual). Ethical choices necessarily involve value judgements rather than scientific fact. Since society consists of individuals who differ in their personal visions of right and wrong, conflict of opinion is inevitable. Social organisation, however, relies on some shared fundamental beliefs which dictate a code of conduct.

There are many different schools of thought within philosophical ethics but the two commonest are:

a) Consequentialist Ethics

This is also known as Teleological ethics or Utilitarianism. In its simplest form an ethically correct action is one that maximises good/happiness and minimises harm/misery. In this system actions are evaluated in terms of whether the consequences satisfy all those affected by the action i.e. "the greatest good for the greatest number". Unlike deontological ethics it allows for actions that would normally be seen as immoral as long as the outcome is good i.e. "the end justifies the means". For example murder is justified during war and euthanasia can also be justified provided the act is done with good intention.

b) Deontological Ethics

In this system of thinking rules or codes dictate behavior. The Ten Commandments in Christianity provide an example of Deontological values, and actions are judged by whether they conform to these laws regardless of the outcome. The principles underlying the rules do not necessarily come from God e.g. the ‘law of nature’ is theoretically derived from observation of the natural world. Kant was a Prussian philosopher who attempted to define a “supreme moral law” which gives intrinsic moral worth to human beings and dictates that they should be treated by others in the same way as they treat themselves. Unfortunately such ethical ‘laws’ often conflict with each other (e.g. see principle of double effect) and there are few laws which are applicable under all circumstances (e.g. it may be permissible to kill at times of war).
Whilst these two systems of thinking are not mutually exclusive they do not always give consistent guidance and ethical debate can often be broken down to analysis of the importance of each argument.

1.1.2.2 Medical Ethics
Doctors are bound by the same ethical codes as the rest of society. In addition, due to their influence over morbidity and mortality of other people, they have always had a particular duty to behave ethically. Doctors appear to have “special, supererogatory, moral obligations to their patients – that is, moral obligations that are over and above the ordinary moral obligations we all have to each other” (Gillon 1985).

Medical ethics has been defined as “the analytic activity in which the concepts, assumptions, beliefs, attitudes, emotions, reasons and arguments underlying medicomoral decision making are examined critically” (Gillon 1985).

There are four moral values that are particularly pertinent to medicine. Beauchamp and Childress (1989) are usually credited in outlining them first, but they are ancient principles that can be traced back to early philosophy.

a) Autonomy
This is the right of patients to think and decide freely and independently. Kantian philosophy argues that respect for autonomy is a logical feature of being a rational agent and that an individual’s right to exercise autonomy is limited by respect for the autonomy of other rational agents (Gillon 1985).

b) Beneficence
This is the obligation to help the patient or ‘do good’. Few would argue against this principle in which the patients’ interests come first, but there is often debate about what the ‘good’ action is and whether the doctor is the best person to decide this (ie the conflict of Paternalism against autonomy).

c) Non-Maleficence
This is the obligation to avoid harming a patient or ‘not to do harm’. The maxim “Primum non nocere” which means “first (or above all) do no harm” implies that this principle is more
important than the others but clearly many medical procedures necessarily involve potential risks as well as benefit and many would contest that non-maleficence is an overriding principle.

d) Justice
This is the fair or proportionate treatment with regard to others. In medicine this usually means the obligation to ensure a fair distribution of resources. This ethical principle is probably the one that causes the most controversy. There are many different definitions of justice which rely on differing weights for different moral principles.

Most debates in medical ethics revolve around the weight that should be given to each of these principles when they appear to contradict each other. For example in deciding whether to perform CPR the principle of beneficence, which compels us to attempt to improve health and ultimately prolong life can be at odds with...

- Autonomy – where the patient chooses less aggressive treatment,
- Non-maleficence – where suffering is caused by denying a patient a dignified death or by prolonging unacceptably poor quality life, and
- Justice – where time and money is spent when it could be given to other patients.

Although many of the principles of medical ethics are ancient, views and practices have changed substantially over the centuries. The most dramatic recent change is a shift towards a greater emphasis on patient autonomy with a subsequent diminishing of paternalistic medicine where ‘the doctor knows best’.

Codes of Medical Practice
The moral or ethical duties of doctors were first defined by Hippocrates (a Greek physician and philosopher working approximately 460 – 377 BC). The Hippocratic oath is shown in figure 1a. A modern international version of this code called the Declaration of Geneva was created in 1948 and revised in 1968 and 1983. The Declaration of Helsinki (1964) defined ethical behavior for medical research including the need to gain informed consent for experimental research. The Royal College of Physicians of London have had an ethical code since 1520 and the General Medical Council has a rulebook which is intermittently updated. The latest version was issued in 1995 and is called ‘Good Medical Practice’ (GMC website)
These codes and declarations all contain rather general guidance on moral principles. They produce little controversy and are rarely of use in providing help for physicians in individual ethical dilemmas.

Figure 1a The Hippocratic oath

*I SWEAR by Apollo the physician, and Aesculapius, and Health, and All-heal, and all the gods and goddesses, that, according to my ability and judgment, I will keep this Oath and this stipulation to reckon him who taught me this Art equally dear to me as my parents, to share my substance with him, and relieve his necessities if required; to look upon his offspring in the same footing as my own brothers, and to teach them this art, if they shall wish to learn it, without fee or stipulation; and that by precept, lecture, and every other mode of instruction, I will impart a knowledge of the Art to my own sons, and those of my teachers, and to disciples bound by a stipulation and oath according to the law of medicine, but to none others. I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous. I will give no deadly medicine to any one if asked, nor suggest any such counsel; and in like manner I will not give to a woman a pessary to produce abortion. With purity and with holiness I will pass my life and practice my Art. I will not cut persons laboring under the stone, but will leave this to be done by men who are practitioners of this work. Into whatever houses I enter, I will go into them for the benefit of the sick, and will abstain from every voluntary act of mischief and corruption; and, further from the seduction of females or males, of freemen and slaves. Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret. While I continue to keep this Oath unviolated, may it be granted to me to enjoy life and the practice of the art, respected by all men, in all times! But should I trespass and violate this Oath, may the reverse be my lot!

Acts and Omissions

There is a moral difference between acts (or acts of commission) and omissions (acts of omission). The most common example of this is in the euthanasia debate. Society, and the law, recognise that doctors may allow patients to die by not providing medical intervention (e.g., CPR for a patient with end stage cancer) but would not permit the active killing (e.g., purposeful injection of lethal substance) for the same patient. Although the outcome may be the same the former action would be seen as an act of omission and the latter an act of commission (Gillon 1985).
The Principle of Double Effect
There are occasions in medicine where well-intentioned interventions have some associated foreseeable bad outcomes. The doctor may be permitted to perform the intervention providing they are aiming for the good effect and they believe that the good will substantially outweigh the bad effect. The commonest example is that of palliative care drugs given to patients who are dying. The doctor may know that a side effect of drugs such as morphine and sedatives might be to accelerate death but as long as they are being administered for the purposes of pain-relief (and not with the intention of causing death) the double effect is morally defensible. There are intrinsic considerations of the relative probability and importance of the good and bad outcomes involved in this dilemma and many Roman Catholics, whose ideology is largely deontological, would reject actions that others would allow (Gillon 1985).

Ordinary and Extraordinary Means
The distinction between ordinary and extraordinary means (sometimes called proportionate and disproportionate means) rests on the degree of burden the act involves for the doctor, the patient, the family and society. At one end of the scale an ‘ordinary’ means might involve the provision of food to someone with broken legs who can no longer cook for themselves. At the other end of the spectrum an extraordinary means might be the provision of total life-support (ventilation, artificial feeding, dialysis etc) for a patient on an intensive care unit. The distinction, which was first suggested by the Roman Catholic Church, allows for withholding of extraordinary measures but not ordinary ones. It can be immediately seen that the classification into ordinary and extraordinary relies on assessment of the burden of the means in relation to many other factors. There is ongoing debate as to whether the provision of artificial feeding is an ordinary means (Gillon 1985).

Law and Ethics
The law is based loosely on society’s ethical principles but does not stem from it directly. It is not true that something that is within the law is ethically correct or indeed that illegal things are necessarily unethical (Mason and McCall Smith 1999).

The law often allows a fair amount of flexibility for doctors to interpret what is morally defensible. Self-regulation from within the profession is often used eg research ethics committees determine whether a research project is ethical. Another example of self-regulation is the so-
called “Bolam Test” in which a body of responsible medical opinion is used as the yardstick for medical negligence cases (Davies 1996).

**Capacity/Competence**

Society accepts that some of its members, such as children and adults with severe cognitive problems, do not have the ability to make decisions for themselves. A person is said to be ‘competent’ when they have the ability to make a given decision for themselves. Capacity is a legal term with the same meaning but the two words are often used interchangeably. The British Medical Society (BMA website) and the Department of Health (DoH website) and the General Medical Council (GMC website) all provide guidance for doctors on consent and competence.

Competence is decision specific ie a person might be competent to make one decision but not competent to make a different decision. Important and/or complicated decisions require a higher level of competency than simple or unimportant decision (Re MB).

Competence for the same decision can vary with time eg a patient with delirium may be temporarily incompetent even though they are normally fully competent. Hospital patients have been shown to have substantially lower levels of competence compared with age and education matched community-dwelling elders (Fitten and Waite 1990) but there is little known about whether this is a temporary, illness-related effect or whether there is a selection bias. Longitudinal studies are required in this area.

Assessment of capacity deals with the process of decision-making and does not depend on the actual choice made. Competent patients may legally and ethically make unwise or unusual choices (Molloy et al in Capacity to Decide, Appelbaum and Grisso 1988). In the case of Sidaway v. Bethlem RHG the judge ruled that ‘The patient is entitled to reject [professional] advice for reasons which are rational, irrational or for no reason.’

The law presumes that an adult is competent until proven otherwise (Mason and McCall Smith 1999). In the case of Re C (1994) a court upheld the right of a schizophrenic patient to refuse to have his leg amputated and some legal criteria for judging whether a patient is competent were suggested:

- the patient should be able to comprehend and retain treatment information,
- the patient must believe this information in relation to himself,
• the patient should be able to weigh the information, balancing the risks and benefits in order to make a choice.

In a more recent the court of Appeal elaborated the test for incompetence (Re MB). The patient must be able to comprehend and retain the information which is material to the decision, especially the likely consequences of having or not having the treatment in question. The patient must be able to use the information and weigh it in the balance as part of the process of arriving at the decision.

Whenever a doctor allows a patient to make an autonomous choice the assumption is that the patient is competent. Where the competency of a patient is in question there is an expectation that the physician should be able to assess this. The practice of geriatric medicine often involves patients with impairments of capacity since dementia and delirium both occur more commonly with increasing age. A discussion of assessment of capacity to make an advance directive is found in section 1.4.2.4.

Markson et al (1994) analysed a postal questionnaire from over 800 doctors in the USA. They found that only 89% of physicians knew the correct standards for competence and even fewer were able to correctly apply standards to a hypothetical scenario. The authors questioned the assumption that physicians are experts at assessing competence.

1.1.2.3 Medical ethics and the application of life-sustaining treatments

Longevity and continued physical health with advancing age are undoubtedly increasing in Western society. The expectation of these outcomes is also increasing. It is only relatively recently that medical science has allowed us to maintain and extend life beyond a point which was not available to our grandparents, let alone Hippocrates! Thus, the appropriate application of life-sustaining treatment to the elderly population is a very modern ethical dilemma.

Initial enthusiasm for life-saving resuscitation was followed by a growing unease about its universal application (Timmerman 1999). Schneider et al (1993) found that 92.2% of published reports of CPR in the 1960s were optimistic but only 68.2% were optimistic in the 1980s. In the early 1980’s there was a flurry of publications calling for more discretionary use of CPR. The emotive titles of these opinion-leading papers include ‘Thou shalt not strive officiously’ in the UK (Bayliss 1982) and “Must we always use CPR?” in the USA (Blackhall 1987). They argued
that the medical profession was harming patients by performing CPR, which either denied them a dignified death or else extended life of an unacceptable quality. Fusgen and Summa (1978) in a paper titled 'How much sense is there in an attempt to resuscitate an aged person?' argues that medical ambition and apprehension are not appropriate reasons to perform CPR on an elderly patient. They argue that “Medicine cannot continue with the absolutist idea of preservation of life at any price rather it should admit death where it will not be affected by technical tricks” (Fusgen and Summa 1978).

Do-Not-Resuscitate (DNR) orders are now a widely accepted part of hospital practice throughout the developed world. Point prevalence studies of DNR orders in two British hospitals have shown that 31% (Stewart et al 1990) and 9% (Aarons and Beeching 1991) of hospital inpatients have an active DNR order. A national report from the Netherlands estimates that 90,800 DNR orders were made in 1990 and that 61% of all hospital deaths were preceded by a DNR order (van Delden et al 1993).

Distribution ethics, which hinges on the principle of Justice, calls for limitation of life-sustaining treatments because of the resource implications (Levinsky 1996). Counter arguments hinge on discrimination, for example Ebrahim (2000) argues that in many cases elderly patients are being discriminated against by doctors who make do-not-resuscitate orders because of ‘stereotypes of who is worth saving’.
1.1.3 Historical and Current Legal Situation Regarding Limitation of Treatment

1.1.3.1 The United Kingdom

The legal system in the UK is based on centuries of caselaw (where judgements in individual cases determine precedent for future similar decisions). In October 2000 the Human Rights Act (1988) was adopted UK as the first constitutional doctrine of positive rights (Hewson 2000, Human Rights Act website). It is not yet clear how this new legislation will effect decisions about resuscitation. Tables 1b and 1c summerise the timetable and current legal framework for decisions about limitation of treatment.

The right of a competent adult to accept or refuse treatment was established in 1985 (Sidaway v Board of Governors of Bethlem Royal Hospital). The patient who refuses treatment need not justify his choice and it doesn't have to be rational. For example in the case of Re C (1994), a schizophrenic patient detained under the mental health act in Broadmoor who had delusions was given the right to refuse a leg amputation for gangrene. In the judgement of this case some criteria for judging whether a patient is competent were suggested (see above).

Until the 1990's resuscitation status of patients in the UK was determined informally and there was considerable and arbitrary variation in the rates of DNR orders (Doyal and Wilsher 1993). Eventually a complaint was made to the ombudsman by the son of an elderly lady given a DNR order by a junior doctor without consultation. The complaint was upheld and in response to this the Chief Medical Officer wrote to all consultants in the England and Wales in 1991 indicating that CPR decisions were the responsibility of consultants, that they should formulate clear local policies and be responsible for ensuring that their juniors understood them (HSC(PL(CM091)22). More recently the government sent a further circular on resuscitation policy, this time to the chief executives of all trusts in the UK instructing them to ensure that resuscitation policies which respect patients' human rights were in place, understood, accessible to staff and patients and were subject to audit and monitoring (HSC 200/028).

Doyal and Wilsher (1993) are usually credited with proposing the first guidelines about when it is appropriate to withhold CPR from patients in their paper in the British Medical Journal in 1993. A statement giving almost identical guidelines was released by the British Medical Association and Royal College of Nursing in association with the Resuscitation Council (UK) in 1993. This policy was updated in 1999 and again in March 2001 (to reflect the adoption of the
human rights act) and now includes clearer guidance about the role of patients and relatives in such decisions (BMA website). Although there is no legislation corresponding to this guidance it is likely that the courts would support DNR orders conforming to it.

Apart from reinforcing the right of a competent patient to reject CPR either contemporaneously or in a valid advance directive the statement lists three situations in which it is appropriate to consider a DNAR order

- Where attempting CPR will not restart the patient’s heart and breathing
- Where there is no benefit in restarting the patient’s heart and breathing
- Where the expected benefit is outweighed by the burdens of CPR.

It is interesting to compare the oldest (1993) with the most modern (2001) policies from the BMA since the evolution of policy reflects changing priorities in the medical profession and in society as a whole (Stewart et al 2002). The first obvious difference is the size of the guidance which has grown from only 3 pages to 20 pages in the recent document. The terms used have changed eg DNR is now DNAR (do not attempt resuscitation) presumably to emphasise the point that most attempts do not actually result in a successful resuscitation. Another change in language is that the term ‘futile’ is rejected in the more modern document with an explanation that ‘precise definitions of what constitutes futility vary’.

However there appears to be a more fundamental change in the way in which ‘futility’ is considered as well; there is a rejection of a medical-led model of percentage survival to one in which the percentage survival is only a part of decision which is patient-led. For example in considering whether CPR is appropriate ‘the appropriate course of action may be very different in apparently similar circumstances, because the wishes and preferences of the patient are an essential element of the decision’ and ‘doctors …should, were possible, respect patients’ wishes to receive treatment which carries only a very small chance of success or benefit’. This concept of futility has up till recently only been commonly found in the American literature (Curtis et al 1995, Mello and Jenkinson 1997, Tomlinson and Czlonka 1995). For a more in depth discussion of the concept of ‘futility’ please see section 1.3.4.

In accordance with the Human Rights legislation and the shift towards patient autonomy the modern guidance prioritises the role of the patient. In particular it makes clear that a DNAR order may not be recorded against the wishes of a competent patient even if this is against the advice of
the health care team on the basis that 'a competent patient is the best judge of what represents an acceptable level of burden or risk for him or herself, and where there is a chance of the outcome the patient considers acceptable, many will consider the risk of even significant disadvantage a burden worth taking'. The only defence that the medical team seems to have against the possibility of inappropriate demands for conventionally ‘futile’ treatment is that doctors cannot be required to give treatment contrary to their clinical judgement. The 2001 guidelines suggest that in this situation where a consensus of opinion cannot be reached then CPR should be provided while legal advice is sought.

In line with the policy of patient involvement the BMA has recently issued a model patient information leaflet (BMA website). It suggests the leaflet should be modified for local use and made available as a prompt and support to discussions about CPR.

Some doctors feel betrayed by the modern guidelines which they feel have swung too far in the direction of patient autonomy and will lead to

- significant patient distress where doctors are forced to discuss CPR with frail patients who would previously have been designated DNAR on grounds of futility without overt discussions
- a greater reluctance to make DNAR decisions (because of the time and stress involved in discussions with patients and relatives) and consequently to many more inappropriate attempts at resuscitation
- a rise in unsuccessful CPR attempts leading to
  - poor morale of resuscitation teams
  - the possible re-emergance of 'slow-codes' in which a second-rate attempt at resuscitation is made for a patient who is perceived by the team as inappropriate for CPR
  - implications for deployment of valuable resources (time and personnel) away from areas where they might be more effective

**Decisions for Incompetent Patients**

Currently in England, Wales and Northern Ireland no-one can legally make a decision about medical treatment for another adult even when they are judged incompetent to make their own decisions. Relatives and even Guardians appointed by the Guardianship Board, have no rights to
make medical decisions by proxy. In these cases doctors are expected to make decisions in the ‘best interests’ of their incompetent patients.

In the ‘Making Decisions’ policy document there is a proposal to reform The Enduring Power Of Attorney legislation (Website, Luttrel 2001). The new Continuing Power of Attorney is proposed to cover medical and lifestyle decisions as well as financial ones. In parallel with this a court appointed manager could make welfare and healthcare decisions for an incompetent patient where one had not been previously nominated by a patient. This policy has not yet been debated in parliament.

In Scotland the law has always been slightly different as a Tutor Dative could be appointed by the Court of Session to make decisions for an incompetent person. This was a very old law which was rarely utilised and since it has never been tested in court the validity of a refusal of medical treatment by a tutor dative is not clear. In 2000 the Scottish parliament passed new legislation similar to that suggested by the ‘Making Decisions’ paper in which an adult can choose a proxy to make decisions for them (Adults with Incapacity (Scotland) Act 2000). In the absence of a legally appointed proxy then decisions fall back to the doctor to be made on a ‘best interests’ basis.

The modern guidelines on CPR decisions encourage doctors to have more widespread discussions with the rest of the health care team and those close to the patient (usually family). Where the basis for a DNR decision is the absence of any likely medical benefit such discussions should ‘aim to secure an understanding and acceptance of the clinical decision’. In contrast where a DNR decision is based on quality of life considerations, the views of the patient, where possible should be sought. If the patient is not able to discuss the appropriateness of CPR, the views of family can be sought regarding what would be in the patient’s choice in such a situation. Legally and ethically the role of family is to reflect the patient’s views (substituted decision-making) and not to take decisions on behalf of the patient (best interests decision-making).

The BMA booklet ‘Withholding and Withdrawing Life-prolonging Medical Treatment’ gives some useful guidelines for doctors when making decisions for incompetent patients, for example;

- Length of life should be balanced against quality of life and burden of treatments and doctors may decide to withdraw or withhold treatment where it is not in the best interests of the patient,
• There is no legal or moral difference between withholding and withdrawing treatments,

• Where doubt exists about whether a treatment would be beneficial a trial period of treatment should be undertaken,

• Although they carry no legal weight, account should be taken of the views of other health professionals and family when making medical decisions,

• The clinician in charge is ultimately responsible for medical decisions but where serious disagreement occurs review by a court should occur,

• Withdrawal of feeding and hydration of a patient in persistent vegetative state requires a court authorisation,

• The legal situation regarding withdrawal of feeding and hydration for a patient not in persistent vegetative state is not yet clear and consultation and review should occur.

**Advance Decision Making**

The legal situation with regard to advance directives in the UK is discussed in chapter 4, section 1.4.1.3.
<table>
<thead>
<tr>
<th>Date</th>
<th>Document / Event</th>
<th>Explanatory Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985</td>
<td>Sidaway case</td>
<td>Right of a competent adult to refuse medical treatment</td>
</tr>
<tr>
<td>1992</td>
<td>Re T</td>
<td>Test case involving acceptance of legality of an advance refusal</td>
</tr>
<tr>
<td>1993</td>
<td>Guidelines on DNR decisions</td>
<td>Doyal and Wilsher paper and BMA/RCN statement released</td>
</tr>
<tr>
<td>1993</td>
<td>Bland case</td>
<td>Right to withdraw artificial feeding and advance refusal of medical treatment endorsed</td>
</tr>
<tr>
<td>1995</td>
<td>'Advance Statements about medical treatment'</td>
<td>BMA/RCN Code of practice and explanatory notes</td>
</tr>
<tr>
<td>1997</td>
<td>'Who Decides?'</td>
<td>Consultation paper / Green paper</td>
</tr>
<tr>
<td>1999</td>
<td>'Making Decisions'</td>
<td>Policy statement / paper Rejefes legislation for advance directives Proposes extended power of attorney role to cover medical decisions</td>
</tr>
<tr>
<td>1999</td>
<td>Withholding and Withdrawing Life-prolonging Medical Treatment, BMA</td>
<td>Guidance for decision making for competent and incompetent patients</td>
</tr>
<tr>
<td>2000</td>
<td>Adults with Incapacity (Scotland) Act</td>
<td>Grants the right to appoint a proxy decision-maker for health care – Scotland only</td>
</tr>
<tr>
<td>2000</td>
<td>Human Rights Act Adopted in UK</td>
<td>Positive bill of rights</td>
</tr>
<tr>
<td>2001</td>
<td>Latest BMA/RCN/Resuscitation Council guidelines on DNAR decisions</td>
<td>Updated guidance</td>
</tr>
</tbody>
</table>
Euthanasia

Active euthanasia (in which a person is assisted to commit suicide) is illegal in the UK and doctors caught doing it are liable to manslaughter charges. Passive euthanasia (not providing treatment that would prolong life and therefore allowing death to occur 'naturally') is legal and underpins much palliative care where efforts are made to improve quality rather than quantity of life in a patient whose death is inevitable. A valid advance directive can be used to refuse life-prolonging treatment and may therefore constitute a form of passive euthanasia. Many physicians prefer to avoid using the term passive euthanasia since the term can be confusing and it does not accurately describe the motives behind their care.

The Voluntary Euthanasia Society is a pressure group set up by a group of doctors in London in 1935 and continues to campaign for legislation to legalise active euthanasia (Voluntary Euthanasia Society website). Euthanasia is also illegal in the USA and the Hemlock Society was established in 1938 and is equivalent to the Voluntary Euthanasia Society in its ideas and aims. Successive UK governments have refused to consider such legislation and professional medical bodies such as the British Medical Society (see website) and the National Council for Hospice Care (see website) have always rejected euthanasia. There is a sector of society which continues to campaign for legalisation of euthanasia and occasionally individual cases or changes in law in other countries hit the media headlines. The latest challenge in August 2001 came from a 42 year-old patient with end-stage motor-nerone disease who wanted her husband to be able to assist her to kill herself legally. Her case was rejected by the UK high court and an appeal to the European court of Human Rights failed to overturn this ruling. Mrs Pretty died naturally in a hospice shortly after her appeal was heard.

In May 1995 The Northern Territory in Australia passed the Rights of the Terminally Ill Act which allowed doctors to assist a terminally ill person to terminate their own life (voluntary active euthanasia) (Ryan and Kaye 1996). There was massive public outcry and in March 1997 a private member's bill at the Senate overturned the Northern Territory ruling and there is now no provision for legal assisted suicide anywhere in Australia.

By contrast, the Netherlands has permitted acts of euthanasia for two decades and an estimated 3600 cases of voluntary euthanasia are carried out each year. The government has recently introduced legislation which outlines the conditions which need to be present during voluntary euthanasia in order to protect the doctor involved from charges of manslaughter (Sheldon 2001).
1.1.3.2 Australia

As in the UK, common law in Australia dictates that mentally competent adults have the right to consent to or refuse medical treatment throughout the continent. In three states (Victoria, South Australia and Australian Capital Territory) there is also legislation to support contemporaneous medical decisions (Taking Charge 1999).

The law regarding advance decision-making and decision making for incompetent patients varies between the five States and two Territories of Australia (see Table Ic). Western Australia is similar to the UK in having very little legislation whilst many of the other states have legislation for some kind of written directive or appointment of a proxy decision-maker. This is a rapidly changing area and many of these laws were passed in the last few years with further changes planned in many states. The information in table Ic was correct as of April 2000 (Taking Charge 1999, Interjurisdictional Committee on Guardianship and Administration Website 2000).

1.1.3.3 The United States of America

America has always been ahead of the rest of the world with legislation about end-of-life decision making. This is due to several different factors:

- a cultural leaning towards personal freedom and autonomy,
- a very aggressive interventionist system which is driven by a fee-for-service and high levels of litigation, and
- higher levels of education about, and expectations of, medical interventions (Bayliss 1982, Currie 1988).

One fundamental difference between the law in the UK and the USA is the American right of the next of kin to make medical decisions for an incompetent relative. There is a hierarchy of people, starting with husband/wife, that doctors must consult for consent to provide or withhold treatment from an incompetent patient.

The first State to pass legislation about instructional advance directives was California in 1976. This was the Natural Death Act (1976) which provided for a fairly rigid living will in the event of a ‘terminal condition’. Expansion and evolution of the law in all states took place over the next two decades fuelled by some landmark Federal Laws passed in the early 1990s (Lush 1993).
Nancy Cruzan was left in a persistent vegetative state following a car accident in Missouri. Her family and friends fought to allow her life-support to be discontinued. Following this case the Federal Government passed The Self-Determination Act 1991 which required all government-funded health providers (hospitals, nursing homes and hospices) to give all patients the opportunity to complete a directive when they entered that institution.
### Table 1c: Legal framework for medical decision-making for incompetent adults in the United Kingdom and Australia

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UK</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>England</td>
<td>No legislation Valid under common law</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Scotland</td>
<td>No</td>
<td>Yes – since Adults with Incapacity Act 2000</td>
<td>No</td>
<td>Yes, possibly a Tutor Dative, Not tested</td>
</tr>
<tr>
<td><strong>Australia</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New South Wales</td>
<td>No</td>
<td>Yes 'enduring guardian'</td>
<td>Yes 'responsible person'</td>
<td>Yes</td>
</tr>
<tr>
<td>Western Australia</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>South Australia</td>
<td>Yes only for palliative care and persistent vegetative state</td>
<td>Yes either enduring guardian or medical power of attorney</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Tasmania</td>
<td>No but can make conditions on an enduring guardian</td>
<td>Yes 'enduring guardian'</td>
<td>Yes 'person responsible'</td>
<td>Yes</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>Yes only for current medical condition. Also oral statements</td>
<td>Yes enduring power of attorney</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Northern Territories</td>
<td>Yes but only for terminal illness</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Victoria</td>
<td>No but can make statement on an enduring POA</td>
<td>Yes enduring power of attorney</td>
<td>Yes 'person responsible'</td>
<td>Yes</td>
</tr>
<tr>
<td>Queensland</td>
<td>Yes but only on standard forms</td>
<td>Yes enduring power of attorney</td>
<td>Yes 'Statutory health attorney'</td>
<td>Yes – From July 2000</td>
</tr>
</tbody>
</table>
Chapter 1.2

Survival following CPR and prediction of outcome

Life is pleasant.
Death is peaceful.
It's the transition that's troublesome.

Issac Asminov (1920 - 1992)
1.2.1 Outcome After Attempted CPR

1.2.1.1 Survival rates

Success after in-hospital CPR is usually measured by percentage of patients undergoing CPR who are still alive after a designated period of time. Initial survival rates (percentage recovering spontaneous cardiac output and or breathing following CPR) are higher than survival to later times since many patients remain gravely ill post-arrest and will die in the next few hours/days. Survival to discharge from hospital is the commonest and most useful measure of success since it is easy to record and usually marks the end of an acute illness.

There are hundreds of published reports of survival rates after CPR from different centers over the last four decades. Table 1d summerises the mean immediate, discharge and one year survival rates reported in five major review papers. Individual studies within these reports show marked variation with survival to discharge rates between 3% (Jordon et al 1964) and 70% (Kouwenhoven et al 1960). It is most likely that this variation is explained by different settings and patient populations reported in these studies.

Schneider et al (1993) found no change in CPR survival rates over a 30 year period while Saklayen et al (1995) report that CPR survival rates have gradually increased, perhaps due to improved levels of staff training. De Bard (1981) found that although success rates have not changed in the last twenty years the number of patients on whom CPR is attempted is gradually increasing. He postulates that if CPR is attempted on a wider range of sicker patients then to maintain a static success rate implies that the quality of CPR and the total number of patients being saved is increasing over time. There are few direct comparisons over time in the same hospital setting and they are difficult to interpret due to confounding factors such as differences in patient selection, staff training, facilities and equipment.

Long term survival after CPR is much less well studied. In a six year study from a single hospital in America DeBard (1981) reports five year follow up of 223 patients discharged alive; 75% of the survivors were still alive at one year, 50% after two years and 20% after five years. By contrast Peatfield et al (1977) in an earlier study reported that 60% of 93 patients discharged alive after CPR were still alive at five years with a 7% annual death rate. Both these studies suggest that number of CPR survivors still alive each year declines in a linear fashion. It has been
suggested that the death rates in this population are similar to those expected in a post-myocardial infarction group (Peatfield et al 1977).
Table 1d Survival rates after in-hospital CPR in the five major review papers

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Number of in-hospital arrests</th>
<th>Initial survival</th>
<th>Survival to 24 hours</th>
<th>Survival to discharge</th>
<th>Survival at one year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tunstall-Pedoe et al (1992)</td>
<td>12 British Hospitals 1985 - 1986</td>
<td>2 838</td>
<td>45%</td>
<td>32%</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>McGrath (1987)</td>
<td>42 international studies 1961 - 1984</td>
<td>12 961</td>
<td>38.5%</td>
<td>14.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>De Bard (1981)</td>
<td>64 international studies 1960 - 1980</td>
<td>13 266</td>
<td>39%</td>
<td>17%</td>
<td>12.2%</td>
<td></td>
</tr>
<tr>
<td>Schneider et al (1993)</td>
<td>98 international studies 1960-1990</td>
<td>19 955</td>
<td></td>
<td>15%</td>
<td>10.9%</td>
<td></td>
</tr>
</tbody>
</table>
1.2.1.2 Quality of survival

It is simplistic to look at outcome of any intervention simply in terms of survival. In order to make informed decisions patients and doctors also need to know what kind of lifestyle survivors of CPR might expect to have. Unfortunately all the studies which examine quality of life in a survivor population are all are flawed by having no prospective pre-arrest data. Another problem interpreting many of these studies is the difficulty in distinguishing the effect of the CPR from the effect of the underlying illness. For example patients who have a myocardial infarction complicated by cardiac arrest may have alterations in quality of survival relating to the underlying cardiac disease rather than the CPR. Evidence of quality of survival is available in the into brain damage, cognition, employment and dependence as well as quality of life scores.

Brain Damage (Including Vegetative State)

This greatly-feared consequence of CPR has been reported in between 0.5% and 3% of survivors (table 1e) although long-term survivors in this damaged state are even fewer.

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Brain Damage</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>De Vos et al (1999)</td>
<td>162 post-CPR patients who survived to discharge from hospital</td>
<td>5 cases (3%) of ‘vegetative state’</td>
<td>4 out of the 5 of these patients died within the first 3 months of discharge</td>
</tr>
<tr>
<td>Schneider et al (1993)</td>
<td>Review of 2009 post-CPR survivors</td>
<td>33 (1.6%) had ‘permanent neurological impairment’ half of whom had ‘severe’ damage</td>
<td>found no trend in the rate of central nervous system complications over three decades</td>
</tr>
<tr>
<td>De Bard (1981) (own series, not review)</td>
<td>201 post-CPR survivors</td>
<td>1 (0.5%) had neurological damage serious enough to impair everyday function</td>
<td></td>
</tr>
<tr>
<td>Bedell et al (1983)</td>
<td>41 post-CPR survivors</td>
<td>1 had a new ‘gross impairment of mental status’</td>
<td>this patient died within two months of discharge</td>
</tr>
</tbody>
</table>
Cognition

Following successful CPR in 88 patients De Vos et al (1999) found that only 15 (17%) of his cohort were cognitively impaired (defined as Mini-Mental State Examination (MMSE) score of less than 23). The mean MMSE for survivors was 27/30. In another series of 424 survivors of out-of-hospital CPR 64% of patients reported a better or unchanged memory while only 36% were aware of a deterioration in their memory (Bergner et al 1984).

Sauve et al (1996) looked in detail at cognition using a battery of neuropsychological tests at various stages within six months of CPR. At six months post-arrest half the survivors had normal cognition but 25% had moderate or severe impairment of cognition. There was a significant improvement over time with the percentage of patients having any kind of impairment dropping from 84% to 70% to 67% to 50% when measured at six-weekly intervals. ‘Time to awakening’ was found to predict neurological recovery, with poorer outcome in patients who remained unconscious for longer periods after the arrest.

Depression

De Vos et al (1999) looked for depression using Centre for Epidemiologic Studies’ Depression Scale (CRSDS) in which scores greater than 16 indicate depression. They found 14 (16%) of patients at a median of 15 months after discharge following CPR were depressed. In an earlier study of 30 patients the mean CRSDS rose from 21 at the time of discharge to 11 six months later where the mean community controls scored 9 (Bedell et al 1983). Bedell et al (1983) concluded that depression might be a transient feature of recovery after CPR.

In contrast The Profile of Mood States (POMS) was used in a follow-up study of 45 patients following aborted sudden cardiac death in America (Sauve et al 1996). The authors were unable to explain the low to average emotional distress data compared to a control population. They also found a significant reduction in tension and depression scores over the 6 months following CPR.

Dependence/Employment

It is particularly hard with employment/independence to separate the physical from the emotional impact of CPR. For example Bedell et al (1983) commented that many of the ‘housebound’ survivors were so as a result of fear rather than physical incapacity. The larger studies suggest that around three-quarters of CPR survivors remain fully independent and in employment after successful CPR (see table 1f).
Table 1f Summary of studies providing data on dependency and/or employment changes following successful CPR

<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Dependency</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>De Vos et al (1999)</td>
<td>90 in-hospital CPR survivors</td>
<td>66 (74%) independent&lt;br&gt;12 (13%) restricted in activities but remained self-caring&lt;br&gt;12 (13%) dependent on others for activities of daily living</td>
<td></td>
</tr>
<tr>
<td>Robinson (1994)</td>
<td>13 long-term (mean 31 months) in-hospital CPR survivors</td>
<td>10/13 (77%) living independently at a mean of 31 months post discharge</td>
<td></td>
</tr>
<tr>
<td>Fitzgerald et al (1997)</td>
<td>162 survivors of in-hospital CPR two months post-arrest</td>
<td>91 (56%) had equal or greater function compared with pre-arrest&lt;br&gt;71 (44%) had diminished functioning&lt;br&gt;Katz Index of activities mean of 1.2 disabilities before CPR and 2.5 disabilities after CPR&lt;br&gt;In 71 patients who did deteriorate there was a mean increase of 4 disabilities. Elderly and those who had been in hospital &gt;3 days before the arrest were more likely to have a functional decline</td>
<td></td>
</tr>
<tr>
<td>Bedell et al (1983)</td>
<td>33 in-hospital CPR survivors</td>
<td>5 (15%) required new institutionalisation&lt;br&gt;10/33 (30%) were newly housebound</td>
<td>5/9 (55%) had retired from previous employment</td>
</tr>
<tr>
<td>Sunnerhagen et al (1996)</td>
<td>26 survivors of out-of-hospital CPR all aged 75 or under</td>
<td>5/26 (19%) of survivors were living in a nursing home</td>
<td>4/17 (24%) remained in full time employment</td>
</tr>
<tr>
<td>Bergner et al (1984)</td>
<td>424 out-of-hospital CPR survivors</td>
<td></td>
<td>320 (75%) no change in work status&lt;br&gt;87/170 (51%) remained in full-time employment</td>
</tr>
</tbody>
</table>
Quality of Life

De Vos et al (1999) interviewed 90 CPR-survivors using the Sickness Impact Profile (SIP) which is a 136-item questionnaire measuring quality of life. Patients had significantly poorer scores than a group of elderly controls but had better scores than a group of stroke survivors. In regression analysis they found that admission diagnosis was the most important predictor of quality of life and they conclude that differences in the diseases leading to CPR rather than the procedure itself underlie quality of life outcomes.

In a separate study involving 424 out-of-hospital arrest survivors the mean SIP scores were actually higher than those of a sample of age and sex matched controls in the same geographic area (Bergner et al 1984).

SIP was also used by a group from The Netherlands to compare 69 in-hospital CPR survivors with a matched group of 69 patients who had been in an intensive care unit but not required CPR (Miranda 1994). They found no significant difference between SIP scores in the two. They conclude that CPR itself does not increase physical handicap and that the functional status of patients before hospital admission may actually be a more important factor.

Nichol et al (1999) used The Health Utilities Index Mark 3 to assess quality of life in 86 patients at a mean of 9.9 months post discharge. A score of 1 indicates perfect health and 0 indicates death. There was a wide variation in survivors’ scores but the majority had only minor impairment in overall quality of life. The mean study population score of 0.72 +/- 0.22 was only slightly worse than that of the general population mean of 0.85 +/- 0.16. There was a significantly higher score for patients who had required shorter duration of CPR.

Considering the significant levels of increased dependency, institutionalisation and cognitive impairment found in many studies it is surprising that there are not more dramatic results for the quality of life.
1.2.2 Factors That Predict Outcome After CPR and Morbidity Scores

Only the minority of patients who die in hospital have terminal resuscitation attempts because many are deaths are expected and do-not resuscitate (DNR) orders are made in advance. One summary of the literature found that 28% of all hospital deaths and 1.5% of all hospital admissions received attempts at CPR (De Bard 1981). Saklayen et al (1995) found fifteen studies which reported the percentage of hospital deaths receiving CPR and found a variation from 10% to 57%. Both De Bard (1981) and Saklayen et al (1995) report an increasing percentage of patients undergoing CPR with time. There are many reasons for DNR orders (see chapter 1.1.3) and practice will vary between countries, hospitals and even between different physicians working in the same clinical area. The prevalence of DNR orders is likely to be related to the survival statistics for CPR in that area since hospitals with higher terminal CPR rates are likely to include more futile resuscitation attempts and therefore have lower survival rates.

Admission policy will also have a major impact on survival in different hospitals as variation in casemix (eg number of CPR candidates who have multiple pathologies, have cancer or acute myocardial infarction) will affect outcome (Saklayen et al 1995).

In the last two decades there has been an enormous amount of time and money dedicated to improving the skills of the resuscitation team and the equipment they use (see chapter 1.1.1). There have also been advances in post-arrest intensive care. It is likely that this investment has improved survival rates but there is little evidence for this, as controlled trials of these changes have not been undertaken.

1.2.2.1 Peri-arrest and post-arrest factors
These are factors that can only be measured at the time of, or shortly after an arrest, and are therefore of no value in making DNR orders in advance. They can, however, help physicians to decide to quickly terminate attempts at resuscitation that appear to be hopeless.

Place of Arrest
Patients who arrest out of hospital have lower survival rates, both immediate and longer term, than those who arrest in hospital (Saklayen et al 1995). Tunstall-Pedoe et al (1992) reported the initial survival to be half that for in-hospital CPR and Murphy et al (1989) less than a fifth of the in-hospital rate.
Specialist units such as intensive care or coronary care units record better survival rates than general wards (Tunstall-Pedoe et al 1992, Saklayen et al 1995, De Bard 1981, McGrath 1987). It is not clear if this discrepancy is due to speed and competence of response or whether it is due to patient selection since no case-controlled studies are available.

Saklayen et al (1995) and Schneider et al (1993) compared results between different types of hospital and found higher success rates in community compared to teaching hospitals. It is again unclear if this is a casemix or competency effect. Veterans’ Administration Hospitals fare worse than any other type of hospital presumably due to the high numbers of elderly patients with multiple pathology.

Mode of Arrest
It is not always possible to determine if patients have a cardiac or respiratory arrest as the initial cause of collapse since in either case they rapidly cause failure of the other system. Tunstall-Pedoe et al (1992) reported no difference in survival for the two different modes of arrest at one year but that those with cardiac arrest had higher initial survival. In contrast Saklayen et al (1995) reported better survival to discharge following primary respiratory arrest compared with primary cardiac arrest.

Disease Process
CPR will never be successful where the underlying pathology is irreversible eg ruptured left ventricle or aorta. De Bard (1981) reviewed unsuccessful CPR cases at autopsy and estimated that around 7.5% of cases were unsalvageable from the start. Clearly this information is rarely available to the attending arrest team.

Arrest Rhythm
It is well established that patients arresting with cardiac rhythms amenable to electrical cardioversion such as ventricular fibrillation and ventricular tachycardia have a better prognosis than those with asystole or electromechanical dissociation (De Bard 1981, Schneider et al 1993, Saklayen et al 1995, McGrath 1987).
Speed of Initiation of CPR and Witnessed / Unwitnessed Arrests

Delay to initiation of CPR will worsen metabolic disturbance (increase acidosis and hypoxia) and decrease the chance of a successful outcome. Unwitnessed arrests are known to have a worse outcome than witnessed arrest (Tunstall-Pedoe et al 1992, Saklayen et al 1995, O’Keeffe et al 1991, So et al 1994) probably due to delays in initiating CPR.

Speed to Regain Output / Duration of CPR

Patients who recover quickly after CPR are more likely to survive to discharge from hospital. Several studies show that survivors have shorter mean arrest procedures than non-survivors (Schneider et al 1993, Saklayen et al 1995, McIntyre 1993). In addition Tunstall-Pedoe et al (1992) reported increasing mortality with increasing number of DC shocks delivered. ‘Time to wakening’ i.e. time from arrest to time when patient will respond to voice is also correlated with survival as well as functional recovery (Sauve et al 1996, So et al 1994).

Post-Arrest Scores

The prediction of awakening score (using motor response, pupillary response, eye movement and blood glucose level) and the Advanced Cardiac Life Support score (using witnessed/unwitnessed arrest, cardiac rhythm, whether bystander CPR instituted and speed of response of emergency services) are scores which combine factors to predict survival after the arrest. They have not been validated and are not commonly used (So et al 1994).

1.2.2.2 Pre-arrest factors

These prognostic factors are available to doctors before the arrest and are therefore most suitable for influencing DNR orders.

Sex

Males and females seem to fare equally well after CPR once matched for age (Tunstall-Pedoe et al 1992) although there are approximately twice as many male than female arrests in most studies so there may be some selection and casemix bias.

Age

There is disagreement in the literature about the influence of age on survival after CPR. There are many studies which note a decreasing survival rate with increasing age (Tunstall-Pedoe et al 1992, Schneider et al 1993, Saklayen et al 1995, O’Keeffe et al 1991, McGrath 1987, Taffet et al

There are two major studies specifically designed to look at resuscitation in an aged population. Murphy et al (1989) collected data from 259 in-hospital arrests in patients aged over 70 at five separate hospitals including three chronic care or aged care institutions. The overall in-hospital survival to discharge rate was only 6.5% This was a frail population and included patients from chronic care and long-term care institutions. One quarter of the patients were moderately or severely functionally impaired prior to the arrest and there was no younger control group. Murphy concludes that CPR ‘offers little benefit for most elderly patients’.

In contrast Tresch et al (1994) retrospectively reviewed the outcome of 151 patients who underwent CPR at a teaching hospital in the USA (both in and out of hospital arrests). Survival measured at discharge was 26% and there was no difference between the 78 patients who were aged over 70 and the 73 aged under 70. They explain their results by the fact that all the patients selected for CPR had good functional status with the younger group having similar dependency scores as the older group. Indeed only 18% of the hospital deaths during the study period were resuscitated which is unusually selective for an American study.

It can be concluded that increasing age is a marker of increasing frailty and not a risk factor per se. A good outcome for resuscitation in the elderly is possible if patients are carefully selected.

**Number of Previous CPR Attempts**

De Bard (1981) found no patient who had more than four arrest attempts survived to discharge.

**Social Functioning**

Tresch et al (1994) looked at functional status and found that it was an independent predictor of survival after CPR. Survival was 41% in the group who were independent pre-arrest and 17% in the dependent group. Bedell et al (1983) defined a group of patients who had a ‘homebound lifestyle’ prior to admission and demonstrated that they had a survival of only 4% (6/137) as opposed to 27% (35/128) who were active outside the home. It is likely that social functioning is a marker of frailty and multiple medical diagnoses in the same way as old age.
Time in Hospital Prior to Arrest

The majority of arrests occur in the first few days of hospital admission, with around 50% occurring on the first day of hospital admission (Schneider et al 1993). There is no analysis in the literature of whether time in hospital before arrest influences survival.

Specific Pathology

Uncomplicated myocardial infarction is said to have the best outcome after resuscitation (Ebell 1992). Coronary care units have achieved rates of more than 50% survival to discharge (Sayer et al 2001). This is probably because of the high rate of ventricular fibrillation and the selection of younger patients with single organ pathology.

There are no other diagnoses that seem to confer a favourable outcome. For example Schneider et al (1993) found low success rates with dissecting aneurysm, sepsis, central nervous system disease, trauma, uraemia, cancer and pulmonary embolism. Saklayen et al (1995) found cirrhosis and sepsis accompanying CPR had very poor prognosis and that increased number of diseases decreased survival rates. Bedell et al (1983) performed logistic regression analysis and found hypotension, pneumonia, renal failure, cancer and homebound life style to be significant predictors of mortality after CPR.

APACHE scores

The APACHE (Acute Physiology, Age, Chronic Health Evaluation) score was developed to help predict death in an acutely ill population requiring intensive care (Knaus et al 1991). This complex score combines clinical history and examination variables with laboratory data to produce a numerical score. It was not designed specifically for CPR candidates and is long and unwieldy to calculate. Most authors agree that the APACHE scores (APACHE II and later APACHE III) do not discriminate effectively between survivors and non-survivors following in-hospital CPR (Beer et al 1994, Ebell et al 1997). However Ebell and Preston (1993) were more positive and suggest that combining APACHE II with other clinical parameters might improve specificity.
1.2.2.3 Morbidity Scores

Individual pre-arrest factors are not sensitive or specific enough to predict outcome after CPR but patients who have more than one adverse feature rarely survive (Ebell 1992). Morbidity scores combine several different factors that are available before the arrest to attempt to predict outcome of CPR more accurately. There are three published morbidity scores and table 1g shows how the variables are combined to calculate the scores.

The Pre-arrest Morbidity Score (PAM)

George et al (1989) developed this score by assigning values to fifteen different clinical variables to achieve a score ranging from 0 (low morbidity) to 25 (high morbidity). Five of the variables (hypotension, uraemia, malignancy, pneumonia and homebound life style) were chosen because they were significant predictors of survival in the multivariate analysis in the study by Bedell et al (1983) and each was assigned three points. The authors assigned one point to five other variables (angina, S3 gallop, oliguria, sepsis, and heart failure) that were only predictive by univariate analysis. Finally they added five other variables (acute myocardial infarction, mechanical ventilation, recent cerebrovascular event, coma and cirrhosis) because they were felt to be important factors in their own clinical intuition scoring only one point for each of these.

George et al (1989) went on to test their score and found the PAM score to be superior to individual pre-arrest factors in predicting outcome after CPR. It is not clear from the paper whether the PAM was developed before or after the data collection and it is possible that various different scoring systems were tested before the PAM was finalised.

The Prognosis After Resuscitation Score (PAR)

Ebell (1992) included the Bedell study with 12 other survival studies published between 1980 and 1991 in a meta-analysis. He also included an unpublished study of 218 patients of his own. In the 14 studies he found age over 70, serum creatinine greater that 130mmol/l, homebound life style, cancer, sepsis and pneumonia were associated with decreased survival whilst acute myocardial infarction (MI) was associated with increased survival. Based on the APACHE II score he assigned values between 10 (metastatic cancer) and 2 (age over 70) to the adverse predictive variables and −2 to acute MI. The PAR is the shortest of the three morbidity scores and uses only seven variables. It is also the only score that assigns a different weight to metastatic and non-metastatic cancer. Possible scores lie between −2 (best prognosis) and 25 (worst prognosis).
The Modified PAM Index (MPI)
A modification of the PAM score was proposed by Dautzenberg et al (1993) following a literature review of 32 studies of survival published between 1960 and 1992. Since he used different inclusion criteria he only used six of the same studies as Ebell (1992) for his review. He examined the 15 variables used in PAM and compared them to the number of trials that supported their predictive value and suggested modifications to the weighting assigned to individual variables. For example he upgrades recent cerebrovascular event to two points because ten trials have shown it to be a consistently poor prognostic factor. He also added dementia as a variable and divided MI into early (less than two days after admission) and late categories. Only MI requiring CPR after day 2 scores a point. There are 16 variables in the MPI with scores possible between 0 and 24.
### Table 1g The three morbidity scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>PAM</th>
<th>PAR</th>
<th>MPI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Metastatic</td>
<td></td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Non-metastatic</td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Sepsis (on admission)</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Homebound</td>
<td>3</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Pneumonia (on admission)</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Creatinine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 220 mmol/l</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Over 130 mmol/l</td>
<td></td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Age over 70</td>
<td></td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Acute MI</td>
<td>1</td>
<td>-2</td>
<td></td>
</tr>
<tr>
<td>First 2 days</td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>After day 2</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Hypotension (&lt;90 mmHg systolic)</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Heart failure</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Angina</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Gallop rhythm</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Oliguria</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Ventilated</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Coma</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Acute Stroke</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Cirrhosis</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>Score (Range)</strong></td>
<td>0 to 25</td>
<td>-2 to 25</td>
<td>0 to 24</td>
</tr>
</tbody>
</table>
There are several rather unscientific methods used in the development of these morbidity scores. For example, it is not clear how George et al. (1989) decided on the relative weighting for the variables used for the PAM, how they justified their 'clinical intuition' or why they chose to use only the Bedell study. Dautzenberg himself describes his modification of the PAM variables as being 'arbitrary and crude'. The PAR study uses a metanalysis technique but this would be unlikely to stand up well to standards of metanalysis in the modern era of evidence based medicine.

There are some obvious inconsistencies between the scores e.g. acute myocardial infarction scores minus two on the PAR score (indicating improved prognosis) but plus one on the PAM. Advanced age is given an adverse weighting in PAR and MPI but not PAM. Some variables such as dementia and cirrhosis only occur in one score. Potentially the same patient could have quite different scores using the different scoring systems.

Some of the variables are very loosely defined, for example 'homebound', which scores highly especially on PAR, is rather difficult to determine, and the assumption is that patients are homebound through functional impairment. The variable 'cancer' lumps together relatively benign conditions such as carcinoma of the prostate with more aggressive cancers that have much more impact on life expectancy.

The studies that evaluate the use of morbidity scores in clinical practice and their findings are summarised in Table 1h.
Table 1h Clinical evaluations of morbidity scores

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>PAM</th>
<th>PAR</th>
<th>MPI</th>
</tr>
</thead>
<tbody>
<tr>
<td>George et al (1989)</td>
<td>American Teaching Hospital</td>
<td>No survivor &gt; 8</td>
<td>Not assessed</td>
<td>Not assessed</td>
</tr>
<tr>
<td></td>
<td>140 resuscitation attempts (34 (24.3%) successful)</td>
<td>PAM correlated linearly with short and long-term survival</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cohn et al (1993)</td>
<td>American Teaching Hospital</td>
<td>No survivor &gt; 8</td>
<td>Not assessed</td>
<td>Not assessed</td>
</tr>
<tr>
<td></td>
<td>43 Survivors of CPR identified from billing records over 4 years</td>
<td>10 of the dead group scored &gt; 8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>O'Keeffe et al (1991)</td>
<td>Irish Teaching Hospital</td>
<td>No survivor &gt; 4</td>
<td>No survivor &gt; 5</td>
<td>Not assessed</td>
</tr>
<tr>
<td>O'Keeffe and Ebell (1994)</td>
<td>274 consecutive resuscitation attempts over a two year period (25 (9.1%) successful)</td>
<td>sensitivity 9.2% specificity 100%</td>
<td>sensitivity 23.7% specificity 100%</td>
<td></td>
</tr>
<tr>
<td>Ming Nam et al (1999)</td>
<td>24 patients requiring CPR during haemodialysis</td>
<td>Mean PAM = 10.5</td>
<td>Not assessed</td>
<td>Not assessed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No survivors to discharge (1 patient survived 6 months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ebell et al (1997)</td>
<td>656 patients in 3 centers in USA Mixed race with over 50% black African Americans</td>
<td>11/656 (1.7%) had PAM&gt;8</td>
<td>131/656 (20%) had PAR &gt;8</td>
<td>Not assessed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>none survived to discharge</td>
<td>6/131 (4.6%) survived to discharge</td>
<td></td>
</tr>
<tr>
<td>Kerner et al (1997)</td>
<td>71 patients from Canadian teaching hospital</td>
<td>0/32 with PAM=&gt;7 survived</td>
<td>Not assessed</td>
<td>Not assessed</td>
</tr>
</tbody>
</table>
Four of the studies (George et al 1989, Cohen et al 1992, O’Keeffe et al 1991 and 1993, Kerneman et al 1997) showed that morbidity scores can provide a cut off above which none of their cohort survived and therefore concluded that the scores were potentially useful in making DNR decisions. However it is noteworthy that the cut off suggested in these studies varied from a PAM of 4 to 8 and it might be necessary to calculate local cut offs before utilising these scores.

It is also noteworthy that in a study by Ebell et al (1997) there were 6 survivors of CPR who had PAR scores >8. In this study there were no clear trends towards worse outcomes in patients with higher PAM and PAR scores. The authors comment that the low survival rate in their cohort (5.3%) reduced the statistical power to detect an effect of the scores but this cannot explain their survivors with high PAR scores.

O’Keeffe et al 1997 found that PAR with a cut off of >5 functioned in a similar way to PAM. They then went on to compare the PAR with the PAM in the same group of patients using the area under a receiver-operating characteristic curve and concluded that the PAR was a better predictive instrument (O’Keeffe et al 1997). Ebell et al (1997) also found that the PAR had a slightly larger area under the curve (0.564) than the PAM (0.519). The MPI has not been evaluated in clinical practice or compared with the other two scores.

Other uses of Morbidity Scores
Morbidity scores can also be used to assess or guide resuscitation policy. For example Dautzenberg et al (1996) used PAM and MPI to analyse do-not-resuscitate orders in a psychogeriatric unit. He found a poor correlation and suggested that factors other than medical futility (such as quality of life and depression) were influencing DNR decisions.

Stewart et al (1996) calculated the morbidity scores of elderly medical inpatients and found that 30% of all patients were predicted not to survive CPR using a combination of PAM and PAR. They used this data along with mental test scores to demonstrate that in only 41% of all patients and 17% of patients who had a DNR order need the doctor discuss the DNR order with the patient (see section 1.3.3.3). In a second example Kernemanet al (1997) used PAM to identify a population of patients with a poor chance of successful CPR in order to assess how many had had discussions about CPR preferences documented.
Chapter 1.3

Perceptions of Patients, Relatives and Health Care Workers Regarding the Appropriate Application of Life-Sustaining Treatments

If there is no quality of life well I think no resuscitation. If there is quality of life which the relatives believe the patient would find acceptable they should go for resuscitation.

Informant 4, Qualitative Australian Study
1.3.1 Patients’ Perceptions

1.3.1.1 Wishes for resuscitation
As previously discussed it is fundamental to the ethical principle of autonomy that the patient, where possible, be involved in decisions about life-sustaining treatment. Furthermore, apart from a doctor, a competent patient is the only one who is legally allowed to make decisions about medical treatments in the UK.

Institution of life-sustaining treatment such as CPR is nearly always done in an emergency and patients cannot give consent contemporaneously as they may for other treatments. The majority of patients who are ill enough to require life-sustaining treatments will not be capable of expressing opinions just prior to needing it. For example in one study of acute stroke only 8% of patients could be involved in discussions about CPR at the time the decision was made (Alexandrov et al 1995). In another study of DNR orders less than a quarter of patients could be consulted about the decision (Bedell et al 1996).

Research on patient views has therefore largely focused on cross-sectional surveys of populations of elderly people and the results of some of these are summarised in tables 1i (United Kingdom) and 1j (rest of the world).

Many of these studies have a high exclusion rate (eg Gunasekera et al (1986) screened 716 patients to get 134 (19%) to include in their study), and the results may therefore be not representative of the whole population. Most of the UK studies examine elderly inpatient populations and there is little information about healthy community-dwelling elderly. The American studies more commonly take place in residential care populations and this probably reflects the interest in advance directives in such institutions in the USA.
Table 1i Surveys of patients’ willingness to undergo CPR – United Kingdom

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Exclusions</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gunasekera et al 1986</td>
<td>134 patients on acute geriatric wards mean age 80.7</td>
<td>Screened 716 AMTS&lt;7/10 Psychiatric illness 2 refused</td>
<td>42.5% Wanted CPR 47% Refused CPR 10% Unsure</td>
</tr>
<tr>
<td>O’Keeffe et al 1993</td>
<td>100 inpatients, outpatients or dayhospital Geriatric Services Ireland median age 76</td>
<td>2 refused 15 &lt;15/30 MMSE 16 &gt;10/30 GDS</td>
<td>3% Wanted CPR 74% Refused CPR 13% Doctor to decide 10% Relative to decide</td>
</tr>
<tr>
<td>Robertson 1993</td>
<td>322 Urological Outpatients after recovery from a brief general anaesthetic Scotland</td>
<td>Screened 333 2 refused 9 did not understand the term resuscitation</td>
<td>97% Wanted CPR 2% Refused CPR 1% Unsure</td>
</tr>
<tr>
<td>Liddle et al 1994</td>
<td>100 consecutive patients on an acute geriatrics ward mean age 82</td>
<td>Screened 137 24 dementia 5 communication 6 refused</td>
<td>78% Wanted CPR</td>
</tr>
<tr>
<td>Mead et al 1995</td>
<td>180 patients on geriatrics, orthopaedics and vascular surgery wards and outpatient clinics (mixed ages)</td>
<td>AMTS&lt;7/10 GDS&gt;5/15</td>
<td>78% of 86 patients over 70 Wanted CPR 100% of 94 patients under 70 Wanted CPR</td>
</tr>
<tr>
<td>Mead and Tumbull 1995</td>
<td>100 geriatric inpatients</td>
<td>Screened 130 21 confused 4 depressed 5 refused</td>
<td>73% Wanted CPR 18% Refused CPR 9% Unsure</td>
</tr>
</tbody>
</table>
Table 1j International surveys of patients’ willingness to undergo CPR

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Exclusions</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wagner 1984</td>
<td>163 female residents of ‘Mather Home’ mean age 85 USA</td>
<td>10 incompetent 1 refused</td>
<td>6.7% Wanted CPR 47% Refused CPR 34% Physician to decide</td>
</tr>
<tr>
<td>Frankl et al 1989</td>
<td>200 medical inpatients USA</td>
<td>Screened 544</td>
<td>90% Wanted CPR ‘if current health could be restored’</td>
</tr>
<tr>
<td>Gerety et al 1993</td>
<td>52 Nursing Home Residents USA</td>
<td>Screened 82 13 communication 11 died 6 refused</td>
<td>67% Wanted CPR 4% Unsure</td>
</tr>
<tr>
<td>Schonwetter et al 1991</td>
<td>64 veterans attending Geriatric outpatients USA</td>
<td>Screened 108 33 dementia 2 refused</td>
<td>74% Wanted CPR</td>
</tr>
<tr>
<td>Schonwetter et al 1996</td>
<td>132 subjects in a retirement Community aged over 63 88% had a living will USA</td>
<td>Screened 204 47 refused 16 dropped out 9 MMSE&lt;24/30 7 GDS&gt;5/15</td>
<td>66% Wanted CPR</td>
</tr>
<tr>
<td>O’Brien et al 1995</td>
<td>421 Nursing home residents USA</td>
<td>Screened 1458 552 (38%) eligible of whom 421 (76%) agreed to participate</td>
<td>60% Wanted CPR 33% Wanted tube feeding</td>
</tr>
<tr>
<td>Watson et al 1997</td>
<td>95 Elderly inpatients (mixed wards) New Zealand</td>
<td>Communication MMSE &lt;20/30 depression</td>
<td>79% Wanted CPR on admission 46/70 (69%) Wanted CPR at discharge</td>
</tr>
</tbody>
</table>
Table 1j continued International surveys of patients’ willingness to undergo CPR

<table>
<thead>
<tr>
<th>Study</th>
<th>Population</th>
<th>Exclusions</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hui et al</td>
<td>Total 543 subjects Hong Kong (382 from residential care)</td>
<td>Response rate 77% in residential homes</td>
<td>74% Wanted CPR</td>
</tr>
<tr>
<td></td>
<td>161 inpatients geriatrics wards</td>
<td>Response rate 85% in hospital</td>
<td>90% Wanted CPR</td>
</tr>
</tbody>
</table>

In these studies between 60% and 90% of elderly patients in the UK and throughout the world would want to have CPR. A few surveys were exceptions and it is likely that these may either have sampled a different cohort of patients or else the phrasings of the questions have biased results. The earliest study (Gunasekera et al 1986) may have sampled a different cohort of patients, only half of whom had any idea that CPR existed. The order of their questions may also have influenced results. The patients were first asked whether ‘every’ elderly patient should be resuscitated and then taken through different criteria (age, physical and cognitive impairment) before being asked their views about CPR in themselves. The order and wording of the questions might have introduced bias.

The study by O’Keeffe et al (1993) was conducted in Ireland and had only 3% acceptance of CPR. This was partly because in almost a quarter of patients chose to allow the doctor or relatives to decide and therefore didn’t have to decide whether they wanted CPR or not. Ninety percent of the sample was of Roman Catholic religion and this may have influenced attitudes (see section 1.3.1.2 for discussion of the influence of religion on CPR). The patient selection method was unclear and this might have introduced bias. Finally the methodology required patients to answer whether “I want my doctor to keep me alive no matter how sick I am”, or “there will be a time when I want my doctor to stop keeping me alive” prior to the questions about resuscitation. These extreme options may have influenced patients to think more negatively about CPR.

Robertson’s study (1993) sampled an unusual population of patients all of whom were interviewed after an outpatient urological procedure and were therefore reasonably fit. The very high level of CPR acceptance (93%) may relate to this. In addition the patients might have felt
relieved and grateful after their recent surgical intervention and this could influence them to be more accepting of medical technology. Despite this Robertson’s study might be more representative of the views of fit community dwelling elderly who have not been studied extensively. It could be argued that CPR decisions are less relevant to a fit patient group and that their views might change if they were to become unwell (see section 1.4.2.3 for a discussion of this area).

Hui et al (1997) explored this phenomenon by comparing elderly inpatients with a population from residential care in Hong Kong. The inpatients were older, had more medical diagnoses and were less independent. However the inpatients were also more knowledgeable about CPR, more likely to want to make decisions about CPR for themselves and significantly more likely to want CPR (90% vs 74%). This discrepancy may well be explained by the much higher rates of ‘fear of death’ found in the inpatient group (50% vs 2%).

Views of Patients Who Have Experienced Resuscitation

In the studies presented above very few, if any, of the patients surveyed had actually undergone CPR. There are three reports of interviews with patients who have survived a CPR experience and they indicate that patients are not universally grateful for having their lives saved in this manner.

Fusgen and Summa (1978) interviewed eighteen patients who had survived for more than six months after in-hospital CPR in Nuremberg. Half the patients were under 60 and all of them were happy to undergo CPR again if required. In contrast despite the fact that all nine of the patients aged over 60 were ‘satisfied with [their] current life and state of health’, only 2 (22%) said they would be happy to undergo CPR again.

Bedell and Delbanco (1984) interviewed 24 patients who were competent following CPR procedures and found that whilst 15 (63%) were be happy to have CPR again, 8 (33%) had not wanted CPR and did not want it in the future. Six months later 6 of the 8 patients who had not wanted CPR were still alive and none of them had changed their views.

In contrast Bayer et al (1985) interviewed 13 elderly patients three months after discharge following CPR and none of them expressed regrets about having been resuscitated. Their current opinions about CPR were not elicited.
Other Life-Sustaining Treatments

The majority of opinion surveys concentrate on views about CPR but some have additional questions. Heap et al (1993) looked just at artificial ventilation and found that of 118 elderly subjects who completed a survey only 35 (30%) would be willing to have this treatment if indicated, 66 (56%) would accept it under certain circumstances and 17 (14%) would refuse it whatever the circumstances. O’Brien et al (1995) examined wish for tube feeding and found that 33% of American nursing home residents would be happy to have this if they became unable to swallow.

Distress Caused By Discussions About Life-Sustaining Treatments

Most authors quote very low (O’Keeffe et al 1993 – 5%, Watson et al 1997 - 6%, Hill et al 1994 - 1%, Morgan et al 1994) or absent (Mead and Turnbull 1995, Robertson 1993) distress rates in patients during or after discussions about CPR. However, a much quoted report by Schade and Muslin (1989) reported six cases collected from clinical practice over seven years where such discussions were unsuccessful or had had adverse psychological effect. Most of these discussions were with younger adults who had haematological cancer. Their findings may be unusual cases and might not be generalisable to an elderly population with a mixture of diagnosis who might have lower expectations of cure and a lesser fear of death.

Sayers et al (1997) interviewed patients twice, and although there was no distress demonstrated during the initial interview, 6 out of 19 (32%) refused to be interviewed again and indicated distress or annoyance caused by the first interview. It is possible that adverse psychological features may develop some time after the interview and that the low rates quoted by most studies are significant underestimates.

As part of a questionnaire to patients with a DNR order Stolman et al (1990) asked patients if the discussion of CPR was ‘cruel and insensitive’ and 66% said ‘no’, 13% said ‘yes’ and 18% said ‘sometimes’. 
1.3.1.2 Factors predicting patients’ wishes for CPR

Attempts to determine what factors influence patients’ wishes for CPR have largely involved trying to correlate views with known variables such as demographics and disability state. The following subheadings describe the factors that have been studied to date.

**Age**
Gunasekera et al (1986) found that age over 90 was significantly associated with desire not to be resuscitated but it is not clear how many patients they based this finding on. O’Brien et al (1995) found that the percentage of patients wanting CPR was 50% aged over 90 and 75% under 50 years. Most studies have been unable to demonstrate an effect of increasing age on resuscitation preference (Robertson 1993, Mead and Turnbull 1995, Liddle et al 1994, Gerety et al 1993). This might be because they included few younger adults.

**Sex**
Five studies have found that men are significantly more likely than women to accept CPR (Gunasekera et al 1986, Watson et al 1997, Frankl et al 1989, Hui et al 1997, O’Brien et al 1995). No studies have found the reverse trend but several have been unable to demonstrate a gender influence (Robertson 1993, Mead and Turnbull 1995, Liddle et al 1994).

**Marital Status**
Several studies have found that married people are significantly more likely to accept life-sustaining treatment than widowed or single people (Hui et al 1997, Schonwetter et al 1991, Watson et al 1997, Heap et al 1993, O’Brien et al 1995).

**Living Arrangements**
This factor is obviously closely linked with marital status. Watson et al (1997) found 96% acceptance of CPR patients living with a spouse compared with only 57% of those living in residential care. Other studies have demonstrated no difference in opinions depending on living arrangements (Mead and Turnbull 1995, Gunasekera et al 1986, Liddle et al 1994).

**Education**
Schonwetter et al (1991), Miller et al (1992) and Kerridge et al (1999) found that patients who had achieved a higher educational level were significantly more likely to opt out of CPR.
Disability/ Independence


Religion

Influence of religion is controversial. In one study those of Roman Catholic religion were more likely to request life-sustaining technologies (Schonwetter et al 1991). In contrast in a study from Ireland in which 92% of patients were Catholics only 3% wanted CPR (O’Keeffe et al 1993). One study found that religious belief influenced patients’ decisions about treatments in 38% of a group of American nursing home patients. There was no exploration of the way in which religion influenced their views (Gerety et al 1993).

Diagnosis

Frankl et al (1989) surveyed 73 patients with a ‘terminal illness’ and 124 with a ‘non-fatal diagnosis and found the former group had a significantly lower wish for life-support (33% vs 53%).

Depression

The presence of depression as assessed by the Geriatric Depression Scale was the only independent predictor of view on CPR in logistic regression (Gerety et al 1993). Those who had higher scores (more depressed) were less likely to accept CPR and the authors recommend that patients with depressive symptoms should have treatment for depression before an advance directive is made.

Life Value Statements

Schonwetter et al (1996) used 13 life value statements to try to elucidate what factors influence CPR preference. They found a correlation between lower desire for CPR and those who desired good quality of life over increased length of life. Other life values (e.g., wish to maintain capacity, family relations, physical comfort) were not statistically different between groups of patients wanting and refusing CPR in their current state but did correlate in hypothetical disease states. This implies that people feel that their life values will change if they become ill.
Mead et al (1995) gave patients a choice of ten life values. ‘I do not want to be a burden on my family’ was the commonest one chosen by the older age group while ‘I want to maintain my capacity to think clearly’ was seen as most important in the younger group.

Quality of Life
In a study of 258 elderly outpatients from Seattle patients’ self-reported global quality of life was significantly associated with resuscitation preference. However, none of the individual quality of life domains was independently associated and in multi-variate analysis only 2% of the variance in CPR was accounted for by quality of life. They conclude that ‘older patients’ preferences for the care of life-threatening illness may be influenced primarily by criteria other than quality of life’ (Uhlmann and Pearman 1991).

Ethnicity
An American study found that African Americans (n=47) were significantly more likely than whites (n=351) to want CPR (O’Brien et al 1995). The authors postulate that this sector of society ‘felt disenfranchised from the health service and therefore chose to err on the side of overtreatment’. Most other studies have not looked at large enough groups of ethnic minority patients to analyse this effect.

Hypothetical Scenarios
Many studies have used hypothetical scenarios to assess the way that factors such as disability would influence patients’ decisions about resuscitation. All studies have found that a cognitive impairment scenario results in a much-reduced percentage of patients wanting CPR (Miller et al 1992, Robertson 1993, Kerridge et al 1999). Perhaps the most dramatic result is from Robertson (1993) who found that 97% of his patients would want CPR in their current state but only 10% would want it if they were ‘senile and no longer able to recognise your family and friends’. Reductions in wish for CPR with a hypothetical physical disability are generally not so low (Kerridge et al 1999, Everhart and Pearlman 1990).

Very few people want resuscitation with advanced cancer or permanent unconsciousness (Kerridge et al 1999). However, a study from the USA shows that a small subsection of patients would accept enormous disability. Frankl et al (1989) interviewed 200 inpatients in California and found that 90% would want life-support if they would be returned to current health, 30%
still wanted CPR if they would become non-independent upon discharge, 16% would still accept it if they had a ‘hopeless prognosis’ and 6% if they would ‘remain comatose’.

The problem with this kind of study is it they moves away from contemporaneous and relevant decisions to hypothetical ones ie it really assess advance directives rather than current opinion. This move has implications for accuracy as well as competency (see chapter 1.4.2).

1.3.1.3 Qualitative studies of patients’ views about CPR

Qualitative research in general

Qualitative research developed in the arena of social sciences out of a desire to explain phenomena that cannot be measured by traditional quantitative techniques. The distinction between qualitative and quantitative methodology is not one of scale (although usually quantitative studies use larger populations) or subjectiveness (although quantitative studies are often seen as more objective). The essential difference is in the nature of the question being asked. Qualitative research is better suited to answer questions such as how? or why? than to describe associations or outcomes. Quantitative techniques are designed to obtain facts and do not suit the analysis of perceptions, ideas, intentions or beliefs. Finally qualitative research techniques aim to integrate events in the context they occur and to take account of multiple variables. By contrast quantitative work is better suited to control for or decontextualise intervening factors.

It has been suggested that qualitative research in medicine might complement quantitative research in three different ways (Pope and Mays 1995).

- qualitative work can be valuable as a preliminary to quantitative data collection eg focus groups might help clarify the areas that should to be covered or appropriate language to use in a questionnaire study
- qualitative work can provide an alternative approach to a problem. Added to quantitative work a multi-level analysis with a wider picture can be obtained
- qualitative studies can explore complex phenomena not amenable to quantitative work.

Table 1k compares quantitative and qualitative research methodology.
Table 1k A comparison of qualitative and quantitative research techniques

(Streubert and Carpenter, 1999)

<table>
<thead>
<tr>
<th></th>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Researcher status</td>
<td>Objective neutral observations</td>
<td>Subjectivity of observer acknowledged</td>
</tr>
<tr>
<td></td>
<td>Researcher independent of study</td>
<td>Researcher part of process</td>
</tr>
<tr>
<td>Hypotheses</td>
<td>Pre-established theory generated by researcher to be proved/disproved</td>
<td>Research design guided by initial hypotheses but specific hypotheses derived from data</td>
</tr>
<tr>
<td>Analysis</td>
<td>One truth</td>
<td>‘Truth’ derived from a specific point of view</td>
</tr>
<tr>
<td></td>
<td>Statistics, summaries</td>
<td>Logical reporting</td>
</tr>
<tr>
<td></td>
<td>Prediction / Control</td>
<td>Description, understanding, interpretation, explanation</td>
</tr>
<tr>
<td>Subjects</td>
<td>Random selection/series</td>
<td>Purposeful selection</td>
</tr>
<tr>
<td></td>
<td>Controls</td>
<td>Principal of statistical control inappropriate</td>
</tr>
<tr>
<td>Sample size determined by</td>
<td>Statistical power</td>
<td>Sample range determined</td>
</tr>
<tr>
<td></td>
<td></td>
<td>theoretically</td>
</tr>
</tbody>
</table>

Research questions suitable for qualitative research can be categorised as…

1. **Exploratory** – investigating a poorly understood area to identify categories of meaning and generate hypotheses
2. **Descriptive** – document and describe a phenomenon
3. **Explanatory** – explain patterns and identify plausible relationships within a phenomenon.

Quantitative research hypotheses must be specified in advance. In qualitative research an exploratory analysis may be used to generate hypotheses which can then be tested iteratively (analytical deduction). There are many different types of qualitative methodology and the specific collection methods, sampling procedures and interpretive strategies are used to create unique question-specific design that evolves throughout the research process (Crabtree and
Millar 1999). Good qualitative methodology is flexible and can be modified to be responsive to the particular situations as they arise in real life.

The classification of different types of qualitative research can be confusing but the following comprise some of the commoner types.

- **Ethnography** is rooted in the tradition of anthropology. Ethnographic research is used to describe and explain human culture. It may be used in health care to understand the influences of a particular culture on health care experiences.

- **Phenomenology** is allied to the theory of philosophy. It seeks to explore the real life experience of an individual and attempts to discover the meaning of a given situation for that person.

- **Grounded Theory** was developed as a research method by Glaser and Strauss in 1967. A grounded theory can be defined as ‘one that is inductively derived for the study of the phenomenon it represents’ (Streubert and Carpenter 1999, Strauss and Corbin 1990). The theory is developed as the data is collected and analysed ie the researcher does not begin with a theory. The sample size cannot therefore be pre-determined and the researcher must analyse data as it arrives.

The following are features of a qualitative research project.

**Sampling**

Methods of sampling should generate raw data that truly represents the phenomenon that is being studied. It is rarely useful to sample by random selection as in quantitative research because the aim is not to generalise to a population statistically. In qualitative research the sampling method is usually ‘purposive’ (ie sample based on known characteristics or experiences). The criteria for selection should still be made explicit and the influence of the selection process should be considered. Types of sampling strategy include

- **Opportunistic** (sample chosen as opportunity arises)
- **Snowballing** (where one respondent is asked to identify others who meet the same study requirements)
- **Complete collection**
- **Extreme case sampling**
- **Typical case sampling**
• Maximum variation sampling
• Sequential sampling (as in grounded theory)

The sampling units are usually human and may vary from a single person (case study) to a whole population (e.g., women who smoke during pregnancy). However, units may also be non-human for example
• events (such as episodes of treatment)
• time periods
• interactions
• organisations
• acts
• statements
• documents

Generally, sample size is smaller than in quantitative research and is often theoretically determined by the subject studied and the methods used. The sample size in qualitative research is not necessarily determined in advance (this is especially true of grounded theory where sample size is determined by ‘saturation’). Saturation occurs when no new themes are identified in consecutive units. It is sometimes appropriate to ‘repeat sample’ with the same subjects if the research questions are refined or widened.

Data Collection Techniques
These include
• Observation – including field notes (of structured or unstructured situations), recordings (videos, tapes), and self-recording (diaries and journals)
• Interviews – structured, unstructured or semi-structured. Interviews are usually of individuals but groups of people can be used e.g., in focus group work
• Material – such as archives, documents, artefacts, films etc
• Questionnaires – more commonly used for quantitative research but may be suitable for some simple well-defined objectives

Investigator Involvement
The investigator is an integral part of the data collection and will, consciously or unconsciously, influence the data (not an external passive observer as in traditional experimental work).
Analysis of qualitative data should acknowledge and assess this influence. The investigator must be reflexive and make attempts to minimise their own views and influences during data collection. Awareness of their own pre-conceptions makes it easier to avoid bias during the study. Trust and rapport between interviewer and informant is vital to ensure a full and frank interview.

**Analysis of Interviews**

Interviews are usually transcribed for analysis purposes but during analysis the written data should be interpreted alongside any field notes which record non-verbal communication. Even aspects of verbal communication can be lost in the transcription process eg voice tone can convey emphasis, sarcasm and humour.

Although a computer programs can be used to manipulate large amounts of data analysis is done by ‘hand’. There are many types of analysis but the method chosen should be transparent and rigorous.

Content analysis is one of the simpler types of analysis and utilises a predefined classification code to count occurrences within each category. By contrast in grounded theory analysis is done as the data arrives and initially the data is coded and clusters of concepts are formed. These clustered concepts evolve into themes and further exploration and evaluation of themes then allows a unifying theory to be developed.

Any conclusions should explain core variables (which occur frequently and which link and explain much of the variation in the data) but an attempt should also be made to look for ‘deviant’ cases where the conclusion does not hold. It is approved practices to check with participants to see if the analysis is comprehensible to them. The status of the data should be recognised as fact, respondent perception or perhaps most commonly the way in which respondents choose to relay the account to the investigator. The latter case acknowledges the influence of the investigator in the data collection.

**Reporting**

The report developed should be supported by original data from the ‘field’ to show the relationship between the evidence and the conclusions. The effectiveness of such research rests on the power to convince, on the understanding demonstrated and on the imagination and
empathy demonstrated. Much has been written on judging the validity of qualitative research and various criteria for judging such research have been generated (Pope and Mays 2000)

**Qualitative research pertaining to CPR**

Most attempts at reporting factors influencing patients' views about CPR in the medical literature are quantitative. For example Kerridge et al (1998) used a written questionnaire and asked patients to rank eight factors in order of importance for use in CPR decision-making. This is not a qualitative method since ideas are put into patients' minds ie it is hypothesis-driven.

Sayers et al (1997) quote some unsolicited reasons for decisions about CPR given by 19 patients during tape-recorded interviews. Quotes such as "I live alone. When my time has come I want to go. At my age and with the pain, there's no need to come back" and "I would want to be brought back. Where there's life there's hope even if someone is in a coma". In another study patients with a DNR order in the USA were asked why they did not want to be resuscitated. Half the patients offered quality of life reasons such as 'I don't want to live an abnormal life hooked to machines' while others said 'age', 'God's will' and 'no reason' (Stolman et al 1990). Although these two studies collect data which might be seen as qualitative the authors do not appear to have explored these opinions further and do not suggest any unifying theory of how decisions are made.

There is one study that employs established qualitative research techniques in interviews with ten patients hospitalised on a coronary care unit in Wisconsin, USA (Larson 1994). Three of their patients did not want CPR and 6/10 had made advance directives. The main findings were;

- patients did not want to live in a vegetative state
- patients wanted to know the truth about their illness
- patients saw the doctor as an information provider
- patients believed that the decision about CPR should be theirs and their family's.

It is surprising that the authors report that all the ten patients expressed very similar views. Although this may represent bias in the study reporting it is more likely that the sample contained patients of similar background and therefore views.
1.3.1.4 Patients’ knowledge about CPR

Elderly patients in the UK have poor knowledge about CPR. In two British studies 47% and 53% of patients interviewed had never even heard of the technique (Gunasekera 1986, Liddle et al 1994). It appears likely that the Americans have superior knowledge of CPR compared with the British. Schonwetter et al (1996) found that 92% of subjects in a retirement community in Florida knew the purpose of CPR. Miller et al (1992) and Murphy et al (1994) also found a good general knowledge in an elderly American community-dwelling population. As education and patient involvement in decisions becomes commoner it is likely that future cohorts of elderly patients will be better informed.

It is well established that the majority of patients throughout the world get their knowledge about CPR from television, especially hospital dramas (Mead and Turnbull 1995, Schonwetter et al 1991, Miller et al 1992, Kerridge et al 1999). Television depicts CPR in a very positive light and this may account for some public misconception. Diem et al (1996) assessed the outcome of CPR attempts as depicted in three major American dramas between 1994-1995; there was a 75% initial success rate and a 67% survival to discharge.

This exposure to inaccurate media reporting of CPR is likely to be responsible for the consistent finding that patients overestimate success rates. Prior to education patients estimate success rate of CPR at between 41% and 62% (Murphy et al 1994 – 41%, Schonwetter et al 1991-54%, Miller et al 1992-62%, Kerridge et al 1999 - 99% estimated success better than 30%). This is at least five times the real survival rate (see chapter 1.2.1.1).

Patients’ knowledge of CPR can be significantly increased by education (Schonwetter et al 1991, Kerridge et al 1999). But the effect is only moderate (15% still had zero knowledge scores after education (Schonwetter et al 1991)) and knowledge is not retained well (Sayers et al 1997). Patient education is effective whether the information is given verbally, in a written format (Kerridge et al 1999) or even by videotape (Siegert et al 1996).

How Information about CPR Affects Patients’ Views

Where patients are educated about CPR and particularly the disadvantages and low success rates a proportion of them will change their minds about whether they would wish to have it themselves. Schonwetter et al (1991) found that 5 of 64 (8%) changed views about CPR after
education but the direction of change was mixed so that no significant trend was detected. However, the majority of studies has shown patients become more negative about CPR after education about the procedure and success rates (O’Brien et al 1995, Morgan et al 1994, Hui et al 1997, Kerridge 1999, Miller et al 1992).

Miller et al (1992) found that acceptance of CPR dropped from 81% when given a 90% chance of survival to 38% with a more realistic 10% chance of survival estimate. In a study by Morgan et al (1994) those wanting CPR dropped from 41% to 22% after a probability of survival of 10-17% was discussed. This study of 371 retired Americans went on to determine the minimum survival rate that made CPR acceptable by using visual representations of survival rate. There was quite a range of opinion; 25% didn’t want CPR regardless of survival rate, 33% required a 50% or greater survival rate, 20% were happy with a 10% survival rate and 10% would still accept CPR with a 1% survival rate. Watson et al (1997) interviewed 70 patients twice during a hospital admission (mean of 18 days apart) and found that 12 (17%) had changed their minds about CPR. These patients had significantly higher levels of knowledge about CPR at their second interview and it may be that they had had time to digest this information before coming to a decision.

In order to make a meaningful decision about CPR (ie be competent) patients should have been given sufficient education about advantages and disadvantages of the technique as well as realistic success rates.

1.3.1.5 Patients’ views on who should make decisions about resuscitation

Table 11 and Im summarise the results from studies that asked patients who should decide about CPR. It is hard to compare these studies since they ask different questions. Some assess whether patients favour involvement with CPR decisions while others ask who should be the final decision-maker. A larger percentage of patients favour communication with doctors than actually wish to be in charge of the ultimate decision. For example Mead and Turnbull (1995) found that while 86% were willing to be consulted only 19% felt that they should make the final CPR decision. It may be that patients are expressing a wish to be kept informed rather than a wish to influence treatment. This might also explain why studies that encourage or allow patients to nominate more than one decision-maker seem to indicate acceptance of shared decisions.
More recent studies, those from USA, and those which include younger patients report higher rates of patients wishing to be responsible for CPR decisions. The American population differs from the UK in having higher rates of knowledge about CPR and having more frequently been involved in discussions about CPR (see section 1.3.1.3). For example Frankl et al (1989) found that 16% of the patients they questioned had discussed life-support with their physician. There is a cultural leaning towards Americans desiring higher rates of patient involvement in decisions about CPR.

By contrast, in the UK it is remarkable how many patients are happy for others, usually doctors, to make the final decision (O’Keeffe et al 1993, Gunasekera et al 1986, Liddle et al 1994, Mead et al 1995). This finding would argue against many policies and guidelines that put the patients in charge of such decisions. In addition, doctors seem to want patients to be involved in decisions more often than the patients themselves do. In one study from Australia 55% of patients felt they should be the main decision-maker while 29% felt this should be the doctor. In contrast 85% of the doctors interviewed in the same study felt that the patient should decide and only 14% felt that it should be the doctor’s decision (Kerridge et al 1998).

Whilst most authors found that the majority of patients are happy to be consulted about their views on CPR it is notable that there is a significant minority of patients who do not want this. Frankl et al (1989) found that 30% of those with a terminal illness and 41% of patients without terminal illness did not want to discuss their views about life support. Mead and Turnbull (1995) found that 14% of patients and 39% of relatives did not want to be consulted and Stolman et al (1990) found that 24% of patients who had a DNR order did not wish to be consulted. It is possible that this subsection of patients is the one most likely to suffer harm from such discussions (Stolman et al 1990, Schade and Muslin 1989).
Table 11 Studies of patients’ views of who should decide about CPR – UK

<table>
<thead>
<tr>
<th>Study</th>
<th>Patient Sample</th>
<th>Should you be consulted?</th>
<th>Who should decide?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gunasekera et al 1986</td>
<td>134 patients on geriatric admission wards UK</td>
<td>80% happy to discuss views</td>
<td>32% Self</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>57% Doctors</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>11% Relative</td>
</tr>
<tr>
<td>O’Keefie et al 1993</td>
<td>100 Geriatric inpatients and outpatients Ireland</td>
<td>39% favored routine discussions</td>
<td>5% Self</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>69% Doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>18% Relatives</td>
</tr>
<tr>
<td>Morgan et al 1994</td>
<td>100 inpatients mean age 80 UK</td>
<td>89% felt they should be consulted</td>
<td>19% Self</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>64% Doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>14% Relative</td>
</tr>
<tr>
<td>Hill et al 1994</td>
<td>100 medical inpatients UK</td>
<td>100% favored discussions</td>
<td>59% Self with Doctor</td>
</tr>
<tr>
<td>Liddle et al 1994</td>
<td>100 consecutive patients on an acute geriatrics ward mean age 82 UK</td>
<td></td>
<td>28% Self</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>43% Doctor</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>34% Shared between patients/doctors /relatives</td>
</tr>
<tr>
<td>Mead et al 1995</td>
<td>180 patients on geriatrics, orthopaedics and vascular surgery wards and outpatient clinics (mixed ages) UK</td>
<td>Ranked order Doctor &gt; Self &gt;Relative Younger patients gave lower rating to doctors</td>
<td></td>
</tr>
<tr>
<td>Mead and Turnbull 1995</td>
<td>100 geriatric inpatients UK</td>
<td>35% favored routine discussions</td>
<td>45% Relatives to be consulted</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>23% against Relatives being consulted</td>
</tr>
</tbody>
</table>
Table 1m International studies of patients’ views of who should decide about CPR

<table>
<thead>
<tr>
<th>Study</th>
<th>Patient Sample</th>
<th>Should you be consulted?</th>
<th>Who should decide?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lo et al 1986</td>
<td>152 Outpatients mostly over age 65 USA</td>
<td>68% favored discussions 53% wanted doctors to initiate</td>
<td>If incompetent 79% Relatives 13% Doctors</td>
</tr>
<tr>
<td>Stolman et al 1990</td>
<td>97 Competent patients with DNR order USA</td>
<td>67% Shared decision 13% Self alone 10% Doctor alone 8% Relative alone</td>
<td></td>
</tr>
<tr>
<td>Schonwetter et al 1991</td>
<td>64 Geriatric Outpatients USA</td>
<td>92% favored routine discussions</td>
<td>88% Self with doctor 73% Self with relative</td>
</tr>
<tr>
<td>Miller et al 1992</td>
<td>248 Elderly outpatients USA</td>
<td>45% Self 27% Doctor 51% Relative/Spouse (multiple responses allowed)</td>
<td></td>
</tr>
<tr>
<td>O’Brien et al 1995</td>
<td>421 Nursing home residents USA</td>
<td>69% Doctor ‘should make most important medical decisions’</td>
<td></td>
</tr>
<tr>
<td>Watson et al 1997</td>
<td>95 Elderly inpatients New Zealand</td>
<td>75% Self 22% Doctor 3% Relatives</td>
<td></td>
</tr>
<tr>
<td>Kerridge et al 1998</td>
<td>152 Inpatients mixed ages Australia</td>
<td>30% favored routine discussions</td>
<td>80% Self 80% Doctor 57% Partner 36% Nursing staff (&gt; 1 answer possible)</td>
</tr>
</tbody>
</table>
Table 1m (continued) International studies of patients’ views of who should decide about CPR

<table>
<thead>
<tr>
<th>Study</th>
<th>Patient Sample</th>
<th>Should you be consulted?</th>
<th>Who should decide?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hui et al 1997</td>
<td>382 Residential home Hong Kong</td>
<td></td>
<td>47% Doctor alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>19% Self alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>6% Relative alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>33% Combination</td>
</tr>
<tr>
<td>161 Elderly inpatients Hong Kong</td>
<td></td>
<td></td>
<td>35% Doctor alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>41% Self alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1% Relative alone</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>59% combination</td>
</tr>
</tbody>
</table>

1.3.1.6 Stability of patients’ views about CPR

Everhart and Pearlman (1990) interviewed twenty patients within 24 hours of transfer out of an intensive care unit and one month later. 85% had stable views about resuscitation and 70% had stable views of resuscitation with mechanical ventilation between the two interviews (Kappa values 0.47 and 0.44). The 15% who changed their minds about resuscitation all became more negative about treatment at follow up but the 20% were more positive about resuscitation with ventilation at follow up. This was a highly selected sample; during the study period only 30 out of 80 survivors of ITU were recruited and only 20 completed a follow-up interview. The authors conclude that ‘life-sustaining treatment preferences solicited during a serious illness are reliable and may be used in decision-making when a patient becomes unable to communicate’. This seems a rather bold conclusion when a significant minority of a highly selected group changed their mind over a short period of time.

In another study of stability of views 100 geriatric patients were questioned about CPR on admission to hospital (Potter et al 1994). Unfortunately the authors only re-interviewed the 8 (8%) patients who refused CPR on admission. Three of these eight patients were willing to accept CPR on recovery. Potter et al (1994) make the opposite conclusion that sick patients do change their minds about treatment.
Watson et al (1997) interviewed 70 patients twice during a hospital admission (mean of 18 days apart) and found that 12 (17%) had changed their minds about CPR. In a similar study by Sayers et al (1997) 19 patients with mean age 83 and AMTS>7/10 were recruited. Six patients refused to be re-interviewed and 2 of the remaining 13 (15%) had changed their minds one week later.

All these studies are small but it can be concluded that a significant minority of patients do not hold fixed views about CPR. The studies were conducted during an acute medical illness and it is possible that in stable health conditions there would be less variability of views (see discussion in section 1.4.2.3)
1.3.2 Relatives’ Views on Resuscitation and Proxy Decision-Making

Relatives, or other types of proxy decision-maker, can make decisions on one of two bases;

- Substituted Judgement – in which the proxy attempts to replicate the decision that an incompetent patient would make were he or she able to do so. The proxy attempts to ‘stand in the shoes’ of the incompetent patient.

- Best Interests Decision – in which the proxy attempts to determine what would be in the best interests of the patient. The proxy is exerting their social right to decide what is best for the patient (Emanuel and Emanuel 1992).

Ethically, the substituted judgement promotes autonomy whereas the ‘Best Interests’ model is more paternalistic. In practice the distinction is blurred and both methods will often yield the same answer.

In the UK relatives have no legal right to make medical decisions (except for minors) and there is currently no provision to appoint proxies in medical enduring powers of attorney. By law the physician in charge is responsible for making a best interests decision for an incompetent patient (see section 1.1.3.1). Despite this, doctors do frequently consult relatives, usually to gain insights into the patient’s function and viewpoint, ie more along the substituted judgement line.

Relatives seem to want to be involved in decisions about CPR more frequently than patients want them to be. One study from the UK in which 100 competent patients and their next of kin were interviewed found that 89% of relatives felt they should be consulted about CPR decisions and 37% of the group felt that decisions should involve them but not the patient. By contrast, over a third of the matched group of competent patients felt that they should be consulted but not the relative (Morgan et al 1994).

Substituted Judgement

Ethical justification for proxies to make substituted judgement relies on them being able to predict accurately what the patient would have chosen thereby promoting patient autonomy. Unfortunately there are many carefully conducted studies that provide evidence that proxy decisions correlate with patient decisions little better than would be expected by chance alone (Frankl et al 1989, Seckler et al 1991, Uhlmann et al 1988). These very similar studies assessed the concordance of patients’ and proxies’ views about CPR in current health and hypothetical
ill-health scenarios using Kappa coefficient. Kappa values were not significant in the majority of scenarios presented and the authors conclude that proxy decisions are unreliable.

Gerety et al (1993) and Seckler et al (1991) found that relatives do not systematically err in either withholding or providing treatment. Uhlmann et al (1988) found that spouses consistently overestimate patients' preferences for CPR.

There is evidence that patients rarely discuss their views about life-sustaining treatment with their families or else have very indirect or general discussions which are unlikely to be of help in the future (Emanuel and Emanuel 1992). O’Brien et al (1995) found that of nursing home patients able to nominate a proxy decision-maker only 31% had ever discussed their treatment preference with that individual. The introduction of detailed advance directives and formal appointments of enduring power of attorney for health care may improve the accuracy of proxy decisions.

Patients seem confident that their proxies will accurately predict their views (Seckler et al 1991). Emanuel and Emanuel (1992) suggest that proxy decisions would be more legitimate if patients are educated and specifically acknowledge that their proxy might not make the same decision as them at the time a proxy is formally appointed.

Best Interests Decisions
Proponents of proxy decision-making believe that the closeness of proxies puts them in a better position to make a best interests decision for the patient than impartial observers such as doctors. Furthermore society does grant that the connection between family members gives them some priority in decision making. However, in the UK especially, there has always been anxiety about granting legal right to the family to decide about its incompetent members. Another advantage of proxy best interests decisions is that it is a simple and practical way of making decisions for incompetent patients (Emanuel and Emanuel 1992).

In order to judge what is in the best interests of the patient regarding life-sustaining treatments proxies have to consider quality of life. A review of this area by Sprangers and Aaronson (1992) reveals that ‘significant others’ underestimate quality of life for patients with chronic disease. They are particularly bad at estimating aspects of quality of life which are not concrete and
observable (e.g., functional status is better estimated than psychological distress). It is possible that this underestimation of quality of life may lead to bias in 'best interests' decisions.

Apart from the inaccuracy of their decisions, other concerns about relatives making decisions include:

- **Possible psychological stress and guilt.** There is evidence that people are more likely to request treatment for a loved one that they would be to accept that treatment for themselves (Darzins 1993) and this may well be to avoid the responsibility of making decisions which are perceived as leading to the death of a loved one.

- **Conflict of Interests.** Patients are usually emotional and financial burdens on their proxies which might exert an improper influence. It is also important to realise that proxies are often carers and, as such, decisions to prolong life will directly affect their role as a carer. This may influence views either for or against treatment but also lends some legitimacy to their decisions (Emanuel and Emanuel 1992, Bruce-Jones 1996).

**Relatives Witnessing Resuscitation**

Whether relatives should be allowed into the resuscitation room to witness CPR on their loved-ones is a modern and highly controversial issue. Traditionally relatives have been asked to wait outside the area in which CPR is taking place but in the late 1990s it was proposed that it might be beneficial for relatives, and possibly even patients, if they were allowed to remain and witness the procedure (Wise 1996, Robinson et al 1998).

Many doctors oppose relatives witnessing resuscitation on the grounds that:

- it may cause additional suffering to relatives (Wise 1996),
- it adds additional stress to staff and may impair the usual functioning of the CPR team. In particular, there are concerns that it might cause futile resuscitation to continue longer for fear that the relatives may feel that not enough effort was made (Wise 1996),
- it invades the rights of privacy of the patient who is unable to give consent to their being present at the procedure (Stewart and Bowker 1997).

There is little evidence to suggest what the average relative would wish to witness CPR or whether patients really want their relatives present during the procedure. A group from Cambridge randomised relatives to be invited to witness CPR in a relative. Eight relatives who witnessed CPR reported no adverse psychological outcomes and three survivors of CPR did not
object to their relatives being present (Robinson et al 1998). From this very small and inadequately matched pilot study the group concluded that it was no longer appropriate to exclude relatives from the resuscitation room.
1.3.3 Health Care Professionals’ Views About CPR

It would be expected that medical staff, through their personal experience of CPR would be more negative about CPR outcomes than patients. However the high technology excitement coupled with the extensive training now received (see section 1.1.1) may well have the opposite effect. Only a quarter of Australian health care professionals gave a reasonable estimate of in-hospital mortality after CPR (Kerridge et al 1999). In another questionnaire study from London, medical and nursing staff overestimated survival following CPR with mean estimates of 21% in UK and 31% in USA. Doctors who had attended more than 25 CPR attempts were more realistic and there was an inverse relationship between expectation of survival and number of arrests attended (Wagg et al 1995). Miller et al (1993) found that American physicians were similarly over-optimistic about CPR outcome particularly following severe infection, metastatic cancer and dialysis which are all known to be conditions with very low survival rates after CPR.

Kerridge et al (1999), Hauswald and Tanberg (1993) and Darzins (1993) have observed that physicians are much less likely to accept aggressive treatment for themselves in a hypothetical scenario than patients given the same scenario. This might be due to a natural tendency to assign higher levels of treatment to others than to oneself rather than an influence of medical experience. There is evidence that non-medical proxies also tend to choose more treatment for another than they would choose for themselves (Uhlmann et al 1988, Darzins 1993).

Miller et al (1993) found that 45% of physicians in USA had discussed their own views about life-sustaining treatment with relatives, 3% with their personal physician and 10% had formalised their wishes in a living will or endurable power of attorney for healthcare. Unfortunately this survey did not inquire what the views were.

Role of nurses

Although nurses are very involved in implementing CPR decisions they traditionally play a small role in the process of decision-making. The role of nurses is changing away from unthinking carers towards independent practitioners and their role in CPR decisions might well be growing. One recent study found that 36% of patients and 37% of healthcare professionals felt that nurses’ opinions were important in CPR decisions (Kerridge et al 1999) but most of the older studies do not even include ‘nurses’ as an option in their questionnaires. Kerridge et al (1999) suggest that the fact that many nurses are involved in each patient and that they work in shifts may present barriers to nurses becoming involved in their patients’ CPR decisions.

In an American study of DNR implementation there was documented evidence that a nurse had taken part in DNR discussions in 10% of DNR orders. However, the authors comment that in all cases the nurses had strong feelings and that in 67% of cases they had actually been involved in making the decision (Bedell et al 1986). A study from The Netherlands found that nurses had been consulted about CPR decisions in 70% of cases (van Delden et al 1993). It is likely that nurses’ involvement in such decisions is significant but ‘unseen’ and unrecorded.

Finally, due to their proximity to patients, nurses are responsible for raising the alarm for the majority of cardiac arrest calls and therefore are in a position of some power. Aarons and Beeching (1991) sent a questionnaire to doctors and nurses on all wards in a Liverpool hospital and found that there was agreement between doctors and nurses over whether a patient should receive resuscitation in 210/241 (87%) of cases. The nurses were also asked whether they would call the crash team and in 26 cases they said they would not despite the fact that there was no formal DNR order documented in the medical notes. This survey was conducted over a decade ago and before there was a hospital policy on DNR, but it clearly demonstrates that nurses had strong views about CPR which they were prepared to act on independently.
1.3.4 How CPR Decisions Are Made in Practice

A discussion of Futility

The word ‘futility’ is used with two quite different meanings in the literature (Curtis et al 1995, Mello and Jenkinson 1997, Tomlinson and Czlonka 1995). The first will be called ‘medical futility’ in this text and is the situation in which the patient’s clinical condition is such that the chance of survival after CPR is so small that CPR is not deemed an effective treatment. ‘Medical futility’ is usually determined by the medical profession independently and discussion with the patient or family is aimed at obtaining an understanding of the decision (Tomlinson and Brody 1988, BMA statement, Stewart et al 1996). A discussion of medical futility and its estimation is found in sections 1.2 and 3.

The second use of the word is more qualitative and involves a decision about whether CPR has a net benefit for the patient’s quality of life. It relates less to the success rate of the treatment and more to whether the treatment is felt appropriate given the patient’s overall situation. Where quality of life is very poor, eg for patient in persistent coma, is the goal of extending that life by providing CPR in the patient’s best interest? As this involves value judgements it is much harder for the doctor to determine in isolation and usually involves more time-consuming discussions with the patient, proxy or carers involved (BMA statement, Mello and Jenkinson 1997, Tomlinson and Brody 1988).

Tomlinson and Brody (1988) subdivide CPR decisions based on poor quality of life into two further categories; those where pre-arrest quality of life is unacceptable and those where quality of life that is likely to follow resuscitation is unacceptable. They make the distinction because in the former case withholding and withdrawing other treatments aimed at extending life would also be appropriate whereas the latter case involves a change in quality of life around the time of CPR and therefore such decisions are not applicable for other treatments. Although this subdivision makes theoretical sense there is little evidence to help physicians predict which patients will undergo a change in quality of life due to CPR and therefore pre-arrest quality of life is the only really useful guide for these decisions in practice.
There is considerable overlap between these two futility definitions since many medical illnesses influence quality of life (and therefore qualitative futility) as well as the chance of surviving CPR.

The two concepts of futility and patients opinions are often intermingled. Curtis et al (1995) examined DNR orders in two hospitals in Seattle by telephone interviews with residents. He found that whilst ‘futility’ was the rationale for the 91/145 (63%) of these orders patient/surrogate opinion played a part in 88% of cases ie in only 12% of DNR orders was the rationale solely medical futility.

The ethical justifications for withholding medically futile CPR include (Tomlinson and Czlonka 1995);

- principle of non-maleficence demands that physicians decide which treatments are likely to work. Being forced to perform treatments they feel are not beneficial may be contravening this principle,
- patient autonomy can only really be exerted when there is a choice to make. If there is effectively no real option then it is deceptive for the physician to offer a ‘bogus’ choice,
- the patient’s right to autonomy is limited by other people’s right to just use of resources and allowing futile treatments might ‘waste’ resources.

Medical literature in the UK seems much more willing to utilise the concept of ‘medical futility’ than in the USA. For example Tomlinson and Czlonka wrote from USA in 1995 that ‘Futile resuscitation… is the only intervention that requires consent for an order to withhold it; other futile interventions are typically not offered or discussed.’ This difference between the cultures is likely to be due to the greater acceptance of a paternalistic medical system in the UK compared with the American emphasis on patient autonomy (Bayliss 1982, Currie 1988).

In a qualitative study of decision-making by Mello and Jenkinson (1997) the attitudes of health care workers in the USA and the UK were compared. There were physicians on both sides of the Atlantic who felt obliged to provide medically futile resuscitation if the patient requested it and those who felt equally strongly that they were not obliged either medically or morally to provide futile treatment. Interestingly junior doctors in the UK believed they had a moral obligation to provide CPR if the patient wanted it where the older physicians were much happier to make a
medical futility decision. Whether this is due to confidence in diagnosing medical futility or reflects changing social attitude is not clear.

**Involving Patients in DNR Decisions**

It is clear that patients are often incompetent to be involved in CPR discussions at the time they are initiated (see section 1.3.1.1). Three reasons why physicians may avoid discussions of CPR with competent patients have also been identified;

- the physicians themselves find discussions uncomfortable. One study found that 30% of physicians admitted to being uncomfortable discussing CPR with patients (Stolman et al 1990).
- physicians fear their patients find discussions uncomfortable or will be adversely affected (Bedell and Delbanko 1984, van Delden et al 1993). Schade and Muslin (1989) in their descriptive report of seven patients who were adversely affected by discussions of CPR suggest that physicians should take into account their knowledge of the patient’s ability to cope with such discussions and the particular doctor-patient relationship. Furthermore information should be given incrementally and ongoing discussion should be guided by the patient’s reactions.
- physicians feel it is not necessary because treatment is medically futile (see above).

Stewart et al (1996) used the medical futility concept to assess a series of 128 elderly medical inpatients (mean age 84). They found that 41 (32%) of patients were judged incompetent and 39 (30%) scored >4/25 on a PAM (ie were judged medically futile). They concluded that only 53 (41%) of all their patients should be involved in DNR discussions. 29 (23%) of the patients had a DNR order entered in their notes and of these only 17% were judged capable of being involved in such discussions. Until the late 1990’s many authors advised doctors that it was not necessary to discuss CPR with patients or relatives where a DNR order was made on the grounds of medical futility (Stewart 1995, Stewart et al 1996, Schade and Muslin 1989, Blackhall 1987). This view is now changing and the latest suggestion from the BMA advises that DNR orders are routinely discussed with all competent patients and with families where the patient is not competent (BMA guidelines).

Where patients are not competent to be involved in discussions then the need to involve them is removed. It is possible that DNR orders are postponed either consciously or unconsciously until
the patients’ condition has deteriorated so doctors and or relatives can make the decision without such difficult discussions. Few would admit to this practice but Bedell et al (1986) found that the patient was involved in only 22% of DNR orders, usually because the patient was incompetent by the time the order was made (mean of 7 days after admission). They calculate that over 80% of these patients had been competent at admission and had deteriorated. Furthermore, in five out of 389 DNR orders the patient had requested CPR and the DNR order had been instituted after they had become unresponsive. Bedell et al (1986) argue that CPR status should be discussed earlier in the hospital stay.

Both doctors (Miller et al 1993) and patients (Lo et al 1986) believe it is the doctor’s responsibility to initiate resuscitation discussions with patients.

In a comparative study by Mello and Jenkinson (1997) American doctors felt a greater responsibility to talk to patients about their CPR status and never wrote DNR orders without this discussion. The British doctors and nurses were familiar with DNR orders entered without consultation. Given this it is a little surprising that American physicians were found to be much more likely to overrule a DNR order than the UK doctors were. All of the UK doctors and nurses stated that they always followed DNR orders. In contrast 5/7 of the American nurses and 7/10 doctors either had or could envisage overruling a DNR order that they felt was inappropriate. This finding was confirmed by Miller et al (1993) who found that only 83% of Doctors in Ohio would honor a DNR order if the patient was not terminally ill.

Further confirmation of the situation in USA comes from a study by Swig et al (1996) which reported that in San Francisco it was common for patients or their surrogates to be offered CPR when it was clinically futile. 36/69 (52%) of the physicians interviewed felt that patients should be offered CPR regardless of potential medical benefit despite a hospital resuscitation policy that specified that it was not necessary to do this. It is not clear if the doctors felt an ethical obligation to offer CPR or whether they were afraid of the potential medico-legal ramifications of not doing so.

Throughout the world surveys suggest that doctors feel patients should be involved in CPR decisions (Kerridge et al 1998 – 98% believed patients’ views important, Miller et al 1993 – 98% felt patients’ views important, Bedell and Delbanco 1984 - 93% patient should be consulted) but it is important to recognise that these studies do not necessarily reflect actual clinical practice.
There is evidence that patient involvement is much lower than physicians report is desirable. Bedell and Delbanco (1984) reported that while 93% of senior physicians and 100% of house officers believed that the patient should be consulted in decisions about CPR, in practice such discussions with the patient had occurred in only 13% of arrests. Discussions with family had occurred in 22% of arrests. Patient involvement in DNR decisions after stroke is as low as 8% (Alexandrov et al 1995). Lo et al (1986) found that although 68% of the group of American outpatients favored discussions only 6% had actually had them.

O’Keefe (2001) has recently reported his attempts to discuss CPR with all patients aged over 65 admitted under his care for whom discussions about CPR might be appropriate. The main finding was that he managed to have successful discussions with very few patients. 40/65 suitable patients were excluded due to incompetence, severity of illness or severe anxiety. Of the remaining 25 competent patients 2 discussions were abandoned because the patient did not wish to continue and in six patients O’Keefe ‘did not feel comfortable raising the issue’. Overall CPR discussions were held with only 17/159 (11%) of admissions during the study period. The main barriers to such discussions were patient competence, time and environment constraints (difficulties with having sensitive discussion in crowded busy environments) and the observed or anticipated patient distress caused by ‘breach of faith’ in discussions about CPR with patients who sought reassurance. This study clearly demonstrates the practical problems of involving patients with CPR decisions.

Hospital Policy
Almost all hospitals and some departments now have a resuscitation policy but this is a comparatively new trend and it is not clear if it influences the way in which DNR orders are made. Although an audit from a district hospital in London found that introduction of a written policy for DNR orders improved documentation, communication and consultant involvement in such orders it did not answer the question of how the policy affected the type/quality of such decisions (Stewart et al 1994). Audit of how closely physicians adhered to policy demonstrated that improvement in practice that was achieved by the audit was not sustained over time (Hayes et al 1999).

Aarons and Beeching (1991) evaluated 297 patients in a Liverpool hospital at a time when it did not have a formal DNR policy and found that only 24 (27%) of 88 patients whom doctors considered ‘unsuitable for resuscitation’ actually had DNR orders. They also found that
communication between nurses and doctors and documentation of resuscitation decisions in the medical and nursing notes was extremely poor.

A much later study demonstrated that UK doctors and nurses have a good working knowledge of their hospital DNR policy but that they were not always compliant with it (Mello and Jenkinson 1997). There was a poor correlation between the policy and practice of DNR orders.

In contrast Swig et al (1996) found a very poor knowledge of resuscitation policy in a hospital in San Francisco. Only 57/69 (82%) physicians questioned knew there was a policy and of these 15% said they disagreed with it and 3 physicians were significantly misinterpreting the policy.
Chapter 1.4

Advance Directives

When making your choice in life,
do not forget to live.

Dr Samuel Johnson (1709-1784)
1.4.1 Background

1.4.1.1 Definitions
An advance directive (AD) is a statement, usually written, made by a mentally competent adult which aims to influence health care decisions in the event that in the future they are not capable of making such decisions contemporaneously (Lush 1993). Advance directives have been developed as a means of promoting personal autonomy beyond a point where the patient is not normally able to direct their health care.

ADs are also known as Living Wills since they have some similarities with financial wills but are designed to be implemented while the person still lives, albeit in a state of altered competence. The term living will is usually used to describe a fairly inflexible written document containing statements refusing life-sustaining treatment. Advance Directives can be written or verbal, do not necessarily follow a certain format and can specify the acceptance or refusal of treatment in a general or specific way.

Luis Kutner is credited with being the ‘inventor’ of AD. He proposed the idea at a pro-euthanasia meeting in 1967 (Lush 1993). The idea was quickly taken up by others and although there are still links with the euthanasia movement there are many proponents of ADs who oppose euthanasia.

ADs can be classified into two types.
Instructional directives; the majority of which specify refusal of treatments such as CPR (sometimes called advance refusals) although there is no reason why they should not contain orders to continue treatment that would conventionally be offered. They often also contain a circumstance in which the instruction is to be carried out (eg ‘If I have severe dementia then I refuse attempts at CPR’) rather than coming into force as soon as the patient is incapable. A surgical consent form may be thought of as a form of instructional directive in that it gives advance consent for a procedure to be carried out while the patient is anaesthetised (and therefore incompetent).

Proxy directives; which specify a person/persons who should make surrogate decisions about healthcare if the patient is no longer competent. This form of AD is sometimes called an Enduring Power of Attorney for Health Care since it is similar to the financial enduring power of
attorney which allows the appointment of a nominated person to control the finances of another person.

Although these two forms of directive are distinct, ADs can have an instructional component as well as a proxy directive. In this case the proxy’s job is usually to interpret and implement the instructions left by the patient.

It has been argued that oral statements should have the same ethical and legal weight as written ones but most authorities suggest a written format with witnesses is more likely to be followed (Sommerville 1995). In some parts of the world legislation demands a specific format for AD and in others the will must be witnessed by a lawyer or a physician. Several standardised forms have been developed by private groups such as ‘Let me Decide’ (Clarnette and Molloy), Joint Center for Bioethics and the Voluntary Euthanasia Society and others (Robertson 1995). Figure 1n contains an example living will format.

Figure 1n An example of an advance directive
Available from The Voluntary Euthanasia Society, 13 Prince of Wales Terrace, London W8 5PG or downloadable as a PDF file from their website http://www.ves.org.uk

LIVING WILL

TO MY FAMILY, MY DOCTOR AND ALL OTHER PERSONS CONCERNED THIS DIRECTIVE is made by me (full name in capitals)
of (address)__________________________________________________________

at a time when I am of sound mind and after careful consideration.
I DECLARE that if at any time the following circumstances exist, namely:
1. I suffer from one or more of the conditions listed in the schedule; and
2. I have become unable to participate effectively in decisions about my medical care; and
3. Two independent doctors (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment involving severe distress or incapacity for rational existence,
THEN AND IN THOSE CIRCUMSTANCES my directions are as follows:
1. that I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life;
2. that any distressing symptoms (including any caused by lack of food and fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that may shorten my life.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and I absolve my medical attendants from any civil liability arising out of such acts or omissions.
I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask my medical attendants and any person consulted by them to bear this statement in mind when considering what my intentions would be in any uncertain situation.

I RESERVE the right to revoke this DIRECTIVE at any time, but unless I do so it should be taken to represent my continuing directions.

SCHEDULE
A Advanced disseminated malignant disease (e.g. widespread lung cancer).
B Severe immune deficiency (e.g. AIDS).
C Advanced degenerative disease of the nervous system (e.g. motor neurone disease).
D Severe and lasting brain damage due to injury, stroke, disease or other cause.
E Senile or pre-senile dementia (e.g. Alzheimer’s disease).
F Any other condition of comparable gravity.

*I nominate (name in capitals) ________________________________
of (address) ______________________________________________
tel. no) ___________________________________________________
as a person to be consulted by my medical attendants when considering what my intentions would be in any uncertain situation (*Delete if not applicable)

My General Practitioner is (name of GP)
of (address) ______________________________________________
tel. no) ___________________________________________________
*Before signing this directive I talked it over with my GP (*Delete if not applicable)

Signed ________________________________
Date ________________________________

WE TESTIFY that the maker of this Directive signed it in our presence, and made it clear to us that he/she understood what it meant. We do not know of any pressure being brought on him/her to make such a directive and we believe it was made by his/her own wish. So far as we are aware we do not stand to gain from his/her death.

Witnessed by:
Signature: ________________________________ Signature: ________________________________
Name: ________________________________ Name: ________________________________
Address: ________________________________ Address: ________________________________

This directive was reviewed and confirmed by me on the following dates
(sign your name each time you enter a date)
Disease specific ADs are designed for a single disease process and therefore can be more specific in which treatments are refused and under which circumstances (Singer 1994). An HIV specific AD is available from the Terrence Higgins Trust.

Although the main aim of ADs is to enhance patient autonomy other beneficial effects may also be obtained. They may prompt discussions between doctors and their patients about terminal care and this can be reassuring for patients. They may also be helpful for doctors and relatives who would otherwise be trying to determine what treatment is in the patients’ best interests without any clear guidance from the patient.

1.4.1.2 Historical development of advance directives
During the last century there has been a social change in the developed world with increasing education levels and decreasing class system. This has led to a growth in the power of individuals to exercise their right to make life-style decisions. The change has been reflected in medicine where patients expect increasing involvement in medical decisions. Alongside this shift towards patient autonomy is a change towards increasing mistrust of the medical profession. Doctors are no longer seen as unimpeachable, all-knowing professionals. There is a massive growth rate of litigation against doctors in the USA and this trend is being repeated now in Europe. It is this potent combination of increasing autonomy and decreasing trust in the medical system that has fuelled the development of Advance Directives.

The media have played an important role in AD development by highlighting controversial test cases. In America there was the Curzon case in which a young woman was severely brain damaged after a car crash in 1983 and was having life-sustaining medical support against the wishes of the family. Eventually, after 4 years of regional and national court battles, the family won an appeal that allowed the withdrawal of artificial feeding (Lo and Steinbrook 1991). In the UK the case of Tony Bland hit the headlines in the early 1990’s. This young man suffered brain damage after being crushed in the Hillsborough football stadium disaster. The high court authorised the withdrawal of artificial feeding in 1993 (Airedale NHS Trust v Bland [1993]). These very unusual but highly emotive cases have probably heightened fear in the general public about suffering a ‘fate worse than death’ at a time they are unable to direct health care, and have therefore encouraged the growth of the AD.
Another growth area is dementia; people are living longer and the prevalence of dementia is increasing. People are more likely to be direct witnesses of their friends and relatives with dementia and may be encouraged to write an AD whilst they are still competent.

The Voluntary Euthanasia Society has been advocating AD in the UK since the 1970s. Less controversial organisations such as Age Concern, The Terrence Higgins Trust and the British Medical Association also support the concept of AD, not to facilitate euthanasia, but to improve patient autonomy.

1.4.1.3 Current legal status of advance directives in the UK, USA and Australia

There is great variation in the degree to which ADs are supported by legislation in different countries and even in different states of individual countries such as USA and Australia. Unfortunately this leads to uncertainty and misunderstanding amongst doctors and patients.

The United Kingdom

The legal position regarding AD has been set through common law. In one of the first major test cases for advance directives an advance decision was given the same legal weight as a contemporaneous one providing certain criteria were met (Re T [1992]). This case concerned a blood transfusion in a Jehovah’s Witness patient. In fact the ruling allowed for a transfusion despite an earlier refusal (because it was felt there had been ‘undue influence’) but the importance of the case is that Lord Donaldson clearly defined the criteria that dictated whether an advance refusal was legally binding (Mason and McCall Smith 1999). In such cases the patient must;

- be adult and mentally competent at the time they made the advance refusal,
- understand the nature and consequences of the refusal,
- intend the refusal to apply in the circumstances that subsequently arose,
- not have revoked the advance refusal,
- currently be incompetent to make a decision.

A year later in the very high profile Bland case an advance directive was not involved however the three judges indicated that if an AD had been available it would have been legally binding (Airedale NHS Trust v Bland [1993]).

In 1994 the High Court issued an injunction supporting an advance refusal of treatment
This case involved a schizophrenic patient who developed gangrene in his foot whilst in detention under the mental health act at Broadmoor. This case is often used to demonstrate that patients can remain competent in one area when they are incompetent in another but it also endorses the right to an advance refusal of treatment (Mason and McCall Smith 1999).

Despite recommendations by the Law Commission in 1991 that there should be some legislation about ‘anticipatory decisions’ the UK government has, so far, avoided legislating for ADs (Doyal 1995). In December 1997 the Lord Chancellor’s Department issued a consultation paper called “Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults” which covered a wide range of issues including living wills. The policy document that resulted from this process “Making Decisions” concludes that “Given the division of opinion…. and the flexibility inherent in developing case law…it would not be appropriate to legislate at the present time”.

Doctors are therefore guided by caselaw and guidelines from medical bodies such as the one from the British Medical Association (BMA) and the Royal College of Nursing (RCN) called ‘Advance Statements about Medical Treatment’. This document welcomes the development of advance directives and suggests how they might be best implemented. The following summarises the code of practice;

- An unambiguous and informed advance refusal is as valid as a contemporaneous decision
- Patients should not be able to refuse ‘basic care’ (care solely or primarily designed to alleviate pain, symptoms or distress)
- Patients cannot request treatments that are illegal (eg euthanasia) or which would not normally be offered to them
- Oral statements are valid, but written ones will supply better evidence of patients’ views
- AD should aid, not replace, open dialogue between patients and doctors
- AD should not be made at times of stress (eg shortly after admission or a terminal diagnosis) or under undue pressure (eg from relatives)
- Doctors should ensure patients are mentally competent, have sufficient knowledge of the medical condition and treatment options and that they are aware that these legally-binding documents may have disadvantages
- Special care and exceptions may arise with minors, pregnant women and those detained under the mental health act
• Storage and notification of ADs should be the patients’ responsibility but General Practitioners and Specialists treating the chronically ill should obtain copies for their medical records

• In an emergency if an AD is not provided or if there is doubt about the legitimacy of an AD then clinically appropriate treatment should be provided

• Where a healthcare professional has a conscientious objection to implementing a valid AD the care should be handed to another practitioner

In the UK there is no legal precedent for nomination of a proxy healthcare decision maker although in the “Making Decisions” policy document there is a proposal to reform The Enduring Power Of Attorney legislation to cover medical and lifestyle decisions as well as financial ones. In parallel with this a court-appointed manager could make welfare and healthcare decisions for an incompetent patient where one had not been previously nominated by a patient. This policy has not yet been debated in parliament.

The United States of America

America led the world in the introduction and legalisation of ADs. This is probably as a result of their high technology medicine, which is driven by fear of litigation and a fee-for-service system (Currie 1988). The Americans as a nation also value independent choice very highly.

The first state legislation supporting ADs was passed in California in 1976 (The Natural Death Act) and many other states passed their own version of this over the next ten years (Lush 1993). The Natural Death Act demanded a mandatory format and could only be enacted by a patient who had a terminal diagnosis. In general more recent legislation has been less prescriptive in the format and allows a greater variety of treatments to be refused under a wider variety of circumstances. From 1982 onwards states began to issue legislation for the appointment of endurable power of attorney for healthcare.

A Federal Act called ‘The Self Determination Act’ was passed in 1991 which made it a legal requirement that any patient entering a hospital, nursing home or hospice was offered the opportunity to make an AD on admission (Lush 1993, La Puma et al 1991).
Australia

There is no national legislation governing ADs. The first state to pass legislation was South Australia with the ‘Natural Death Act’ in 1983. Western Australia is similar to the UK in having very little legislation, although ADs carry weight under common law. Many of the other states have legislation for some kind of written directive or appointment of a proxy decision-maker. This is a rapidly changing area and many of these laws were passed in the last few years with further changes planned in many states. See Table 1c in chapter 1.1 for details of legislation in the different states in Australia.
1.4.2 Problems with Advance Directives

1.4.2.1 Availability of advance directives

In order to influence medical care an AD has to be readily available to the physician caring for an incompetent patient at the time when decisions about CPR etc have to be taken. Admission to hospital is often an unpredictable event and there is evidence that availability of ADs is poor. The SUPPORT study found that even after the introduction of a nurse facilitator only half of ADs that were reported to exist by patients/surrogates were lodged in the medical record by day three of admission (Teno et al 1997).

Investigators in a different study reported that ADs were “invariably” and “without exception” filed in the inactive medical notes and were therefore not available to physicians (Schneiderman et al 1992). There is also evidence that communication of DNR orders and Advance Directives in the other direction (from Hospital to community based Nursing Homes) is poor (Ghusn et al 1997).

Danis et al (1991) studied 175 nursing home patients with ADs over a two year period and found that the AD was still available in the nursing home chart in 74% of cases and was transferred to the hospital in only 35% of cases at the time of an outcome event (death or admission to hospital).

1.4.2.2 The use of advance directives for rationing of resources

ADs are designed to promote autonomy and could be used to request the use of intensive medical treatment but the majority of ADs contain refusals of high technology medicine. Theoretically ADs should limit end-of-life costs by reducing expensive treatment and possibly even reducing length of life at a time when patients require costly nursing care. Since the proportion of elderly in Western society is increasing and health care costs are rising ADs are attractive to health care managers and governments as they may provide a socially acceptable way of rationing medical care (Callahan 1996, Levinsky 1996, La Puma et al 1991, Emanuel and Emanuel 1994).

In fact there is little evidence that utilising ADs has much impact on health care resources. There is only one study that demonstrated substantial cost saving but this has methodological flaws (Weeks et al 1994). The study retrospectively examined health charges in a cohort of 336 patients who died, 66 of whom had advance directives. After adjusting for diagnosis they found a ratio of
1:1.35 between those with and without an AD. Since this was an uncontrolled retrospective observational study it is not clear whether it was the AD per se that was limiting health care costs. Another possible bias is that the paper only examined deaths, which obviously selects patients with a poor prognosis. It is possible that a different result would have been observed had all admissions been examined.

In a subanalysis of the SUPPORT study Teno et al (1997) (see section 1.4.3.3) concluded that increasing the documentation of ADs was not associated with a reduction in hospital resource use. In fact there was a trend towards the intervention group costing more than the control group. The study also found that there was bias in the AD recording with older, less wealthy, less educated and those requesting less medical treatment being more likely to have their AD recorded than those requesting more aggressive treatment. If ADs requesting more treatment are less often recorded this might explain why studies employing retrospective chart review such as Weeks et al (1994) have found the presence of an AD correlating with cheaper hospital costs.

In a smaller study from California involving 204 patients with life-threatening illnesses Schneiderman et al (1992) found no reduction in costs in the 100 patients randomly assigned to be given the opportunity to complete an advance directive. The study was not powered to detect a change in health care costs but the trend observed was, insignificantly, towards increased health care costs in those patients with an advance directive.

Hanson and Rodgman (1996) found that, controlling for health status, patients who had an AD were more likely to visit physicians, had more days in hospital and although they used hospices more often they were 20% more likely to die in hospital. This might have been due to the higher socio-economic class and rate of private insurance in the group with ADs. They conclude that “descendents with living wills forgo specific treatments but remain intensive users of routine medical services”.

In their summary document called ‘The illusion of cost savings at the end of life’ Emanuel and Emanuel (1994) argue that the possibilities for cost-savings have been grossly overestimated. They suggest several possible reasons for this

- Low technology, palliative care is still expensive particularly when it is provided in specialist hospice units.
• Patients will sometimes request more care in an AD than the doctor would suggest. This is particularly true of proxies.

• Since it is often impossible to know when patients have entered the last stage of their life medical intervention will usually continue until prognosis is clear. Retrospective data about health expenditure in the last month of life cannot easily be applied where it is not clear if the patient is dying. DNR orders are often made late in the progress of an illness once a substantial amount of money has been spent.

1.4.2.3 Stability of choice in advance decision-making

Advance directives, by their very nature, usually involve making decisions about a future incompetent ‘self’. There are two interrelated problems with this (see below). The first is that people are inaccurate in predicting what they would want under different circumstances. They also seem to be unaware that their choices might be inaccurate. The second problem is an ethical debate about whether it is right for the future incompetent ‘self’ to have their life shortened by the wishes of the previous, different person.

The accuracy of prediction of wishes for treatment

Slevin et al (1990) questioned one hundred patients who had been referred to an oncology unit and one hundred controls matched for age, sex, ethnic origin and occupation. Subjects were asked to assess their willingness to have a hypothetical intensive chemotherapy regimen (with side effects such as nausea, hairloss, tiredness, weakness, and requiring frequent admissions to hospital and many needles and drips) in relation to different cure rates. Most cancer patients were willing to accept the treatment with a very small chance of benefit. The median benefit required to make the treatment acceptable for the cancer patients was 1% chance of cure. Although there was a lot of individual variation the control patients were much less willing to accept treatment. The median cure rate that was acceptable for the controls was 50%. These patients hadn’t yet received treatment and the matching appeared to be accurate so there was something about actually having a disease, which dramatically changed perceptions of the risk-benefit balance.

There is little evidence to support the theory that the subset of people who choose to make a living will are better at predicting how they would feel in the event of illness/disability than those that do not. Danis et al (1994) recruited community dwelling people aged over 65 from a Medicare program in North Carolina. Participants were interviewed about their preferences for various medical interventions at baseline and two years later with 2073 participants completing
both interviews. Overall there was a substantial variation in the percentage of respondents desiring six hypothetical life-sustaining treatments. Over the two year period preferences moved in a slightly negative direction (42% wanted less treatment, 38% more treatment and 20% no change). However, people who had had an accident, period of hospitalisation, who had become more immobile, more depressed or had lost social support were significantly more likely to want more treatment at the follow up interview than people who remained well. Of the participants, 175(8%) had made living wills and their choices remained more stable with time, especially in those who choose to forgo the most treatment, only 4% of whom chose more treatment at follow up. However one fifth of the subgroup had experienced the adverse life events listed above and in this group there had been a shift towards wanting more treatment. The authors conclude that 'patients possessing a living will generally had more stable preferences, but this was not the case when they had had various difficulties'. Unfortunately it could be argued that it is precisely in the case of ‘such difficulties’ that living wills are designed to be implemented.

Section 1.3.1.5 discusses the evidence that a significant number of patients do not hold stable views about resuscitation. All these studies have shown that at least 10% of hospital patients change their mind about CPR over short periods of time (Potter et al 1994, Everhart and Pearlman 1990, Watson et al 1997, Sayers et al 1997). It is interesting that the direction in which patients’ views alter is not uniform ie some patients become more accepting of CPR with time and some less so.

Ryan (1996) provides a possible explanation for inaccuracy of people’s estimates of what treatment they wish to receive when they become ill. He suggests that fit people cope with the horror of illness/disability by denying that it will ever happen to them. They tell themselves that if it does then they will avoid the suffering by ‘opting out’ i.e. choosing less treatment. When confronted with the illness this defence mechanism fails and people are forced to adapt in different ways. In practice many medical decisions are made in advance (eg a consent for an operation). The fundamental difference with advance directives is that they are usually designed to come into play when there has been a major change in the patient’s circumstances (e.g. a serious accident causing brain damage). It is this change which appears to lead to inconsistencies in decision making.

It is only possible to obtain evidence about changes in patients' views when they survive and retain or regain competence. It has been suggested that advance directives should only be used
where incompetence is irreversible (Ryan 1996). Apart from the practical problem that it is often clinically impossible to determine whether incompetence is irreversible, there is no reason to suggest that patients who happen to survive are not representative of those who do not.

It is possible to make a competent decision even if you are choosing to ignore some pertinent facts (Luttrell and Sommerville 1996) or if your decision appears foolish to others (re C [1994] (adult; refusal of medical treatment)). Society allows people to take risks and advance directives may be more legitimate if patients are aware that they might change their mind and are willing to take that risk. Unfortunately it is very hard to convince people that they may be mistaken in their own wishes and it is very hard for fit patients to imagine their own life with illness; this is the whole basis of the defence mechanism described above. A patient with a progressive condition such as motor neurone disease, AIDS or cancer is in a much better position to make an advance directive and in this sort of situation it might be a more valuable tool for the patient and the doctor.

The ‘different person’ debate
Incompetent patients (eg with dementia) often appear quite content with their quality of life even though it may seem restricted and even demeaning to observers. Such patients often ‘assent’ to treatment aimed at improving or prolonging their life even though they are incompetent and cannot therefore give consent. Some feel that the previous competent patient should not be allowed to make a judgement about their later self (Ryan 1996, Robertson 1991). This argument requires that there are several different ‘selves’ during a lifetime and that one’s beliefs at one time are no more valid than at another.

Others believe in only one true autonomous being that should be able to dictate its future course. They argue that it is possible to determine the true self and that it would destroy the autonomy of this person to ignore their wishes when they change (Luttrell and Sommerville 1996). The ‘Ulysses argument’ is based on the story of the Greek sailor who wants to hear the Sirens sing but knows they will lure him to his death. He instructs the other sailors to tie him up, block their ears and then sail to where he can hear the singing. Can his subsequent calls to untie him be overruled by the order from a former self not under the influence of the Sirens? The answer will depend on perceptions of the different weights you give to the two ‘selves’ in the story. A similar dilemma occurs in patients who suffer intermittently from mental illness.
1.4.2.4 Competence to complete an Advance Directive
As previously described (chapter 1.3.1.3) in order to be competent to direct their own healthcare a person must understand the treatment options as well as the consequence of accepting or refusing the treatment. In addition to this, an AD usually requires a patient to project into the future and imagine what decision they would make in an altered state of health. This adds an extra dimension to the thought processes and is likely to require a higher level of competence than contemporaneous decisions (Silberfeld et al 1993). Finally it has been suggested that the more serious the decision the greater the capacity required (Donaldson in re T, Molloy in Capacity to Decide) and as ADs frequently contain life and death decisions a high degree of capacity is clearly needed.

Making an advance directive is a purely cognitive process and is not amenable to physical testing (such as assessment of driving or cooking skills). However competence to complete an AD does not seem to be closely related to performance on general cognitive function screening tests such as the mini mental state examination (Janofsky et al 1992, Fitten and Waite 1990). It is possible that intelligence and previous exposure to medical treatments are more important contributors to competence than memory and concentration (Fazel et al 1999).

Silberfeld et al (1993) were among the first to suggest some guidelines for assessing competence to complete an AD. These included the requirement that patients recognise that their opinions might change in the future. Such guidelines are cumbersome and lack reliability and validity but they led to the development of other tools. There are three published tools that are designed specifically to assess competence to complete an AD.

a) The Hopkins Competency Assessment Test (HCAT)
In 1992 a group of psychiatrists from John Hopkins University (Baltimore, USA) published a simple tool for screening patients’ capacity to give informed consent (Janofsky et al 1992). An essay explaining the principles of consent to treatment, possibility of future incompetence and the option of writing an endurable power of attorney for health care was read out to patients. Three essays were provided containing the same information but with different reading ages. The patients’ understanding of the information was then tested using 6 questions and a mark out of 10 was derived. Following an evaluation of the HCAT against independent assessment by a forensic psychiatrist in 41 patients a cut off of below 4 was suggested as representing incompetence. This tool only assesses ability to understand the function of ADs not the actual impact of making a
living will on the patients’ future. The authors propose it as a screening test for rapid assessment of patients but it does not appear to have been widely used and there are no reported evaluations of the tool in clinical practice.

b) Screening Instrument to Assess Capacity to Complete a Directive (SIACAD)
Molloy et al developed the SIACAD to accompany their published AD called ‘Let Me Decide’ (Clarnette and Molloy 1989). There are 24 questions that assess knowledge required for the directive. The authors have evaluated the instrument and a score of 16/24 is said to give a 95% confidence that the person is able to complete the directive. It is suggested that scores of 9/24 or less exclude the patient and scores between 9 and 16 require that the patient be given further information/education and re-screened.

The group have also produced an instrument called the Decisional Aid for Scoring Capacity to Complete a Directive (DASCAD) which is based on scoring during an open-ended, loosely structured interview (Molloy et al 1999). This is a structured method of producing a global competency score and is necessarily operator dependent. It is recommended that this instrument is used for patients who are borderline on the screening instrument. There have been no published external validations of these tools.

c) The Oxford Patient Centred Approach to Assessment of Competence to Complete an AD
This tool is based on clinical vignettes (Fazel et al 1999). The patient is presented with two hypothetical clinical situations and options for management are explained. A semi-structured questionnaire is then used to assess the patient’s wishes, the reasons behind them and the implications of their choices for them and their families. A score between 0 and 10 is derived. The score was compared with a gold standard of global judgement of competence by two independent psychiatrists who listened to tape recordings of the original patient interviews. A cut off of 6 or more out of 10 indicated competency with a sensitivity of 96% and specificity of 94%

A further discussion of this tool can be found in Chapter 6.

Fazel et al (1999) evaluated the tool in 50 patients with dementia (new presentations to psychogeriatric services) and 50 controls (recruited from lunch clubs). They found that 80% of those with dementia and 22% of elderly volunteers were judged as incompetent to complete an advance directive. Interestingly, incompetent patients were significantly more likely to accept the hypothetical treatments than the competent group (Fazel et al 2000).
1.4.3 Advance Directives in Clinical Practice

1.4.3.1 Physicians’ views of advance directives
Some would say that the medical profession has been quite slow to acknowledge the role of AD. It is possible that this is because many doctors are unsure of the legal status of ADs. In view of the confusing and varied state of legislation it is not surprising that many physicians’ knowledge of ADs is limited. In 1995, twelve years after the Natural Death Act was passed in South Australia only 74/117 (63%) of General Practitioners completing a postal survey were aware of the law and only 22% had ever discussed ADs with a patient (Ashby et al 1995).

Knowledge levels are likely to be even poorer amongst UK doctors since there is no legislation and common law can be confusing to interpret. A recent survey of NHS Trusts in the UK found that only one quarter had developed or intended to develop policies on ADs. A small percentage (n=17) of trusts provided a copy of their policy for analysis and they were found to ‘vary widely in approach, content and consistency in understanding of the legal issues’. The paper calls for some national guidelines on which local guidelines could be based (Diggory and Judd 2000).

1.4.3.2 Patients’ views of advance directives and completion rates
A national cross-sectional study of a random selection of deaths in the USA in 1996 showed that around 10% of those who died had completed some sort of AD (Hanson and Rodgman 1996). Women, white race, higher educational attainment, higher income and presence of private health insurance were associated with increased AD completion. Patients with certain diagnoses such as cancer or lung disease were more likely to complete them. Patients with low functional scores and those with severe cognitive impairment rarely had an AD.

Emanuel et al (1991) conducted an outpatient interview with over 400 patients and 135 general public in Boston. Over 93% of those who agreed to be interviewed desired some form of AD but only 15% of outpatients and 18% of the general public had already completed an AD. There was no correlation between age, health or demographic features and the wish to execute an AD, and the authors conclude that there is not an easily definable ‘target’ population.

There are fewer surveys in the UK where knowledge and take-up rates for advance directives are much lower. One recent study of 74 elderly inpatients found that 61% had never heard of AD but after education three-quarters felt they might be interested in completing one (Schiff et al 2000).
A similar degree of ignorance is found in Australia where a project provided education to groups of elderly patients in the community; 472 people completed questionnaires and only 19% had heard of ADs. After the education session there was a high level of interest in completing an AD but the there was no follow-up on how many actually did (Wall S and Shanley C – unpublished data).

All these surveys have a common theme; target elderly populations express interest in making an AD but have low rates of actual completion. In the UK this can largely be explained by ignorance but a study by Emanuel et al (1991) revealed several barriers to completion of AD even in a well-educated population,

- Patients felt it was the responsibility of doctors to initiate discussions about AD
- Patients felt that they were not old enough or in poor enough health for AD to be relevant to them
- A few patients (5%) found the topic distressing to discuss.

1.4.3.3 The Influence of advance directives on the application of life-sustaining treatments

Most of the research in this area comes from America around the time of the Federal Self Determination Act (1992) which required all health-care providers to offer patients the opportunity to make an AD.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT study – Teno et al 1995, Teno et al 1997) is the largest investigation into the use of formal advance directives. This study enrolled 9105 seriously ill patients (a quarter of whom died during the hospital admission) at five teaching hospitals in the United States over a four-year period (1989-1994). After the implementation of the Patient Self Determination Act in 1992 patients were randomised into a control group and one in which a specially trained nurse facilitated communication between patients, families and doctors about treatment preference and documented ADs. The study therefore provided information on whether the Self-Determination Act (and the publicity surrounding its implementation) and/or the intervention of the nurse communicator affected CPR decision-making. Since the patients in the study were already very sick the nurse did not aim to promote completion of new AD but to improve communication and adherence to existing ADs.
Medical chart documentation of the presence of an existing AD rose from 1.5% to 12% following the Patient Self Determination Act. There was no change in the rate of patients/surrogates reporting of the presence of an AD (which was around 20%) and so the Act seems to have improved documentation and not the rate of completion of ADs (which did not change much after the Act). It is important to note that even after the Act, less than half of ADs that the patient/surrogate was aware of were actually documented in the medical record by day three of the admission. There was bias in the recording with older, less wealthy, less educated and those requesting less medical treatment being more likely to have their AD recorded. The nurse communicator intervention also increased documentation rates for pre-existing ADs.

Advance Directives were found to have no impact on physicians’ decisions about CPR. Half of the patients with an AD and a preference to forego CPR did not have a DNR order. This was partly because a minority of ADs documented wishes about CPR (only 5.2%) with the majority simply naming a proxy decision-maker or making statements not relevant to the current condition. Even where there was clear documentation only a third of physicians were aware of the presence of the AD in the record. Finally there was little evidence that ADs were improving patient-doctor communication with only 41% of patients ever having consulted a physician about their AD.

Schneiderman et al (1992) conducted a smaller but more detailed study involving 204 patients with a range of life-threatening illnesses treated in two hospitals in California. Half the patients were randomised to receive information (face to face or by post) and the paperwork required to complete a valid AD. Two thirds (66%) of the group given the option completed and returned an AD and all of them chose to limit life-sustaining treatments to some degree. Half the patients died during the follow up which was at least 34 months long. At regular intervals patients completed questionnaires and if any patient was admitted to hospital a member of the research team ensured that an AD was placed prominently in the notes. The authors found no change in medical outcome (length of stay in hospital, cost of health care, length of survival) between the group given the opportunity to complete an advance directive and the controls. In addition there was no difference in psychosocial outcomes such as quality of life, patient satisfaction, health locus of control and sense of coherence. The conclusion was that ADs “had no significant positive or negative effect on patient’s well-being, health status, medical treatments or medical treatment charges”.
Another negative trial based in a Nursing Home in Carolina produced ADs for 175 patients (126 for competent patients and 49 from relatives of incompetent patients) and then monitored effectiveness over two years. Ninety-six outcome events (hospitalisation or death) occurred and in only 75% was care given in accordance with the AD. In 6 cases care was more aggressive and in 18 was less aggressive than had been requested in the AD. The results could not be explained by failure to insert the AD in the medical record because inconsistent care was significantly commoner for patients where the AD was in the medical record than when it was not registered. Incompetent patients and those who remained in the nursing home rather than hospital setting were significantly less likely to have their AD respected. The authors conclude that factors other than the autonomous wishes of the patient, such as medical futility and rationing, were influencing decisions (Danis et al 1991).

Possible explanations for the fact that AD do not seem to influence outcome include

- ADs are not available at the time they are needed (see section 1.4.2.1)
- ADs are rarely applicable in the clinical situation as it arises. Most studies use fairly rigid tools and it is possible that directions did not cover the unforeseen circumstances. Many documents were are specific enough (eg only 5.2% of AD in the SUPPORT study documented wishes about CPR with the majority simply naming a proxy decision-maker or making broad irrelevant statements (Levinsky 1996)).
- ADs might actually be promoting more aggressive treatment in some patients. For example proxies might be more likely to accept treatment than patients, and ADs which just nominate a proxy could therefore increase requests for medical treatments.
- Patients who remained competent can make decisions contrary to the spirit of their AD. As discussed earlier patients who are confronted with an illness situation may request more treatment and overrule their AD (Levinsky 1996).
- ADs do not necessarily improve communication between patients and their doctors. Treating doctors may be unaware they exist and are rarely involved in their construction. The SUPPORT study used a third party to improve communication and this might be less effective than direct contact between doctor and patient.
- ADs are still completed by the minority of patients and therefore the effect on the overall hospital population is likely to be negligible (Teno et al 1997).

Finally, it has been suggested that studies should be looking at process rather than outcome (Teno et al 1997). In a recent editorial Linda Emanuel (2000), who has been a great proponent of
ADs, admits that living wills have not fulfilled their promise. However she goes on to argue that advance care planning which is a process of discussion, a component of care, and a method of team-building between patients and health care professionals must continue to be developed and encouraged. By contrast the legal documentation as an AD has a small role in this process. The desired effect on patient, family and healthcare worker has more to do with process than outcome and they are hard to measure and compare with a control group.
Chapter 1.5

Aims and Hypotheses
Aims and Objectives

The aims of this thesis are broadly divided into three parts.

a) Exploring patients’ views about CPR and artificial feeding,
   • To determine what percentage of different patient populations (elderly inpatients, post-stroke group in hospital and in the community) would wish to have life-sustaining treatment
   • To determine the knowledge level about CPR in these different patient populations
   • To determine the influence of educational material about CPR on choices about life-sustaining treatment
   • To determine what percentage of a patients admitted to hospital with acute stroke or to geriatric wards are able to discuss CPR within two weeks of admission
   • To look for associations between views about CPR and factors such as age, sex, marital status, disability, depression, quality of life and social support
   • To examine stability of patients’ views about CPR over time
   • To perform a qualitative analysis of factors determining patients’ views about CPR.

b) Assessing Morbidity Scores,
   • To assess the ability of morbidity scores to predicting CPR outcome (both in hospital mortality and long-term survival) in a hospital population
   • To compare the utility of the three morbidity scores.

c) Investigating the use of Advance Directives,
   • To determine the level of knowledge of patients about advance directives
   • To determine the knowledge of General Practitioners on the legal status of advance directives in the UK
   • To determine competence to complete an advance directives in an inpatient post-stroke population
   • To assess if changes in competency with time influence CPR opinions
   • To perform a qualitative interviews determining views about advance directives.

99
Hypotheses

The following is a list of the individual hypotheses for each chapter of this thesis.

Chapter 2 – The Southampton Study

- Elderly inpatients on specialist geriatric wards know about CPR (including the techniques used and the in-hospital survival rate)
- Provision of educational material about CPR does not influence the views of elderly inpatients about life-sustaining treatment
- There is no relationship between age, sex, marital status, disability, and self-rated quality of life and the wish for CPR

Chapter 3 – Morbidity Scores

- Morbidity scores cannot be calculated retrospectively from data available from clinical notes
- Morbidity scores cannot predict a group of patients for whom CPR is unsuccessful
- Morbidity scores cannot predict long-term survival
- Length of hospital stay prior to arrest is not related to survival after CPR
- Different morbidity scores predict the same group of patients as having unsuccessful CPR
- The Modified PAM Index is a superior tool to the other two morbidity scores (PAM and PAR)

Chapter 4 - London/Winchester Study

- General practitioners have a good working knowledge of the law regarding advance directives
- GPs working in Winchester and Newham have equivalent knowledge levels regarding advance directives

Chapter 5 – The Oxford Study

- Elderly patients discharged to the community after stroke know what CPR is (know the techniques used and the in-hospital survival rate)
- Provision of educational material about CPR does not influence patients views of about life-sustaining treatment
• There is no relationship between age, sex, marital status, disability, and quality of life and the wish for CPR

Chapter 6 – The Australian Quantitative Study
• All patients admitted to hospital after an acute stroke are able to discuss CPR within the first two weeks
• All patients admitted to hospital after an acute stroke who are capable of discussing CPR are competent to make an advance directive within the first two weeks
• Patients with recent acute stroke know what CPR is (know the techniques used and the in-hospital survival rate)
• Provision of educational material about CPR does not influence the views of post-stroke patients about life-sustaining treatment
• There is no relationship between age, sex, marital status, disability, and quality of life and the wish for CPR
• Patients admitted to hospital with acute stroke do not change their minds about CPR, artificial feeding or their choices in advance directives between hospital and home
• There is no difference in the level of competence to complete an advance directive for patients immediately after stroke and several months into their recovery.

Chapter 7 – The Australian Qualitative Study
Hypotheses are not appropriate in qualitative studies. The unstructured interviews aimed to obtain patients’ views in three broad areas;
• Views about CPR and other life-prolonging treatment
• Views about who should decide on when CPR should be given
• Views on advance directives.
Chapter 2

What are the opinions of elderly inpatients’ about CPR?

The Southampton Study

Data collected 1993
Published as abstract 1994
Full paper published 1996 (Bruce Jones et al 1996)
2.1 Introduction

It has been shown that doctors are poor at predicting the CPR wishes of their patients (Uhlmann et al 1988, Seckler et al 1991, Bedell and Delbanco 1984). In addition they generally underestimate the quality of life that their patients experience (Starr et al 1986) and might therefore make DNR orders for incompetent patients believing that they are in their best interests.

Most previous British studies of patients’ opinions have questioned them at discharge from hospital, yet it is on admission that resuscitation plans are first made. This study examines the resuscitation wishes and determinants of these for elderly patients on admission to the Elderly Care Units of Southampton General Hospital and Poole Hospital. It also explores the patients’ wishes to be included in CPR decisions and their views on who should be making such decisions. Additional data were collected at the time of discharge from hospital to assess the stability of patients’ views.
2.2 Methods

A consecutive series of patients admitted as emergencies were interviewed within two working days of admission using a questionnaire (see Appendix A).

Exclusions included;
- moribund condition including coma
- an Abbreviated Mental Test score less than 7/10 (Hodkinson 1972)
- overt mental illness (taking antidepressant or major tranquilliser drugs or under psychiatric care)
- dysphasia and other significant communication difficulties.

Subjects were given a brief standardised description of CPR (see appendix A) stating that resuscitation is “often unsuccessful” but not giving outcome statistics.

The three core questions asked were
- ‘If your heart were suddenly to stop beating in hospital would you want vigorous attempts to be made to revive you?’
- ‘Would you want this to be decided by your self/family/doctor or a joint decision?’
- ‘Do you think you should be asked your wishes regarding resuscitation when you come into hospital?’

Other questions determined what factors were thought most important in CPR decisions and about previous consideration and discussion of CPR. Knowledge and experience of CPR, perceived health and dependency, the Barthel Activities of Daily Living Index (Mahoney and Barthel 1965) and social history were also recorded. Finally, patients were asked whether they had found the questionnaire stressful. The core questions were repeated where possible during the two days prior to discharge.

The study received local Ethical Committee approval and each subject gave written consent at the beginning of the first interview.
The centres were treated as a single population for statistical analysis. Associations between answers to the three core questions and demographic and background health and social factors were tested by Chi-square tests for categorical variables and the Mann-Whitney test or the Kruskal-Wallis test as appropriate for continuous variables.
2.3 Results

**Patient Characteristics**

There were 595 acute admissions to the units during the study period and 214 patients with a wide range of acute medical conditions were interviewed (table 2a). The inclusion rate was 36% and the commonest exclusion was impaired mental function (186 patients). Fifty-six eligible patients (21%) declined to participate. Patients were aged 66-97 (median 84), and 65% were women.

**Table 2a Diagnoses / reasons for admission for 214 patients interviewed**

<table>
<thead>
<tr>
<th>Diagnosis / Reason for Admission</th>
<th>Poole</th>
<th>Southampton</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Myocardial infarction/angina</td>
<td>8</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Cardiac dysrhythmias</td>
<td>2</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Heart failure</td>
<td>13</td>
<td>13</td>
<td>26</td>
</tr>
<tr>
<td>Pulmonary embolism</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Deep venous thrombosis</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Chest infections</td>
<td>10</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Acute asthma/emphysema</td>
<td>3</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Stroke/Transient ischaemic attacks</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Other neurological diagnoses</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Renal disease/failure</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Urinary tract infection</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Gastrointestinal haemorrhage</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Other gastrointestinal problems</td>
<td>8</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Anaemia</td>
<td>3</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Carcinomatosis</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Musculoskeletal problems</td>
<td>9</td>
<td>12</td>
<td>21</td>
</tr>
<tr>
<td>Leg ulcers, pressure sores/cellulitis</td>
<td>7</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Falls/immobility</td>
<td>11</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Collapse</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>112</td>
<td>102</td>
<td>214</td>
</tr>
</tbody>
</table>
The questionnaire was well received and only 8 respondents (4%) replied that it was stressful.

Nearly all (95%) the subjects had been in hospital previously. Ten patients said they had received CPR but only five could remember what happened. Some knowledge of CPR was claimed by 116 patients (54%), mostly gained from television. Seventeen patients (8%) had participated in a resuscitation decision about a relative.

Resuscitation preference
Answers to the core questions at admission and discharge are given in table 2b. The core questions were repeated within the two days prior to discharge in 121 patients (56%). The remainder were discharged very soon after the initial interview, died in hospital or were lost to follow-up.

Table 2b Answers to the three core questions

<table>
<thead>
<tr>
<th>(a) Resuscitation preference</th>
<th>On admission</th>
<th>At discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR</td>
<td>129 (60%)</td>
<td>63 (53%)</td>
</tr>
<tr>
<td>No CPR</td>
<td>64 (30%)</td>
<td>47 (40%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>21 (10%)</td>
<td>8 (7%)</td>
</tr>
<tr>
<td>(b) Who should decide?</td>
<td>N = 211</td>
<td>n = 119</td>
</tr>
<tr>
<td>Patient</td>
<td>91 (43%)</td>
<td>56 (47%)</td>
</tr>
<tr>
<td>Family</td>
<td>17 (8%)</td>
<td>8 (7%)</td>
</tr>
<tr>
<td>Doctor</td>
<td>30 (14%)</td>
<td>15 (13%)</td>
</tr>
<tr>
<td>Joint decision</td>
<td>73 (34%)</td>
<td>40 (34%)</td>
</tr>
<tr>
<td>(c) Should patients be asked?</td>
<td>N = 214</td>
<td>n = 115</td>
</tr>
<tr>
<td>Yes</td>
<td>144 (67%)</td>
<td>82 (71%)</td>
</tr>
<tr>
<td>No</td>
<td>57 (27%)</td>
<td>33 (29%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>13 (6%)</td>
<td>0</td>
</tr>
</tbody>
</table>
Stability of Choice

Most patients wanted CPR both on admission (60%) and at discharge (53%). At discharge twenty patients had changed their minds but there was no statistically significant trend in the direction in which they changed their minds (table 2c). Of 67 patients initially wanting CPR, 58 still did so and of 39 patients not wanting CPR on admission 36 had unchanged views. Eight of the 12 who were unsure initially were able to make a choice for or against CPR at discharge.

Table 2c Comparison of preference for CPR for 118 patients at admission and discharge

<table>
<thead>
<tr>
<th>Preference for CPR at admission</th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preference for CPR at discharge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>58</td>
<td>2</td>
<td>3</td>
<td>63</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>36</td>
<td>5</td>
<td>47</td>
</tr>
<tr>
<td>Not sure</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>39</td>
<td>12</td>
<td>118</td>
</tr>
</tbody>
</table>

Determinants of CPR preference

Table 2d demonstrates the characteristics of patients according to their wish for CPR. More of the married patients (73%) wanted CPR than other groups especially the widowed (52%; p<0.01). The patients wanting CPR were younger than those saying “no” but only women showed this difference when each sex was analysed separately. No significant age difference was found within each marital status grouping. Similarly, a greater proportion of men (77%) than women (51%) wanted CPR, but not when corrected for marital status.

Sixty-six patients (31%) had already considered their resuscitation wishes and 37 (17%) had discussed them with someone, in most cases with a family member. Fewer of these patients (42%) wanted CPR than those who had not already considered their wishes (68%).
Patients not wanting CPR tended to be widowed (72%), had fewer social contacts and higher self-rated dependency, and two-thirds needed help with daily activities.

Table 2d Characteristics of patients 193 patients who expressed a preference for or against CPR

<table>
<thead>
<tr>
<th></th>
<th>CPR</th>
<th>No CPR</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=129)</td>
<td>(n=64)</td>
<td></td>
</tr>
<tr>
<td>Median age (years)</td>
<td>83.0</td>
<td>85.5</td>
<td>* (b)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women</td>
<td>71</td>
<td>52</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>58</td>
<td>12</td>
<td>*** (a)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>single</td>
<td>11</td>
<td>6</td>
<td>*** (a)</td>
</tr>
<tr>
<td>married</td>
<td>51</td>
<td>11</td>
<td>** (a)</td>
</tr>
<tr>
<td>widowed</td>
<td>64</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>Median pre-admission Barthel score</td>
<td>18</td>
<td>17</td>
<td>* (b)</td>
</tr>
<tr>
<td>Mean Self-rated dependency (scale 0-10)</td>
<td>2</td>
<td>5</td>
<td>** (b)</td>
</tr>
<tr>
<td>Independent for ADL</td>
<td>73</td>
<td>22</td>
<td>*** (a)</td>
</tr>
<tr>
<td>Needing help with ADL</td>
<td>56</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Previously considered CPR wishes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>28</td>
<td>31</td>
<td>*** (a)</td>
</tr>
<tr>
<td>No</td>
<td>100</td>
<td>32</td>
<td></td>
</tr>
</tbody>
</table>

- $p < 0.05$  ** $p < 0.01$  *** $p < 0.001$

(a) Chi squared test

(b) Mann-Whitney test

Given the choice of the eight factors that might be important in the patient’s decision about CPR, usual health (38%), age (36%), “life at home” (32%) and the family’s wishes (28%) were the considerations thought most important (Table 2e). Patients who refused CPR were significantly more likely to cite age as a deciding factor and those who accepted CPR were more concerned about usual health, life at home and wishes of family (Table 2e).
Table 2e Decisive factors in subjects’ CPR preferences
(Numbers quoting each of the seven factors as important in their decision about CPR divided according to CPR preference. Multiple responses were permitted).

<table>
<thead>
<tr>
<th></th>
<th>CPR</th>
<th>No CPR</th>
<th>Total</th>
<th>X² test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current illness</td>
<td>22</td>
<td>10</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Usual health</td>
<td>61</td>
<td>16</td>
<td>81</td>
<td>**</td>
</tr>
<tr>
<td>Life at home</td>
<td>52</td>
<td>10</td>
<td>68</td>
<td>**</td>
</tr>
<tr>
<td>Wishes of family</td>
<td>49</td>
<td>8</td>
<td>60</td>
<td>***</td>
</tr>
<tr>
<td>Religious beliefs</td>
<td>7</td>
<td>6</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>24</td>
<td>42</td>
<td>76</td>
<td>***</td>
</tr>
<tr>
<td>Previous experience of CPR</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

** p < 0.01 *** p < 0.001 (Chi-squared test)

Who should decide?
Three quarters of patients wanted participation, alone or jointly. Table 2f shows the characteristics for the patients who wanted to decide themselves compared with those who wanted others to make the decision. Results at discharge were very similar and the thirty-seven patients who changed their choice displayed no statistically significant trends.

Single and widowed patients (and therefore women) favoured deciding for themselves, whilst a greater proportion of married patients than of other groups wanted a joint decision. Patients desiring participation, alone or jointly, were older than those wanting their family or doctor to decide, but when analysed by sex and by marital status, only women and single patients showed this difference, suggesting that it was due to marital status (Table 2f). Patients with prior knowledge of CPR were less likely than those without to leave the decision to others. Those who wished to choose for themselves tended to have previously considered (38/91 patients, 42%; p<0.05) and to have rejected CPR (48/84 patients, 57%; p<0.001) and attached less importance to their family’s wishes. Only 8% of patients wanted their family alone to make the decision.
Table 2f Characteristics of subjects favouring each type of decision

<table>
<thead>
<tr>
<th></th>
<th>Self (n=91)</th>
<th>Family (n=17)</th>
<th>Doctor (n=30)</th>
<th>Joint (n=73)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Median age</strong></td>
<td>85.0</td>
<td>79.0</td>
<td>81.5</td>
<td>84.0 *** (b)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>women</td>
<td>67</td>
<td>12</td>
<td>14</td>
<td>44 * (a)</td>
</tr>
<tr>
<td>men</td>
<td>24</td>
<td>5</td>
<td>16</td>
<td>29</td>
</tr>
<tr>
<td><strong>Married patients</strong></td>
<td>21</td>
<td>6</td>
<td>13</td>
<td>30 ** (a)</td>
</tr>
<tr>
<td><strong>Single/widowed</strong></td>
<td>70</td>
<td>11</td>
<td>17</td>
<td>38</td>
</tr>
<tr>
<td><strong>Prior knowledge of CPR</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>55</td>
<td>4</td>
<td>10</td>
<td>45 ** (a)</td>
</tr>
<tr>
<td>no</td>
<td>35</td>
<td>13</td>
<td>20</td>
<td>28</td>
</tr>
<tr>
<td><strong>CPR wish</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>36</td>
<td>16</td>
<td>27</td>
<td>49</td>
</tr>
<tr>
<td>no</td>
<td>48</td>
<td>0</td>
<td>1</td>
<td>14 *** (a)</td>
</tr>
<tr>
<td><strong>Deciding factors</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>current illness</td>
<td>12</td>
<td>1</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>usual health</td>
<td>31</td>
<td>4</td>
<td>17</td>
<td>27</td>
</tr>
<tr>
<td>life at home</td>
<td>27</td>
<td>4</td>
<td>10</td>
<td>26</td>
</tr>
<tr>
<td>wishes of family</td>
<td>11</td>
<td>11</td>
<td>10</td>
<td>26 *** (a)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>40</td>
<td>3</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td><strong>Agree with being asked wishes on admission</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>66</td>
<td>9</td>
<td>12</td>
<td>56 *** (a)</td>
</tr>
<tr>
<td>no</td>
<td>20</td>
<td>6</td>
<td>18</td>
<td>13</td>
</tr>
</tbody>
</table>

* p < 0.05  ** p < 0.01  *** p < 0.001  (a) X² test  (b) Kruskal-Wallis test

**Should patients be asked?**

Two thirds of patients said they wished to be consulted about CPR. There were no statistically significant trends between admission and discharge. As expected, those who wanted to choose themselves about CPR, alone or jointly, tended to agree with being asked.
2.4 Conclusions

In 1993, when this study was conducted, there was a lot of debate in the medical press about DNR orders. The formal guidelines had not yet been released and British practice was informal and inconsistent (Baskett 1986, Doyal and Wilsher 1993). There was general agreement that patients' views should be incorporated more frequently into CPR decisions but patients were being consulted infrequently. This study was the largest of several inpatient surveys conducted in British hospitals in the early 1990s (Liddle et al 1994, Mead et al 1995, Morgan et al 1994, Mead and Turnbull 1995).

Feasibility

One simple but important finding was that it is feasible to involve elderly patients in discussions of resuscitation early in hospital stay. In fact two thirds of the patients felt they ought to be asked about their views. The results, like those of other UK inpatient surveys (O'Keeffe et al 1993, Morgan et al 1994, Mead and Turnbull 1995, Robertson 1993) do not support physicians' common fear of provoking anxiety in their patients (Scade and Muslin 1989). This study provided no evidence that the early timing of the discussions increased the rate of patient anxiety, with only 4% finding the questionnaire distressing.

In contrast to these other studies patients were offered a 'not sure' response option. One in ten of the patients was unable or unwilling to make a decision about resuscitation on admission and 7% were 'not sure' at the time of discharge. There is clearly a group of patients who do not hold strong views on resuscitation and it may be inappropriate to force a decision from them in either the research or clinical setting.

Unlike previous surveys this study sought to interview patients soon after emergency admission, when such discussions are most relevant. A penalty of this design was the low inclusion rate (36%) for the first interview. It is not known how representative the views of this group would be compared with the other two thirds of this geriatric inpatient cohort or indeed those of the elderly population in general. Whilst many of those who could not participate in the initial interview would have remained incompetent throughout their hospital stay it is possible that a proportion would have been able to answer questions at discharge and no attempt was made to recruit these
patients later on. This may account for the higher inclusion rates of other surveys which did not aim to recruit early (Mead and Turnbull 1995, Liddle et al 1994).

**Trends in Decisions**

In common with other work the study demonstrates that old age lessens the desire for resuscitation (Gunasekera et al 1986, O’Brien et al 1995) and that men desire it more than women (Gunasekera et al 1986, Watson et al 1997, Frankl et al 1989, Hui et al 1997, O’Brien et al 1995). This study, however, found that these differences were due to marital status which is also known to influence CPR opinion (Hui et al 1997, Schonwetter et al 1991, Watson et al 1997, Heap et al 1993, O’Brien et al 1995). Living alone is known to be associated with decreased desire for CPR (Watson et al 1997, Mead and Turnbull 1995, Gunasekera et al 1986, Liddle et al 1994) and this factor is probably closely linked with marital status.

Patients in this study had a very broad range of diagnoses and there were insufficient numbers in any given diagnostic group to look at this as an influence on CPR decisions. It would be interesting to conduct a similar questionnaire on some specialist wards were this variable could be considered in more depth.

**Stability of view**

Although the follow up rate (56%) was sub-optimal 17% of patients who were interviewed twice had changed their minds about CPR by the time of discharge. Potter et al (1994) found that most patients initially against CPR scored highly on a depression inventory and some had changed their minds by discharge, but the numbers involved were very small. One of the exclusion criteria for this study was depression. Two more recent studies have subsequently confirmed these findings by demonstrating that between 17% (Watson et al 1997) and 15% (Sayers et al 1997) of patients change their minds about CPR between admission and discharge. More research is needed on stability of view. It would be interesting to follow individual patients over a period of time with repeated admissions to determine whether a pattern emerges.

**Education**

Participation in decisions requires an understanding of the CPR procedure and, as in other British studies only half our patients had even partial knowledge of CPR
(Gunasekera 1986, Liddle et al 1994). Even patients relatively knowledgeable about CPR have been found to grossly overestimate the chance of success (Murphy et al 1994, Schonwetter et al 1991, Miller et al 1992, Kerridge et al 1999). This misplaced optimism may explain our finding, in common with several studies, that elderly patients usually do want CPR even if they are severely ill or disabled. This study provided only brief information about CPR and did not include any survival statistics. Effective education can have a very significant impact on patients’ preferences (Morgan et al 1994) and a lower acceptance rate might have been obtained if the patients had been given more detailed information.

Who should decide?
Most subjects in this study wished to decide about resuscitation themselves, either alone or jointly, particularly those with prior knowledge of CPR or without a spouse. This finding is in contrast to other studies from the UK which suggest a higher proportion of patients wish their doctor to make the decision (Mead et al 1995, Liddle et al 1994, Morgan et al 1994). However it is hard to compare the studies directly since the question was asked differently in each survey. A larger percentage of patients seem to favour communication with doctors than actually wish to be in charge of the ultimate decision (Mead and Turnbull 1995). In this study patients could opt for a ‘joint decision’ and 34% of them did so. It may be that patients are expressing a wish to be kept informed rather than a wish to influence treatment.

Questionnaire problems
One concern with questionnaires such as this is whether respondents give their true opinions or perceived "proper" answers. When consenting to the study patients were asked to answer honestly and their opinions were sought using a uniform questionnaire and a standard interview.

The questionnaire employed non-validated and crude measures of social isolation and quality of life. The question designed to assess the determinants of CPR choice was a multiple choice one and was likely to be over-suggestive to patients. An open-ended qualitative question would probably have been better to explore this area.
Summary
The Southampton study demonstrated that the majority of elderly inpatients is in favour of CPR for themselves and favours being involved in decisions about it. Some important trends were found with older, female, unmarried and socially isolated patients being more likely to reject CPR. Despite these trends the attitudes of individuals remain largely unpredictable. Where DNR decisions are based on quality of life then patients’ opinions are important and should be sought. This study demonstrates that patient participation in resuscitation decisions is practical, reliable and unstressful as well as being popular with patients. The majority of elderly patients’ views are stable for the period of hospitalisation, and thus questioning soon after admission is worthwhile but doctors should be aware that a small proportion of patients will change their minds about CPR.
Chapter 3

Do Morbidity scores predict outcome after cardiopulmonary resuscitation?

The Winchester Study

Data collected 1995 - 1996
Published as abstract 1997 and 2000 (long term follow-up study)
Full papers published 1999 (Bowker and Stewart 1999) and 2001 (Spice et al 2001)
3.1 Introduction

Ideally a morbidity score should be easy to calculate from readily available information and accurately predict failure to survive CPR. This study was designed to assess whether morbidity scores would be useful to clinicians at the bedside in making decisions about resuscitation.

There are relatively few clinical studies of the Pre-Arrest Morbidity Score (PAM) and the Prognosis After Resuscitation Score (PAR) and there are no published validations of the Modified PAM Index (MPI) (see section 1.2.2.2). The studies that are available contain small numbers of patients and have come to different conclusions as to the cut-off score that should be used to predict death after CPR. For this reason it has been suggested that local validation of the scores should be undertaken (O'Keeffe and Ebell 1994). Only two previous studies have compared PAM with PAR and it is not clear how these scores interact in the same population or how they compare with MPI.

All three scores are designed to predict survival to the point of discharge from hospital. This study is unique as it also examines the role of morbidity scores in predicting long-term survival.
3.2 Methods

This study involved a retrospective review of records from a consecutive series of adult patients undergoing CPR at the Royal Hampshire County Hospital. This hospital is a 550-bed acute district general hospital. It is unusual in having a well-developed information technology system. There are computer-held records for all nursing notes, prescriptions and laboratory and radiological investigations. The period of study was from September 1994 to June 1996.

The majority of cases were identified from records of cardiac arrest calls held by the hospital switchboard for audit purposes. These records gave date, time and clinical area for all arrest calls. Using the computer held ward records to identify which patients were on that ward at that time we could then review nursing notes for that day for the whole ward. Although this was time consuming we were able to identify which person had arrested in the majority of cases. We also searched clinical coding data and mortuary records to identify further cases where a cardiac arrest had occurred without a call via the switchboard.

The following patients were excluded from analysis,

- Children (age under 18) and neonates
- Those in whom resuscitation was initiated outside the hospital
- Second or subsequent cardiac arrests during the same hospital admission (ie only one arrest was coded per hospital admission although the same patient could be included twice if they had two separate admissions, each with an arrest)
- Those in whom no CPR occurred or there was no convincing evidence from the case notes that a true cardiac arrest had occurred.

Name, age, length of stay in hospital prior to the cardiac arrest, location and outcome of arrest were recorded for each patient. We also recorded whether the patient was discharged alive from hospital or died before discharge. Discharge to a rehabilitation unit or transfer to another hospital did not count as discharge unless the patient was subsequently discharged to the community.
A single observer (LB) reviewed all medical case-notes, computerised nursing notes and computer held laboratory and radiology results in order to calculate PAM, PAR and MPI scores (see Table 1g). The most recent available data prior to the arrest were used. Standard definitions were used for some of the less clear-cut variables (Table 3a). Most of these definitions were taken from those in the original descriptions of morbidity scores.
Table 3a Definitions used for scoring morbidity scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>Morbidity Scores employing variable</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homebound</td>
<td>PAM, PAR, MPI</td>
<td>Pursued no activity outside home (except when taken out by others), or required significant support services, or living in residential care</td>
</tr>
<tr>
<td>Cancer</td>
<td>PAM</td>
<td>Proof of diagnosis (e.g., histology) required</td>
</tr>
<tr>
<td></td>
<td>PAR</td>
<td>Current problem (e.g., excluded resected/cured)</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td>Not skin cancer (except melanoma)</td>
</tr>
<tr>
<td>Sepsis</td>
<td>PAM</td>
<td>Diagnosis at admission</td>
</tr>
<tr>
<td></td>
<td>PAR</td>
<td>Positive cultures or two of pyrexia, leucocytosis, sputum, lung consolidation, positive urinalysis, cellulitis in the presence of appropriate clinical picture</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
<tr>
<td>Pneumonia</td>
<td>PAM</td>
<td>Admission diagnosis</td>
</tr>
<tr>
<td></td>
<td>PAR</td>
<td>Sepsis plus consolidation on chest x-ray or signs of consolidation</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
<tr>
<td>Heart failure</td>
<td>PAM</td>
<td>Symptoms of cardiac failure, despite treatment</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td>Confirmed by radiological or clinical findings</td>
</tr>
<tr>
<td>Stroke</td>
<td>PAM</td>
<td>During that admission</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
<tr>
<td>Myocardial Infarction</td>
<td>PAM, PAR, MPI</td>
<td>During that admission</td>
</tr>
<tr>
<td></td>
<td>PAR</td>
<td>Two out of symptoms, electrocardiogram changes and enzyme rise</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
<tr>
<td>Oliguria</td>
<td>PAM</td>
<td>Less than 300ml in 24 hours or anuric despite catheter more than 6 hours</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
<tr>
<td>Hypotension</td>
<td>PAM</td>
<td>Blood pressure less than 90 systolic (sustained or one reading within 6 hours of arrest)</td>
</tr>
<tr>
<td></td>
<td>MPI</td>
<td></td>
</tr>
</tbody>
</table>
To determine long-term survival the hospital computer record was searched and General Practitioners were contacted for all those who had survived to discharge. The follow up was completed in December 1999.

Ethical committee approval was not felt to be necessary by the local ethics committee because the study only involved case note review.

Data was entered in numeric form and analysed using the Statistical Package for Social Sciences (SPSS) software. Chi squared analysis was used to compare dichotomous data. Non parametric (Mann Whitney U test) and parametric (t-test) analysis was used to compare the means of continuous data in the living and dead group.
3.3 Results

There were 427 cardiac arrest calls put through switchboard during the study period and a further 17 arrests were identified where a call had not been made via the switchboard. In 75 instances, we were unable to identify a patient who had suffered a cardiac arrest in the clinical area where the call had been directed. A further 87 cases were excluded because they did not meet our entry criteria for the study (see table 3b).

Table 3b Details of 87 arrest calls excluded from the study

<table>
<thead>
<tr>
<th>24</th>
<th>Repeat arrests</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(second or subsequent arrests for same patient during single hospital admission)</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CPR initiated out of hospital</td>
<td></td>
</tr>
<tr>
<td>57</td>
<td>No CPR required including</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 14 respiratory arrest only</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 9 vasovagal syncope</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 5 bradycardia</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 2 anaphylaxis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 3 pulmonary embolism</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 2 stroke</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 3 grand mal fit</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 5 arrest cancelled</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 14 other</td>
<td></td>
</tr>
</tbody>
</table>

In 14 cases no medical notes were available for analysis and in 4 the notes were available but there was insufficient data recorded to calculate morbidity scores. Data on 264 patients who suffered cardiac arrest were therefore available for analysis. Out of these patients, 28 survived (10.6%) to be discharged from hospital. Figure 3c illustrates the structure of the study.
Figure 3c Structure of study

427 arrests through switchboard
17 arrests not through switchboard

Total 444

369 75 no trace of arrest

18 arrests identified but medical notes unavailable or inadequate

351

87 exclusions (see table 3b)

264 available for study

236 (89.4%) died in hospital

28 (10.6%) survived to discharge from hospital

16 alive
12 died by end of follow up
at end of follow up
3.3.1 Age and Sex

There were 156 males and 108 females in the survey. Of the 28 survivors, 15 were male. There were no significant differences in outcome by sex. There was no significant difference between the mean age of patients who died and those who survived. Table 3d summarises this data.

Table 3d Age, sex and time to arrest for all patients and for survivors and non-survivors shown separately

<table>
<thead>
<tr>
<th></th>
<th>All patients (n = 264)</th>
<th>Survivors (n = 28)</th>
<th>Non-survivors (n = 236)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Range</strong></td>
<td>Range</td>
<td>Mean</td>
<td>Median</td>
</tr>
<tr>
<td><strong>Sex</strong> (male)</td>
<td>59%</td>
<td>54%</td>
<td>53%</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td>42—94</td>
<td>74</td>
<td>74</td>
</tr>
<tr>
<td><strong>Time (days)</strong></td>
<td>0—98</td>
<td>7.4</td>
<td>2</td>
</tr>
</tbody>
</table>

Notes Time = number of complete days between admission and arrest ie 0 = arrested on day of admission, 1 = arrested day after admission and so on. There was missing data for number of days to arrest for two patients.

3.3.2 Place of arrest

Overall there were data for 236 patients who died after a CPR procedure and this represented 18.4% of all hospital deaths in the study period. Medical wards had the majority of the deaths and the highest percentage of patients receiving CPR prior to death (Table 3e). In this study there were only 14 arrests in the emergency department but 6 of these patients survived giving the highest survival rate of any area in the hospital.
Table 3e Place of arrest and percentage of those who died who received CPR in different clinical areas of the hospital

<table>
<thead>
<tr>
<th>Clinical Area</th>
<th>Total number of deaths</th>
<th>Number (%) having CPR</th>
<th>Number (%) of successful CPR* attempts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical wards</td>
<td>887</td>
<td>214 (24%)</td>
<td>20 (9.3%)</td>
</tr>
<tr>
<td>Surgical wards</td>
<td>207</td>
<td>31 (15%)</td>
<td>1 (3.2%)</td>
</tr>
<tr>
<td>Emergency department</td>
<td>81</td>
<td>14 (17%)</td>
<td>6 (43%)</td>
</tr>
<tr>
<td>Other (including ITU)</td>
<td>109</td>
<td>5 (4.6%)</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>Total</td>
<td>1284</td>
<td>264 (20.1%)</td>
<td>28 (10.6%)</td>
</tr>
</tbody>
</table>

* successful = alive at time of discharge from hospital

3.3.3 Length of hospital stay prior to cardiac arrest

The mean length of time from admission to cardiac arrest was 1.7 days (range 0-15 days) for survivors and 8 days (range 0-98 days) for those who died (where arrest on the same day of admission = 0 days and on the day after admission = 1 day). This difference was statistically significant (P<0.001). Of the survivors, 16 (57%) arrested on the day of admission and only one arrested more than a week after admission. Table 3d shows the data and Figure 3f represents this graphically.
Figure 3f: Bar graph showing length of time to arrest for all patients divided into groups of those who survived and those who died following CPR.
3.3.4 Pre-arrest clinical factors and morbidity scores

Table 3g shows the mean morbidity scores for the group of survivors compared with those who died. There was a statistically significant difference between the morbidity scores of the two groups. The three histograms in Figures 3h, 3i and 3j show the three morbidity scores for all 264 patients divided into two groups; survivors and those who died.

Table 3g Mean morbidity scores for survivors and non-survivors

<table>
<thead>
<tr>
<th></th>
<th>Range</th>
<th>Mean</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAM</td>
<td>All patients</td>
<td>0-13</td>
<td>4.04</td>
</tr>
<tr>
<td></td>
<td>Alive</td>
<td>0-6</td>
<td>2.04</td>
</tr>
<tr>
<td></td>
<td>Dead</td>
<td>0-13</td>
<td>4.28 #</td>
</tr>
<tr>
<td>PAR</td>
<td>All patients</td>
<td>-2-18</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alive</td>
<td>-2-7</td>
<td>1.39</td>
</tr>
<tr>
<td></td>
<td>Dead</td>
<td>-2-18</td>
<td>4.99 #</td>
</tr>
<tr>
<td>MPI</td>
<td>All patients</td>
<td>0-11</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Alive</td>
<td>0-6</td>
<td>2.21</td>
</tr>
<tr>
<td></td>
<td>Dead</td>
<td>0-11</td>
<td>4.78 #</td>
</tr>
</tbody>
</table>

* Mann-Whitney U Test p<0.00001
# T-test p<0.005
Figure 3h Histogram demonstrating PAM scores for survivors and those who died following CPR shown separately

Figure 3i Histogram demonstrating PAR scores for survivors and those who died following CPR shown separately
Figure 3j Histogram demonstrating MPI scores for survivors and those who died following CPR shown separately

From the graphs it is easily seen that no patient with a PAM score greater than 6, a PAR score greater than 7, or a MPI greater than 6 survived to discharge. Table 3k shows the number of patients falling above or below these ‘cut-offs’ for each of the morbidity scores.
Table 3k Outcome for patients above and below the derived morbidity score ‘cut offs’

<table>
<thead>
<tr>
<th></th>
<th>Dead</th>
<th>Alive</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PAM</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAM&gt;6</td>
<td>47</td>
<td>0</td>
</tr>
<tr>
<td>PAM &lt;=6</td>
<td>189</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>236</td>
<td>28</td>
</tr>
<tr>
<td><strong>PAR</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAR&gt;7</td>
<td>68</td>
<td>0</td>
</tr>
<tr>
<td>PAR &lt;=7</td>
<td>168</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>236</td>
<td>28</td>
</tr>
<tr>
<td><strong>MPI</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPI&gt;6</td>
<td>53</td>
<td>0</td>
</tr>
<tr>
<td>MPI &lt;=6</td>
<td>183</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>236</td>
<td>28</td>
</tr>
</tbody>
</table>

Using these ‘cut-off’ values (which define a group who did not survive resuscitation with a specificity of 100%) the number of patients who were correctly identified as having unsuccessful resuscitation by the PAM score was 47 out of a total of 236 patients that died. The sensitivity of the PAM score was therefore 20%. The sensitivity of the PAR score was 29% and MPI was 22%. Table 3l shows the sensitivities for scores and combinations of scores using these derived cut-offs.
Table 3I Sensitivities of morbidity scores and combinations of scores in predicting death after CPR

<table>
<thead>
<tr>
<th>Diagnostic Criteria</th>
<th>Number of CPR attempts correctly predicted as futile by test</th>
<th>Sensitivity of test (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAM &gt; 6</td>
<td>47</td>
<td>20</td>
</tr>
<tr>
<td>PAR &gt; 7</td>
<td>68</td>
<td>29</td>
</tr>
<tr>
<td>MPI &gt; 6</td>
<td>53</td>
<td>22</td>
</tr>
<tr>
<td>PAM &gt; 6 and PAR &gt; 7 and MPI &gt; 6</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>PAM &gt; 6 or PAR &gt; 7 or MPI &gt; 6</td>
<td>100</td>
<td>42</td>
</tr>
<tr>
<td>PAR &gt; 7 or MPI &gt; 6</td>
<td>97</td>
<td>41</td>
</tr>
</tbody>
</table>

NB All tests are defined to give 100% specificity

The three scores identified different sub-populations of patients for whom CPR ultimately proved unsuccessful (see Figure 3m). Only 21 of the patients who received unsuccessful CPR were identified by all three scores. By using all three scores independently in the same population, the sensitivity for predicting unsuccessful CPR rises to 42%. 
Figure 3m Venn Diagram to demonstrate the overlap in patient groups correctly identified as having unsuccessful CPR using the three different morbidity scores:

- PAR > 7 (68)
- MPI > 6 (53)
- PAM > 6 (47)
3.3.5 Long-term survival

Table 3n shows the outcome for 28 patients who survived to discharge from hospital. This is time to death (12 patients) or time to follow up (16 patients). Follow up occurred on the 12th of December 1999 which was a mean of 54 months (range 44 - 64) after the initial cardiac arrest. Figures 3o and 3q shows this information graphically.

Table 3n Shows the fate of the 28 patients who were discharged alive

<table>
<thead>
<tr>
<th>Patient</th>
<th>Length of follow up or survival time (days)</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>15</td>
<td>Died</td>
</tr>
<tr>
<td>2</td>
<td>37</td>
<td>Died</td>
</tr>
<tr>
<td>3</td>
<td>39</td>
<td>Died</td>
</tr>
<tr>
<td>4</td>
<td>52</td>
<td>Died</td>
</tr>
<tr>
<td>5</td>
<td>69</td>
<td>Died</td>
</tr>
<tr>
<td>6</td>
<td>92</td>
<td>Died</td>
</tr>
<tr>
<td>7</td>
<td>163</td>
<td>Died</td>
</tr>
<tr>
<td>8</td>
<td>302</td>
<td>Died</td>
</tr>
<tr>
<td>9</td>
<td>453</td>
<td>Died</td>
</tr>
<tr>
<td>10</td>
<td>482</td>
<td>Died</td>
</tr>
<tr>
<td>11</td>
<td>1213</td>
<td>Died</td>
</tr>
<tr>
<td>12</td>
<td>1333</td>
<td>Alive</td>
</tr>
<tr>
<td>13</td>
<td>1362</td>
<td>Alive</td>
</tr>
<tr>
<td>14</td>
<td>1382</td>
<td>Alive</td>
</tr>
<tr>
<td>15</td>
<td>1432</td>
<td>Alive</td>
</tr>
<tr>
<td>16</td>
<td>1434</td>
<td>Alive</td>
</tr>
<tr>
<td>17</td>
<td>1540</td>
<td>Alive</td>
</tr>
<tr>
<td>18</td>
<td>1546</td>
<td>Alive</td>
</tr>
<tr>
<td>19</td>
<td>1548</td>
<td>Alive</td>
</tr>
<tr>
<td>20</td>
<td>1591</td>
<td>Alive</td>
</tr>
<tr>
<td>21</td>
<td>1687</td>
<td>Alive</td>
</tr>
<tr>
<td>22</td>
<td>1707</td>
<td>Died</td>
</tr>
<tr>
<td>23</td>
<td>1731</td>
<td>Alive</td>
</tr>
<tr>
<td>24</td>
<td>1770</td>
<td>Alive</td>
</tr>
<tr>
<td>25</td>
<td>1821</td>
<td>Alive</td>
</tr>
<tr>
<td>26</td>
<td>1824</td>
<td>Alive</td>
</tr>
<tr>
<td>27</td>
<td>1916</td>
<td>Alive</td>
</tr>
<tr>
<td>28</td>
<td>1922</td>
<td>Alive</td>
</tr>
</tbody>
</table>
There is a bi-modal distribution ie patients are either in either ‘short-lived’ (<500 days) or ‘long-lived’ (>500 days) category. The characteristics of the short-lived (n=10) and the long-lived (n=18) groups can be compared using T-tests (Table 3p). It should be noted that two of the patients who are known to have died (after 1213 days and 1707 days) are classified as long-livers.
Table 3p Morbidity scores, age and time to arrest for 28 survivors divided into short-lived and long-lived groups

<table>
<thead>
<tr>
<th></th>
<th>Mean (range)</th>
<th>t-test significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short-lived *</td>
<td>2.5 (1 – 5)</td>
<td>p = 0.26</td>
</tr>
<tr>
<td>Long-lived *</td>
<td>1.6 (0 – 6)</td>
<td></td>
</tr>
<tr>
<td>PAR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short-lived</td>
<td>1.8 (0 – 5)</td>
<td>p = 0.053</td>
</tr>
<tr>
<td>Long-lived</td>
<td>2.8 (-2 – 7)</td>
<td></td>
</tr>
<tr>
<td>MPI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short-lived</td>
<td>1.3 (2 – 5)</td>
<td>p = 0.002</td>
</tr>
<tr>
<td>Long-lived</td>
<td>1.6 (0 – 6)</td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short lived</td>
<td>77 (61 – 86)</td>
<td>p = 0.013</td>
</tr>
<tr>
<td>Long-lived</td>
<td>68 (52 – 83)</td>
<td></td>
</tr>
<tr>
<td>DAYS #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short lived</td>
<td>4.9 (0 – 15)</td>
<td>p = 0.003</td>
</tr>
<tr>
<td>Long lived</td>
<td>0.7 (0 - 2 )</td>
<td></td>
</tr>
</tbody>
</table>

* Short-lived group (n=10) lived less than 500 days after the resuscitation
* Long-lived group (n=18) lived longer than 500 days (n=2) or still alive at follow up

Despite the small numbers there is a significant difference between the two groups for age, MPI and number of days in hospital before arrest. Non-Parametric tests (Mann-Whitney u and Kolomogrov Smirnov) give very similar results.
Figure 3q Kaplan Meier survival curve for patients who survive to discharge after in-hospital CPR.

Censored indicates that from that point we do not have data for the patient (length of follow up for patients varied). The graph demonstrates a rapid death rate up to 500 days, with a flattening of the curve after that signifying a much lower death rate.
3.4 Conclusions

3.4.1 Study design

It was possible to calculate morbidity scores retrospectively from data available in patient case notes and computer held records. In less than 7% of arrests was the data completely missing or inadequate for the purposes of calculating scores.

The population studied was probably representative of British acute district general hospitals. Unsolicited patients of all ages, including the frail elderly were included in the study. The percentage of all deaths where CPR was attempted (approximately 20%) is in keeping with reports from other hospitals (see section 1.2.2). The survival rate (11%) is within the range quoted by most authors (see section 1.2.1.1).

Most of the 75 arrest calls to switchboard in which there was no identifiable patient who had arrested were to the emergency department. Many of these calls were probably for out-of hospital cardiac arrests (it is usual practice for nurses in the emergency department to make arrest calls if they receive notice of gravely ill patients about to arrive by ambulance).

It is possible that some cardiac arrest attempts have not been included in the study. In those clinical areas where medical staff are readily available (e.g., intensive care and emergency department) cardiac arrest calls may not be made through switchboard. This may account for the low number of arrests included from these areas and the relatively higher numbers on general wards. It is possible that the quality of CPR is better in these units than general wards. Our results confirm that the success rate for resuscitation in the emergency department was higher than the wards. However, general wards are the setting in which morbidity scores are most likely to be of use and there is an almost complete set of records from this source.

In addition, arrest calls may not be made if resuscitation attempts are quickly successful, where as prolonged attempts are more likely to result in a cardiac arrest call. This means in this study the unsuccessful attempts are more likely to have been detected than the successful ones; thus, the overall figure for survival after CPR in the hospital may be an underestimate.
As this is a retrospective study the quality of the medical notes will have influenced the accuracy of the morbidity scoring. The fully computerised nursing notes and investigation results meant there was very little missing data. However, it is possible that the patient’s clinical condition was not accurately reflected in the notes. Scores recorded retrospectively may differ from those calculated contemporaneously since the doctor at the bedside can gain additional information by examining or questioning the patient. Conversely it is also possible that data was used that would have been unavailable to the attending physician (eg test results available only after the patient had died).

There is no measure of the degree of inter or intra-observer reliability of the morbidity scores either in this study or previous published work. One observer recorded all the scores and it was impossible to blind them to the outcome of the arrest. This may have unconsciously influenced the coding accuracy.

3.4.2 Morbidity scores
All three scores did accurately identify a group of patients who did not survive resuscitation. The PAM score has now been assessed in several different patient populations (a total of 1491 arrests) and no patient with a score of greater than 8/25 has survived to discharge (George et al 1989, O’Keeffe and Ebell 1994, Cohn et al 1993, Ebell et al 1997 and Kernerman et al 1997). However the majority of patients whether they died or survived had low morbidity scores and this is manifested in the low sensitivities of the scores. This is because there are many other factors, apart from those measured by morbidity scores, which contribute to a poor outcome after CPR (eg a delay to initiation of CPR, unfavourable arrest rhythm, quality of CPR etc).

While patients with high morbidity scores usually die, it does not follow that those with low scores survive. In other words the morbidity scores have a high specificity and a low sensitivity. The calculated sensitivities of the scores will depend on the threshold for performing CPR. Many patients with DNR orders are likely to have had high scores and if these patients had been given CPR the calculated sensitivities might be higher. Sensitivities for the scores will therefore vary according to local DNR policies. Sensitivities are most useful to compare the three scores within a defined population.
The cut-offs for the tests were defined with 100% specificity since most clinicians would rather attempt CPR on several patients on whom it subsequently proves unsuccessful than risk withholding CPR from one patient in whom it would have been successful. If 97% specificity was acceptable (balanced against the trauma of unsuccessful CPR and the risk of long-term brain damage) then sensitivities for the scores would be higher.

In line with this study a cut-off for PAM of 7 or 8 has been advocated in all but one of the previous studies (George et al 1989, Cohn et al 1993, Ebell et al 1997 and Kernerman et al 1997). The notable exception was in an Irish study by O'Keeffe and Ebell (1994) who found no survivor with a PAM of greater than 4. Analysis of this study shows that all the scores were lower than in this study (the mean PAM of the non-survivors was 2.6 compared to 4.0 in this study). It seems most likely that the method of scoring in this study was less inclusive. An alternative explanation is that their population had unusually low morbidity, either through exclusion of patients with high morbidity from CPR or through a different patient profile (eg did the frail elderly go to a separate unit?).

The PAR has only been assessed in two other populations; Ebell et al (1997) reported 6 patients who survived with a PAR score over 8 whereas O’Keeffe and Ebell (1994) had no survivors who scored over 5 but this study is not easy to compare with others (see above). In common with the Irish study we found that the PAR was more sensitive than the PAM.

The MPI has not been previously assessed in clinical practice. It seems to function in the same way as the other scores in accurately identifying a group who do not survive CPR. It has similar sensitivity to the PAM which is perhaps not surprising since it has only minor modifications on the PAM coding. The MPI is not an improvement on the PAR (sensitivity MPI 22% compared with PAR 29%). The MPI only identified one extra unsuccessful resuscitation above that which was predicted by the PAM and PAR scores.
Using a combination of scores might be a better but slightly unwieldy tool e.g. calculating the MPI in addition to the PAR almost doubles the number of patients correctly identified as having unsuccessful CPR in this study.

The 'homebound' variable was particularly difficult to determine from case notes and the assumption is made that patients are homebound because of functional impairment. This may not always be the case and a more objective measure of functional status would probably improve the use of this variable.

Clinical use of these scores may be limited by the necessity to regularly recalculate the scores to take account of changing patient status. The scores may need local evaluation before they are adopted. This study only provides evidence for their use in the general ward setting. The scores may have a role in education (e.g. as a teaching aid for junior doctors) and as a tool for further research. Doctors might also be able to use morbidity scores with patients who want information on chances of successful CPR in order to make informed decisions.

3.4.3 Other Prognostic Factors
In common with other authors, this study found that the sex of the patient did not influence outcome after CPR. There was a trend towards younger patients surviving more often but this only reached statistical significance for long-term survival (see below).

Patients who survived had been in hospital for less time when they arrested and most survivors arrested within a day or two of admission. It might be expected that patients with a deteriorating clinical course are likely to be in hospital longer and would be likely to have a poor outcome after CPR. Future developments in morbidity scores might well include another variable for length of stay in hospital prior to arrest.

The better prognosis of early compared with late arrests after acute MI has been well established and was used to redefine the MPI. Subgroup analysis of the 89 MI patients in our study confirmed this association.
3.4.4 Long-term survival

Survival to discharge is usually used as an indicator of satisfactory outcome since it is accepted that these patients have a reasonable prospect of long-term survival. The numbers in this study are small (only 28 survivors), but the findings, showing a bimodal pattern of survival following discharge from hospital, seem to contradict those of other studies which have shown a linear decline (DeBard 1981, Berger and Kelley 1994 and Peatfield et al 1977).

Those who die early after discharge are older and arrest well into their hospital admission, whereas those who survive long term tend to arrest within the first day or two. This suggests that there may be two separate groups. The long-term survivors who arrest early might be those with primary arrhythmia or ischaemic heart disease and few other medical problems. This group may represent the bulk of those reported in other studies, explaining the apparent linear decline in survivors over years. Those who die early after discharge may be more representative of general ward patients with multiple medical problems that arrest well into their time in hospital. Because of the way the data for this study were collected these patients were relatively over-represented.

Pre-arrest morbidity scores would not be useful in clinical practice where a threshold score (above which patients would be less likely to survive) is needed. The specificity of the test is not high enough to predict long-term survival ie some patients with the highest scores survived long term. Pre-arrest morbidity scores were developed from survival studies that used discharge from hospital as an endpoint and it is not surprising that they appear unhelpful in predicting long-term survival which may depend on different clinical factors.

Since some patients who survive to discharge after CPR die early afterwards, survival to hospital discharge may not always be the best outcome measure for successful CPR.
Chapter 4

Do General Practitioners in the UK know when living wills are legal?

The Newham/Winchester Study

Data collected 1997
Published as abstract 1997
Full paper published 1998 (Bowker et al 1998)
4.1 Introduction

There is growing public awareness that patients should be involved in medical decisions and there is support for greater use of living wills (or advance directives) which allow patients to extend their right to autonomy into a period when they would not be able to express their views.

The BMA advises patients to involve their general practitioner when drafting an advance directive (BMA booklet). This is to ensure that the patient understands the nature of the treatments they are refusing and the implications of that refusal in relation to their own health. Although it is likely to be mainly hospital doctors who implement advance directives, GPs are more likely to be involved at the planning stage.

There is specific legislation in many states of America, Canada and Australia requiring doctors to adhere to valid advance directives (see section 1.1.3.1). A survey of GPs in South Australia, which has had legislation for advance directives called 'The Natural Death Act' since 1983, reported that despite this legislation 63% of GP’s were unaware of the provision for advance directives and only 19.6% had the relevant paperwork available (Ashby et al 1995).

In the United Kingdom there is no specific legislation about living wills but under certain circumstances living wills would carry legal force under common law (Luttrell 1996). In the case of Re T (Adult: Refusal of Treatment)[1992] the right to refuse medical treatment in advance was established. Later, in the highly publicised Tony Bland case, the judges stated that had a living will been available it would have been legally binding (Airedale NHS Trust v Bland [1993]). Following this case the House of Lords Select Committee on Medical Ethics published a report recommending that the health care professions develop some guidelines. In 1995 the British Medical Association (BMA) in conjunction with The Royal College of Nursing (RCN) published a code of practise.

This BMA booklet gives excellent clear guidance on the law regarding advance directives. The following is a summary of the main points;

- English common law recognises the right of patients to make statements in advance refusing
treatment under certain circumstances

- Doctors are obliged to comply with advance refusals provided that they are satisfied that the patient was competent and fully informed at the time the statement was made, was not acting under duress and that the circumstances which have arisen are as envisaged by the patient. Doctors who do not comply with valid advance refusals may be liable to a charge of battery.

- To be valid advance refusals do not necessarily have to be written in a specific format or witnessed by a doctor or a lawyer. It is however often recommended that doctors or lawyers witness statements and that they are written on pre-prepared forms in order that they are less likely to be challenged at a later date.

- Although patients may legally refuse treatments in advance they have no right to request treatment. As with contemporaneous treatment, doctors have no legal obligation to give a treatment that is not clinically indicated, even if the patient requests it.

- There is no legal provision at present for patients to nominate a surrogate or proxy decision-maker to give consent for them when they become incompetent. In these circumstances doctors are obliged to act ‘in the best interests’ of an incompetent patient. This will often involve discussions with friends and family but the final legal responsibility for clinical decisions for an incompetent patient rests with their doctor, not their family.

- A patient detained under the mental health act may still make valid decisions about health care not covered by the terms of their detention (ie providing they are competent they can make their own decisions about physical treatment but can be overruled on decisions relating to their mental illness).

The aim of the study was to determine the level of knowledge about the legal status of living advance directives in a sample of GPs who refer to two district general hospitals in the South of England (one in Winchester and one in Newham).
4.2 Methods

Postal questionnaires were sent to all 270 GPs who refer patients to two district general hospitals in inner city London (Newham General Hospital) and semi-rural area of Hampshire (Royal Hampshire County Hospital, Winchester). A sample of the questionnaire is in Appendix B. The questionnaires were sent with a personal covering letter from the local consultant. A single reminder was sent four weeks later. The questionnaires were anonymous.

Doctors were first asked to indicate whether they were aware that some forms of advance directive could carry legal force. Those who indicated that they were not aware of this were simply asked to return the questionnaire. Those who were aware of this were then asked to answer six further questions about details of the law.

Every GP who returned their questionnaire was sent a free copy of the BMA code of practice at the end of the study. Chi squared analysis was used to compare the differences between answers from Winchester and London GPs.
4.3 Results

Significantly more questionnaires were returned in Hampshire (130 of 134) than London (84 of 136) \((p<0.0001)\). Overall 214 (79\%) were returned. Three questionnaires were deemed invalid (as the respondent had not followed the instructions correctly), leaving a total of 211 for analysis.

**Question 1**  Did you know that some types of Living Will have legal force at present in the UK?

<table>
<thead>
<tr>
<th></th>
<th>London</th>
<th>Winchester</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>51 (62%)</td>
<td>56 (43%)</td>
<td>107 (51%)</td>
</tr>
<tr>
<td>yes</td>
<td>31 (38%)</td>
<td>73 (57%)</td>
<td>104 (50%)</td>
</tr>
</tbody>
</table>

Chi-squared analysis shows there was a significant difference \((p=0.008)\) in the answers between the two groups of GPs.

Only the respondents who answered yes to question 1 \((n=104)\) were invited to answer questions 2 to 8.

**Question 2**  To be legally valid a Living Will must be witnessed by a doctor.

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>false</td>
<td>67   (64%) or 32% of total</td>
</tr>
<tr>
<td>true</td>
<td>15   (15%)</td>
</tr>
<tr>
<td>don't know</td>
<td>22   (21%)</td>
</tr>
</tbody>
</table>

It is a recommendation rather than a requirement that a doctor witnesses a living will. Living wills do not even have to be written. Witnessed oral statements where competence is not at issue may be just as legally binding as a written statement (Sommerville 1995).
To be legally valid a Living Will must be witnessed by a lawyer.

false (correct)  56 (54%) or 26% of total
true (incorrect)  27 (26%)
don't know 21 (20%)

There is no requirement for the involvement of a lawyer although they may be able to advise on the wording of a living will. Patients are responsible for ensuring their own living wills are available for doctors. They should keep a copy of their wills in the GP notes, hospital notes (if relevant) and with their next of kin.

Doctors are legally obliged to give any treatment which a patient requests in a valid living will.

false (correct)  68 (65%) or 32% of total
true (incorrect)  13 (13%)
don't know 23 (22%)

Patients cannot request treatments which are illegal (eg euthanasia) or are not clinically indicated. The BMA code of practice suggests that patients should not be able to refuse ‘basic care’ such as hygiene and pain relief measures.

Doctors are legally obliged to withhold any treatment which the patient refuses in a valid living will.

true (correct)  44 (42%) or 21% of total
false (incorrect)  35 (34%)
don't know 25 (24%)

An unambiguous and informed advance refusal is as valid as a contemporaneous decision and cannot be overruled by a doctor or a relative.
Question 6 Patients detained under the mental health act can make a legally valid living will in some circumstances.

true (correct)  27 (26%)  or 13% of total
false (incorrect)  49 (47%)

A patient detained under the mental health act may still make valid decisions about health care not covered by the terms of their detention. In 1984 a judge upheld the right of a schizophrenic patient detained in a psychiatric hospital to refuse leg amputation (Re C 1994)

Question 7 Patients can legally nominate a relative or friend to make clinical decisions on their behalf in a living will.

false (correct)  15 (14%)  or 7% of total
true (incorrect)  60 (58%)
don't know  29 (28%)

In English law no person can legally make health care decisions for another adult. Where a living will nominates a proxy decision-maker the doctor may wish to be guided by them as good witnesses to what the patient may have wanted but legally they should act in the ‘best interests’ of the patient. A Power of attorney covers only financial and property matters.

Overall analysis

Figure 4a shows the proportion of correct answers graphically. For all six supplementary questions a higher percentage of the Winchester than London GPs answered correctly but this did not reach significance for any single question.

Thirty-one GPs (15% of all GPs) answered four or more out of six questions correctly. Only one GP answered all six questions correctly.

The responses to questions 4, 5 and 7 were analysed separately since these were arguably the
most important areas of knowledge in order to give patients accurate legal advice. Only three GPs (1.4%) who returned their questionnaires answered all three of these questions correctly and thirty-four (16%) answered two correctly.

Figure 4a Bar chart showing the proportion of correct answers for the 104 GP's who answered questions 2 to 7
4.4 Conclusions

About half of the GPs were unaware that Living Wills currently carried some legal force in English Law, and most of the rest did not know important aspects of the law.

It is possible that the lack of specific legislation for living wills partly explains doctors’ confusion over the legality of living wills. However in Australia, where there has been statutory legislation for over a decade, there appears to be an equal level of ignorance (Ashby et al 1995).

GPs in Hampshire appeared to know more about living wills than their colleges in London. This apparent disparity might be explained by the higher response rate in Hampshire. Alternatively it might reflect a higher number of enquiries about living wills from the patients in this area although there are no data on levels of patient demand. Finally it could be related to differences in the age, training and interests of the GPs in the two very different environments. Knowledge levels were not high in either area and it would be interesting to repeat the survey with the same GP’s in a few years time, with hospital doctors or even with selected patient groups.

Those who advocate more widespread use of Living wills should be aware of the results of this survey and perhaps should initially concentrate on educating doctors about their correct legal standing.
Chapter 5

What are the attitudes of patients following disabling stroke to life-sustaining treatments such as cardiopulmonary resuscitation (CPR)?

The Oxford Study

Data collected 1997 - 1998
Published as abstract 1998
5.1 Introduction

Stroke is one of the most common chronic disabling conditions of adult life. The disabilities caused by stroke are greatly feared for example Gage et al (1996) questioned 83 patients who had atrial fibrillation and found that 58 (83%) rated severe stroke as equal to or worse than death. In another study 117 patients at risk of stroke were asked to score hypothetical outcomes between 0 (worst outcome) and 100 (best outcome). The mean score for stroke causing severe motor impairment was significantly lower than for death (8.4/100 compared with 9.8/100) (Stolman et al 1994).

Given this fear of stroke it is not surprising that Uhlmann et al (1988) found that subjects’ wishes for CPR dropped from 83.9% to 38.3% when asked to assess their views in current health and then hypothetically following a severe stroke. In a similar study of 30 patients who had survived a period on an intensive care unit wish for CPR dropped from 87% to 53% in the stroke scenario (Everhart and Pearlman 1990).

Surveys of opinion in a mixed geriatric inpatient population have not been able to demonstrate that disability and dependency are significantly associated with views about CPR (Mead and Turnbull 1995, Gunasekera et al 1986, Liddle et al 1994, Frankl et al 1989, O’Brien et al 1995). This might be because patients are in fact more willing to undergo medical treatment when they actually have a condition than they are when they are fit and are considering their views hypothetically (Slevin et al 1990, Ryan 1996). There are no studies reporting the wishes for CPR specifically in a group of patients already affected by stroke and this was the main aim of this study.

A study of patients’ views after stroke might be difficult because stroke frequently impairs communication and cognition, especially in the early stages, making contemporaneous discussions about CPR impossible. In a Canadian review of decision-making in acute stroke only 8% of patients were able to participate in a DNR order at the time it was made (Alexandrov et al 1995). This study determined the views of patients several months after stroke when they were clinically stable, had had a chance
to become accustomed to their disabilities and when a higher proportion of patients would be able to give their opinions about CPR.
5.2 Methods

The Oxford stroke register database was used to identify a series of patients aged fifty or above who were admitted to the acute medical services in Oxford with a new diagnosis of stroke. Some patients with stroke who were not on the stroke register (because their stroke had not led to admission in Oxford Hospitals) were also recruited from the Geriatric Day Hospital. Patients were recruited between 7 and 48 weeks after their stroke, once they had been discharged into the community.

In each case a letter was sent to the patients' general practitioner (GP) to enquire if they were suitable for interview. If the GP had no objection, the patient was then sent a single postal invitation. Patients who were willing to participate were interviewed either in their own home or in the Geriatric Day Hospital if they were attending there for treatment.

The clinical notes were reviewed to obtain details of the pathological stroke type (Bamford et al 1991), length of hospital stay, resuscitation status while in hospital, worst disability and disability at discharge measured by Barthel scale (Mahoney and Barthel 1965).

A semi-structured questionnaire was used to interview the patients to obtain demographics, social circumstances and level of knowledge about resuscitation (see appendix C). The patients' level of understanding about CPR was assessed by asking them to describe some techniques that might be used. Patients scored one point each for knowledge of any of the following: mouth to mouth breathing, chest compression, ventilation by endotracheal tube, intra-venous infusion (fluids or blood), oxygen administration, electrical cardioversion, cardiac monitoring (ECG), or drug administration (any route). Marking was generous and patients were prompted e.g. 'what would the doctor actually do?' 'Have you seen it on the television?' in order to maximise their score. Patients were also asked to estimate the success rate of in-hospital CPR (where success was defined as percentage of patients surviving to discharge from hospital).
Following assessment of their knowledge patients were given an education session. This included a short description of CPR (covering all the techniques listed above) and information that the average survival rate for CPR after in-hospital arrests was around 10%. The possible disadvantages of CPR were discussed including; initial survival but death prior to discharge, indignity, inability of family to be close at time of death and the small risk of long-term survival with brain damage. The content of this information was standardised but the order and detail was altered by the interviewer to suit the level of comprehension of the patient. Patients were encouraged to ask questions and discuss issues.

The patients’ wishes for resuscitation were elicited before and again after the education session. Finally patients were asked to estimate what their opinions on resuscitation had been prior to their stroke.

At the time of interview the following scales were employed (see Appendix C);

- Barthel Index (Mahoney and Barthel 1965), to assess disability
- 15-point geriatric depression scale (Sheikh JI and Yesavage 1986), to quantify depressive symptoms
- Dartmouth COOP Chart (Nelson et al 1990) - 2 questions only, a simple visual scale measuring patients’ self-rated quality of life and perceived social support

Two investigators who were not involved with the patient’s clinical management did all interviews (LB and a research nurse). Patients were assured their responses were confidential and would not be made available to the hospital or GP. The study was approved by Oxford medical ethics committee (reference NAPREC 97.041).

Eight patients who attended the Geriatric Day Hospital were interviewed twice to assess repeatability. No patient changed his/her mind about resuscitation over a two-week interval.
Statistical Methods

The data was analysed using Statistical Package for Social Sciences. T-tests or Chi-squared tests were used for normally distributed data and Mann-Whitney Test U tests for data not normally distributed.
5.3 Results

5.3.1 Response rate and demographics

Figure 5a demonstrates the method of recruitment and Table 5b shows the reasons for exclusion. There were 433 patients aged over 50 on the stroke register during the fifteen-month study period (01.04.97 to 31.06.98). 226 patients fell into our predetermined exclusion criteria (see table 5b). An interview was completed in 90 (43.5%) of the eligible patients.

220 invitations were sent to patients, 13 (5.9%) further patients were excluded before or at the time of interview, 117 (53.2%) patients did not reply and 90 (40.9%) patients participated in the study so the response rate to a single postal invitation was 41%.

In addition ten patients who were not on the stroke register were recruited directly from day hospital. A total of one hundred completed interviews were therefore available for analysis.
Figure 5a Demonstrating the recruitment of 100 stroke patients

433 Patients on stroke register

306 GPs contacted

220 Invitations sent to patients

92 Patients visited

90 Patients interviewed

Total 100 Patients recruited

127 Exclusions before invitation

86 Exclusions from GP contact

117 No reply to invitation

11 Replied but refused invitation

2 Excluded at time of interview

10 patients recruited from day hospital
**Table 5b Details of the 226 exclusions from study**

<table>
<thead>
<tr>
<th>Reason for Exclusion</th>
<th>Number (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Died</td>
<td></td>
</tr>
<tr>
<td>• In Hospital</td>
<td>123 (54.4%)</td>
</tr>
<tr>
<td>• After Discharge</td>
<td>35 (15.5%)</td>
</tr>
<tr>
<td>Pre-stroke Barthel &lt;10/20</td>
<td>4 (1.8%)</td>
</tr>
<tr>
<td>Unable to communicate</td>
<td></td>
</tr>
<tr>
<td>• Dysphasia</td>
<td>11 (4.8%)</td>
</tr>
<tr>
<td>• Dementia (AMTS&lt;7)</td>
<td>11 (4.8%)</td>
</tr>
<tr>
<td>• Non-English speaking</td>
<td>3 (1.3%)</td>
</tr>
<tr>
<td>• Further acute illness</td>
<td>10 (4.4%)</td>
</tr>
<tr>
<td>• GP specified ‘unsuitable’ – no details</td>
<td>8 (3.5%)</td>
</tr>
<tr>
<td>Moved out of area</td>
<td>10 (4.4%)</td>
</tr>
<tr>
<td>Interview declined</td>
<td>11 (4.8%)</td>
</tr>
<tr>
<td>Total</td>
<td>226 (100%)</td>
</tr>
</tbody>
</table>

NB Table shows data for all patients regardless of which stage of recruitment they were excluded from the study. AMTS was Abbreviated Mental Test Score (Hodkinson 1972).

Table 5c shows the characteristics of the 100 patients interviewed. Fifteen patients had dysphagia, five of whom received naso-gastric or gastrostomy feeding at some stage. Thirty patients had dysphasia at presentation although all these had recovered enough language to be interviewed by the time they were recruited to the study.
Table 5c Characteristics of the study population in relation to their wish for CPR

<table>
<thead>
<tr>
<th></th>
<th>Wanted CPR (75 patients)</th>
<th>Declined CPR (24 patients)</th>
<th>All patients (100 patients)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>Median 73</td>
<td>76.5</td>
<td>75</td>
<td>* p=0.08</td>
</tr>
<tr>
<td></td>
<td>Mean (range) 72.2 (50-91)</td>
<td>76 (64 – 86)</td>
<td>73.3 (50 – 91)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>Male 41 (54.7%)</td>
<td>11 (45.8%)</td>
<td>52 (52%)</td>
<td># p=0.43</td>
</tr>
<tr>
<td>Time in hospital</td>
<td>Mean (range) 34.5 (2-131)</td>
<td>38.1 (1-154)</td>
<td>35.7 (1-154)</td>
<td>* p=0.64</td>
</tr>
<tr>
<td>Time to interview</td>
<td>Mean (range) 163.0 (48-337)</td>
<td>162.1 (47-324)</td>
<td>162.1 (47-337)</td>
<td>* p=0.9</td>
</tr>
<tr>
<td>Residence</td>
<td>Residential care 1 (1.3%)</td>
<td>3 (12.5%)</td>
<td>4 (4%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home alone 25 (33.3%)</td>
<td>9 (37.5%)</td>
<td>37 (37%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home with others 49 (65.3%)</td>
<td>12 (50%)</td>
<td>62 (62%)</td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>Partner/married 44 (58.7%)</td>
<td>12 (50%)</td>
<td>57 (57%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Single 4 (5.3%)</td>
<td>3 (12.5%)</td>
<td>7 (7%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Widowed 20 (26.7%)</td>
<td>9 (37.5%)</td>
<td>29 (29%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Divorced 7 (9.3%)</td>
<td>0 (0%)</td>
<td>7 (7%)</td>
<td></td>
</tr>
<tr>
<td>Stroke type</td>
<td>LACI 27 (36%)</td>
<td>12 (50%)</td>
<td>40 (40%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TACI 8 (10.7%)</td>
<td>1 (4.2%)</td>
<td>9 (9%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PACI 22 (29.3%)</td>
<td>5 (20.8%)</td>
<td>27 (27%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>POCI 8 (10.7%)</td>
<td>2 (8.3%)</td>
<td>10 (10%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>PICH 10 (13.3%)</td>
<td>4 (16.7%)</td>
<td>14 (14%)</td>
<td></td>
</tr>
</tbody>
</table>
Table 5c continued

<table>
<thead>
<tr>
<th></th>
<th>Wanted CPR (75 patients)</th>
<th>Declined CPR (24 patients)</th>
<th>All patients (100 patients)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Barthel</strong></td>
<td>Median</td>
<td>19</td>
<td>17.5</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Mean (range)</td>
<td>16.8 (2-20)</td>
<td>15.7 (2-20)</td>
<td>16.5 (2-20)</td>
</tr>
<tr>
<td><strong>Worst Barthel</strong></td>
<td>Median</td>
<td>9</td>
<td>7.5</td>
<td>9</td>
</tr>
<tr>
<td>(score out 20)</td>
<td>Mean (range)</td>
<td>8.5 (0-18)</td>
<td>8.7 (2-17)</td>
<td>8.4 (0-18)</td>
</tr>
<tr>
<td><strong>Current GDS</strong></td>
<td>Median</td>
<td>4</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>(score out 15)</td>
<td>Mean (range)</td>
<td>4.6 (1-14)</td>
<td>5.7 (2-12)</td>
<td>4.8 (1-14)</td>
</tr>
<tr>
<td><strong>Quality of life</strong> $</td>
<td>Median</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mean (range)</td>
<td>3.5 (1-5)</td>
<td>3.2 (1-5)</td>
<td>3.5 (1-5)</td>
</tr>
<tr>
<td><strong>Social support &amp;</strong></td>
<td>Median</td>
<td>4</td>
<td>4.5</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mean (range)</td>
<td>4 (1-5)</td>
<td>3.8 (1-5)</td>
<td>4 (1-5)</td>
</tr>
</tbody>
</table>

**Notes:** First two columns show data for 99 patients who expressed a preference for CPR or not. Final column also includes one patient who was unable to decide. Type of stroke by Bamford classification (LACI = lacunar infarction, TACI = Total anterior circulation infarct, PACI = Partial anterior circulation infarct, POCI = Posterior circulation infarct, PICH = Primary intracerebral haemorrhage). Data for Quality of life and social support scale available for only 92 patients.

$ Quality of life 1= very bad, 2= pretty bad, 3= good and bad equal, 5= very good

& Social support 1= none at all, 2= a little, 3= some, 4= quite a bit, 5= as much as I want

* T-Test

# Pearson Chi-square

@ Mann-Whitney
5.3.2 Wishes for life-sustaining treatment

At the beginning of the interview patients were asked ‘If you collapsed now, and there were people around who could do resuscitation, would you want to have it?’ 85 (85%) said ‘yes’ 14 (14%) said ‘no’ and 1 was unsure.

Following the education session the patients were asked again if they would want resuscitation. 75 (75%) now wanted CPR, 24 (24%) did not and 1 patient was still unable to make a decision. All subsequent analysis of resuscitation preferences was based on post-education opinion.

We asked patients whether they would accept artificial feeding if they had another stroke and the doctors recommended naso-gastric or gastrostomy tube feeding. Sixty percent would accept this treatment, 30% would not and 10% were unable to decide.

5.3.3 Pre-education level of knowledge about CPR and effect of education

Seventeen patients were unable to describe any of the techniques used during CPR. 33 (33%) patients had a poor knowledge (scoring 1 or less), 63 (63%) had a moderate knowledge (scoring 2 to 4) and only 4 (4%) had a good knowledge (scored 5 or more). The mean score was 1.9 with a range of 0 to 5 and a median of 2.

Thirteen patients were unable or unwilling to estimate the success rate of in-hospital CPR. The other 87 patients overestimated success rate and guessed a mean survival of 55.8% (range 10 to 100, median 50). 73% guessed at 50% or more success rate. Six patients thought that 90% or more of patients having in-hospital CPR survived to discharge.

Despite the poor level of knowledge about CPR the majority (89%) of patients were not influenced by detailed information about the pros and cons of the procedure. 11 patients changed their minds about CPR after education. Nine decided against it having initially said ‘yes’, one became unsure having previously wanted CPR and one who was unsure before refused it after education. No one became more positive about CPR after education. See table 5d.
Table 5d The influence of educational material on patients’ wishes for CPR

<table>
<thead>
<tr>
<th>Pre-education wish for CPR</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post education wish for CPR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>75</td>
<td>0</td>
<td>0</td>
<td>75</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>14</td>
<td>1</td>
<td>24</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>14</td>
<td>1</td>
<td>100</td>
</tr>
</tbody>
</table>

5.3.4 Determinants of CPR preference

Table 5c shows data for those who wanted and declined resuscitation separately. Although there appears to be a trend towards older, more disabled, more depressed and those with a lower self-reported quality of life and social support refusing CPR, none of these factors reaches statistical significance. Six out of the nine patients with Barthel scores less than 8 wanted resuscitation. Seven out of the ten patients aged over 85 wanted resuscitation. Sixteen (72%) of the 22 patients who spent more than 60 days in hospital after their stroke wanted CPR.

Patients were asked to assess whether they would have wanted to have CPR if they had been asked prior to their stroke. Whilst the overall figures were similar with 75% of patients feeling they would have wanted CPR before their stroke, when the data were examined more carefully 25 patients felt they had changed their minds because of their stroke (Table 5e). Some qualitative information was available for the patients who changed their minds. The twelve patients who had become more negative usually cited poorer quality of life or fear of extension of stroke during resuscitation attempts as reasons for wanting less treatment. The thirteen patients who had become more positive about CPR explained this by an increased awareness and fear of death, a greater appreciation of life or an increased faith in the medical profession.
Table 5e Patients’ estimate of how their stroke had influenced their preferences for CPR

| Estimated Pre-stroke preference for CPR |
|-----------------|---|---|---|---|
| Current for CPR | Yes | No | Unsure | Total |
| Yes             | 62 | 13 | 0     | 75   |
| No              | 12 | 11 | 1     | 24   |
| Unsure          | 1  | 0  | 0     | 1    |
| Total           | 75 | 24 | 1     | 100  |

5.3.5 Comparison of patients’ views with CPR status while in hospital

Data on the resuscitation status of patients while in hospital were available in 88 cases. In 20 (23%) cases a DNR order was recorded in the medical notes. The remaining 68 (77%) patients would therefore have received CPR on the event of a sudden deterioration. Table 5f shows how patients’ views compare with their resuscitation status at the time of discharge from hospital. One third of patients would not have had the level of treatment they appear to want.

Table 5f Comparison of patients’ preferences for CPR with their resuscitation status as recorded in medical notes at time of discharge

<table>
<thead>
<tr>
<th>Patients’ wishes for CPR at interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR status in Hospital</td>
</tr>
<tr>
<td>-----------------</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

# Data not shown for one patient who was ‘unsure’ of his wishes for CPR. This patient was designated DNR in the medical notes.
5.3.6 Views about relatives as witnesses to resuscitation

Following education about CPR patients were asked ‘If you were having resuscitation would you like your relatives to be in the room with you?’ Seventy-eight (78%) patients were against relatives being present in the resuscitation room, 17 (17%) were in favour and 5 (5%) were undecided. Many patients expressed strong feelings that they would not want relatives present during resuscitation, commonly because they felt it would create additional suffering for their loved ones.
5.4 Conclusions

The percentage of patients opting for CPR (75%) and artificial feeding (60%) was higher than might have been predicted from studies that look at stroke as a hypothetical scenario (Uhlmann et al 1988). However the overall proportion of patients wanting CPR was similar to previous surveys of elderly UK inpatients with mixed pathology and disability (Liddle et al 1994, Mead and Turnbull 1995, Bruce-Jones 1996).

One of the limitations of this study is that fewer than half of those potentially eligible for the study were interviewed. In the minority of cases the GP, patient or relative specified why an invitation was refused but in the majority of cases there is no indication as to the reason for non-response. It is possible that the volunteers had a better physical and/or emotional outcome than those who did not reply to the invitation and this may have biased the results. The study does however contain patients with a range of disability. By the time of the interview, there had been a substantial improvement for most patients and the mean Barthel score was 16.5 with half living independently within their own environment. However, while a few suffered only minor strokes, the majority had substantial deficits as shown by a mean worst Barthel score of 8.4/20 and an average length of stay in hospital of over a month.

Another possible methodological criticism is that the group of patients recruited directly from day hospital (n=10) might be inherently different to those recruited from the stroke register (n=90). There were no significant demographic or diagnostic differences between these two groups and this factor seems unlikely to have influenced the conclusions of the study. Although the author conducted the majority of interviews, a research nurse conducted some, and this may also potentially introduce variability. The nurse was trained by the author and interviews were largely scripted and structured (see appendix C). There was no statistically significant difference found between the responses of the two groups who had different interviewers. However in an ideal situation a formal inter-rater reliability study should have been performed on the questionnaire.
Survivors with adverse features (lower Barthel, higher GDS, and lower quality of life scale, longer hospital stays) were more likely to decline CPR but these differences were not significant. Even if trends had reached statistical significance they would not be useful as surrogates for patients’ wishes since there is such a wide degree of overlap between the groups. A high proportion of patients with very low Barthel scores, with ages over 85 and those spending long periods in hospital still opted for CPR even after education. It is possible that the instruments used are not precise enough to measure these factors but the author believes that it is more likely that other factors (such as personal philosophies and experiences or cultural and religious beliefs) that were not measured are playing a major role in decision-making.

Many studies have shown that physicians are not good at predicting patient preferences for CPR (Uhlmann et al 1988, Seckler et al 1991, Starr et al 1986, Bedell and Delbanco 1984). This may be because the variables that physicians use, often subconsciously, to estimate patients’ wishes for CPR (age, disability, quality of life and pre-illness views expressed by the patient) are not reliable indicators of what the patient might want.

The poor correlation between patients’ wishes and the resuscitation status while in hospital may result from several different factors. The interview was conducted several months after discharge and it is possible that the patient had different views while in hospital. It is also possible that if the patient been re-admitted around the time of the interview the CPR status would have been different to that recorded during their acute stroke admission. For the patients who wanted resuscitation but were designated not for CPR in hospital (n=10) it may be that a decision had been made on medical criteria that they would not survive resuscitation (ie CPR would be medically futile). At the time the study was conducted it was not common practice to discuss CPR decisions with patients when the decision was made on the basis of medical futility alone. The views of the twelve patients who did not want CPR but were for resuscitation while in hospital were probably not elicited in hospital. It is unlikely that the medical team was aware of such views and ignored them.
This study confirms the finding that elderly patients are poorly informed about CPR and that education about CPR adversely influences their acceptance of this treatment has been reported elsewhere (Murphy et al 1994, O'Brien et al 1995, Morgan et al 1994, Hui et al 1997, Kerridge 1999, Miller et al 1992).

Some patients' views about CPR have been shown to vary with during hospital admissions (Watson et al 1997, Sayers et al 1997) but there is very little known about how they vary over longer periods of time and especially with changes in health and quality of life status. In this study one quarter of the patients felt that their views about life-sustaining treatment had changed as a result of the stroke. The retrospective method of data collection can be criticised as inherently inaccurate but this is a very interesting result that would be clinically meaningful, especially if replicated in a prospective trial. Advance directives rely on the fact that patients can predict their wishes for treatment accurately before they become ill. If a substantial number of patients have volatile views this would cast doubts on the validity of advance directives.

It is interesting that the direction that patients' views changed was not predictable. The patients who felt they had became more negative about treatment since the stroke seem to follow the pattern suggested in hypothetical studies such as Uhlmann et al (1988) were increasing disability corresponded with decreasing wish for life-sustaining treatment. In contrast the 13 patients who felt they had become more willing to accept CPR after their stroke add weight to the argument that illness and disability can make patients more rather than less willing to accept treatment (Ryan 1996). A study by Danis et al (1994) suggests that people are more likely to become acceptors of intensive medical treatment when they have become more vulnerable (through hospitalisation, an accident, immobility, depression or decreased social support). Slevin et al (1990) found that patients with a diagnosis of cancer were much more willing to undergo chemotherapy than a matched group of controls who did not have the diagnosis were hypothetically willing to.
In summary this study demonstrates that the majority of patients are willing to accept CPR after a disabling stroke, that simple variables like age and disability scores are not good at distinguishing which patient will refuse treatment and that patients views about CPR are not necessarily stable over time.
Chapter 6

In patients suffering an acute stroke, what is their level of competence to complete an advance directive and how stable are their decisions about life-sustaining treatments?

The Australian Quantitative Study

Perth

Data collected 1999 - 2000
Published as abstracts 2000 and 2001
6.1 Introduction

Although there is a growing belief that patients should be involved in decisions about CPR, studies that look at clinical practice have found that the rate of patient involvement is low (Alexandrov et al 1995, Bedell et al 1986, Bedell and Delbanco 1984). There are three major possible reasons for the low involvement rate.

1. Patients might be physically unable to take part in decisions (e.g. unconscious, dysphasic).
2. Patients might be physically able, but mentally unable, to take part in decisions (i.e. incompetent).
3. Physicians might be unwilling to approach the patient (e.g. they feel it is unnecessary or likely to harm the patient).

This study assessed a consecutive series of patients with the diagnosis of acute stroke to determine the percentage of such patients with whom it is possible to have meaningful discussions about CPR.

 Patients who appear physically capable of discussing CPR might not have the intellectual capacity to make informed decisions during their illness. The second main aim of the project was to examine the competence of this group of patients to make end-of-life decisions. It is possible that competence levels for any given patient change over short periods of time. By assessing competency during the early stages of hospital admission and following discharge from hospital any alteration in competency can be examined.

In much of the literature concerning patients’ involvement in end-of-life decisions there is an assumption that patients have stable views about medical treatment. Surveys of patient opinion about CPR tend to be cross-sectional samples with little or no attempt at longitudinal sampling. There is some evidence that patients’ views do not remain static; for example between 15% and 17% of patients change their minds about CPR over the short periods of time between admission and discharge from hospital (Watson et al 1997, Sayers et al 1997). One hypothesis is that opinions might be more likely to change if there is a significant change in the circumstances of the individual. Stroke usually causes a sudden and substantial change in the quality of life for patients, especially in the areas of health, physical independence and social role,
and therefore might be expected to be associated with changing views about life-sustaining treatment.

The Oxford Study (chapter 5) demonstrated that patients believe that their opinions about life-sustaining treatment do change as a result of stroke but in a non-predictable fashion i.e. some become more positive and some more negative about CPR. This earlier study relies on patients’ estimates of pre-morbid views and might be inaccurate. Ideally a prospective study, sampling views before and after stroke, would be most informative but as stroke is unpredictable a very large study would need to be done to obtain this information. As a compromise this study was designed to determine how CPR views change during the recovery after stroke. The symptoms and disability of stroke are usually maximal at onset with a gradual resolution. This study sampled views soon after stroke and at a later period to examine the stability of choices about life-sustaining treatment.
6.2 Methods

The Royal Perth Hospital in Western Australia serves a local population of approximately 500,000 and provides a tertiary referral centre for surrounding rural areas. All stroke patients (regardless of factors such as age and severity of stroke) are eligible for referral to the stroke ward which provides a diagnostic and rehabilitation service. About half the surviving patients will be discharged directly back to the community with the other half moving either to Shenstone Park Hospital for specialist neurorehabilitation, or to smaller, locally-based rehabilitation units.

Any patient aged over 50 years with a clinical diagnosis of acute stroke was eligible for inclusion in the study and the majority of patients were recruited by daily liaison with the stroke ward. Occasionally further patients were recruited who had not been admitted to the stroke ward (eg where the diagnosis was unclear at presentation or where the patient was admitted directly to a community rehabilitation hospital). An attempt to interview all patients within 14 days of their admission was made. If a patient was initially unsuitable for interview then they would be reassessed frequently during the first two weeks to ensure they had not improved enough to take part in the study.

Patients were felt to be unsuitable for interview if they fell into the following categories for all of the first two weeks of admission

- unconscious or drowsy
- non-English speaking
- obviously very confused and/or AMTS of less than 7/10
- dysphasia of a severity that the patient could not understand or answer questions
- nursing or medical staff felt that patient would be adversely effected by the study

The same semi-structured questionnaire was used to interview the patients as had been used in the Oxford study (Chapter 5). Table 6a summarises the information that was obtained from each patient and appendix D contains a sample questionnaire including the patient information sheet.
Table 6a Information collected for each patient (see appendix D)

<table>
<thead>
<tr>
<th>Source of Variable</th>
<th>Variable</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Notes</td>
<td>Demographics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pathological stroke type</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Length of hospital stay</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Resuscitation status in hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bamford classification (Bamford et al 1991)</td>
<td></td>
</tr>
<tr>
<td>Interview with</td>
<td>Residence</td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>Pre-education views about CPR</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Level of knowledge about CPR</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post-education views about CPR</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Views on artificial feeding</td>
<td></td>
</tr>
<tr>
<td></td>
<td># Views about advance directive scenarios x 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Standard educational information given to each patient</td>
<td></td>
</tr>
<tr>
<td>Scales</td>
<td>AMTS (Hodkinson 1972)</td>
<td>Dartmouth COOP Chart-2 questions only; a simple visual scale measuring patients self-rated quality of life and social support</td>
</tr>
<tr>
<td></td>
<td>Barthel Index (Mahoney and Barthel 1965)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15-point geriatric depression scale (Sheikh JI and Yesavage 1986)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dartmouth COOP Chart (Nelson et al 1990)</td>
<td></td>
</tr>
<tr>
<td></td>
<td># SF-12 (Ware et al 1995)</td>
<td></td>
</tr>
<tr>
<td></td>
<td># Competency tool (Fazel 1999)</td>
<td></td>
</tr>
</tbody>
</table>

# This information was not collected in the Oxford study (chapter 5)

The competency tool developed by Fazel et al (1999) was also administered. This tool measures competency to complete an advance directive using hypothetical scenarios (see section 1.4.2.4). Fazel tested three hypothetical scenarios but the good consistency between them suggests that only two need to be used. One of the scenarios involved hypothetical stroke and it was felt that it would be confusing and possibly distressing for the patient so the other two scenarios were employed. The first scenario involved a hypothetical situation of a gastrointestinal bleed in the case of a patient with mild dementia and asked patients to choose if they would want investigation or not. The second was a hypothetical case of a patient with severe dementia in a nursing home who gets severe chest infection, and asks whether the
patient would want no treatment, tablet antibiotics or admission to hospital and intravenous antibiotics (full scenarios in appendix D). The patient was allowed to clarify any aspect of the hypothetical case and then tested on their understanding and decision making for the case using 9 standardised questions (see appendix D). The patient could score between 0 and 10 on each scenario and the final competency score was the mean score for both scenarios. A score of 6 or greater indicates competence to make an advance directive (Fazel et al 1999). Preference for treatment in both hypothetical case scenarios was also recorded.

Patients were telephoned after discharge and if they agreed, were visited in their own home at a time convenient to them and re-interviewed using identical interview proforma and scales.

All the in-hospital interviews were conducted by one investigator (LB) who was not involved with the patient's clinical management. The chief investigator (LB) or another doctor working as a trainee registrar in Geriatrics – Sean Maher (SM) - conducted the follow-up interviews.

At both interviews patients were assured their responses were confidential and would not be made available to the hospital or GP. Written consent was obtained for each person at the beginning of the first interview. The study was approved by Royal Perth Hospital Ethics Committee (Reference EC 2000/010).

Statistical Methods
The data was analysed using Statistical Package for Social Sciences. T-tests or Chi-squared tests were used for normally distributed data and Mann-Whitney Test U tests for data not normally distributed.
6.3 Results

6.3.1 Proportion of stroke patients available for first interview
Patients were recruited between 1.10.99 and 14.6.00 (8.5 months). During this time 169 patients aged over 50 years were identified as having a diagnosis of acute stroke. An interview was achieved in 60 patients (35%). Table 6b shows the reasons why the other 109 patients were not included in the study. Seventy one patients (42%) were ineligible for interview (ie physically or mentally incapable by our pre-determined criteria) 8% refused interview and 14% were not included because the patient had died, been discharged or had failed to be recruited within 14 days of admission. The demographics and medical characteristics of the sixty patients recruited are shown in Table 6c. None of the patients interviewed had do-not-resuscitate orders in the medical notes.

Table 6b Proportion of patients recruited to study and reasons for exclusion from study

<table>
<thead>
<tr>
<th>Number of patients (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interview completed</strong></td>
<td>60 (35%)</td>
</tr>
<tr>
<td><strong>Patient ineligible for interview</strong></td>
<td>71 (42%)</td>
</tr>
<tr>
<td>Dysphasia</td>
<td>34</td>
</tr>
<tr>
<td>Non-English speaking</td>
<td>14</td>
</tr>
<tr>
<td>Unconscious/Drowsy</td>
<td>13</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>6</td>
</tr>
<tr>
<td>Staff felt inappropriate</td>
<td>4</td>
</tr>
<tr>
<td><strong>Patients eligible but refused interview</strong></td>
<td>14 (8%)</td>
</tr>
<tr>
<td><strong>Patient probably eligible but interviewer not able to conduct interview in time period</strong></td>
<td>24 (14%)</td>
</tr>
<tr>
<td><strong>Total number of patients aged over 50 with acute stroke</strong></td>
<td>169 (100%)</td>
</tr>
</tbody>
</table>
Table 6c Demographics and medical characteristics of all 60 patients

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>68</td>
<td>67</td>
<td>50</td>
<td>88</td>
</tr>
<tr>
<td>Barthel Score (out of 20)</td>
<td>13.2</td>
<td>13.5</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td>AMTS (out of 10)</td>
<td>9.2</td>
<td>9</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>GDS (out of 15)</td>
<td>3.6</td>
<td>3</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>SF-12 Physical score</td>
<td>36.99</td>
<td>37.02</td>
<td>18.07</td>
<td>57.24</td>
</tr>
<tr>
<td>SF-12 Mental score</td>
<td>51.98</td>
<td>54.06</td>
<td>24.98</td>
<td>66.80</td>
</tr>
<tr>
<td>Time in Hospital before Interview (days)</td>
<td>6.58</td>
<td>6</td>
<td>0</td>
<td>18</td>
</tr>
<tr>
<td>Total time in hospital (days)</td>
<td>41</td>
<td>17</td>
<td>1</td>
<td>212</td>
</tr>
<tr>
<td>Sex (number and % male)</td>
<td>39</td>
<td>65%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>5</td>
<td>8.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/partner</td>
<td>39</td>
<td>65%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>11</td>
<td>18.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>5</td>
<td>8.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home with others</td>
<td>45</td>
<td>75%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home alone</td>
<td>14</td>
<td>23.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residential care</td>
<td>1</td>
<td>1.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type of Stoke (Barnford Class)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TACI</td>
<td>4</td>
<td>6.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PACI</td>
<td>19</td>
<td>31.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LACI</td>
<td>19</td>
<td>31.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>POCI</td>
<td>15</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PICH</td>
<td>2</td>
<td>3.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inattention/Perceptual problems</td>
<td>8</td>
<td>13.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dysphasia</td>
<td>11</td>
<td>18.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dysphagia</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>11.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requiring n-g feeding</td>
<td>4</td>
<td>6.7%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6.3.2 Views about life-sustaining treatment

Table 6d summarises the patients’ views about life-sustaining treatment (after education). If it were required, forty-nine patients (81.7%) wanted CPR for themselves and 43 (71.7%) were in favour of artificial nutrition. In the hypothetical scenarios involving dementia preferences for treatment were lower; 44 (73.3%) were in favour of active management of a lower gastrointestinal bleeding if they were mildly demented whilst only 25 (42.4%) would want to be hospitalised for treatment of a chest infection if they had severe dementia.

Table 6d Views about life-sustaining treatment for all 60 patients

<table>
<thead>
<tr>
<th>Treatment type</th>
<th>In favour of treatment</th>
<th>Against treatment</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR</td>
<td>49 (81.7%)</td>
<td>10 (16.7%)</td>
<td>1 (1.7%)</td>
</tr>
<tr>
<td>Artificial feeding</td>
<td>43 (71.1%)</td>
<td>13 (21.7%)</td>
<td>4 (6.7%)</td>
</tr>
<tr>
<td>Scenario 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild dementia + GI bleed</td>
<td>44 (73.3%)</td>
<td>14 (23.3%)</td>
<td>2 (3.3%)</td>
</tr>
<tr>
<td>Scenario 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe dementia + chest infection #</td>
<td>I v a/b 25 (42.4%)</td>
<td>26 (44.1%)</td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td></td>
<td>Oral a/b 3 (5.1%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

# data missing for one patient

There was no association between age, Barthel score, GDS score, COOP social support or quality of life (by COOP or SF-12 scales) and wish to have CPR (Table 6e). SF-12 scores are interpreted by comparisons with a normal population score of 50; scores lower than than 50 indicate worse quality of life than a normal population.

It is not surprising that this group who had suffered a stroke had lower physical (mean 36.99) than mental (mean 51.98) quality of life scores.
Table 6e Characteristics of study population in relation to their wish for CPR

<table>
<thead>
<tr>
<th>Variable</th>
<th>Wanted CPR (n=49)</th>
<th>Refused CPR (n=10)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>67.7</td>
<td>68.6</td>
<td>T-test NS</td>
</tr>
<tr>
<td>GDS (out of 15)</td>
<td>3.7</td>
<td>3.1</td>
<td>T-test NS</td>
</tr>
<tr>
<td>SF 12 – Physical score</td>
<td>36.7</td>
<td>39.5</td>
<td>T-test NS</td>
</tr>
<tr>
<td>SF 12 – Mental score</td>
<td>51.9</td>
<td>52.4</td>
<td>T-test NS</td>
</tr>
<tr>
<td>Total Time in Hospital (days)</td>
<td>41.6</td>
<td>42.3</td>
<td>T-test NS</td>
</tr>
<tr>
<td>Barthel (out of 20)</td>
<td>13.2</td>
<td>14.3</td>
<td>T-test NS</td>
</tr>
<tr>
<td>COOP – quality of life (out of 5)*</td>
<td>3.9</td>
<td>4.0</td>
<td>T-test NS</td>
</tr>
<tr>
<td>COOP – social support (out of 5)*</td>
<td>3.9</td>
<td>4.0</td>
<td>T-test NS</td>
</tr>
</tbody>
</table>

NS = Not significant
* see table 5c for explanation of COOP scoring system

6.3.3 Level of knowledge about life-sustaining treatment
Seven patients (11.7%) had a poor pre-education level of knowledge (defined as being able to name none or one technique used in CPR), 43 (71.7%) had a moderate level of knowledge (were able to name between 2 and 4 techniques used in CPR) and 10 (16.7%) of patients were well educated (knew more that 4 techniques). The mean number of techniques known was 3.1 (range 0 – 6) and the median was 3.

Before education the patients’ mean estimate for the success rate (survival to discharge) after CPR was 71.6% (range 10 to 99%). Five patients (8.3%) were unable/unwilling to estimate success rate and 42 (70%) guessed that half or more of patients survive to discharge after CPR.

Nineteen patients (68.3%) had thought about CPR before, 14 (23.3%) had discussed their wishes with a family member and one (1.7%) with a doctor. No patient had
made an advance directive but 5 (8.3%) had heard of them and 2 (3.3%) had thought about making one themselves.

The effect of education about CPR techniques and success rates on acceptance of CPR is shown in table 6f. Seven patients changed their minds with none of the patients becoming more positive about the technique.

Table 6f The effect of education about CPR on patients' views

<table>
<thead>
<tr>
<th>Post education wish for CPR</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial wish for CPR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>49</td>
<td>6</td>
<td>1</td>
<td>56</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>10</td>
<td>1</td>
<td>60</td>
</tr>
</tbody>
</table>

Just over half (31 patients, 51.7%) felt that they should be routinely consulted about CPR decisions. In the event that they were unable to be consulted about a CPR decision 33 (55%) felt that their families should make the decision whilst 26 (43.3%) felt is should be the doctors' decision alone.

Three-quarters of the patients (47 (78.3%) would not want their relatives to be present if they were to undergo CPR. Only 12 (20%) favoured relatives in the resuscitation room.

Two patients were unable/unwilling to estimate what their preference for CPR would have been pre-stroke. Table 6g shows how the patients felt their views had changed as a result of stroke; fifty-one patients (85%) felt their views had not changed, 4 (6.6%) felt more negative about the technique and 4 (6.6%) felt more positive.
Table 6g  The patients’ estimate of how stroke had changed their views about CPR

<table>
<thead>
<tr>
<th>Estimate of pre-stroke preference for CPR</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>44</td>
<td>4</td>
<td>0</td>
<td>48</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>6</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
<td>10</td>
<td>1</td>
<td>60</td>
</tr>
</tbody>
</table>

6.3.4 Competency to complete an advance directive

The mean, median and range of competency scores are shown in table 6h. Figure 6j shows the total competency scores for all 60 patients.

Table 6h  The mean, median and range scores shown for both scenarios separately and for the total competency score (calculated from the mean of both scores)

<table>
<thead>
<tr>
<th>Score</th>
<th>Mean</th>
<th>Median</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 1  Gastrointestinal bleed and mild dementia</td>
<td>6.8</td>
<td>8</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Scenario 2  Chest infection and severe dementia #</td>
<td>6.5</td>
<td>8</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Total Competency score (mean of scenarios 1 and 2)</td>
<td>6.6</td>
<td>7.5</td>
<td>0.5</td>
<td>10</td>
</tr>
</tbody>
</table>

# Information missing for 1 patient who refused further testing after first scenario. This patient scored 5/10 on first scenario and this figure was used for the mean score.

There was a good correlation between the scores from the two different scenarios (see scatterplot in figure 6i).
Figure 6i Scatterplot to show correlation of competency scores for the two scenarios

Figure 6j Histogram showing total competency scores for all 60 patients in the study
The suggested cut off to indicate competency is a score of 6 or more. Using this definition our group of patients contained 42 (70%) who were competent to make an advance directive and 18 (30%) who were not. Within the incompetent group 11 patients scored less than 4

The incompetent group was significantly older, had lower Barthel scores, Mental test scores and lower mean knowledge scores than the competent group. There was no difference between the incompetent and competent patients in their wish for life sustaining treatment (see table 6k).

Table 6k Comparison of the competent and incompetent groups of patients

<table>
<thead>
<tr>
<th></th>
<th>Competent (n=42)</th>
<th>Incompetent (n=18)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean)</td>
<td>65.5</td>
<td>74.3</td>
<td>T-test p=0.01</td>
</tr>
<tr>
<td>Barthel (mean)</td>
<td>14.9</td>
<td>9.2</td>
<td>T-test p=0.0001</td>
</tr>
<tr>
<td>AMTS (mean)</td>
<td>9.4</td>
<td>8.7</td>
<td>T-test p=0.01</td>
</tr>
<tr>
<td>SF12 Physical (mean)</td>
<td>38.54</td>
<td>33.01</td>
<td>T-test Not significant</td>
</tr>
<tr>
<td>SF12 Mental (mean)</td>
<td>52.19</td>
<td>51.41</td>
<td>T-test Not significant</td>
</tr>
<tr>
<td>Knowledge level</td>
<td>3.5</td>
<td>2.4</td>
<td>T-test Not significant</td>
</tr>
<tr>
<td>GDS (mean)</td>
<td>3.6</td>
<td>4.2</td>
<td>T-test Not significant</td>
</tr>
<tr>
<td>Time in hospital before interview (mean days)</td>
<td>7.0</td>
<td>5.56</td>
<td>T-test Not significant</td>
</tr>
<tr>
<td>Sex (number and % male)</td>
<td>27 (64.3%)</td>
<td>12 (66%)</td>
<td>Chi-squared Not significant</td>
</tr>
<tr>
<td>Wish for CPR (number and % Yes)</td>
<td>33 (71.4%)</td>
<td>16 (88%)</td>
<td>Chi-squared Not significant</td>
</tr>
<tr>
<td>Wish for Artificial Feeding (number and % Yes)</td>
<td>30 (71.4)</td>
<td>13 (72.2%)</td>
<td>Chi-squared Not significant</td>
</tr>
</tbody>
</table>
6.3.5 Views and competency at follow-up

Follow-up interviews were conducted with 51 patients; 85% of the original group. In 3 cases we could not trace the patient after discharge, in 4 cases the patient refused the second interview and in 2 cases the patient had moved overseas. In five cases the patient lived so far away that a face-to-face interview was not possible and for these cases a telephone interview was conducted.

The mean age, Barthel score in hospital, AMTS, GDS and SF 12 and initial competence score were not significantly different between the group who did and those who did not have a follow up interview (t-test). There was no significant difference between the percentage of patients who wished for CPR and artificial feeding at initial interview in the group who was followed up and the group who were not (chi-squared test).

The mean time between the stroke and second interview was 152 days (range 78 - 269) and the follow-up interview was conducted at a mean of 110 days after discharge (range 8 – 258).

Level of knowledge

Knowledge scores and level of planning about CPR for the 51 patients who were re-interviewed are shown in Table 61. There was a very small improvement in knowledge levels and patients had become slightly more realistic about success rates in the time between the two interviews. The concept of advance directives was discussed with all patients at the first interview however three-quarters (49 (81.6%)) of the patients claimed they had not heard of them at follow-up and none of the patients had completed one.

Education about CPR techniques and success rates at the second interview had a very similar effect as during the first interview. Six (11.8%) of the patients decided against CPR who had previously been in favour of it. No one became more positive after education.
Table 61: The level of knowledge and degree of planning about CPR and other life-sustaining treatments compared for the 51 patients who were interviewed twice

<table>
<thead>
<tr>
<th></th>
<th>In-hospital Interview (n = 60)</th>
<th>Post-discharge Interview (n = 51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge score #</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.1</td>
<td>3.4</td>
</tr>
<tr>
<td>Range</td>
<td>0 - 6</td>
<td>0 - 7</td>
</tr>
<tr>
<td>Knowledge score</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor (score&lt;2)</td>
<td>7 (11.7%)</td>
<td>9 (17.6%)</td>
</tr>
<tr>
<td>Moderate (score 2-4)</td>
<td>43 (71.7%)</td>
<td>31 (60.8%)</td>
</tr>
<tr>
<td>Good (score&gt;4)</td>
<td>10 (16.7%)</td>
<td>11 (21.6%)</td>
</tr>
<tr>
<td>Estimated % success rate for CPR</td>
<td>71.6%</td>
<td>50.4%</td>
</tr>
<tr>
<td>Mean</td>
<td>10% - 99%</td>
<td>1% - 95%</td>
</tr>
<tr>
<td>Range</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thought about CPR?</td>
<td>Yes 19 (31.7%)</td>
<td>Yes 17 (33.3%)</td>
</tr>
<tr>
<td>Discussed CPR with family?</td>
<td>Yes 14 (23.3%)</td>
<td>Yes 12 (23.5%)</td>
</tr>
<tr>
<td>Discussed CPR with Doctor?</td>
<td>Yes 1 (1.6%)</td>
<td>Yes 3 (5.8%)</td>
</tr>
<tr>
<td>Advance Directive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heard of?</td>
<td>Yes 5 (8.3%)</td>
<td>Yes 11 (21.6%)</td>
</tr>
<tr>
<td>Thought about making?</td>
<td>Yes 2 (3.3%)</td>
<td>Yes 1 (2%)</td>
</tr>
<tr>
<td>Made an AD?</td>
<td>Yes 0 (0%)</td>
<td>Yes 0 (0%)</td>
</tr>
</tbody>
</table>

# Number of CPR techniques correctly identified by patient before education given
Views about life-sustaining treatment

At follow-up 40 patients (78.4%) would accept CPR and 11 (21.6%) refused it. Only 32 (63.2%) would accept artificial feeding methods with 12 (23.5%) refusing it and 7 (13.7%) undecided. Two thirds of group (34 patients (68%)) were in favour of treatment in scenario one with only a half (24 patients (48%)) accepting any kind of treatment in the second scenario.

In 43 cases (84.3% of those re-interviewed) patients did not change their minds about CPR between the two interviews. Eight (15.7%) patients did change their minds with 3 (5.9%) becoming more positive and 5 (9.8%) becoming more negative about CPR. (see table 6m and table 6n).

Table 6m Comparison of patients views about CPR at first and second interview

<table>
<thead>
<tr>
<th>Wish for CPR at first hospital interview</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wish for CPR at follow-up interview</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37</td>
<td>2</td>
<td>1</td>
<td>40</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
<td>6</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>8</td>
<td>1</td>
<td>51</td>
</tr>
</tbody>
</table>

The competency scores at both interviews for the eight patients who changed their view about CPR are shown in table 6l. Only one patient had a significant change in their competency score between the two interviews. The other 7 patients were either competent at both interviews or incompetent at both interviews.
Patients’ views about artificial feeding were less stable than for CPR. Sixteen (34%) had changed their minds by follow up whereas only 34 (68%) had stable views (see table 6o).

The views on treatment in the hypothetical dementia scenarios were not stable either. In scenario one (mild dementia and gastrointestinal bleeding) 36/49 (73%) had stable views, 4 (8%) became more positive about investigation and treatment and 9 (18%) became more negative. In scenario two (severe dementia and chest infection) 29/45
(64%) had stable views, 3 (7%) wanted more treatment and 13 (29%) wanted less treatment.

Additional notes on patients who changed their minds about CPR
In some of the cases when the interviewer was aware that the patient’s views about CPR had changed at follow-up the patient was challenged with their original opinion and asked why they had answered differently. Informal field notes from both interviews provide some interesting insights.

Case#534
An 83-year-old man with AMTS of 10/10 and competency of 7.5/10 in hospital had chosen to have CPR. At follow-up (with AMTS still 10/10 and competency of 8/10) he clearly stated he would not want resuscitation. He was adamant that he had long-standing views about not wanting life-sustaining treatment which he had discussed with his family. He had no recollection of accepting CPR in hospital and felt that his choice must have been recorded incorrectly by the interviewer.

Case#502
An 84-year-old woman who lived alone in a retirement village had refused CPR while in hospital because she ‘couldn’t walk’ and was fearful of losing her independence. At follow-up she was back in her own home and walking short distances with a frame. She admitted that she was frustrated and depressed about not being able to do her knitting and attend all the social engagements she used to but she wanted CPR because she ‘loved life’. She had no memory of her choice in hospital.

Case#520
A 74 year old married lady who had needed a NG tube in hospital because of dysphagia had initially been positive about all forms of life-sustaining treatment in current situation and hypothetical scenarios. At follow-up she was much more negative, refusing CPR and treatment in both of the dementia scenarios. She knew she had changed her mind and explained that she had been thinking about things since discharge. She could recall the exact day that she had changed her mind. Her husband was in hospital and very disabled and she felt that this, along with her own illness experience, had influenced her views.
Case #535
Despite an AMTS of 9/10 this 82-year-old man scored only 1/10 on the competency test. He was very indecisive and answered ‘don’t know’ to the CPR question in hospital. At follow up his AMTS was 10/10 and competency score was only 2.5/10 but he had no hesitation in answering ‘Yes’ to the question about CPR both before and after education.

Case #557
66 year old woman who was clearly competent at both interviews had chosen not to have CPR in hospital because she felt her ‘quality of life’ was poor and was worried about ‘being a burden on her family’. Three months later she chose to have CPR because she ‘could see that she was getting better’. Her Barthel score had risen from 9/20 to 20/20 between the two interviews. She was aware that she had changed her mind.

Case #547
A 58-year-old man who had lived alone wanted CPR in hospital. He talked a lot about his family and wanted to stay alive because of them; in particular he enjoyed seeing his grandchildren. At follow-up he was living in residential care and had a very low mood (GDS had risen from 3/15 to 12/15). He did not want to have CPR because he felt he had a very poor quality of life and ‘didn’t get to see his grandchildren or get out of the hostel’. He had high AMTS and competency scores at both interviews.

Competency at follow-up
Competency scores in hospital and at follow-up were available for fifty patients since one patient did not finish the questionnaire. Overall there was a slight improvement in competency scores over time (mean competency score at the first interview was 6.6 (range 0.5 - 10) and at the follow-up interview was 7.72 (range 0 - 10)). Competency scores were identical in 10 patients, had increased in 30 cases and decreased in 10 cases. The majority of patients (29 patients (58%)) had no change or a minor change (ie less than two points) in their competency score (see figure 6p). Sixteen patients had a change of between two and four points and in five patients there was a change of greater than four points. All of the five patients with a large change had an increase in their scores.
Figure 6p Bar chart to show the change in competency scores between the first and follow-up interviews. A negative value indicates a decreased competency.

Using the threshold of 6/10 to indicate competency these changes resulted in a reclassification of competence in eight patients; seven were newly competent and one was newly incompetent (see table 6q).

The change in competency was not mirrored by a change in the AMTS (mean AMTS of the group was 9.2 at both admission interview and at follow-up). One patient scored less than the inclusion criteria of 7/10 on AMTS at follow up. This patient was clearly incompetent at both interviews (scoring 0.5 and 1 on competency tests) but had scored 7/10 at the first interview.

Table 6q Change in competency between first and follow-up interview

<table>
<thead>
<tr>
<th>Competency at follow-up interview</th>
<th>Competent</th>
<th>Incompetent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competent</td>
<td>34</td>
<td>7</td>
<td>41</td>
</tr>
<tr>
<td>Incompetent</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>15</td>
<td>50</td>
</tr>
</tbody>
</table>
6.4 Conclusions

Recruitment
Forty-two percent of this series of patients were physically not able to discuss CPR preference within the first two weeks of admission with acute stroke. The requirement of early recruitment made it likely that the most severe strokes would have been more likely to be excluded. Alexandrov et al (1995) found that only 8% of stroke patients given a DNR order were capable of discussing CPR but the majority of these patients were in the severe disability category. Alexandrov et al (1995) did not report any discussions with patients who were felt by the doctors to be appropriate for CPR and this group of patients is likely to be at the opposite end of the severity spectrum to ours, all of whom were designated for CPR at the time they were interviewed. O'Keefe (2001) has recently described a series of acute geriatric patients with mixed diagnoses and found that two thirds of them were incapable of discussions about CPR on admission to hospital.

Stroke as an admission diagnosis has additional mechanisms for rendering people unable to share their views (eg dysphasia, unconsciousness) compared with mixed general medical admissions. It is therefore not surprising that inclusion rates for similar studies in mixed elderly inpatients are much higher than in this group (Liddle et al 1994 - 73%, Mead et al 1995 - 77%).

There was a significant minority of patients (8%) who refused to be interviewed. The impression of the author was that these patients found the idea of discussing CPR distasteful or depressing. An even higher refusal rate (21%) was observed during the Southampton study (chapter 2). Other authors have reported that between 14% and 41% of patients do not wish to discuss their views about life-sustaining treatment with their doctor (Mead and Turnbull 1995, Stolman et al 1990 and Frankl et al 1989).

The Effect of Patient Education
Ninety-five percent of the group knew the procedures involved in basic resuscitation and 1 in 6 patients could describe more complex procedures. This group appears to have higher level of knowledge than previous studies of elderly British inpatients (Gunasekera 1986, Liddle et al 1994, Bruce-Jones et al 1995) but similar levels to those quoted by Kerridge et al (1999) in a recent survey of younger Australian
patients. Population education levels do seem to be rising with time and Kerridge et al found that young patients have significantly higher knowledge levels.

Despite the reasonable knowledge of techniques of resuscitation, patients still overestimated the success of CPR. This is a well-established phenomenon, which probably stems from the unrealistic depiction of CPR by the media (Murphy et al 1994, Miller et al 1992, Kerridge et al 1999, Diem et al 1996). The proportion of patients wishing to have CPR dropped from 93.3% to 81.7% after provision of information about techniques and success rates. The effect of educational material on acceptance of CPR is well established (Schonwetter et al 1991, Morgan et al 1994, Miller et al 1992, Kerridge et al 1999 and others).

The educational material presented appears to be poorly retained with mean knowledge scores being very little changed at the follow-up interview. The modest improvement in knowledge after education and its poor retention has been noted elsewhere (Schonwetter et al 1991, Sayers et al 1997). Doctors should be aware that a single education session does not ensure that patients retain a good understanding of the issues surrounding CPR.

Although it was not the aim of the study, it is surprising that the first interview had not provoked patients to discuss their views or make an advance directive.

**Views on CPR**

Over 80% of patients favoured CPR for themselves in their current situation. Since all the patients would have received CPR in hospital, ten patients (16.7%) would have been given more treatment than they appear to want. In this small group we were unable to demonstrate that simple variables such as age, sex, stroke type, disability scores or competency scores correlated significantly with wish for CPR. There was a similar conclusion from the Oxford study (chapter 5). It is important that doctors do not attempt to use such variables when making substituted judgements on DNR for incompetent patients. It would be equally incorrect to assume that patients who are young and physically not badly affected will always want to have CPR.

We did not specifically assess competence to decide on CPR but it is very likely that some of the patients who were incompetent to make an advance directive would also
have been incompetent to answer the questions on current wish for CPR. Further work should explore how competency to make CPR decisions is related to competency to make an advance directive.

There was no evidence that incompetent patients would wish for less treatment (in fact the trend was for the reverse effect) and some of the patients with the highest competency score still refused CPR. Fazel et al (2000) have postulated that incompetent patients are more likely to opt for medical treatment than competent patients are. It is possible that it requires a higher degree of competency (and perhaps insight into current state) to refuse CPR than to accept it but it is not known if patients with a progressive condition such as dementia reverse their choices as there competence decays. A longitudinal study is clearly required.

Views pre-stroke

Eight patients (13.3%) felt that their views about CPR before their stroke might have been different. This is similar to the findings from the Oxford study where 25% of patients felt that the experience of stroke had changed their minds (see chapter 5). This study also confirms the almost equal split between the patients who felt stroke had made them more positive about CPR and those who wanted less treatment after the stroke. There are no other reports which ask for retrospective views on CPR before an event however there is ample evidence that patients’ views are not fixed (Sayers et al 1997, Watson et al 1997, Danis et al 1994).

Competency

Whilst the mean AMTS was lower in the incompetent group it was still 8.7/10 which would not be seen as particularly poor. This study supports the theory that AMTS does not serve as a good instrument to estimate competence (Fazel et al 1999, Fitten and Waite 1990).

In the group with whom an interview was conducted (60 patients) one third were judged incompetent to complete an advance directive. Fazel et al (1999) used the same tool and found that 22% of community-dwelling elderly attending a lunch-club were incompetent to make an advance directive and 80% of those attending a memory clinic. This is the first study using this tool with hospital inpatients. Fitten and Waite (1990) also used clinical vignettes to assess competence and found that 28% of an
elderly inpatient population were judged to have ‘clear decisional impairment’ despite scoring in the normal range on an MMSE. Doctors may well be surprised that so many of their apparently sensible patients are not competent to make these important and complex decisions.

Competence is decision specific and it can be argued that making advance directives requires a higher level of competence than is needed for contemporaneous decisions because it involves assessment of risk/benefit in a hypothetical situation. It is possible that these ‘incompetent’ patients were actually competent to make a range of immediate, relevant decisions about their health care. However, this study demonstrates that an assessment of competence is required before involving stroke patients in complex advance care planning since a significant number of such patients cannot make meaningful decisions.

Follow-up data views and competency
The finding that a significant minority of patients (17.5%) change their minds about CPR between the early and later stages of recovery after stroke is a very important one. This is one of the few prospective studies that have looked at how views actually change but it is consistent with the findings of Watson et al (1997) and Sayers et al (1997) which were both conducted over a shorter period of time while the patient was still in hospital. This volatility of views is also supported by the fact that patients felt their opinions had changed as a result of the stroke, since the factors causing them to change in hospital might well reverse again when they returned home, leading to another change in CPR preference. The relevance of this finding for clinical practice is that views expressed by patients at one time should not be carried forward indefinitely. In other words resuscitation decisions based on patient opinion should be frequently reassessed.

Competency scores were, for most patients, better at the follow-up interview and the percentage judged as competent to make an advance directive rose from 70% to 82%. This improved score may well be as a result of improved neurological functioning (eg cognition, concentration, speech and language) with resolution of the stroke. It is also possible that there was a learning effect although the relatively long period between the two interviews and the very small changes in knowledge about CPR seem to argue against a major learning effect in this study. Another possibility is that the
environment of the interview altered the score. Patients might feel more confident in their own home than they did in a hospital bed and this could influence their performance.

This change in competency levels produces a paradox for proponents of patient involvement in decisions since the time when the decisions are clinically relevant is the time when fewest patients are capable of being involved. It is important to note that change in competency status was not a major factor in the change in view about CPR. If it had been just improved competence influencing decisions then it would only be necessary to reassess patients who were incompetent or of borderline competence at the initial interview. This study clearly demonstrates that even patients who are clearly competent to make decisions can have volatile views.
Chapter 7

What factors influence patients’ opinions about CPR and end of life decisions?

The Australian Qualitative study
7.1 Introduction

Patients differ in their views of how CPR decisions should be made and by whom both within and between different surveys. Quantitative studies that have found diverse views have not found that views are predictable using the simple variables studied (see chapters 1.3, 2 and 5). It is likely that these studies have not adequately described all the themes and contexts of such decisions leaving an inadequate theoretical framework on which to test hypotheses.

Advocates of qualitative research would see this area as ideally suited to qualitative research techniques (see section 1.3.1.2 for discussion of qualitative research) because of the type of question being posed. Quantitative research can reveal what percentage of elderly patients will refuse CPR but qualitative methods are needed to understand why they make this choice at this time and in this context. Qualitative methodology is more appropriate when there is a need

- To describe multiple truths rather than define a single rule
- To accept unique personal views (rather than a need to generalise)
- To explore a possible contextual, socially-based phenomenon
- To accept researcher involvement during interviews.

This qualitative study was designed to compliment the quantitative studies by providing a descriptive background, by generating hypothesis for phenomenon described in qualitative work and by suggesting future areas of study.
7.1 Methods

This study employed qualitative research techniques in order to explore certain aspects of end of life decision-making which had been encountered while conducting the preceding quantitative studies. The author had already reviewed much of the quantitative literature and talked to many patients in structured interviews about CPR. At early research meetings pre-existing opinions and theories were explored openly to allow a more honest and open approach to the subject.

A loose interview guide was developed which aimed to cover four main fields,

- views about resuscitation and who should have it
- views about who should decide about resuscitation
- views about criteria for such decisions
- views about making advance decisions for resuscitation.

During the early interviews, informants spontaneously volunteered opinions in other areas. These areas, which were explored with subsequent informants, included,

- views about how to deal with conflict over resuscitation decisions
- views about various other death-related topics
- views on euthanasia.

A subsection of informants were selected from the group of 60 post-stroke patients included in the quantitative study described in chapter 6. A note was made contemporaneously as to the suitability of the patient for future qualitative interview. The subjects were selected purposively to include those who

- at the time of their interview in hospital seemed happy to share their views ie did not demonstrate distress at questioning in potentially emotive areas
- we ensured the sample contained some patients who were in favour of CPR for themselves and some who did not want CPR
- we included patients who had unusual views about life-sustaining treatment eg one subject was selected because they indicated that religious belief had a baring on their views
The selected patients were approached approximately three months after discharge from hospital and asked if they would mind a ‘tape-recorded in-depth interview’. Only one person approached in this way was unwilling to take part in the study.

Informants were interviewed in their own home at a time convenient to them by both the author, Lesley Bowker (LB) and a senior nurse with experience in the field of qualitative research, Saras Henderson (SH). Usually one person asked questions and the other took field notes but both researchers were able to clarify issues and ask questions. Since all the patients had already shared their views about CPR with LB whilst an inpatient it was not difficult to build trust and rapport between interviewer and informant. Patients were reminded that the interviews were confidential and would not influence their future medical care. No patient objected to having the interview tape-recorded. Interviews were open and largely unstructured. Patients were allowed to talk freely on the topic and often moved spontaneously from one area to another without the need for prompting questions.

A secretary transcribed tape-recorded data word-by-word and the text was checked to ensure that it was faithful to the original interview. Data coding and initial analysis were performed on the text after each interview. Both researchers coded all interviews independently and then compared coding and developed clustered concepts and eventually coding themes together. After eight interviews the investigators had developed a coding system which was adequate to describe the data collected. Final data coding was done using the NUD.IST (Non numerical Unstructured Data Indexing searching and Theory-building - version 4) software.
7.2 Results
Table 7a shows the basic demographics of the eight patients interviewed. Patients were interviewed between 10 and 21 weeks (mean 14.8 weeks) after their stroke. Interviews lasted between half and three-quarters of an hour. The completed transcribed text yielded between 10 and 17 pages of text (mean 12.6 pages per informant.

Several themes were identified and a coding system/tree was developed. Appendix E contains a sample of one interview complete with the initial hand coding to illustrate how the coding was developed from the text. Figure 7b illustrates how the main coding themes are interrelated and Table 7c lists the full coding system that was ultimately developed.

The ‘NUD.IST’ programme was then used to generate printouts for each individual coding theme, which contained any reference to that topic, contained at any point in any of the eight interviews. Appendix F contains an example of the printout for the topic of 3.1.1 (see table 7c). Finally the themes were analysed by the author and conclusions were drawn.
**Table 7a Informant characteristics**

<table>
<thead>
<tr>
<th></th>
<th>Sex</th>
<th>Age</th>
<th>Ethnic origin</th>
<th>Occupation</th>
<th>Stroke type*</th>
<th>Barthel in hospital</th>
<th>Barthel at time of interview</th>
<th>Time since stroke (weeks)</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>F</td>
<td>71</td>
<td>Australian</td>
<td>Housewife</td>
<td>POCI</td>
<td>14</td>
<td>18</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>60</td>
<td>Australian</td>
<td>Transport manager (still working)</td>
<td>POCI</td>
<td>16</td>
<td>20</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>55</td>
<td>Australian</td>
<td>Prison Officer</td>
<td>PACI</td>
<td>20</td>
<td>20</td>
<td>18</td>
<td>Had undergone successful carotid endarterectomy since discharge</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>68</td>
<td>Born UK</td>
<td>Senior Policeman</td>
<td>POCI</td>
<td>6</td>
<td>19</td>
<td>14</td>
<td>Had been on home haemodialysis for 7 years</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>72</td>
<td>Australian</td>
<td>Chef</td>
<td>PACI</td>
<td>20</td>
<td>20</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>58</td>
<td>Born UK</td>
<td>Housewife</td>
<td>PACI</td>
<td>20</td>
<td>20</td>
<td>12</td>
<td>Daughter had undergone CPR and period on ITU</td>
</tr>
<tr>
<td>7</td>
<td>M</td>
<td>81</td>
<td>Born UK</td>
<td>Naturalised Australian</td>
<td>LACI</td>
<td>13</td>
<td>16</td>
<td>14</td>
<td>Pre-existing disability since Polio in childhood</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>58</td>
<td>?</td>
<td>?</td>
<td>POCI</td>
<td>19</td>
<td>20</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>75% male</td>
<td>65</td>
<td>?</td>
<td>?</td>
<td>19.1</td>
<td>14.8</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*POCI = Posterior circulation infarct, LACI = Lacunar infarct, PACI = Partial Anterior Circulation Infarct*
7c The coding system developed and employed during the analysis of the qualitative interviews

<table>
<thead>
<tr>
<th>1. Decision for self about CPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Criteria for deciding about CPR</td>
</tr>
<tr>
<td>2.1 Quality of life</td>
</tr>
<tr>
<td>2.1.1 Good Q of L eg thinking, independence, family</td>
</tr>
<tr>
<td>2.1.2 Bad Q of L eg pain, nursing home, mobility, wheelchair</td>
</tr>
<tr>
<td>2.2 Fate</td>
</tr>
<tr>
<td>2.3 Religion / Culture</td>
</tr>
<tr>
<td>2.4 Medical Futility</td>
</tr>
<tr>
<td>2.5 Burden of CPR (Family / Society / Doctors)</td>
</tr>
<tr>
<td>2.6 Age</td>
</tr>
<tr>
<td>2.7 Impact/experience of Illness on decision-making eg makes you prioritise</td>
</tr>
<tr>
<td>3. Who should decide about CPR?</td>
</tr>
<tr>
<td>3.1 Doctors</td>
</tr>
<tr>
<td>3.1.1 Reasons why doctors eg code of ethics, knowledge</td>
</tr>
<tr>
<td>3.1.2 Reason why not doctors / problems eg abuse power, burden, fallible</td>
</tr>
<tr>
<td>3.1.3 When doctors/not doctors eg when none else</td>
</tr>
<tr>
<td>3.2 Self</td>
</tr>
<tr>
<td>3.2.1 Reasons why self eg live with decision</td>
</tr>
<tr>
<td>3.2.2 Reason why not self / problems</td>
</tr>
<tr>
<td>3.2.3 When self/not self eg unconscious</td>
</tr>
<tr>
<td>3.3 Relatives</td>
</tr>
<tr>
<td>3.3.1 Reasons why relatives eg know patient’s views</td>
</tr>
<tr>
<td>3.3.2 Reason why not relatives / problems eg emotionally involved, conflict</td>
</tr>
<tr>
<td>3.3.3 When relatives/not relatives eg when temp treatment</td>
</tr>
<tr>
<td>3.4 Strategy for conflict</td>
</tr>
<tr>
<td>3.4.1 Doctor with self eg second opinion, time trial</td>
</tr>
<tr>
<td>3.4.2 Doctor with family eg lie</td>
</tr>
<tr>
<td>4. Advance Directives</td>
</tr>
<tr>
<td>4.1 In favour/reasons not to have AD</td>
</tr>
<tr>
<td>4.2 Not in favour/reasons for no AD</td>
</tr>
<tr>
<td>4.3 Problems with AD eg conflict, competence, duress, currency</td>
</tr>
<tr>
<td>4.4 Feelings about AD eg uncomfortable, ignorance</td>
</tr>
<tr>
<td>5. Government and the law</td>
</tr>
<tr>
<td>5.1 Who decides about CPR</td>
</tr>
<tr>
<td>5.2 Advance directives</td>
</tr>
<tr>
<td>6. Death Related Topics</td>
</tr>
<tr>
<td>6.1 Organ donation</td>
</tr>
<tr>
<td>6.2 Estate Wills</td>
</tr>
<tr>
<td>6.3 Funeral</td>
</tr>
<tr>
<td>6.4 Euphemisms /Attitudes to death</td>
</tr>
<tr>
<td>7. Euthanasia</td>
</tr>
</tbody>
</table>
7.3.1 Informants’ views about resuscitation for themselves

Seven out of eight of the informants wanted resuscitation in their current state of health. They saw it as a life-saving procedure and regarded life itself as worth saving.

- ‘My belief is that life is precious above all else’ - Informant 1
- ‘where there is life there is hope and I would like... I feel resuscitation should be used on patients if there is any chance of bringing them back’ - Informant 4
- ‘if a person goes down the first thing you think about is resuscitating them anyway, that’s why you do it – to save lives.’ - Informant 7

Informant 7 graphically described his wish for CPR by comparing it to the struggle for breath when choking.

- ‘Well, that is a similar situation – you know if you get food down the wrong way and you get into violent coughing and you can’t take your breath in (informant demonstrated by taking deep breath in) and you know – I fight like mad because the choking situation – only – you just have to fight it – haven’t you? You can’t just die through not being able to breathe in.’

However several of those in favour of CPR for themselves spontaneously qualified this by stating circumstances where they felt it would not be appropriate for them.

- ‘I think when you still have got life ahead of you and you think you can make a go of it you should be resuscitated, you know, attempt resuscitation. When you get older in your 70s and 80s...’ - Informant 3
- ‘if it looks like I could pull through without any great trouble – yes, resuscitation is OK... if they find on examination that I won’t be capable of looking after myself I don’t want resuscitation’ - Informant 5

Informant 6 did not want CPR and reasoned that she felt she had had her allotted time and had fulfilled her social role.

- ‘No, I don’t think you should do it unless as I say you are young or you’ve got many years in front of you’
- ‘I think then nature should take its course – it’s your time’
- ‘If I was younger I would have had say five children ...um and it would have meant that I would have had to have left my children and my husband would have had the burden of bringing them up... So if they could have brought me back to
you know, so I wasn’t a vegetable, um... I suppose yes, I would have said “Yes, I’ve got these children to bring up first” you know what I mean, before my time is up. But now because they are all married...’

7.3.2 Informants’ views about criteria for deciding about CPR

7.3.2.1 Quality of life
Most of the informants were in agreement that quality of life was the most important determinant of when CPR should be used.

- ‘If they don’t have a real quality of life they should be allowed to pass on.’ - Informant 2

- ‘If there is no quality of life well I think no resuscitation. If there is quality of life which the relatives believe the patient would find acceptable they should go for resuscitation.’ - Informant 4

- ‘I know in my mind that I am going to get worse, now when it gets really bad... I’d rather be out of it because quality of life is the most important thing that you can have.’ - Informant 3

There was recognition that determining quality of life might be difficult and personal opinions were likely to vary.

- ‘because you don’t know the quality of life that person actually thinks is quality of life. Um... and everybody has got a different idea of what the quality of life is.’ - Informant 3

- ‘The question is who would judge where the quality of life ends? And who would impose that?’ - Informant 3

- ‘I mean for me personally – no... but other people would have different ideas on that’ – Informant 6

- ‘...the computer is quality of life for some people – they don’t move away from it. Football is quality of life for other people, so each person has a different outlook on their quality of life.’ - Informant 3

- ‘My father for instance...apart from the memory etc and not knowing most of the time who anybody was or where he was or anything he was really quite well...I suppose it could have been worse... not much to be living like that compared to
my life ...but I mean you can’t compare the two I know, but I suppose there was a
life as far as he was concerned there was a life there but I suppose really I’d say
keep them alive... I suppose’. - Informant 1

There were multiple factors that were put forward as components of quality of life but
by far the commonest and most important was cognition. The word ‘vegetable’ was
used spontaneously by 6 of the 8 informants, usually to represent a person with
limited awareness and/or cognition.

- ‘I think the main thing is I don’t want to be left as a vegetable.’ - Informant 4
- ‘If I was virtually a vegetable, that wouldn’t be any quality of life at all to me.’ -
  Informant 1
- ‘Not knowing where they are or and who they are, there is no quality of life. That
  person might have a memory, might be able to be thinking to themselves even if
  they are in a coma. So they are only re-living, they are not living – they are only
  re-living’ – Informant 3
- ‘I want to have some mental facility and if possible the ability to look after
  myself; but that is of lesser importance. The main thing would be mental ability to
do things’ – Informant 4

Some patients were concerned to avoid pain and dignity at the end of life.

- ‘Patient comfort – um... unless the patient is going to be consistently in pain from
  that point onwards well, that would be an important factor in deciding whether or
  not to resuscitate’ – Informant 4
- ‘Where somebody is so ill and in so much pain and there was no so-called light at
  the end of the tunnel for them except downright pain, more pain, more pain and
  misery and misery for everybody else, I can understand doctors possibly wanting
to do something like that and to allow the person a dignified death’ – Informant 1
- ‘Most of our older friends have said the same thing that when their time is up let
  me go without having pain or discomfort or you know... ’ – Informant 6
- ‘When you are old you want your dignity – you don’t want to die like that’ –
  Informant 6

207
One informant believed that physical ability was an important aspect of quality of life.

- 'It is when you are sort of sitting in a wheelchair or sitting at home and you can't do all these things...you see I have always been a very active person so for me it would be terrible to be shut indoors all the time - you know - so that is what I mean by quality of life' - Informant 6

However most informants felt that physical disabilities could be overcome as long as mental abilities were preserved.

- 'but if I had been sort of conscious in a wheelchair I think although I can't do much for myself but I was brain-live I wouldn't want to do it (refuse CPR) because there are so many things you can interest yourself in. You don't have to have arms and legs.' - Informant 7
- 'I might be paralysed from the neck down but I can watch the TV and that's my quality of life.' - Informant 3
- 'I think my mental abilities would be more important to me than physical abilities' - Informant 4
- 'You know I can accept a wheelchair, there's no great problem with that.' - Informant 2
- 'I mean if you are disabled in the rest of your body but if you can think you can dream - can't you? And think about what you are doing and what you want to do and so forth - no that is not the end of the line.' - Informant 7

The ability to be independent in self-care was highlighted as an important aspect of quality of life by several informants.

- 'But in my particular case I think the ability to look after myself I rank fairly highly of importance' - Informant 4
- 'They are the two things that are primarily in my mind, when I can't look after myself and I have to depend on others to look after me, so I don't want that to happen' - Informant 5
- '...if you are relying on other people that is not a real quality of life.' -Informant 2
- ' I mean, you can't dress yourself, you can't feed yourself, you can't walk to the toilet yourself, you can't go outside, you really don't know where you are or what you are doing. So - no... I think that is the ultimate.' - Informant 6
The idea of going into institutional care was seen as unpleasant.

- ‘...where would I go? Probably to a nursing home and remain in bed for the rest of my life. There would be no quality of life.’ - Informant 1

- ‘If the doctor tells me that I have got to go into a nursing home or hospital to be bathed and fed and clothed I will just tell him that I will stay where I am... I don’t want that to happen to me.’ - Informant 5

Two informants commented specifically about not wanting to be on a life-support machine.

- ‘If you are going to have to stay on life support for a long while I think that is a No-No’ – Informant 6

- ‘yes (withhold CPR) if I was in a coma or anything like that and I have been in it for years on life support’ – Informant 7

And one specifically mentioned artificial feeding.

- ‘Your quality of life would not be very good would it if you have got to be fed by a tube all the time.’ – Informant 2

7.3.2.2 Age

Informant 5 described how age had forced him to think about CPR.

- ‘you just think about these things (CPR) – you will think about them later on when you get another 30 years older! – you know when you are having a sleepless night or something like that these things go through your mind and you think what am I going to do with myself when I am 70 odd or whatever... and it is just the natural progression of life. ...-so these things go through your mind all these little by-products go through your mind to know what is going to happen to you later on’

Participants spoke of age quite frequently but their attitude towards ageing and quality of life was varied. Some clearly felt that increasing age was associated with poorer quality of life.

- ‘I mean, you know like an older person. I think you’ve lived your life whereas a young person, if you have nothing wrong with your parts and say you fell out of a tree or had an accident or something like this, then perhaps if everything is right you have still got quality of life ... But for an older person, um... there isn’t
always that quality of life is there? Once you get older you sort of - we have all got creaky bones or something like this, you know (laugh)' – Informant 6

• ‘I know in a sense I am bringing an age factor into it .... I am only talking from my personal experience but if I was of an age where I have lived a full life and I didn’t know what was going on and I was in my own little world, didn’t recognise anybody else; and all you are doing is prolonging the agony.’ – Informant 8

Some informants expressed the view that older people have had their share of life and medical treatment and that they should make room for younger people.

• ‘I think I have been around and worried enough people (laugh) – yes um... if I was 83 and in that position I would say “look let me go” but if I was 21 ... I have got miles and miles in front of me...’ – Informant 8

• ‘my thoughts are – that at my age, I have had my life. If I was 50 years younger – I would fight all the way, I would want all the help I could get, but when you get to this stage in life and you have had a good life ...’ – Informant 5

However some felt age could not be used as a criterion for decisions about CPR.

• ‘Old age... you can’t put it as such once you get to this age because my father is 80 he works in his veggie garden enjoying life. You can’t go specifically on age, it has got to be whether you are going to be a vegetable irrespective of age.’ – Informant 2

• ‘I keep bringing age into it too. I don’t want to make any barriers there - I think everybody is entitled to the same amount of care..’ - Informant 8

• ‘So we don’t know where to cut off – we can’t say “we are not going to look after you after you are 70” we can’t stop that but we can look at what the quality of life is for that person and the decisions have got to be made’ – Informant 3

One informant recognised that treatments were less likely to be successful with advanced age and felt this justified withholding treatment.

• ‘...because as a younger person on their age you have got a better chance, better recuperative chance than what probably the person of elderly ... of older years and probably some frailty. Whereas if you are 45... you would probably have a better chance of withstanding any treatment...’ – Informant 8
7.3.2.3 Being a burden

Many patients spoke of being a burden when sick and felt that this was a reason to
withdraw medical treatment. The burden was usually envisaged for family.

- ‘Why do they want to be on a life support, do they think, are they thinking just of
themselves? Or are they thinking of other people? ... they are not worrying about
their family – they are being very, very selfish – that is my opinion.’ – Informant 3
- ‘I suppose they would have to look at how it (CPR) is going to affect them,
certainly my wife, and how it is going to affect her life because they would need a
lot of assistance and they are obviously going to impinge on her life and I think
that should be a consideration, it should be taken into account.’ – Informant 4

One patient felt so strongly about being a burden that she talked of suicide.

- ‘I think it takes a lot of courage in that situation to actually take your own life but
I think that is what I would do rather than be a burden on anyone or my family or
anyone else you know’. – Informant 6

Others worried about the burden on the medical profession or on society.

- ‘If I am not responding…. – stop – why should they (doctors) stress themselves
out when they know in their own mind, in their educated mind that it is not going
to work.’ – Informant 3
- ‘Because if you are a vegetable you are a burden on society, you are a burden on
everyone including your family…’ – Informant 2
- ‘I can’t see the point in trying to preserve people like that where they are going to
be a vegetable and a burden on the rest of the community. I can’t see the value in
that at all.’ – Informant 5

There was an awareness of advanced technological medicine as being a finite resource
and that some patients would be unfairly denying others access by refusing to forego

- ‘Who are you to stop somebody else getting on that life support system to be able
to be saved maybe. It is holding that equipment up. He has been on that for a
week, he hasn’t made any changes – off?’ – Informant 3
- ‘I feel I have had a pretty fair go and someone else could have my spot in there
and have something done to them which, you know may be helpful to them.’ –
Informant 5
7.3.2.4 Religion

Most informants agreed that religious beliefs should be respected and several informants discussed Jehovah’s Witnesses’ refusal of blood.

- ‘You should respect other people’s religious beliefs.’ – Informant 2
- ‘with blood for instance...I mean, I don’t agree with it, but that is something that they feel very very strongly about... and I think that if that is their wish and their belief than that is all that matters in that case.’ – Informant 1

However there was only one informant who volunteered religion as an influence on CPR decisions. She spoke of God’s ability to give and take life.

- ‘I think it (life) is a gift, it is not something automatic...it is something that is given to us. I suppose from the spiritual side it is a gift and ... I just believe that when I die it is not going to be my decision. I go when I am called – when I am told “This is it, this is the day” then I go and that’s it.’ - Informant 1

7.3.2.5 Fate

Two patients were fatalistic about death and the therefore believed that the outcome of CPR would be determined by fate.

- ‘I believe... this is my personal thought about it, is that if you are meant to live, if you are meant to live spiritually, you live. If you are not then your number is in the frame that’s the end. ...I still believe that we were put on this earth for a certain amount of time and that is it... I am not afraid of death if it is going to happen, it is going to happen and all the resuscitation in the world won’t save me but I want to try in case my number is not in the frame.’ – Informant 3
- ‘I still think when your time is up you will go there is no one who will be able to keep you alive- especially the older you get.’ – Informant 6
- ‘...that was their outlook on life (Her grandparents’ views), you know, like when your time came you went, ...if you had a heart attack or you had something serious that was your time. So that’s it. It was expected – well in a few days they won’t be here ...when it was time for you to go you would go, if it wasn’t your time you would survive.’ – Informant 6
7.3.2.6 Futility
Informants spoke at some length about medical futility as a reason to switch off life support machines but no one felt that a low success rate influenced their current view of CPR for themselves. There was clearly recognition that CPR could sometimes be futile but none of the informants felt that this applied to them at the time of the interview.

- ‘If it was really bad, if I had all sorts of things wrong with me or something very major and the doctors didn’t think that it was going to do me any good, there was nothing going to be achieved from it rather than just leave me as I was or comfortable or whatever the term is.’ - Informant 1
- ‘If it is not going to be any chance whatsoever nobody would blame them (doctors) for not doing it.’ - Informant 3
- ‘I know what the percentage of the outcome (for CPR) would be and the outcome is going to be very, very low..’ - Informant 5
- ‘From what I have been told previously there is only, you know, approximately 10-20% people that actually survive resuscitation’ - Informant 8

7.3.2.7 The experience of illness
Some informants felt that their own experience of illness had forced them to address the issues surrounding CPR.

- ‘I think if you have a set-back in life it makes you think more about life and what you do and what you don’t do. Well it means you are not infallible.’ Informant -2
- ‘They are all a particular class of patients with long-term illness um... which gives them the opportunity, if you like, to think about their condition and to question things – all renal patients... who um, who have to make decisions themselves about what sort of treatment they want’ - Informant 4

Some patients discussed the influence of observing other people’s illness on their views about treatment.

- ‘Well, seeing she (his wife) was in two lots of intensive cares and they helped her as much as they possibly could – whether my problems would be the same as hers – who knows? ...It probably cemented them (views) as a result of that. I had similar views before she went into hospital and ...yes I would say it probably tipped me off in my final days as to what I wanted done. Yes.’ - Informant 5
• 'I suppose it makes you think – well if she (her daughter who died as a baby) would have lived she would have been a vegetable, you could think, well if I had Alzheimer’s or some disease like this thing, I would be the same, so I would want to not live like that anyway, you know. Yes, I suppose in a way it has had an affect but um... to some extent.' - Informant 6

One very experienced patient felt that he knew more about adjustment to disability than fit people do.

• 'because of my own medical problems I have had to adjust a number of times to different things and I know quite substantial adjustments can be made to one’s lifestyle and um... provided one still has basic abilities their are an awful lot of adjustments that can be made and life can be comparatively comfortable and comparatively useful.' – Informant 4

He also felt he would demand more say in what medical treatment is given

• 'I think it made me realise that I should have more control over treatment than I would have said 27 years ago' – Informant 4

7.3.3 Views about who should decide about CPR

7.3.3.1 The patient as decision-maker

There were only two informants who consistently felt that the decisions about CPR should be theirs.

• 'If I am mentally capable of making decisions it is my decision, if I am not then somebody else can make it for me, I have got no say in it then! But if I am mentally OK – well I will make my own decisions, that’s it final! Finished!...If my wishes aren’t met , well I won’t feel happy about it.' – Informant 5

• 'I also feel where possible the patient should have an input into whether it (CPR) is used or not.' – Informant 4

Although informant 4 believed he should discuss CPR he felt that this might not be appropriate with all patients since such morbid discussions might have a negative effect on other patients.

• 'The majority of patients ... have a high expectation of being cured... and to be asked something negative such as “do you want resuscitation if you collapse?”
um, would possibly alarm them and um, effect their expectations. ...I don’t think anything should be done, particularly at the outset, to undermine that expectation. ...the patient has to be positive in their attitude if they are going to let them become involved in the decision-making process.' – Informant 4

Several explanations of why patients should not always make the final decisions were suggested. The first was the practical problem that the patient is often not able to participate in CPR decisions at the time they are made.

- ‘if possible they (the patient should decide) but in general terms they are usually in a situation where they can’t make a decision’ – Informant 4
- ‘...sometimes you can be in a situation where, for instance if you are unconscious, that it is all out of your hands anyway.' – Informant 7

Some informants were concerned that patients would not be able to make logical, dispassionate decisions. This was also felt about relatives (see later).

- ‘...the problem with that of course is that the patient is always influenced by their current position and they may or may not make a rational decision if they are.’ – Informant 4
- ‘...if it (CPR) was something you had discussed a long time in advance I think that is a different thing but I think if you were asked the question at the hospital or something like that I think then they are too emotional to decide right. You know, you are too near to the subject’ – Informant 6

7.3.3.2 The doctor as decision-maker

A common theme emerged from informants that the doctor should make CPR decisions.

- ‘Well, the medical people should make the decision.’ – Informant 5
- ‘I’d be very happy to leave it to the doctors who...or whoever is in charge to make that decision.’ – Informant 1
- ‘I believe they (doctors) have been making these decisions for years so why not leave it with them?’ – Informant 2
- ‘I think they (doctors) do whatever medical things dictate and they don’t have to say anything to anyone...I think they just do what they have got to do and OK if
Informants expressed feelings of trust or faith in their doctors.

- ‘You virtually put your life in their hands, that’s the way I look at it anyway. You virtually do and hope that they are going to do the right thing.’ – Informant 1
- ‘There is no good of me telling doctor that she should be doing this for me when I have got no idea whether it is going to improve my health or not. We are completely in medical hands when we are sick and we go to them for help’. – Informant 5

There appeared to be three major reasons why doctors were felt the most appropriate to make the decision. The first was that they were knowledgeable.

- ‘You go to the right person to get the right information and if I had a medical problem I would go to a doctor and let them make the decision.’ – Informant 5
- ‘I think it is up to the people with the facts. The doctors and medical people, they are the ones who know all the facts, family don’t.’ – Informant 2
- ‘If he can’t make a decision on that sort of issue (CPR) then he shouldn’t be a doctor – straight out! Because that person should be able to make those decisions on medical learning that he has got.’ – Informant 3

The second is that the profession follows a code of conduct. All the informants who commented on this felt that their ‘code’ would guide them to choose resuscitation for all or most of their patients.

- ‘So nine times out of ten I believe that they (doctors) are going to make the decision to resuscitate, and I believe that they will make that decision because they aren’t God, they are trying to save a life. Their dedication is to heal people, to help people, that is their dedication so if I was too far gone they could make the decision.’ – Informant 3
- ‘Doctors... their oath is, or we are led to believe is, to preserve life. They don’t like to let people die...’ – Informant 8
- ‘...the doctor is ethically required to try and prolong life, do the best they can... no matter what life should be and that is the point the doctor can’t get over’ – Informant 4
And finally the fact that the doctor was not emotionally involved and was therefore better placed to make a decision. This theme also came up when discussing the role of family (see later).

- ‘they (doctors) haven’t got the same emotional attachments to an individual – the emotional attachments of family. Our doctor said to us once “you know I look at a person as you would look at a piece of machinery!” he said it is no different... and I thought, well that’s fair enough. There is just no emotion, you wouldn’t get attached to a car or something...’ – Informant 2
- ‘he (the doctor) would know more than the family. They are talking more from the heart rather than the basic facts.’ – Informant 2

Informants did identify some problems or disadvantages of doctors being in charge of CPR decisions. This was felt by some to be a heavy burden on the doctor.

- ‘It must have some stress affect on the doctor and that is why a lot of them would, maybe not all of them, I’d say 9 out of 10 of doctors would probably like to have a family member involved.’ – Informant 8
- ‘Some people... who have no close relatives... probably the only alternative is to leave it to the doctor to make the decision. That is unfortunate because it is a tremendous responsibility being thrust upon the doctor. A very unfair responsibility but there will be people in that situation.’ – Informant 4
- ‘I don’t think doctors would relish that would they? Making decisions... they really want you to make the decision...’ – Informant 7
- ‘...um pretty hard to be cool calm and collected if you have a woman screaming her head off saying “no, no, no I don’t want him to go”...pretty hard in a lot of times I should imagine for the doctor.’ – Informant 8

There was awareness that such decisions could leave them open to conflict, being sued and accusations of inappropriate motives.

- ‘...and at that committee doctors could decide so that one doctor is not going to get himself in trouble ...and there had been no financial gain or anything like that so you couldn’t say “Oh well, that doctor’s done that because it has been left an inheritance” ...or, do you get what I mean?’ – Informant 6
• 'I wouldn't (decide about CPR) if I was in their shoes because of the fall out... it has not got to that here as yet, but in America everybody sues everybody! (laugh)' — Informant 7
• 'With litigation these days, no doubt family would ask for another opinion...’ — Informant 2

Some were concerned that doctors had too much power.
• ‘...patients are reluctant to put their views um... they are very reluctant to challenge the treatment or anything which is suggested’ — Informant 4
• ‘I know you don’t want to give them (doctors) all the power because they could become another Hitler!’ — Informant 2
• 'down the years patients give too much ... push too much responsibility on to doctors. Um.. it is part of the pedestal that doctors are placed upon... um... doctors are only human beings and they only have a certain amount of knowledge..’ — Informant 4

Only one informant felt that the doctor could be incorrect in his/her judgement
• ‘doctors are not omnipotent’ — Informant 4
• 'I also realised in recent years often how little doctors really know about what is happening.' — Informant 4

He went on to explain.
• ‘A point that might have influenced my thinking about medical practitioners and their prognosis is that when I had bowel cancer 27 years ago my wife was told I would be dead within the year...they can be wrong um, which is probably why I feel most strongly that they should not be left to make the final decision.’ — Informant 4

One patient contradicted himself about who should decide and then pointed out that the choice of the correct decision maker depended on the circumstances of the decision.
• ‘I suppose I am doing a backflip here taking the onus away from the doctor and putting it back on the family when I have been saying that the doctor should make
the decision. But I think circumstances at the time play a great part. The age of
the patient, what association the doctor has had with the patient.' – Informant 4

7.3.3.3 Relatives as decision-makers

The role of relatives in CPR decision making was controversial. The informant who
felt least confident in doctors was most in favour of relatives. He felt that through
their intimate knowledge of him they would make the best decision.

- ‘I feel that the relatives know the patient better than the doctor. The doctor may
  know the medical condition but doesn’t know anything about the patient as far as
  thought, activity and ability are concerned ... provided they are all close and
  provided they know the patient well they should take precedence over medical
  opinion.’ – Informant 4

Two informants qualified that a good knowledge and relationship with the patient was
required to lend legitimacy to a relative making CPR decisions

- ‘I say a responsible relative um... it can’t be somebody who knows nothing about
  the patient, it has to be somebody who is close to the patient, a spouse or the
  parent. Um... who know show the patient functions and various things.... Just
  because he is a relative it does not make him necessarily suitable to make a
  decision. One of the problems is that the person may say to the doctor “I know
  this patient very well” when in fact they don’t. Now the doctor cannot judge that’
  – Informant 4

- ‘I wouldn’t want mine, my son or daughter – for the simple reason that they
  would not be interested. So it is different for me. I mean if they were the son and
daughter who came or even rung me or things like that and we were in touch I
would say “yes I would like them advised” but I mean they are not and they have
made that very very clear that they are just not in the least bit interested. So... but
in other people’s situations, yes.’ – Informant 1

Some informants had had discussions about their preferences for resuscitation and
felt that this informal advance direction would enable the relatives to make decisions
for them.
• 'Well, I have instructed them (family) to. I won't be physically there to make them do it. I have asked them in case I am going to be incapable... they know my wishes.' – Informant 5

• 'I would trust her to make a decision which I would approve of because of our discussion. So although I do not have a formal living will, um, at least I have discussed it to a degree with my wife and children... I think they know my views, they particularly know what I would like to be able to do. They would gear their decisions around that, I am sure.' – Informant 4

One informant, who had not made their views clear to their family, just trusted them to make the right decision.

• 'If you are wanting to paddle your own canoe or make your own destiny then you make all these choices beforehand, but if you can trust somebody else to make them for you then that's it, isn't it?' – Informant 7

But most patients wanted the doctor to guide or inform relatives in their decisions

• 'I wouldn't want him (friend) to be worried over things like that. No I think I would just leave it to the doctors. He would probably like to know about things...but I don't think anything other than that.' – Informant 1

• 'I think the wife has got to be prepared to go with the doctors' decision because they know. In the long term, after the mourning is over, they will probably realise that is was all for the best but it was emotive at the time.' – Informant 8

• 'I think he (the doctor) probably would have to get one of the family who is a little bit level headed and unemotive. I wouldn't want anybody to speak to my wife if I was in that sort of position, that's just off the planet...but perhaps if my brother was there he might...and the person understands and then probably the two of them talk to the immediate family or people who are very emotional about it.' – Informant 8

These quotes also illustrate the main objection to involving relatives in CPR discussions. Informants felt that relatives were too emotional and not objective enough to make the decision not to resuscitate. The comparison with the unemotional doctor was often drawn.
...um pretty hard to be cool calm and collected if you have a woman screaming her head off saying "no, no, no I don’t want him to go" and he sort of takes a clinical approach – pretty hard in a lot of times I should imagine for the doctor.’ – Informant 8

'...family tend to want to keep their parents with them no matter what. I think emotionally at that moment they really can’t make that decision.' – Informant 6

'That’s why I think it is difficult for families to make those decisions. They would probably say "yes, yes, yes" to it all the time but the doctor knows whether it is going to be a permanent thing...he knows more that the family. They are probably talking from the heart rather than the basic facts.' – Informant 2

'I think doctors are probably in a more stable decision-making process than... family and friends would be at the time' – Informant 8

Even the informant who was most in favour of his relatives deciding was concerned about this.

'... although I say I trust them (his relatives) their decision-making process could be affected by the trauma surrounding them' – Informant 4

Two informants felt that it was reasonable for the doctor to deceive the family if they were being unreasonable in demanding treatment.

'I think the doctor would possibly say "yes" he might discuss it with the family and perhaps the patient will live for a few days and peacefully pass-on.' Interviewer 'so the doctor should over-ride?' 'Yes, but I don’t think he should tell them that.' – Informant 2

'No I think it would be better if they could just say that “this person dies in peace” and the doctor could do that, you know what I mean? Even if the family didn’t know about it or something like that, you know, it could be done. Sounds mercenary doesn’t it? (laugh)’ – Informant 6

'Why can’t they just let them slip away? Do you get what I mean? Not say anything to the family – just walk out and say “well, I’m sorry, it’s over”.' – Informant 6

221
Another problem identified with family as decision-maker was the guilt that they may feel.

- ‘How would you live with yourself if you said “No, pull the treatment”... I feel sorry for these parents... they would probably be thinking of it all the time as to — you know- “I got them to switch it off”. ’ — Informant 2
- ‘they (family) could make the wrong decision and perhaps afterwards they would regret that decision... ’ — Informant 6

Doctors where also favoured over relatives because they were able to see the whole picture and would ensure a just distribution of resources.

- ‘...family are too insensitive to the wellbeing of other people who could utilise that facility. Then it should be taken out of their hands and the medical people should be...it should be quite within their rights to make a decision.’— Informant 5

One informant felt that discussions about CPR might cause division in families.

- ‘It can cause rifts in families for no real reason.’ — Informant 2

Only one informant was concerned about relatives with inappropriate motives

- ‘you get some people who are very mercenary and if they thought that the doctors hadn’t done enough they would want to sue them .. ’ — Informant 6

7.3.4 Views about advance directives

There was general acceptance that advance directives were legitimate and should be respected.

- ‘I think it should be acknowledged. If you write down “I do not want to be resuscitated” and then something happens and you are in hospital I don’t think the doctor has a right to go against that really.’ — Informant 1
- ‘I think it is a very good idea.’ — Informant 4
- ‘I can see the point and probably this is what Lesley was saying about the living will sort of thing — you have got to make the decision while you are able to...’ — Informant 8
None of the informants had made formal arrangements for themselves although some thought they ought to but were putting it off.

- ‘I have not done it (make an AD) myself. I think I should have done it... I feel I should formalise it. I am actually in the process at the moment of arranging my funeral so it is a good opportunity to do the two things together.’ – Informant 4
- ‘Yes, I’ve been thinking about it (making an AD) since you were saying that in hospital. I might do (nervous laugh).’ – Informant 6

There were others who had simply never considered it and were rather hesitant about the concept.

- ‘I have never thought about that. You know, prior to this morning I never sort of thought about leaving instructions on what the family should do.’ – Informant 7
- ‘I never even thought about it. Didn’t think of it at all.’ – Informant 8
- ‘I don’t know – I have never thought about it before – I will think about it though in the future. I will give it some thought.’ – Informant 1

One informant did not feel it was appropriate in his current state of health but might consider making an advance directive in the future.

- ‘At this point I wouldn’t but it is something I would consider...but in my case with the problems that I’ve got I think I probably would in the future have to look very seriously at making that sort of decision and having that done rather than having somebody else doing it – it is my will and that’s that..’ – Informant 8

Finally there were informants who didn’t like the concept for themselves at all.

- ‘I don’t think I would do that. I don’t think I would write out a pre-directive.’ – Informant 2
- ‘I don’t believe in writing a pre-will’ – Informant 3
- ‘I wouldn’t like to do that (write an AD), I don’t think I would.’ – Informant 7

Those who were in favour of advance directives felt they would be effective in influencing management.

- ‘I would trust her to make a decision which I approve of because of our discussion. So although I have no formal living will, um... at least I have discussed it to a degree with my wife and children.’ – Informant 4
‘Personally I feel relieved that I would make that decision. I would have to let my doctor know that that is going to be my wishes.’ – Informant 8

Two informants pointed out that advance directives would decrease the pressure on the doctors and relatives.

‘I think if the patient says OK that’s it (advanced refusal of CPR). I believe it makes it a lot easier for the doctor then doesn’t it.’ - Informant 2

‘...to take the pressure off the children.... Well I just think anything that they don’t have to decide and is done for them would be useful at a very traumatic time. ...it will help them if they had a guide from me on what I would like.’ – Informant 4

Informants justified their reluctance to make advance directives for several reasons. Several informants expressed a general distaste for the subject of death and illness and felt this would put them off.

‘I do think people never like to think that anything is going to happen to them and that is probably the major block to get people to make that sort of decision.’ – Informant 8

‘I haven’t got a reason other than probably stupidity (laugh) but, you know, no one wants to think about dying do they? That is probably the only reason.’ – Informant 2

‘Well I think they should (make an advance directive) but the majority of people don’t want to because they hate raising unpleasant subjects.’ – Informant 4

‘They probably would rather talk about the weather than go into a box. It is a fairly morbid subject when it is all said and done and the less morbid you can be the better.’ – Informant 5

Despite the fact that all our informants had been through hospitalisation with a stroke, one informant clearly stated that he was not ill enough or old enough to make such decisions.

‘I feel it is unnecessary at this time. ...it has to be something medically wrong come up with me – of such a nature that I thought it could be, you know, like threatening - I will definitely do it- but not before I had it... ’ – Informant 8

‘Not too many people think along those lines – they think while we are in good health why should we worry about this?’ – Informant 8
Several patients felt uncomfortable making decisions because of uncertainty about the future both in the situation of the decision and possible medical advances that might occur between the advance directive being drawn up and used.

- ‘No, I don’t (want to make an AD), because I can’t tell the future of how it will be... we don’t know what the situation is going to be for that decision to be made. We don’t know whether it is going to be a stroke again, or we don’t know – heart attack, an accident or whatever...’ – Informant 3
- ‘that big cancer that I’ve got ... there might be a cure for it in 12 years time. So you have got to go with the flow, you go with life and decisions can only be made when it happens. That is why I don’t believe in writing a pre-will because you don’t know what advancements are going to happen in time.’ – Informant 3
- ‘but you are not going to start filling in those forms when you are 40 because you don’t know what the situation will be when you get old. I mean judging by what medical science has done in the last 70 years – when I was a kid appendicitis was a killer!’ – Informant 7

Even the informant who was most positive about advance directives was aware that the unpredictability of the future would influence the utility of the document.

- ‘I think there are too many variables within it to make it fixed... um... they would have to look at the situation at the time and then look at my wishes and try to put the two together. Try to get a ...um ...match between them... They could still make contrary decisions but at least it would give them a guideline on the way to go.’ – Informant 4

Other issues included the risk of malevolent influences or incapacity at the time the advance directive was drawn up.

- ‘If they wish not to be resuscitated. Well done! Providing they haven’t made it under any duress or anything like that.’ – Informant 2
- ‘he (the doctor) may think she wasn’t really thinking clearly at the time that she wrote this or this was written 6,8,10 years ago...’ – Informant 1

One informant who felt that his family should decide about medical treatment thought it might be unnecessary and untrusting to write instructions for them.
‘Um yes, yes I would (be willing to write an advance directive). But when I say that I am being a bit disrespectful because they are a good family, this is why I am so set in my mind that everything is going alright... ’ – Informant 4

7.3.5 Other issues

7.3.5.1 The legal framework
Several informants felt that doctors should be better protected by the law when dealing with decisions about life-sustaining treatment.

- ‘I would hate to be a doctor in this day and age because of the general awareness of “let’s sue” (laugh) and that is a big thing at the back of the doctor’s mind. ... I mean I feel it is wrong. It is ridiculous.’ – Informant 8
- ‘...and to say that you would have to legislate. You would have to legislate to make sure that the doctor is not turning it off (life support machines) before the 7 days are up. ... and he has got no convictions from you to sue him for malpractice.’ – Informant 3

Legislation was thought to be too rigid or that the area was too controversial to allow laws to be passed.

- ‘... you must give people a choice mustn’t you? If you legalise it I suppose then that take away the choice doesn’t it?’ – Informant 7
- ‘I don’t think you can write everything in a law because the law, in some of these circumstances, don’t fit.’ – Informant 4
- ‘You would have the Right to Live Commission on your back wouldn’t you? They are howling about this... Yes, it should be legal but you would have Buckleys getting it through! ...well these human rights and the people who are so up to their neck in religion... so it would probably he the better thing but you wouldn’t get any legislation I don’t think anyway... do you?’ – Informant 7
- ‘I would hate to try and bring in legislation. It would be one helluva headache trying to... I would say there would be 90% for it and 10% against it and that 10% would be the stumbling block.’ – Informant 8

There was also a general distaste and distrust of the law.

- ‘I think there are enough laws now. If people aren’t capable for making their own decisions someone should make it for them.’ – Informant 5
God, if you try and legalise everything you would never write the bills to cover it. Honestly I don't think you can put it into -look at our legal system at the moment!' – Informant 2

7.3.5.2 Death-related topics
Although there were no plans to cover these areas informants spontaneously talked about organ donation, funerals and estate wills and euthanasia. Organ donation was often coupled with end-of-life decisions and advance directives

- 'Well, I wrote down to the effect that if any of my body parts can be used for donations, I have already ticked that on my licence, that is to be done.' – Informant 5
- 'Now, another thing I can write down is “when I go you can have my kidney, you can have my eyes, you can have my bits and pieces, whatever you want when I go”.' – Informant 3

Discussion about resuscitation often prompted people to think of their funerals and visa versa.

- 'With my mate I go out fishing with and he has discussed – he has paid for his funeral ... But he has discussed similar things as well and he said “look if I ever get to the stage where I can’t look after myself I’d just like to pass away”.' – Informant 5
- 'I think there is probably a time and a place to discuss all those things...it comes up in conversation sometimes. It is a bit like some people saying they want to be cremated or buried or something like that. I think it’s a, you know, a similar type of thing.’ – Informant 2

Some informants compared estate wills to advance directives.

- 'They do think it is never going to happen to them and probably, you know, in this vein you are looking at “why do we make wills” – now we’ve got wills because we don’t want any argument if something happens to us...' – Informant 8
- '(discussing advance directives) Oh dear! I am having a hard enough time trying to work out (laugh), write out a (estate) will, it is such an awful thing...’ – Informant 1

Discussing end-of-life issues frequently prompted comments on euthanasia. Those who discussed euthanasia were generally in favour of it.
• ‘I believe we may get to the stage where you want the doctor to end the life - it is not so much ending a life, it is ending the pain for them, the suffering and all that.’ – Informant 1

• ‘I think there has been a fair bit of it going on over the years which is not really euthanasia – they just stop treatment and the person dies and I think they should leave it that way.’ – Informant 2

• ‘Like this euthanasia thing – that if anything happened like that to me I would head for North Queensland and see the bloke up there.’ – Informant 5
7.4 Analysis and Conclusions

7.4.1 Decisions about CPR for oneself
Informants generally favoured CPR for themselves because they believed that it was a life-saving procedure and they valued their life. In general they displayed faith in the abilities and motives of the medical profession. However there was acceptance that CPR was not always successful or indeed appropriate. One informant expressed the compromise between the struggle for life and a fatalism by explaining 'I am not afraid of death, if it is going to happen, it is going to happen and all the resuscitation in the world won't save me but I want to try in case my number is not in the frame.' — Informant 3.

Quantitative studies of patients' views about CPR have found that little of the variability in views on CPR can be explained by simple factors such as age or disability (see chapters 1.3, 2 and 5). Informant 6 provides a good example of how an individual's belief system can override population trends. Informant 6 is relatively young (58 years), married and living with her husband, she is not depressed or disabled (Barthel 20/20); except for the fact she is female all these factors in quantitative studies would predict that she would want CPR. However she has no hesitation in rejecting CPR and explains that, as her perceived life-role of bringing up five children has been completed, she no longer feels efforts to prolong her life are appropriate. It is not unusual for informants to talk of older age and diminished social role as a reason to withhold CPR (see 7.4.2) but it is unusual for them to consider that they have reached that stage in life themselves.

Informants spontaneously talked about reasons to withhold CPR but they often lapse into second person speech about 'other' people eg 'If they don't have a real quality of life they should be allowed to pass on.' - Informant 2. Informants frequently described hypothetical future scenarios for themselves and set thresholds that have to be crossed for DNR policies to be enacted. Much of the informants' dialogue centred on defining the circumstances that they believed would confer an unacceptable quality of life for them. One hypothesis is that patients are so horrified about the prospect of illness and disability that they choose less treatment and an early death rather than continue in this hypothetical state (Ryan 1996). Informant 3 demonstrates this 'opt out' clause.
perfectly when explaining, ‘I know in my mind that I am going to get worse. Now when it gets really bad... I’d rather be out of it...’ - Informant 3. This psychological avoidance tactic fails when patients find themselves alive but disabled and they are forced to adapt to their new circumstances. Informant 4 explained how he had made adaptations and how this had influenced his view on what constitutes quality of life. He explained ‘because of my own medical problems I have had to adjust a number of times to different things and I know quite substantial adjustments can be made to one’s lifestyle and um... provided one still has basic abilities their are an awful lot of adjustments that can be made and life can be comparatively comfortable and comparatively useful.’ – Informant 4. After the adaptation has occurred it is likely that people’s criteria/barriers will be adjusted so that it is a new sicker/more disabled future person for whom CPR is not appropriate.

This theory of flexible personal criteria might explain why some patients change their minds about CPR during the course of an acute illness (see chapter 2 and 6). If during an acute illness a patient recognises they have crossed their own threshold for DNR they may choose less treatment. However during recovery they adapt to their new state, adjust their definitions of unacceptable quality of life and choose CPR again. Some authors have associated this initial rejection of treatment with transient depression (Bedell et al 1983, Potter et al 1994). On the other hand patients who don’t initially recognise the extent of their disabilities might later on come to terms with the fact they have passed their barrier (like informant 6 appears to have done) and choose less treatment. In order to look at this theory in more depth a qualitative study of patients sampled before, during and after an illness would be useful.

7.4.2 Factors leading to rejection of CPR
Informants were all able to identify situations in which they felt it would be appropriate to withhold life-prolonging treatment and in some circumstances some informants were even in favour of active euthanasia. The criteria that informants use to define the circumstances in which CPR was to be withheld were many and varied and included things such as quality of life, physical disability, mental impairment, existence on a life-support machine, nursing home residency, dependency, age, pain, and dignity. Views expressed within these categories were diverse, often to the point of being contradictory to those of other informants. For example some informants felt
that advanced age should prohibit CPR whilst others felt that age should not be a
barrier. In some cases the diversity of view can be traced to personal knowledge and
experiences. For example informant 2 felt that his view that age should not be a
criteria for withholding CPR was based on knowledge of his father who continued to
enjoy life at eighty years old.

Individual values as well as experiences were clearly influencing views. ‘...you see I
have always been a very active person so for me it would be terrible to be shut
indoors all the time – you know – so that is what I mean by quality of life’ – Informant
6, contrasted strongly with ‘I might be paralysed from the neck down but I can watch
the TV and that’s my quality of life.’ – Informant 3. This explains why simple
variables that measure for example mobility do not correlate well with opinions on
CPR. A measure of mobility would only useful if it is put in context of an individual’s
unique value system.

Most informants agreed that ‘quality of life’ was helpful in determining appropriate
CPR status but again there was enormous variation in views of what constitutes
‘quality’. Several informants acknowledged that this was a personal and unique
assessment and there was recognition that because of this there would be difficulties
making decisions on behalf of other people. There appeared to be agreement in one
area only and that was the ‘vegetable’ category. A qualitative study of 10 patients on
an American coronary care ward also reported that not wanting to live in a vegetative
state was a recurring theme (Larson 1994). If doctors could clearly define what the
‘vegetable’ concept encompasses they would be fairly safe in withholding CPR in
such patients. Most informants used the word ‘vegetable’ to define a person with
depressed conscious level or severe cognitive impairment. But there are glimpses that
even this category is controversial eg ‘My father for instance... apart from the memory
etc and not knowing most of the time who anybody was or where he was or anything
he was really quite well... I suppose it could have been worse... not much to be living
like that compared to my life... but I suppose there was a life as far as he was
concerned there was a life there but I suppose really I’d say keep them alive...’ –
Informant 1. ‘Vegetable’ may not be a single entity for all people but merely a method
of expressing the personal definition of worst outcome.
In contrast to cognitive impairment the prospect of physical disability seems more acceptable to this group. Stroke is mainly a physical disability and it is tempting to think that this group is more accepting of physical disability than others are because of their experience of and adaptation to it. However other studies of unselected elderly patients have also found that hypothetical physical disability results in a smaller reduction in wish for CPR (Kerridge et al 1999, Everhart and Pearlman 1990) than hypothetical cognitive impairment (Miller et al 1992, Robertson 1993, Kerridge et al 1999).

There were two factors that are commonly involved in DNR decisions that did not appear prominent in the informants’ thoughts. The first was ‘futility’; although patients recognised that CPR would be predictably unsuccessful in some cases this was uncommonly mentioned as a reason to withhold CPR compared with quality of life issues. Studies of clinical practice imply that medical futility is a commoner reason to withhold CPR than quality of life estimates (Curtis et al 1995, Stewart et al 1996). It may be that when patients talk about doctors as knowledgeable it is because they know better when CPR is futile but this is not explicit from the interviews and the informants seem to confer a wider role to doctors than this. A qualitative study of decision-making by health-care workers found that many felt obliged to provide medically futile resuscitation if the patient requested it (Mello and Jenkinson 1997). This may be because patients do not understand or employ the futility concept in the way doctors do. In contrast doctors may feel uncomfortable with quality of life issues that are commonly discussed by patients. It is easy to anticipate that patients and doctors may have difficulty in communicating about CPR when their terms of reference appear so different.

The second factor in DNR decisions is related to the unpleasant experience of CPR itself. Only one patient mentioned dignity and whilst several informants mentioned pain and suffering at the end of life this was not connected with CPR itself. In hospital practice physicians’ and particularly nurses’ fear of exposing patients to unnecessary CPR is a powerful motivator for making DNR orders. The informants do not seem to share this fear of CPR itself but do fear prolonged existence as a ‘vegetable’ or on life-support machines. Health-care professionals have first-hand experience of CPR and this probably fuels their distaste for the procedure. It would be very interesting to
interview a range of health-care professionals to explore their views about DNR orders and compare them with their patients.

7.4.3 Who should be responsible for decisions about CPR?
Although informants were happy to discuss their views about CPR most of them did not see themselves in charge at the time a CPR decision was required. There was a reluctance to commit to advance directives (see section 7.4.4) and most believed they would be incompetent at the time a decision was needed. In the absence of their own input into a CPR decision there was generally an acceptance that the doctor should decide. Considering the social trends towards patient autonomy and away from physician power the views of this group seem remarkably ‘old-fashioned’.

It was surprising in the current climate to find that several informants felt that physician power should overrule the wishes of relatives who could be excluded ‘I wouldn’t want anybody to speak to my wife if I was in that sort of position’ – Informant 8, or even deceived about the decisions ‘Why can’t they (doctors) just let them slip away? Do you get what I mean? Not say anything to the family – just walk out and say “well, I’m sorry, it’s over”.’ – Informant 6.

Several factors were identified as reasons why doctors were favoured as decision-makers including their knowledge, training, integrity and ability to be emotionally detached. By contrast relatives were seen as uneducated and too emotional to make sensible decisions and in general there was agreement that relatives should be informed and guided by the doctor rather than the other way around. In part this was because informants wanted to spare their loved-ones the psychological trauma and guilt, but partly because they didn’t trust them to make a decision at all. There was a common fear expressed that relatives might request inappropriately aggressive treatment and prolong their life as a vegetable. This scenario provoked the suggestions by two informants that the doctor should overrule and deceive a family member by not providing CPR.

Informant 4 stood out as holding quite different views. He was in favour of his own involvement in decisions, of advance directives and his family ensuring that his wishes were respected, even if that meant overruling a doctor’s decision. This attitude
seems to stem from a distrust of doctors who he felt had been mistaken in his medical care before. He felt that other patients ‘give too much ... push too much responsibility on to doctors. Um... it is part of the pedestal that doctors are placed upon.’ – Informant 4. He does however recognise that not all patients would want involvement to the extent that he expects and qualifies that certain patients might be incapable or even harmed by being involved in discussions about CPR.

There is evidence from quantitative surveys that this view is more common in better-educated, younger people and in the American Culture (see chapter 1.3.1.4). Larson’s qualitative study (1994) was based in America and this may explain why he found that all ten of his patients wanted to participate in CPR decisions and that they felt their families had a right and a responsibility to help with such decisions. Australian and English patients appear to more commonly rely on doctors for CPR decisions. The most recent survey in an Australian inpatient population found that 55% of patients felt they should be the main decision-maker, 29% felt this should be the doctor alone and 80% felt that the doctor should be involved in such decisions (Kerridge et al 1998). Whilst DNR policies are increasingly being altered to promote patient involvement it is clear that a substantial number of patients will not only wish but actually expect that doctors to make CPR decisions for them.

7.4.4 Attitudes to advance directives

Studies have shown that although the general public are generally in favour of ADs the completion rate, even in America where knowledge about AD is much higher, remains very low (Emanuel et al 1991, Schiff et al 2000). This qualitative study provides some important evidence to explain the finding that AD completion rates are very low.

Emanuel et al (1991) suggested that some patients find the subject of advance directives distasteful. It is well known that completion rates for financial wills are very low and there is no reason to suspect that completion of ‘living wills’ should be any higher. Patients in this study freely acknowledge that ADs are a distasteful subject. Informants appeared to be comparatively much more comfortable discussing CPR than during discussions about AD.
Although the experience of stroke with its associated hospitalisation and disability seems to induce a small proportion of patients to think about advance planning it is perhaps surprising that many of the patients had not considered it at all. It is possible that patients have simply avoided addressing such 'a morbid subject' – Informant 5, but there seems to be a more complex explanation of this phenomenon. The informants were chosen specifically because of their experience of illness and disability but many clearly state that they do not feel that they are the kind of ‘ill’ people that should be making AD eg 'I feel it is unnecessary at this time. ... it has to be something medically wrong come up with me – of such a nature that I thought it could be, you know, life threatening - I will definitely do it- but not before I had it... ' – Informant 8. This fits in with the observation that most people can clearly identify types of patients for whom CPR would be unsuitable but rarely see themselves as fitting into these categories (see section 7.4.1, Ryan 1996). Informants seem to feel that there is always someone else, who is sicker than yourself, who should be refusing life-sustaining treatment.

Another barrier to completing an advance directive was elucidated; the fear of committing to an irrecoverable course of action under unknown circumstances. There were three components to this fear; that the circumstances that arose were not those anticipated in an AD, that future circumstances may lead to a change in their views, and that an AD might deny access to advances in medicine that were not available at the time it was made. One patient summarised his views by saying 'So you have got to go with the flow, you go with life and decisions can only be made when it happens. That is why I don't believe in writing a pre-will.' – Informant 3. Moore and Shearnam (1999) interviewed a group of mixed-race elderly Americans and found that in contrast to our informants ADs were ‘overwhelmingly’ well received by their group. Despite this difference the study identified very similar barriers to completing AD ie ignorance about ADs, inability to anticipate future circumstances and the possibility of changing ones mind about treatments. Future educational interventions about AD will need to address these fears if they are to be successful in prompting people to make ADs.

Finally, it appears that some patients are happy with the way decisions are likely to be made if they become incompetent and do not feel that an AD is necessary. Many
patients trust their doctors to make decisions (see section 7.4.3) and others are happy to rely on their family eg ‘If you are wanting to paddle your own canoe or make your own destiny then you make all these choices beforehand, but if you can trust somebody else to make them for you then that’s it, isn’t it?’ – Informant 7.
7.4.5 Analysis of qualitative study including methodological critique

A medline search reveals very little original research using qualitative techniques in traditional medical journals compared with the vast number of quantitative publications. There are very many opinions expressed in editorials, letters and review articles but these tend to reflect the views of doctors, or the views of patients as reported and interpreted by doctors. There are several possible reasons for this:

- Much qualitative research is published in journals, books and theses which are not listed on medline.
- Many doctors are untrained and unfamiliar with qualitative research techniques resulting in a reluctance to utilise them and possibly even a publication bias against qualitative research in traditional medical press.
- Qualitative research in this area is fraught with ethical dilemma. Open discussions about death and dying are intrinsically uncomfortable for most people and are particularly socially unacceptable when conducted with people who are ill and near to death (who are the patients that doctors commonly have access to). It may be that this area is considered too tricky by many physicians for research projects or that such proposals are rejected by ethics committees. In one study of out-of-hospital CPR in the USA the author comments that ‘Before I could start my ethnographic work, I went through a protracted nine month negotiation with a university and two hospital institutional review boards…. I was not allowed to talk to patients who had survived CPR or to relatives of patients’ (Timmermans 1999).

Criticisms

Epidemiological or grounded theory

The main criticism of this project is that methodologically it is not ‘wide’ enough to provide epidemiological/descriptive information that can be generalised nor is it ‘deep’ enough in its analysis for a true grounded research project (See section 1.3.1.3 for discussion of different qualitative techniques).

The analysis as presented is more appropriate to content analysis than grounded theory. In a content analysis the scripts would usually be assessed using a pre-defined coding system which groups patients together who have similar views and attempts to
explain and generalise by looking at the sample as a whole. Although the coding system in this project was not generated in advance the analysis tended to try and group and generalise (e.g., a statement such as 'A common theme emerged from informants that the doctor should make CPR decisions' would be more appropriate for a content analysis than a grounded theory project. A grounded theory project would analyse views for a single subject at a time and try to identify theoretical models to interpret these views.

The sampling strategy utilised could also be criticised as not ideal for either a content analysis or grounded theory. For a content analysis a complete sample, typical sample or extreme sample from the group of stroke patients might have been more appropriate to cover the range of views. The study did purposively sample patients who were in favour and who were against CPR for themselves and this could be considered a form of extreme sampling but the sampling strategy was not really explicit from the start and greater attempts should have been made to ensure a mixture of views were represented in the data. It might also have been appropriate to try and sample patients who had refused or been medically unable to co-operate with the initial in-hospital interview or even to sample some patients whose stroke had not led to a hospital admission to study whether their views were different.

Although the sampling strategy for grounded theory does not require the 'breadth' of view that allows a good content analysis the sampling used in this study was not ideal for a grounded theory project either. Sequential sampling, in which patients are purposively sampled to elucidate theories generated in earlier interviews, was not used. 'Snowballing', in which informants or staff suggest the names of patients who are known to hold certain viewpoints might also have been appropriate for grounded theory analysis.

The sample size of eight was certainly too small for a comprehensive descriptive study using content analysis. Although very small numbers of subjects can be used for theory generation in a grounded theory study it is unlikely that this study would have provided 'saturation' i.e., it is likely that the sample size was insufficient to fully explore all the facets of opinion in these areas. This does not invalidate the data.
obtained or the conclusions as presented but the reader should be aware that the
description is incomplete and generalisability is likely to be poor.

Influence of previous quantitative interview
All the patients were recruited following inclusion in the quantitative research arm of
the study. It is important to acknowledge that their experience with the more rigid
quantitative tool may have influenced their responses to the qualitative interview. This
influence may be as subtle as a change in the vocabulary that is used (eg patients may
be more happy using technical terms such as CPR) or there might be more
fundamental influences which actually cause patients to think about CPR in a
different way. The questionnaires were designed to present unbiased, factual
information and to encourage patients to reveal their own thoughts and views but it is
possible that even such open questioning may have been influential. For example by
asking patients whether they would want relatives or doctors to make CPR decisions
for them if they were unable may have prompted a chain of thought or even
discussions with others about what should happen if they were incompetent. While it
is not invalid to ask the opinions of this group of patients it must be acknowledged
that their responses are not necessarily the same as a matched group of stroke patients
who have not previously taken part in a questionnaire which contains some
educational information.

Researcher-subject interaction
All qualitative research acknowledges the role of the researcher in influencing the
responses of participants. Although the influence of the doctor-patient relationship
was minimised by interviewing in the patients own home, at a time distant from their
stroke and with reassurances that the interview was confidential and could not
influence their current/future medical treatment it is very likely that the status of the
interviewers remained highly influential. Doctors and health care professionals are
held in high esteem and patients interviewed in research studies may well be keen to
express opinions which they perceive will please the doctor. All the informants had
been through the personal trauma of acute stroke and had been reliant on hospital for
several days or months. They may feel a debt of gratitude for the care they have
received and feel that they are paying back some of this by taking part in a research
study. Patients may not believe in the true confidentiality of the survey and would be
discouraged from expressing views which they believe might adversely affect their current or future care. Conversely informants might find that the security of the home environment gives them freedom to express some power over their lives which they may have felt as absent in hospital and lead them to make more extreme comments as a reaction.

Ethics

Whilst the local ethical committee did not put forward any objections to the qualitative arm of the Australian study there are some interesting ethical dilemmas raised by this type of study.

It is hard to obtain a fully informed consent to a largely unstructured interview, as the investigator cannot predict which subject areas will be covered. Topics that are covered are particularly emotive (ie death, disability, quality of life) and the volunteers might not realise the depth to which we wish to explore their experiences, feelings and motivations. For example three different informants discussed their experiences…

- witnessing the dementing process and subsequent death of a father,
- the period of time when his wife was dying on an intensive care unit,
- decisions about life support of a daughter who died in infancy.

It is possible that these three informants had not realised that an interview about their views on CPR would stray into these highly emotional areas, especially since they had all undergone the less intrusive quantitative interviews beforehand. Although the interviewers attempted to be sensitive they were not trained in counselling and the interviews were research motivated. The candidate is unaware of causing any adverse affects but did not have any mechanism for ascertaining negative outcomes for the patients interviewed. Subsequent studies should allow the informants a chance to give feedback on their interview experiences in an unthreatening manner (eg at a time distant from the interview and to an impartial third party). It is possible that the patients found it a positive experience but the main aim of such a follow-up would be to ensure there are no major negative outcomes or to tailor future interviews.

Another possible criticism of the consent process is that the privileged position of a doctor (even one not directly caring for a patient) may put undue pressure on the
patient to agree to take part in the study (see researcher-subject interaction section above). It might be ethically better for an independent person, such as a research nurse, to recruit patients for this type of study or even to ask patients to put their names forward following some written material (such as a poster/flyer placed on the stroke ward or given at the time of discharge). Changing the method of recruitment might have a dramatic effect on casemix (volunteer patients would be likely to have entirely different characteristics to those interviewed in this study) and this would have to be weighed against the advantages of a less ‘pressured’ consent procedure.

Strengths of the work and areas for future study

Despite the methodological flaws this qualitative study has helped put the previous quantitative studies in this thesis into context. It has been particularly useful in highlighting the different ways in which individuals in society weight factors such as age, disability and quality of life in their decisions about CPR. Observations from the quantitative follow-up study (chapter 6) as well as this study suggest that patients might alter their views about CPR over time due to adaptation mechanisms with increasing age, illness and disability. A long-term follow up study of patients who experience reversible or irreversible illness episodes (utilising both quantitative and qualitative techniques) would provide a fascinating insight and would also help in assessing the usefulness of advance directives.

This study exposed problems with the contrasting role of patients, doctors and relatives in the decision-making process including differing patients’ views as to who should legitimately control decisions as well as the possibility that different parties are using different frameworks for such decisions (eg futility versus quality of life). Further qualitative exploration of doctor, patient and relative groups would help clarify these issues further. This could be done using individual sampling or in discussion groups of eg peer group medical students and doctors, patient support/self-help groups or carer groups.

There is some evidence that people hold different views about their own treatment than about those of a relative or loved-one and that doctors would often wish for a different type of treatment for themselves than they would for a patient suffering the same medical condition (Darzins 1993). Qualitative interviews that explore the
grounds for this paradox would be a fertile area for research and might provide insights into proxy-decision making.

Although there might be profound ethical and consent issues a study with contemporaneous but independent interviews with a single patient, their relatives and their physician would be one potential model for examining the interactions between different parties in a single decision-making unit. This type of qualitative data would be suited to a grounded-theory type of analysis.
Chapter 8

Discussion

‘All the world’s a stage,
And all the men and women merely players:
They have their exits and their entrances;’

As You Like It, Act 2, Scene 7
William Shakespeare
Reflective Diary of Research Journey

Overall Learning Path
This research was undertaken as an unsupervised degree and is probably one of the last postgraduate theses accepted by Southampton University in the traditional style of Medical Doctorate. The work comprises several distinct but related projects separated geographically and temporally however, taken together, it is possible to see how research methodology became more refined and how research questions were developed as time progressed. This section of the discussion aims to illustrate how the candidate developed her critical thinking and how the course of the thesis evolved.

Table 8a lists the learning experiences that the candidate has acquired directly during the process of the research journey. The candidate believes that these basic but diverse skills provide a good framework for developing future independent research but, on reflection, there are some ‘gaps’ in the repertoire.

- The candidate has never submitted for a research grant since she has been able to use time from study leave and her own free time and money from ‘soft’ funds available at her various employing institutions. This is a luxury she is unlikely to enjoy as a full time NHS consultant.

- The candidate accepts that she will require further supervision and/or training before she can confidently take on any further qualitative research (in fact she is currently collaborating with Professor Mildred Blaxter in an ongoing mixed quantitative and qualitative study looking at physicians’ attitudes to hospital post mortem examination following the Alder Hay scandal).

- Finally the candidate did not use any reference manager programme (such as EndNote) in writing this thesis and skills in this area would be likely to be helpful in the future.
Table 8a Learning outcomes from the thesis

<table>
<thead>
<tr>
<th>Area</th>
<th>Sub-area</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Technology</td>
<td>Word Processing</td>
<td>Microsoft Word</td>
</tr>
<tr>
<td></td>
<td>Statistics / Data Handling Programmes</td>
<td>Microsoft Excel – chapter 2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>SPSS – chapters 3 to 6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NUDIST – chapter 7</td>
</tr>
<tr>
<td>Presentation</td>
<td>Presenting original research</td>
<td>See abstract list for poster and platform peer-reviewed presentations</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Microsoft Powerpoint</td>
</tr>
<tr>
<td></td>
<td>Viewpoint lectures</td>
<td>Invited speaker at various hospital education meetings</td>
</tr>
<tr>
<td>Research Methodology</td>
<td>Local research ethics committee submission</td>
<td>Chapter 2 – Southampton</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chapter 5 – Oxford</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chapters 6 and 7 – Perth</td>
</tr>
<tr>
<td></td>
<td>Subject recruitment</td>
<td>Chapter 2, 6 and 7 - direct recruitment of ward patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Chapters 4 , 5 – postal recruitment</td>
</tr>
<tr>
<td></td>
<td>Questionnaire design</td>
<td>Chapters 2, 5 and 6</td>
</tr>
<tr>
<td></td>
<td>Medical notes retrieval and analysis</td>
<td>Chapters 3 and 5</td>
</tr>
<tr>
<td></td>
<td>Qualitative Interviews</td>
<td>Chapter 7</td>
</tr>
<tr>
<td>Publication of Research</td>
<td></td>
<td>Re-writing and re-submission based on editorial feedback</td>
</tr>
<tr>
<td>(see Publication list)</td>
<td></td>
<td>Book chapter</td>
</tr>
<tr>
<td>Liaison Skills</td>
<td>Statistical advice</td>
<td>Chapters 2 and 3</td>
</tr>
<tr>
<td>(see Acknowledgements)</td>
<td>Research Nurses</td>
<td>Chapters 5 and 7</td>
</tr>
<tr>
<td></td>
<td>Advice from acknowledged experts</td>
<td>Chapter 5, 6 and 7</td>
</tr>
</tbody>
</table>
Other Experiences

<table>
<thead>
<tr>
<th>Other Experiences</th>
<th>Grant examiner</th>
<th>One grant examined for Australian National Health and Medical Research Council (NHMRC)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Publication external peer reviewer</td>
<td>One paper reviewed for the Australian and New Zealand Journal of medicine (now Internal Medical Journal)</td>
</tr>
<tr>
<td></td>
<td>Teaching</td>
<td>Medical students, multidisciplinary groups, postgraduate peers, grand rounds</td>
</tr>
<tr>
<td></td>
<td>Member of Oxford Clinical Ethics Committee</td>
<td>Particular responsibility for developing DNAR forms</td>
</tr>
<tr>
<td></td>
<td>Local Guidelines Development</td>
<td>In Norwich for ‘certification and verification of death’</td>
</tr>
<tr>
<td></td>
<td>Courses</td>
<td>‘ETHOX’ clinical ethics course ‘Let Me Decide’ competence and advance directives course</td>
</tr>
<tr>
<td></td>
<td>Student supervision</td>
<td>CPR audit by junior doctor Final year medical student essay project</td>
</tr>
</tbody>
</table>

**Questionnaire Design**

Patient questionnaires were the commonest tool used in the thesis and were employed in 1993, 1997 and 1999 (chapters 2, 5 and 6). There were several modifications to the questionnaire design during this time and these can be divided into those which were felt to improve the tool and those which refined the research question.
Improving the questionnaire as a tool

All three questionnaires were designed to ascertain views about CPR in older patients or those disabled by stroke and they all contained some initial standardised information before the patient viewpoint was obtained. In the first study a printed handout was developed (appendix A) but it quickly became apparent that only a small minority of patients were able/willing to read this document and in most cases the interviewer simply read out the document and then answered any questions. The information was given at the beginning of the interview and doubled as information for the consent form. Despite the fact that the information was simple, short and written in plain English the candidate felt it was not always fully understood and remembered possibly influencing the reliability of later questions about CPR. In the second study the standardised information was given in a different manner (appendix C) and one which more accurately mimics the way in which information is given to patients in clinical practice. The patient’s knowledge of the area was first assessed to find out how much they understood already, then the interviewer provided information that confirmed the patients prior knowledge, corrected any misapprehensions and filled in any ‘gaps’. This was an interactive process and the patient was encouraged to ask questions. The interviewer still gave a standard skeleton of information but was able to ‘pitch’ the information at the right level for the patient. Finally, the information immediately preceded the questions about views on CPR and therefore minimised the information lost with time and distraction. Overall the candidate felt this style worked well and it was employed unchanged in the final study. We did obtain some data as to the impact of the ‘information package’ in the last two studies but did not collect similar information for the first study. The candidate believes that the information would have been found less influential on patients’ views when given in the first format.

In the first study almost one in ten patients were unable to express an opinion about CPR. In order to encourage a response (without forcing patients who were truly unable to make a decision to make one) there were two changes in the subsequent questionnaires. Firstly, the information package was adapted (see above) to try to ensure that any hesitancy to give an answer was not based on misunderstanding. Secondly, the wording of the option was changed slightly from ‘not sure’ to ‘don’t know’. This strategy did seem to be successful with the ‘don’t know’ option was used
by only 1% and 2% in the later two studies but obviously some of this difference may relate to different patient populations.

All three studies employed a 10 point AMTS (mainly as a tool to screen out those who it would be inappropriate to interview) and a Barthel score. The first study used some crude and unvalidated questions to assess quality of life and social support, which did not yield very much useful information when it came to analysis. The candidate wanted a better tool for analysing these parameters in subsequent studies but was limited by not wanting to overtax the patients or extend the interview period too much. Following advice, the SF-12 questionnaire and two questions from the COOP scales were employed in the subsequent studies and appeared to work well. Although these scales did not produce dramatically different results (ie self-rated quality of life and social support variables are not closely correlated with views about CPR) the candidate felt that this point was better made using established and validated tools. The 15-point Geriatric Depression scale was also added to the two later studies and this revealed some useful additional information. Some reviewers have commented that the 30 point Mini-Mental State Examination would have been a better scale than the AMTS but it was felt to be overly-long and the use of the competence tool (which more accurately looked at the cognitive function in the area that was being studied) made this rather redundant. By the third study there had been so many scales added to the basic questionnaire that the interview could take 45 minutes with a slow patient. The candidate always undertook the questionnaire section and more difficult scales first to ensure that easier scales were done at the end of the interview when concentration might be waning. In a couple of cases the candidate had to return after a rest to obtain the last few scales when the patient was tiring.

In question 8 (asking about who should make decisions about CPR - themselves, family, doctor or joint) the patient often opted for 'joint decisions'. The candidate felt that this was partly due to phrasing of the question in which 'joint decision' was the final option and the one that the patient might feel was an acceptable and easy compromise. The candidate really wanted to analyse who the patient felt should have priority for such decisions and the question was re-worded into two separate questions (5.1 and 5.2) for subsequent interviews. This allowed a better assessment of the
patient’s views of the ‘power-share’ for CPR decisions that they would favour between themselves and doctors and between doctors and relatives (if they were incompetent).

Following the apparent success of Morgan et al (1994) the candidate wanted to try using a visual analogue scale to assess a percentage survival that patients would find acceptable in order to accept the risks of CPR. This is a complex but clinically useful question which should demonstrate a patient’s willingness to undergo treatment with a small chance of benefit. The linear scale was introduced for a simple question 2.2 (to estimate in-hospital survival) but patients rarely used it preferring to give verbal estimates eg ‘about 90%’. The patient was then asked to use the scale to indicate the answer to question 4.1 (Most people would accept resuscitation if it were always successful. Would you personally accept resuscitation with a success rate of ..) but only a handful of patients were able to comply. The candidate felt that the data was so unreliable that she abandoned this question at the analysis stage and did not include it in the third questionnaire. She concluded that Morgan et al (1994) must have used a very different patient population.

One other question style that was tried and rejected involved hypothetical scenarios. Many of the published studies of patient opinion had used hypothetical scenarios to assess patients’ responses to CPR under different hypothetical medical conditions such as stroke and dementia. Although the participants in these studies were elderly they were not in fact suffering from these illnesses. When developing a pilot for the second questionnaire in 1993 the candidate tried using a hypothetical case of stroke with some stroke inpatients to explore their views about CPR. The idea was to discuss these difficult issues in a non-threatening manner but in fact the patients became confused about whether they were talking about themselves or the hypothetical case. In addition none of the patients seemed inhibited about sharing their own views and the hypothetical scenario was abandoned at an early draft stage.

Refining the research question
The way in which the candidate refined and developed the research questions between the three questionnaires is discussed in the introduction to each chapter. The following section summarises the major steps. The first and second questionnaire
differed substantially in the type of patient recruited. In the first study patients with a huge range of medical conditions were interviewed. One criticism of this study is that this medical diagnostic variability could have confounded the attempt to look for other associations with CPR preference. Utilising a single diagnostic group allowed the candidate to focus on other effects such as disability or depression. Stroke was chosen as a good model because it is a very common disabling condition. Another feature of stroke that made it interesting to study is its abrupt onset; this allowed patients to answer questions about their feelings before and after the event which would have been almost impossible for patients to assess in a gradual onset illness such as dementia or motor neurone disease.

The fact that a significant number of patients felt that their experience of stroke had altered their attitudes to CPR led to a major new hypothesis testing for the Australian study. The candidate was aware that this finding was based on retrospective assessment of what choices the patient might have made and the acute/follow-up design of the second study aimed to capture this information contemporaneously and therefore more accurately. This study design was successful and led to one of the most important findings of the thesis. There is an obvious need to replicate and refine these findings in a large cross-sectional study examining the way in which patients’ views change over longer periods of time with ageing, during the course of acute reversible illness and also with chronic progressive disease.

Another refinement in the Australian quantitative study was the addition of a competence assessment. This addition was prompted by the growing interest in advance directives and the newly published instrument by Fazel and colleges which suggested that a substantial number of elderly volunteers were incompetent to make such advance decisions. It was an important and surprising finding that 30% of the stroke patients interviewed ‘failed’ the advance directive competency test despite having a mean AMTS of over 9/10.
The role of qualitative interviews

From an early stage it was obvious to the candidate that there was a need to not only quantify what percentage of patients rejected CPR but also to understand why patients opted for or against CPR. Some simple correlations with the quantitative information collected (e.g., age, disability, etc.) were found but ultimately it was the lack of such correlations in explaining the patients’ decisions that led to a quest for qualitative information. The Southampton interview did ask patients to choose from a pre-determined and rather arbitrary list of factors which might have influenced their views (appendix A, question 19). The method of questioning seemed to limit rather than encourage a free expression of views and the information obtained was not easy to interpret. In subsequent interviews, the observers did record ‘freehand’ any additional information/clarification of views that the patients gave but this information was never analysed. Eventually, the qualitative study was developed to try and address these gaps in knowledge.

In retrospect, this development might have been better in reverse order, i.e., an initial ‘grounded theory’ based qualitative study might have been invaluable in hypothesis generating which in turn could have defined some questions that could have been explored quantitatively. It would also have been more methodologically robust to have attempted a grounded theory project before the investigators had generated their own ideas based on the extensive quantitative interviews. Although, in reality, to be truly unopinionated and open to novel concepts, the investigator should probably not have been a practising doctor.

The design and analysis of the qualitative data was suboptimal (see discussion in chapter 7) however, the information obtained was invaluable to the candidate in complementing the quantitative findings. The qualitative study illustrated the variety and complexity of opinion that patients hold about CPR as well showing that views are highly contextual and there is potential to explore and understand individuals’ beliefs. There is very little existing published research in this area and this small study is probably most useful to suggest future avenues to explore. Some examples of research questions include..
• How do patients form their views about CPR? – a study similar to the one presented in this thesis but focused on the factors that have formed views about CPR (eg social, experiential, medical factors)

• Views about CPR in different patient groups eg how do younger patients with terminal illnesses view CPR?

• Longitudinal studies of how CPR opinions develop during normal ageing, acute reversible disease and chronic progressive disease should have a qualitative arm.

• Views about CPR in non-patient groups eg doctors, nurses, relatives and carers. A fascinating study would be to interview patient/carer or patient/doctor pairs separately about CPR decisions. This study would be particularly relevant given the increasing call to involve carers and relatives in CPR decisions.

**Personal view evolution**

When the candidate started research in this area she had a rather limited medical model of resuscitation decisions. The combination of a rather logical and scientific mind along with a traditional medical training suggested that such decisions could be made by weighing up pros and cons to find the best solution. Medical education encourages doctors to make medical diagnoses and management plans despite the inherent uncertainty within the ‘art’ of medicine and CPR decisions seemed no different. The work on morbidity scores and CPR outcome was directed towards further clarifying this medical model.

As time and experience accumulated, and in the context of the social changes described below, the candidate realised that CPR decisions were not just the responsibility of the doctor. Talking to patients was rather puzzling because they seemed to hold views in direct contradiction to the medical model of CPR; either requesting treatment that was not medically justified or refusing treatment which would be recommended. Patients were also diverse in their opinions about who should make CPR decisions. Other discoveries that made CPR decisions more challenging included the fact that many, if not the majority of patients for whom it is relevant, cannot be involved in decisions about CPR at the time they need to be made. Data about how commonly patients change their minds about CPR added to the candidates growing uncertainty in this area.
As a busy practising consultant geriatrician the candidate is involved in decisions about life-sustaining treatment on an almost daily basis. There is a very wide gap between ideal scenario suggested by guidelines (which suggest time-consuming and impractical discussions about CPR with patients and relatives at the bedside) and the real life hussle of an NHS ward round. In common with her colleges the candidate has evolved a pragmatic approach to CPR decisions in clinical practice and continues to be surprised by how rarely this causes conflict or problems.

I am commonly asked how my research has influenced my personal practise. I reply that it has increased my understanding in parallel with my uncertainty. The more you know about the complexity of such a decision the harder the decision becomes. Student doctors and nurses often struggle less with CPR decisions than I do.
Summary of Findings and Contextual Commentary

‘All the world’s a stage, and all the men and women merely players: They have their exits and their entrances;’

As You Like It, Act 2, Scene 7, William Shakespeare

The hypotheses, findings and conclusions of this thesis must be appreciated in the context of the time, place and people who are described. The provision of life-sustaining technology to the elderly is comparatively recent and the evolution of the medical science has been paralleled by shifts in social attitudes. The first part of this discussion will outline the background or the ‘stage’ on which decisions about life-sustaining treatment are made.

The second part of the discussion will concentrate on the people or ‘players’ involved and the rules that they employ. The discussion will conclude with predictions of how future ‘performances’ might be conducted.

The Stage

The last century has seen an explosive growth in technological medicine. Almost every system of the body can now be replaced or supported by medical interventions eg dialysis can replace the kidneys, ventilation the lungs and parenteral nutrition the guts. Many of these advances improve health and quality of life but the most dramatic effects occur when they prevent death. Cardiopulmonary resuscitation is perhaps the most obvious intervention that prevents death but it is a mistake to believe that there were no life or death decisions to be made before 1960 when CPR was first described (Kouwenhoven et al 1960). Doctors, through their diagnostic and therapeutic training, have always been able to extend life and reduce morbidity; it is just that the knowledge and tools have become more effective and sophisticated. The recent awareness of the nature and implications of such decisions is probably as much to do with sociological changes as it is to technological ones.

It is possible to identify global trends in health care but there are still very important differences between Eastern and Western systems as well as between different
countries such as USA and the United Kingdom. Historically, medical technology has advanced at the same rate in both these countries but the ways in which the two societies deal with decisions about CPR are quite different. In the UK the provision of comprehensive free health care to all under the National Health Service started in 1949. This government-funded service is entrenched in the British culture and the provision of good quality health care that is free at the point of delivery has probably raised public expectations. Paradoxically another effect has been to produce an awareness of equity; without a fee-for-service system people expect that someone else will decide what level of treatment is appropriate. The oldest of our pensioners who can remember the introduction of the NHS and wartime rationing may have developed a less selfish attitude towards the public sharing of available resources. Obviously, with time this cohort will die and social attitudes will change further. By contrast, in the USA the predominantly private health care system has placed more decisions in the hands of paying customers. Private medicine along with the American philosophy of personal freedom and choice, and the high rate of medical litigation have led to a cultural emphasis of patient choice.

As life expectancy rises and a greater percentage of the population is older, the attitude towards ageing is changing. People expect to maintain health and activity well into retirement and the political weight of the elderly is growing both in terms of numbers and vociferousness. Societies like ‘Age Concern’ in the UK and the powerful ‘grey lobby’ in the USA provide powerful political lobbies. Both overt and covert rationing of healthcare by age has been a feature of the NHS for many years (Grimley Evans 1997). However the distribution of resources based on age alone is now considered ‘ageist’ and is beginning to be as unacceptable as ‘sexist’ and ‘racist’ attitudes (Ebrahim 2000). The government has recently recognised this in its new National Service Framework for older people in which the first standard is titled ‘Rooting out age discrimination’. This document clearly states that ‘NHS services will be provided, regardless of age, on the basis of clinical need’.

Patients are undoubtedly becoming better educated with regard to medical technology. The proportion of people attaining secondary and tertiary education is rising and the media is filled with medical information, both fictitious and factual. Information portrayed in the media are often biased or inaccurate and can lead to
misconceptions eg about the success rate of CPR (Diem et al 1996). However the media have made patients increasingly familiar with medical technology and they feel more confident that they want to be, or have a right to be involved in decisions about life-sustaining treatments. The growing power of the patient has been paralleled by a diminishing role for doctors so that the power base for such decisions is shifting from provider to recipient of medical care.

Perhaps one of the most dramatic changes in social attitudes in the UK is the change in the way that the public perceives doctors. The status of the doctor as a trustworthy, all-knowing professional is changing. The media have fuelled this change by reporting many negative stories about doctors and the medical system. Some of the major stories include the serial murders of Dr Shipman, the retention of babies’ organs at AlderHey hospital and the unacceptably high death rates for paediatric surgery at Bristol. Numerous, often very emotive reports about errors in diagnosis and management, or unprofessional behaviour of some doctors appear in the local and national media on an almost daily basis. The case described in Figure 8b illustrates the role of the media in moulding public opinion and ultimately medical practice.
Mrs Jill Baker was a 66 year-old patient who was suffering from breast cancer with intra-abdominal metastases. She was admitted to a hospital in Portsmouth with pneumonia in April 2000. The senior house officer made a DNR order and recorded in the notes stating 'In view of the underlying diagnosis of metastatic breast carcinoma and the palliative nature of the treatment in the event of cardiopulmonary arrest resuscitation would be inappropriate'. The decision was made without discussion with the patient or family. Mrs Baker recovered and later discovered the DNR order when she asked to see her medical notes. She was very angry and took her story to the Press who published this emotive story with headlines along the line of “My Life Wasn’t Worth Saving” and “Secret ‘not for resuscitation’ code on pensioner’s notes”. Age concern subsequently took up the case and compiled a dossier of one hundred cases where patients had been angered by a DNR order made without consultation. The campaign was based on an assumption that many DNR orders are ageist; a theme echoed in the medical press subsequently editorial by Dr Ebrahim (2000).

This DNR order was presumably, based on medical futility since metastatic cancer and pneumonia both confer a poor prognosis if the patient subsequently deteriorates and arrests. Morbidity scores would have predicted that her chance of surviving CPR was negligible. Press reporting did not take the opportunity of educating the public on the low success rate of CPR in general, and especially with certain underlying pathologies, but concentrated on the doctors’ failure to communicate with the patient and the use of DNR orders as a means of rationing NHS resources.

The repercussion of this, and several other high-publicity scandals, were felt in the UK in the subsequently. Many hospitals created or refined guidelines to increase patients’ and relatives’ participation in DNR decisions.
The public’s changing perception of doctors can also be traced in the escalating rate of complaint and litigation against medical staff. The right of patients to complain about medical treatment was encouraged by a Government document called ‘The Health of the Nation’ which was published in the 1980s and the volume of complaints handled by hospitals has risen enormously. Hospitals have evolved complaint procedures, risk management teams and clinical governance as a way of combating the growing culture of ‘medical accountability’. Doctors, who were previously left to self-regulation, are now expected to comply with guidelines and there will shortly be a requirement for hospital doctors to re-accredit in their speciality. Litigation is growing exponentially and has been paralleled by major increases in medical defence organisation fees.

Given the above, it is not surprising that the role of doctors in decisions about life-sustaining treatment is also changing. Early discussions about DNR policy concentrated on when the doctor felt CPR should be used (Bayliss 1982, Blackhall 1987, Fusgen and Summa 1976). There was a paternalistic feel to these calls on doctors to protect their patients from inhumane attempts at CPR but the doctor was still in charge. Social trends have changed the emphasis of criticism of doctors away from not making the correct decisions themselves towards not enquiring about or respecting patients’ views about CPR.

Another major social shift in CPR decision-making is the growing role of the legal system. America has led the world in developing a legislative framework. Although individual states have slightly different laws there is legislation that governs proxy decision-making and the use of Advance Directives in all of them. The UK government has been resistant to developing legislation but the ‘rules’ have developed through caselaw and professional guidelines. Where twenty years ago doctors would make CPR decisions based on a personal moral code they now are more likely to concentrate on interpreting law and policy with respect to their cases. This change has occurred in only a single generation of doctors with junior doctors holding quite different views on CPR decisions than their senior colleagues (Mello and Jenkinson 1998). The impact of the new Human Rights Act, which came into force in October 2000, and the right to appeal to the European Parliament has not yet been felt on the
British legal system. The right to life (article 2) may be used as a framework for challenging end-of-life decisions.

One interesting aspect of the current guidelines is that CPR is provided to all patients who arrest in the hospital unless a DNR order has been made. In contrast to most major invasive medical procedures CPR does not require explicit patient consent, in fact consent is often required to withhold this treatment. This 'opt out' policy rather than the 'opt in' one used for most medical treatments probably stems from the fact that cardiac arrest is unplanned and universally fatal so that CPR cannot be anticipated, or delayed until consent can be obtained. There is also a possibility that it is a uniquely emotive treatment which patients and doctors feel should be utilised in a different way to other forms of medical intervention.
The ‘Players’ - What do the Patients think about CPR?

Increasing respect for patient autonomy demands that patients play a lead role in decisions about life-sustaining treatments. There has been a feeling expressed especially in the literature that, once fully-educated on the technique of CPR the majority of elderly patients would reject life-sustaining treatment (O’Keeffe et al 1993, Fusgen and Summa 1978, Wagner 1984). This common perception that frail elderly patients will reject CPR might be driven by the fact that younger fit people believe they would reject CPR under such circumstances. The qualitative study of patients who have already suffered disabling stroke (Chapter 7) suggests that in fact people adjust, as they become older and more disabled. It is possible that patients rarely reach a point where their quality of life is unacceptable to them, but young people are mistaken in thinking they can predict this point.

This qualitative hypothesis reinforced by quantitative evidence from this thesis. One of the more important findings of this thesis is that after education 60% of patients on geriatric wards (Southampton study), 75% of elderly post stroke patients in the community (Oxford study) and 82% of patients on an acute stroke ward (Australian study) would wish to receive CPR. These figures are in line with many other population surveys from around the world (see tables II and Ij) which suggest that at least three quarters of elderly patients are likely to request CPR if it is offered.

None of the studies in this thesis found evidence that a patient’s age or degree of disability reliably predicted their view on resuscitation. The failure to find a statistically significant correlation between variables such as age and disability and the wish to receive CPR in any of these three studies does not exclude the possibility of a weak association. Larger studies which analyse multiple factors (including religion, past experiences, social class etc) employing multiple regression analysis might be able to clarify a relationship. However the qualitative interviews (Chapter 7) suggest that even such a quantitative study would fail to produce data which would allow reliable predictions. These interviews reveal that patients perceive the same factors in different, often contradictory ways. For example some patients viewed advanced age as a reason to withhold CPR and others did not, and there were diverse views on what constitutes quality of life. From a practical point of view doctors would value some simple predictors of patients’ views so that they can make decisions for
incompetent patients or to help guide them as to which patients they should discuss DNR orders with. This thesis demonstrates that there are no such simple predictors and that ‘blanket’ policies on resuscitation are likely to be unhelpful.

There is some evidence that increasing age, physical and mental frailty and dependency are likely to be associated with decreasing success rate after CPR (see section 1.2.2). This is probably because they are surrogate measures for multiple pathology and decreasing physiological reserve. Since these factors do not seem to influence patients greatly in their choice of CPR it can be assumed that policies based on patient choice rather than medical appropriateness will result in an increasing number of futile resuscitation attempts. Those who believe that involving patients with CPR decisions will provide a socially acceptable way of rationing expensive treatment would be disappointed by these results!

Problems with involving patients
Although there are social and legal shifts towards involving patients in CPR decisions, unfortunately there are several factors which mean that they are not always well placed to make such decisions.

The first problem is that they are often physically unable to make decisions at the time that they are required. In the UK resuscitation status is rarely considered unless the patient has a reasonable chance of having a cardiac arrest. At this time the patient is so ill that they are often incapable of being involved in the process of decision-making. In the Australian study (chapter 6) around a quarter of the patients were physically incapable of discussing CPR within 14 days of acute stroke. None of those included in the study had a DNR order and it is likely that the percentage of patients with a DNR order that could be involved at the time it was made would be even lower than this. The high exclusion rates from other studies on general elderly care wards (Chapter 2, O’Keeffe 2001, Gunasekera et al 1986, Liddle et al 1994, Mead and Turnbull 1995) suggests that the inability to discuss CPR is not restricted to those with acute stroke.

Another problem is that patients have poor knowledge about medical technology. This is likely to be particularly true for the cohort of older patients who did not have
exposure to intensive medical care technologies when they were younger. In the studies described in Chapters 2 and 5 only about half the patients had even a rudimentary knowledge of CPR and in the younger group described in Chapter 6 one in ten had a poor knowledge about CPR. The studies in Oxford and Australia confirm previous studies’ findings that patients dramatically overestimate the success rate of in-hospital resuscitation (Murphy et al 1994, Schonwetter et al 1991, Miller et al 1992, Kerridge et al 1999).

Correction of the knowledge gap with careful explanation of the techniques and success rate of CPR reduces the wish for CPR. In both studies (chapter 5 and 6) about one in ten patients rejected CPR after such explanations and no one became more positive about the treatment. This figure is similar to that reported by other investigators using different patient populations and education techniques (O’Brien et al 1995, Morgan et al 1994, Hui et al 1997, Kerridge 1999, Miller et al 1992). In research settings information is given in a standardised format and advantages as well as disadvantages are discussed impartially. Discussions in a real clinical setting would probably be tailored to the patient’s clinical situation (eg provide personalised estimate of success rates rather than generalised figures) but they would be likely to be shorter and may not enjoy ideal interview conditions (O’Keeffe 2001). In addition the clinicians personal view of role of CPR as well as the relationship between doctor and patient might introduce considerable bias in discussions. The value of these studies may be limited by the fact that patients realised they were making hypothetical choices and potentially their views might be different if they felt it would affect their future medical care or even the relationship with their doctor. It would be interesting to measure the content and effect of CPR discussions on patients’ views in the real clinical setting.

Another issue about involving patients in DNR orders is that of competence ie the cognitive ability to make informed decisions about CPR. The components of competence have been clearly defined and are amenable to testing but this is rarely done in clinical practice where patients are usually assumed to be competent unless there is obvious evidence to the contrary. One of the major findings of the Australian study (Chapter 6) is that this assumption may be incorrect in a significant minority of patients. In this study a third of those who could be interviewed (ie not including
those with known cognitive impairment) were not competent to make the complex
decisions involved in an advance directive within the first two weeks of stroke. At
follow up 7/50 (14%) of the patients had become competent, or probably regained
competence, but 9/50 (18%) were still incompetent to make an advance directive.
This point must not be confused with poor knowledge of the subject as competence is
tested after appropriate education has been given.

The completion of an advance directive requires a similar but probably slightly more
advanced competence level than that involved in contemporaneous decisions about
CPR. It seems likely that many patients who were incompetent on the advance
directive scenarios would also be unable to participate in CPR decisions, but
competence is decision-specific and ideally a tool to measure competence to decide
about CPR, which could be tailored to an individuals circumstances, should have been
developed and used. This would have mirrored the real clinical situation more
accurately.

Stability of choice is the final concern regarding the choice of patient as decision-
maker. A proportion of patients seem to make different choices when they are unwell,
and a CPR decision may be relevant, than before or after their illness passes (when
they may have higher competency levels but their decision is less relevant). This has
been demonstrated in the Southampton study (Chapter 2) where 20/118 (20%)
patients had changed their minds about CPR between admission and discharge, and in
the Australian study (Chapter 6) where 8/51 (15.7%) had changed their minds
between hospital and the home environment. Analysis of the case reports suggests
that some patients were aware of their change in mind but some were unaware that
they had changed their minds.

There is only one other moderate sized study which found a similar proportion of
patients change their minds about CPR between admission and discharge (Watson et
al 1997). There are a few other reports which contain no more than a handful of
patients who also support this conclusion (Everhart and Pearlman 1990, Potter et al
1994, Bedell et al 1983). There is an obvious need for more research into the stability
of patients’ opinions over time and with changes in their health and social status. A
long-term follow up study of this type would be complemented by some qualitative
information from patients around the time at which their views change to try to understand the mechanisms involved.

This instability of view has several important implications for clinical practice. The first is that it is not safe for doctors to discuss CPR at a single point and assume that a patient’s views will be stable over time, especially if there is a substantial change in their circumstances. Unfortunately, during an acute illness doctors are often unable to ascertain if the patient’s views are unchanged. Doctors are then left with the concern that previously expressed views cannot be relied upon. This problem also lies at the core of advance directives. By their very nature ADs are designed to be implemented when the patient is no longer competent and yet this is a time when there is a major change in the patient’s circumstances.

The role of family in CPR decisions

Most societies recognise that family members have a right to make certain decisions for other family members eg parents can make decisions for minors and up until comparatively recently, husbands for wives. Traditionally as children grow up they make a transition from being dependent on their parents to parents being dependent on them. Children often feel protective towards their parents especially as they become physically and mentally frailer and they may take over more and more of the day-to-day decisions for their parent. The same effect may occur when one spouse becomes dependent on another and the role gradually changes from a partner to a carer. Given this background, it is not surprising that family members often feel they have a right or even a duty to be involved in medical decisions. This is particularly true of incompetent patients but sometimes extends to competent patients when the family is trying to protect the patient from difficult or unpleasant decisions. For example it was not unusual in the past and still common practice in Japan for families and doctors to withhold a diagnosis of cancer from competent patients.

In addition to society’s recognition that families have a greater right to make decisions for incompetent relatives than outsiders, there is also the argument that through their intimate knowledge of that person, they are in a better position to make substitute decisions. There is actually little evidence that relatives are accurate at substitute decision-making (Frankl et al 1989, Seckler et al 1991, Uhlmann et al 1988)
but they may be better or more legitimate judges of ‘best interests’ than health care professionals. Opinion is divided about this role for relatives; on the one hand there is a risk that relatives will want inappropriately to prolong the life of their loved ones to postpone the pain of bereavement. On the other hand relatives might fail emotionally to adjust to their kin’s new physical or mental disability and therefore wish to curtail a life which might be of acceptable quality for the patient, but no longer represents that which their father/mother/spouse would previously have led. Finally there is concern that the motivations of relatives might put their own interests ahead of the patient’s.

The role of the family in end-of-life decision making is one of the most marked differences between the law in the UK and the USA. In the USA the relatives can legally make such surrogate decisions and the doctor must consult them for DNR orders. In the UK relatives have no legal right to make decisions for incompetent adults and doctors treat patients ‘in their best interests’ although their decisions are often informed by discussions with the relatives. There seems to be a shift towards increasing involvement of relatives in CPR decisions fuelled by adverse publicity (see Figure 8a). The latest BMA guidelines encourage discussions with relatives even where the grounds for withholding CPR are medical futility.

Doctors should however be aware that patients themselves do not always favour their family as surrogate decision-makers. The Southampton study demonstrates that a minority (8%) of patients want their family alone to make CPR decisions and other studies have demonstrated that significant numbers of patients would not want their relatives involved in CPR decisions (Morgan et al 1994, Mead and Turnbull 1995). The Australian study (Chapter 6) asked who should decide about CPR if they were unable to and found that half the patients wanted their family to decide and half would prefer it to be the doctor’s decision. An insight into the reluctance of patients to devolve CPR decisions to their relatives is gained from the qualitative study (Chapter 7) in which informants often described their next of kin as uneducated and overemotional. By contrast doctors were generally seen as emotionally detached, rational and trained to make such decisions. Some informants even felt their doctor should be able to overrule or deceive their relatives if their view was contradictory to the doctor’s.
If the government’s proposals for a new continuing power of attorney for health care are enacted then patients will be able to specify in advance who should decide on medical treatment if they became incompetent. This optional policy would seem better than the American system where the next of kin automatically have rights which would not be universally popular.
This section of the discussion will concentrate on the ‘rules’ for withholding CPR, which can be broadly divided into medical futility and quality of life. In the Shakespeare analogy these rules might represent the language of the play.

**Medical futility** initially appears a very simple concept; where a treatment is not going to benefit a patient then there is no moral or legal obligation to provide it and in some cases it can be seen as meddlesome or harmful to expose a patient to it. Most doctors would withhold futile treatment and some would argue that offering futile treatment is deceptive as it gives the ‘illusion of choice’ and fruitlessly raises hopes of patients (Saunders 1992). The situation may be viewed differently by some people, especially in America, who believe that, given sufficient funds, patients should be able to choose treatment even if the medical experts believe it is futile.

Determining when CPR is futile is not always straightforward. Survival is the most obvious outcome to measure after CPR. Studies of survival after in-hospital CPR have demonstrated that only approximately one in five patients will show signs of life after CPR and only one in ten will survive to discharge from hospital (see Table 1d). Long term survival is much less well studied and it seems likely that survivors will not have a normal life expectancy. Life in hospital might be enjoyed by some but most patients value their life after discharge from hospital. It is a combination of convenience and medicalisation that leads us to concentrate on in-hospital mortality. In the small series reported in Chapter 3 there appears to be a subsection of patients who survive for less than 500 days following discharge from hospital. The length and quality of survival (see below) once the patient has been discharged from hospital needs further study.

Many studies and meta-analyses (see section 1.2.2.2) have identified a multitude of diagnoses (eg dementia), demographics (eg age), physical signs (eg hypotension), biochemical tests (eg raised creatinine) and social measures (eg homebound lifestyle) which have been shown to predict a lower chance of survival after CPR. However no individual factor predicts futile CPR accurately enough to enable doctors to withhold CPR from a particular group. It is biologically plausible that more adverse features are associated with a lower chance of survival and George et al (1989) were the first to show that combining fifteen of these factors into a simple ‘score’ improved the
prediction of futile CPR. Ebell (1992) and later Dautzenberg et al (1993) published two further scoring systems.

There has been remarkably little published research into the use of these scores in a clinical setting, especially if you discount these authors’ own evaluation of their scores which might well be systematically biased. The work reported in chapter 3 provides important evidence that these scores do accurately identify a subsection of patients (around one quarter) who are currently exposed to CPR who do not survive to discharge. The three scores each identify a slightly different population of unsuccessful CPR and the sensitivity can be increased by using the scores in combination to around 40% of unsuccessful resuscitation attempts. This was a retrospective study and the scores may not function as well when used prospectively in a different population. Also, the scores need frequent updating (scores are likely to increase as the patient becomes sicker and nearer to arrest) and there is probably some inter-rater variability. In addition it is not known whether it would be acceptable in current practice to withhold CPR for all those patients predicted as futile by the score or whether a proportion of patients who would currently not receive CPR would be exposed to it because of low morbidity scores. These factors suggest that even if scores were employed they are likely to spare substantially fewer than the 40% of patients destined for futile CPR that were identified in the retrospective study. A prospective study is clearly needed to answer these questions.

The study identified a further factor that predicts low survival rate; that of length of time in hospital prior to arrest. There are probably many other factors that could be added to improve the accuracy of such scores. Ideally a large prospective blinded trial would be designed in which data were recorded in advance and all cardiac arrest patients were exposed to CPR with outcome independently rated. This trial will probably never happen because it would be expensive and ethically unsound but there are now internationally agreed guidelines for reporting CPR outcome which might lead to greater accuracy in predicting futile CPR in the future (Cummins et al 1995).

Morbidity scores were developed from an acute hospital population and have not been validated in other settings. Out-of-hospital arrests for example are unlikely ever to benefit from morbidity scores since there is rarely time or sufficient information about
the patient prior to the arrest in order to calculate them. Many older patients in nursing homes, rehabilitation wards or palliative care settings may be considered for DNR orders but are unlikely to score highly on morbidity scores because they use variables such as hypotension, sepsis and uraemia which are unlikely to be present or measured in these settings.

The quality of CPR and speed of response to an arrest is often assumed to be uniform yet it is unlikely that CPR provided by nurses in a long-stay rehabilitation ward would be of the same quality and speed as that provided on a coronary care unit. In his ethnographic study of CPR in an American Emergency Room Timmermans (1999) observed that the duration and intensity of CPR attempts were influenced not only by the medical indicators but by a factor called ‘social viability’. Patients who were younger (especially infants) and who had higher socio-economic functioning were more likely to receive prolonged CPR attempts than patients who were elderly, unkempt or substance abusers. It would be reasonable, but highly controversial, to include a variable for likely quality and speed of CPR provision into any futility estimate.

Decisions about CPR have to be made in advance and have to be dichotomous ie whether the resuscitation team is called for a cardiac arrest or not. CPR itself is protocol-driven and is usually provided by people who do not know the patient and this leaves little scope for providing ‘partial’ CPR. One final problem with the concept of medical futility is that it really provides an estimate of success rather than a black and white answer. Morbidity scores convert a linear scale into a dichotomous one by defining a threshold for predicting futile CPR. The threshold can be moved to provide scores with different degrees of sensitivity and specificity. In this study the threshold for PAM was set at 6/25 because that gave 100% specificity from this series but other authors have set lower (O’Keeffe and Ebell 1994) or higher cut-offs (Ebell et al 1997). No patient with a PAM score of greater than 8/25 has been reported to have survived to discharge but ultimately there might be one exceptional patient who does. If the threshold is set higher and higher the score will become almost useless because the sensitivity will drop. Or, put in a clinical setting, if we want to include everyone who might conceivably survive resuscitation this means including huge numbers of patients who are destined not to survive. What chance of success would
be required to define it as futile- 10%, 1%, 0.1%, 0.01% or 0% It is likely that patients, doctors and financial managers of hospitals would all hold different views on this.

Even if morbidity scores are found not to be applicable in many circumstances and to have rather low sensitivity to be useful in most DNR orders they may well have other roles such as in educating doctors about futility. They may also be helpful in discussions with patients who want an individualised estimate of their success rate after CPR to help them decide about CPR.

Apart from survival there are other, less well studied, outcome measures after CPR. Patients often remain gravely ill and may experience depression (Bedell et al 1983), poor quality of life (De Vos et al 1999) or changed social circumstances (Fitzgerald et al 1997). Hypoxic or other metabolic disturbances at the time of the resuscitation can leave patients physically or cognitively disabled although the rates of this are probably much lower than has been feared by doctors. Ability to predict quality of survival may be just as important but is even less developed than prediction of survival itself.

Regardless of which outcome measure for CPR (survival or quality of survival) is considered the comparison must always be drawn against death, which is the inevitable outcome of cardiac arrest without intervention. Thus assessment of the role of CPR must also include an estimate of how bad the outcome of death is for an individual patient. Death may not be perceived as such a bad outcome for an elderly person who feels that they have completed their lives, for a highly religious patient who anticipates Nirvana/Heaven or for a patient who has come to terms with the inevitability of death after a long progressive illness.

However imprecise our attempts to estimate ‘futility’ they often appear simpler and more objective that attempts to define Quality of Life. The quality of life concept is largely based on the face validity of certain universal values. Unfortunately these concepts are so nebulous as to defy measurement and are not of great practical value in aiding with CPR decisions at the bedside.
One problem with quality of life is that it is very hard for other people to estimate. Physicians and family have been proven to be very poor at estimating a patient’s own view of his/her quality of life (Sprangers and Aaronson 1992). In parallel with this they are poor at estimating whether a patient wishes to receive CPR (Frankl et al 1989, Seckler et al 1991, Uhlmann et al 1988). It is possible that surrogates will tend to get proxy decisions wrong because they are using their own views as to what quality of life entails rather than those of the patient.

In the qualitative interviews (Chapter 7) patients display considerable diversity and some disagreement as to what constitutes a life with quality. Most, but not all, agree that a reasonable degree of cognition is needed for quality to be present and that life in a vegetative state would be unacceptable. Other factors such as dependency, physical disability, social role and age are much more controversial and individuals’ views are not consistent. It is not therefore surprising that the quantitative surveys (Chapters 2, 5 and 6) have not demonstrated strong associations between measures of disability (Barthel), depression (GDS) cognition (AMTS) and social support (COOP scale) and patients’ wishes for CPR. It is possible that these scales were not precise enough or that the studies were not big enough to detect a relationship but it seems more likely that it is not the actual level of dependency but the individual’s view of whether that level is acceptable that determines acceptance of CPR. One patient may be quite happy to accept a level of disability and dependency that would be intolerable to another person.

It is harder to explain why the simple (COOP) and compound (SF-12) quality of life measures do not correlate well with opinions about CPR since such scores allow a degree of interpretation of quality rather than measuring them directly. If decisions about CPR were being based on quality of life alone then a better correlation should have been found. It may be that while quality of life remains a component in decision-making, beliefs in other areas such as religion, fate, medicine may be obscuring the relationship with CPR choice.

The role of advance directives
Advance directives appear to supply a solution to the problem of variable individual views of quality of life whilst promoting autonomy for the incompetent patient. When
they were first discussed in the UK medical literature there were great hopes expressed and Doyal (1995) titled his editorial “Like a will, everyone should have one”. Advance directives have not fulfilled this prediction and are still uncommon in clinical practice. This may be partly due to confusion over their legal status. This thesis demonstrated that in 1997 only around half of the GPs surveyed were aware that ADs carried any force in law (Chapter 4) and the general public is likely to be even less aware.

There is no infrastructure for completing and implementing ADs as there is in the USA so that confusion exists about how and where they should be completed, stored and who is responsible for their interpretation in hospital.

The low take-up of ADs may also be due to a general distaste for discussions about death and dying found in both patients and doctors. Patients in the qualitative interviews (Chapter 7) often pointed out that the topic was uncomfortable and that they would be unlikely to confront it until forced to by advancing ill health. This leads to the paradox that when people do become unwell they are commonly physically or mentally incapable of completing an AD in the same way as they become incompetent to take part in contemporary CPR decisions. The only patients who appear to escape this paradox are those with chronic progressive diseases such as HIV, cancer or severe cardiac or pulmonary failure. These patients may have come to terms with their illness and are willing to contemplate their future medical needs and might therefore be in the best position to make an AD.

Finally it must be remembered that most ADs are actually forms of surrogate decision for oneself as a future incompetent self. As discussed previously, patients do not necessarily have stable views about CPR over time and their views may be especially unreliable they have a significant change in their medical condition. An AD, where a patient in one condition makes a decision which will be implemented when they are in another condition, does not take into account that the individual’s view of quality of life may change (see box 8c). This seems like a rather philosophical point but it was one that several of the patients referred to in the qualitative interviews (Chapter 7). Some patients were unhappy to make CPR decisions in advance because they were concerned about changes in medical practice but also because they were aware they
might change their own minds about the appropriateness of treatment. The possibility of instability in views worries doctors and patients and this may be in part responsible for the low take-up for ADs.

Box 8c A story about advance directives

Fred is a happy, healthy caterpillar but he lives under a cloud of apprehension because he knows that at any stage and with no warning he may pupate. Not only is he worried about the period of time when he knows he will be unconscious and unable to communicate but if he survives this terrible trauma an even worse thing happens...he might turn into a butterfly. Now, to Fred, life as a butterfly is unthinkably bad. None of the values he currently holds would apply to his new existence. Even the simple pleasure of champing though leaves will be denied and he will be forced to suck disgusting nectar through a tube, which is the nearest thing, a butterfly has to a mouth.

Fred is so troubled by the terrible prospect of butterflyhood that he makes a living will. He asks the other caterpillars to take measures to ensure that he doesn’t survive his pupa stage if they ever find him in this pitiful state. He assures them that he would rather die peacefully than survive with the indignity of becoming a butterfly. Some of his friends point out that, however strange it may appear the butterflies seem to enjoy life, despite their terrible disabilities. Fred remains adamant that he knows his own mind and that he should have a right to determine his future.

(Bowker 1999 – unpublished)
Future Performances

There is little doubt that changes in science as well as changes in social attitudes to health, age and the role of doctors has altered the process of dying (see figure 8d). The final part of this discussion will attempt to position this thesis within this rapidly evolving area and postulate on how future 'performances' may differ.

Box 8d A portrait of death over two decades

The same eighty-year-old widow is dying...

In 1968
She has become very thin and frail and is nursed by her youngest daughter. Both she and her family consider that she has had a good share of life and they all realise she is dying. The local GP, who has known the family for years, attends; he is happy with the diagnosis of 'dying' and hospital admission does not enter his mind. He prescribes morphine and she dies within a few days and without a diagnosis. The death certificate reads 'old age'.

In 1989
At the insistence of her son she is admitted to hospital for investigation of weight loss. An ultrasound demonstrates a mass in her abdomen and a laparotomy is planned. A naso-gastric tube is inserted pre-operatively to improve her nutrition. At operation a bowel malignancy is removed. Twelve days post-operatively she suffers a cardiac arrest and CPR is attempted for 25 minutes before her pulse returns but she never regains consciousness and dies on the intensive care unit two days later. The death certificate reads 'pulmonary embolism secondary to carcinomatosis'. She has lived a month longer than in 1968 but all of these days were in hospital.

Certain trends can be identified in the last few decades and these are likely to continue along the same lines. There will be increasing levels of sophistication and technology in medicine. These innovations are likely to be expensive to develop and implement and the nation will have to develop acceptable and robust methods of rationing state-provided health care. Epidemiological predictions suggest that the percentage of elderly people in the population will continue to rise but increasing numbers of healthy, educated elderly may inhibit ageism, permitting access to high quality health care at all ages.
It is very likely that the UK will follow the USA in providing a clearer legislative framework for decisions to withhold life-sustaining treatment. A continuing power of attorney for health care is already planned and the law is likely to evolve rapidly as the more cases are heard under the Human Rights Act.

There are likely to be much clearer and more rigid local policies on DNR orders and particularly on documentation. The decreasing role of doctor discretion and increasing chance of decisions being challenged by complaint or litigation is the main drive for these changes.

In parallel with this the trend towards increasing patient involvement in medical decisions will fuel the development of advance care planning. The simple instructional directive will probably never become widely used because the majority of patients do not complete them and they are often too restrictive to be applicable to the medical circumstances as they arise. Advance care planning in its wider sense of communication, planning and consumer choice within the medical framework is, however, likely to grow. Advance care planning has most potential for those who know they are dying, and who by discussions with their physicians and families may be able to influence the dying process.

The shift away from doctors taking unilateral decisions about CPR may be relieving them of some responsibilities but it is providing new challenges. There will be a greater burden on deciding when and how to involve patients and carers in decisions as well as assessments of competence, motives and legitimacy of living wills. Changes in this area are taking place fast and doctors currently in practice were not trained for this sort of assessment so there is a need for continuing education to ensure the doctors are able to implement changes.
This thesis has highlighted the diversity of ethical and scientific and legal issues involved in decisions about life-sustaining treatment. The subject matter covers areas of medical science, social science, medical ethics and law and a combination of qualitative and quantitative methodology was utilised to try to describe it fully. The thesis also attempts to reconcile some theoretical frameworks with the practical application of bedside decision-making with real patients; for example the thesis adds substantially to the body of information that helps doctors to

- Determine when CPR is likely to be unsuccessful,
- Realise the diversity of views held by patients about life-sustaining treatment and some of the complexities underlying their choices,
- Assess the advantages and disadvantages of advance directives.

It is often said that ‘there is nothing certain in life except death’ and it is equally certain that the issues addressed in this thesis will continue to challenge medicine and society in the future.
Aarons EJ and Beeching NJ
Survey of “Do not resuscitate” orders in a district general hospital
British Medical Journal 1991;303:1504-1506

Advance Statements about medical treatment. Code of practice with explanatory notes
London BMA April 1995

Airedale NHS Trust v Bland [1993] 1 All ER 859
Per Lord Keith, Lord Goff, and Lord Mustill. Airedale NHS Trust v Bland [1993] 1 All ER 821

Alexandrov AV, Bladin CF, Meslin EM and Norris JW
Do-Not-Resuscitate orders in acute stroke
Neurology 1995;45:634-640

Applebaum PS and Grisso T
Assessing Patients’ Capacities to Consent to Treatment

Ashby M, Wakefield M and Beilby J
General Practitioners’ knowledge and use of living wills
British Medical Journal 1995;310:230

Baskett PJF
ABC of Resuscitation. The Ethics of Resuscitation
British Medical Journal 1986;293:189-191

Bamford J, Sandercock P, Dennis M, Burn J and Warlow C
Classification and natural history of clinically identifiable subtypes of cerebral infarction
Lancet 1991;337(8756):1521-6

Bayer AJ, Ang BC and Pathy MSJ
Cardiac Arrests in a Geriatric Unit
Age and Ageing 1985;14;271-276
Bayliss RIS
Thou shalt not strive officiously
British Medical Journal 1982;285:1373-1375

Beauchamp TL and Childress JF
Principles of Biomedical Ethics (3rd Edition)
Oxford University Press, New York 1989

Bedell SE and Delbanco TL
Choices about cardiopulmonary resuscitation in the hospital. When do physicians talk with patients?
The New England Journal of Medicine 1984;310:1089-1093

Bedell SE, Delbanco TL, Cook EF and Epstein FH
Survival After Cardiopulmonary Resuscitation In The Hospital

Bedell SE, Pelle DP, Maher PL and Cleary PD
Do-Not-Resuscitate Orders for Critically Ill Patients in the hospital. How are they used and what is their impact

Beer RJ, Teasdate TA, Ghusn HF and Taffet GE
Estimation of severity of illness with APACHE II: age-related implications in cardiac arrest outcomes
Resuscitation 1994;27:189-195

Berger R and Kelley M
Survival After In-Hospital Cardiopulmonary Arrest of Noncritically Ill Patients
Chest 1994;106;3;872-879.

Bergner L, Bergner M, Hallstrom AP, Eisenberg M and Cobb LA
Health Status of Survivors of Out-of-Hospital Cardiac Arrest Six Months Later
Biegler P, Stewart C, Savulescu J and Skene L
Determining the validity of advance directives
Medical Journal of Australia 2000;172:545-548

Blackhall LJ
Must we always do CPR?

British Medical Association (BMA)
London: BMA 1995

British Medical Association (BMA)
Decisions relating to cardiopulmonary resuscitation. A statement from the BMA and RCN in association with the Resuscitation Council (UK) Initial release 1993, revision June 1999

Bruce-Jones PNE
Resuscitation decisions in the elderly: a discussion of current thinking

Callahan D
Controlling the costs of health care for the elderly- fair means or foul

Chin D, Morphet J, Coady E and Davidson C
Assessment of cardiopulmonary resuscitation in the membership examination of the Royal College of Physicians
Journal of the Royal College of Physicians 1997;31(2);198-201

Clarnette R and Molloy DW
Let Me Decide
Cohn EB, Lefevre F, Yarnold PR, Arron MJ and Martin GJ
Predicting survival from in-hospital CPR; meta-analysis and validation of a predictive model
Journal of General Internal Medicine 1993;8:353-373

Crabtree BF and Miller WL
Doing qualitative Research (2nd Edition)
Sage Publications 1999
ISBN 0-7619-1497-8

Cummins RO, Chamberlain D, Hazinski MF et al
Recommended Guidelines for Reviewing, Reporting, and Conducting Research on In-Hospital Resuscitation: The In-Hospital 'Utstein Style': A Statement for Healthcare Professionals From the American Heart Association, the European Resuscitation Council, the Heart and Stroke Foundation of Canada, the Australian Resuscitation Council, and the Resuscitation Councils of Southern Africa
Circulation 1995: 2213-2239

Currie CT
Life Sustaining Technologies and the Elderly
British Medical Journal 1988:297:3-4

Curtis JR, Park DR, Krone MR and Pearlman RA
Use of the medical futility rationale in do-not-attempt-resuscitation orders

Danis M, Garrett J, Harris R et al
Stability of choices about life-sustaining treatments
Annals of Internal Medicine 1994;120:567-573

A Prospective Study of Advance Directives for Life-Sustaining Care

281
Darzins P, Molloy DW and Harrison C
Treatment for life-threatening illnesses

Dautzenberg PL, Broekman TCJ, Hooyer C, Schonwetter RS and Duursma SA
Review; patient related predictors of cardiopulmonary resuscitation of hospitalised patients.
Age and Ageing 1993;22:464-475

Dautzenberg PL, Hooyer C, Schonwetter RS, Dermout KMT, Veer JK and Duursma SA
Dementia in Resuscitation Policy: A Prospective Study on a Psychogeriatric Ward in a Dutch
General Teaching Hospital
Age and Ageing 1996;25:234-238

Davies Michael
Textbook on Medical Law
Blackstone Press Limited
ISBN 1 85431 842 X

DeBard ML
The History of Cardiopulmonary Resuscitation

DeBard ML
Cardiopulmonary Resuscitation: Analysis of Six Years’ Experience and Review of the Literature

Doyal L
Advance Directives. Like a will, everyone should have one.
British Medical Journal 1995;310:612-613

Doyal L and Wilshire D
Withholding cardiopulmonary resuscitation: proposals for formal guidelines
British Medical Journal 1993;306;1593-1596
Doyal L and Wiltshire D
Withholding and withdrawing life sustaining treatment from elderly people: towards formal guidelines
British Medical Journal 1994;308:1689-1692

Van Delden JJM, van der Maas PJ, Pijnenborg L and Looman CWN
Deciding not to resuscitate in Dutch hospitals
Journal of Medical Ethics 1993;19:200-205

De Vos R, De Haes HCJM, Koster RW and De Haan RJ
Quality of Survival After Cardiopulmonary Resuscitation
Archives of Internal Medicine 1999;159:249-254

De Vos R, Koster RW and De Haan RJ
Impact of survival probability, life expectancy, quality of life and patient preferences on do-not-attempt-resuscitation orders in a hospital
Resuscitation 1998;39:15-21

Diggory P and Judd M
Advance directives; questionnaire survey of NHS Trusts
British Medical Journal 2000;320:24-25

Diem SI, Lantos JD and Tulsky JA
Cardiopulmonary Resuscitation on Television

Doyal L
Advance Directives. Like a will, everybody should have one
British Medical Journal 1995;310:612-613

Ebell MH
Prearrest Predictors of Survival Following In-Hospital Cardiopulmonary Resuscitation; A meta-analysis.
Journal of Family Practice 1992;34:551-558
Ebell MH and Preston PS  
The effect of the APACHE II score and selected clinical variables on survival following cardio-pulmonary resuscitation  
Family Medicine 1993;25:191-196

Ebell MH, Kruse JA, Smith M, Novak J and Drader-Wilcox J  
Failure of three decision rules to predict outcome of in-hospital cardiopulmonary resuscitation  
Medical Decision Making 1997;17(2);171-7

Ebrahim S  
Do Not Resuscitate Decisions: Flogging dead horses or a dignified death? (Editorial)  
British Medical Journal 2000;320:1155-1156

Emanuel L  
How Living Wills can help doctors and patients talk about dying (Editorial)  
British Medical Journal 2000;320:1618-1619

Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM and Emanuel EJ  
Advance Directives for Medical Care – A Case for Greater Use  

Emanuel EJ and Emanuel LL  
The Economics of Dying. The Illusion of Cost Savings at the End of Life  

Emanuel EJ and Emanuel LL  
Proxy decision making for incompetent patients: an ethical and empirical analysis  

Everhart MA and Pearlman RA  
Stability of Patient Preferences Regarding Life-Sustaining Treatments  
Chest 1990;97:159-164
Fazel S, Hope T, and Jacoby R
Assessment of competence to complete advance directives: validation of a patient centred approach

Fazel S, Hope T and Jacoby R
Dementia, intelligence, and the competence to complete advance directives
The Lancet 1999;354:48

Fazel S, Hope T, and Jacoby R
Effect of cognitive impairment and premorbid intelligence on treatment preferences for life-sustaining medical therapy

Fitten LJ and Waite MS
Impact of Medical Hospitalization on Treatment Decision-Making Capacity in the Elderly
Archives of Internal Medicine 1990;150:1717-1721

FitzGerald JD, Wenger NS, Califf RM, Phillips RS, Desbiens NA, Liu H, Lynn J, Wu AW, Connors AF, Oye RK for the SUPPORT investigators
Functional Status Among Survivors of In-Hospital Cardiopulmonary Resuscitation
Archives of Internal Medicine 1997;157:72-76

Frankl D, Oye RK and Bellamy PE
Attitudes of Hospitalized patients towards life support: a survey of 200 medical inpatients
The American Journal of Medicine 1989;86:645-648

Folstein MF, Folstein SE and McHugh PR
Mini-mental state; a practical method for grading the cognitive state of patients for the clinician

Fusgen I and Summa JD
How much sense is there in an attempt to resuscitate an aged person?
Gerontology 1978;24:37-45
Gage BF, Cardinalli AB and Owens DK
The effect of stroke and stroke prophylaxis with aspirin and warfarin on quality of life
Archives of Internal Medicine 1996;156:1829-1836

George AL, Fikj BP, Crecelius PL and Campbell WP
Pre-Arrest morbidity and other correlates of survival after in hospital CPR
American Journal of Medicine 1989;87:28-34

Gerety MB, Chioda LK, Kanten DN, Tuley MR and Cornell JE
Medical Treatment Preferences of Nursing Home Residents: Relationship to Function and Concordance with Surrogate Decision-Makers
Journal of the American Geriatrics Society 1993;41:953-960

Ghusn HF, Teasdale T and Jordan D
Continuity of Do-Not-Resuscitate Orders Between Hospital and Nursing Home Settings
Journal of American Geriatrics Society 1997;45:465-469

Gillon R
Philosophical Medical Ethics
1995 Whiley Medical Publication on Behalf of the British Medical Journal
ISBN 0 471 91222 0

Grimley Evans J
The rationing debate: Rationing health care by age: The case against
British Medical Journal 1997; 314: 822

Gunasekera NPR, Tiller DJ, Clements LTS and Bhattacharya BK
Elderly Patients’ Views on Cardiopulmonary Resuscitation
Age and Ageing 1986;15:364-368

Hanson LC and Rodgman E
The Use of Living Wills at the End of Life
Archives of Internal Medicine 1996;156:1018-1022
Hauswald M and Tenberg D
Out-of-hospital resuscitation preferences of emergency health care workers
American Journal of Emergency Medicine 1993;11:221-224

Hayes S, Henshaw D, Rai GS and Stewart K
Audit of resuscitation decisions has little impact on clinical practice
Journal of the Royal College of Physicians 1999;33:348-350

Heap MJ, Munglani, Klinck JR and Males AG
Elderly patients’ preferences concerning life-support treatment
Anaesthesia 1993;48:1027-1033

Henshaw DJE, Holland M, Stewart KO and Gill MW
Inter-Observer variation in Cardiopulmonary Scoring Systems
Age and Ageing (abstract)

Hewson G
Why the human rights act matters to doctors (editorial)
British Medical Journal 2000;321:780-781

Hill ME, MacQuillan G, Forsyth M and Heath DA
Cardiopulmonary resuscitation: who makes the decision?
British Medical Journal 1994;308(6945):1677

Hodkinson HM
Evaluation of a mental test score for assessment of mental impairment in the elderly
Age and Ageing 1972;1:233-238

Hui E, Ho SC, Tsang J, Lee SH and Woo J
Attitudes toward life-sustaining treatment of older persons in Hong Kong
Journal of the American Geriatrics Society 1997;45:1232-1236
Janofsky JS, McCarthy RJ and Folstein MF
The Hopkins Competency Assessment Test: A Brief Method for Evaluating Patients’ Capacity to Give Informed Consent
Hospital and Community Psychiatry 1992;43(2):132-136

Jordon D, Lavin T, Hamelberg W
Resuscitation experience within the hospital
Journal of the American Medical Association 1964;188:181-182

Kemerman P, Cook DJ and Griffith LE
Documenting Life-Support Preferences in Hospitalised Patients

Kerridge IH, Pearson S, Rolfe IE and Lowe M
Decision making in CPR; attitudes of hospital patients and healthcare professionals
Medical Journal of Australia 1998;169:128-131

Kerridge IH, Pearson S, Rolfe IE, Lowe M and McPhee JR
Impact of written information on knowledge and preferences for cardiopulmonary resuscitation
Medical Journal of Australia 1999;171:239-242

The APACHE III Prognostic System. Risk Prediction of Hospital Mortality for Critically Ill Hospitalized Adults
Chest 1991;100:1619-1636

Kouwenhoven WB, Jude JR and Knickerbocker GG
Closed-chest Cardiac Massage
Journal of the American Medical Association 1960;173:1064-1067
La Puma J, Orentlicher D and Moss RJ
Advance Directives on Admission. Clinical implications and analysis of the Patient Self-Determination Act of 1990
Journal of the American Medical Association 1991;266(3):402-405

Larson DE
Resuscitation discussion experiences of patients hospitalized in a coronary care unit
Heart and Lung 1994;23(1);53-58

Levinsky NG
The Purpose of Advance Medical Planning – Autonomy for Patients or Limitation of Care?

Liddle J, Gilleard C and Neil A
The views of elderly patients and their relatives on cardiopulmonary resuscitation
Journal of the Royal College of Physicians 1994;28(3);228-229

Lo B, McLeod GA and Ssaika G
Patient attitudes to discussing life-sustaining treatment
Archives of Internal Medicine 1986;146:1613-1615

Lo B and Steinbrook R
Beyond the Cruzan Case: The U.S. Supreme Court and Medical Practice
Annals of Internal Medicine 1991;114:895-901

Lush D
Advance directives and Living Wills
Journal of the Royal College of Physicians 1993;27(3):274-277

Luttrell S
Living Wills do have legal effect provided certain criteria are met
British Medical Journal 1996;313:1148 (letter)
Luttrel S
Making decisions: implications for practice of the Government’s proposals for making decisions on behalf of mentally incapacitated adults in England and Wales
Age and Ageing 2001;30-S1:7-9

Luttrel S and Sommerville A
Limiting risks by curtailing rights: a response to Dr Ryan.
Journal of Medical Ethics 1996;22:100-104

Mahoney FJ and Barthel DW
Functional evaluation: The Barthel Index
Maryland State Medical Journal 1965;14:61-65

“Making Decisions”
The Government’s proposals for making decisions on behalf of mentally incapacitated adults
October 1999 Cm 4465

Markson LJ, Kern DC, Annas GJ and Glantz
Physician Assessment of Patient Competence
The Journal of the American Geriatric Society 1994;42(10):1074-80

Mason JK, McCall Smith RA and Laurie GT
Law and Medical Ethics
Butterworths 1999
ISBN 0 406 89636 4

McGowen J, Graham CA and Gordon MWG
Appointment of a resuscitation Training Officer is associated with improved survival from in-hospital ventricular fibrillation/ventricular tachycardia cardiac arrest
Resuscitation 1999;44:169-173

McGrath RB
In-House Cardiopulmonary Resuscitation - After a Quarter of a Century
Annals of Emergency Medicine 1987;16:1365-1368
McIntyre KM
Failure of ‘predictors’ of cardiopulmonary resuscitation outcomes to predict cardiopulmonary resuscitation outcomes
Archives of Internal Medicine 1993;153:1293-1297

Mead GE, O'Keeffe ST, Jack CI, Maestri-Banks AM, Playfer JR and Lye M
What factors influence patient preferences regarding cardiopulmonary resuscitation?

Mead GE and Turnbull CJ
Cardiopulmonary resuscitation in the elderly: patients’ and relatives’ views
Journal of Medical Ethics 1995;21(1):39-44

Mello M and Jenkinson C
Comparison of Medical and Nursing Attitudes to Resuscitation and Patient Autonomy Between a British and an American Teaching Hospital
Social Science and Medicine 1998;46(3):415-424

Miller DL, Jahnigen DW, Gorbien MJ and Simbartl L
Cardiopulmonary Resuscitation: How useful? Attitudes and Knowledge of an Elderly Population
Archives of Internal Medicine 1992;152;578-582

Miller DL, Gorbien MJ, Simbartl L and Jahnigen DW
Factors Influencing Physicians in Recommending In-Hospital Cardiopulmonary Resuscitation
Archives of Internal Medicine 1993;153:1999-2003

Ming-Nan L, Kuan-Yu, Jenq-Wen H and Tun-Jun T
Clinical Findings and Outcomes of Intra-Haemodialysis Cardiopulmonary Resuscitation
American Journal of Nephrology 1999;19:468-473

Miranda DR
Quality of Life After Cardiopulmonary Resuscitation
Chest 1994;106:524-530
Molloy DW, Darzins P and Strang D
Capacity to Decide
New Grange Press 1999
ISBN

Moore CD and Shearman SR
Factors that influence elders’ decisions to formulate advance directives

Morgan CL, Donnelly PD, Lester CA and Assar DH
Effectiveness of the BBC’s 999 training roadshows on cardiopulmonary resuscitation: video performance of a cohort of unforecasted participants at home six months afterwards
British Medical Journal 1996;313:912-916

Morgan R, King D, Prajapati C and Rowe J
Views of elderly patients and their relatives on cardiopulmonary resuscitation
British Medical Journal 1994;308(6945): 1677-1678

Murphy DJ, Murray AM, Robinson BE and Campion EW
Outcomes of Cardiopulmonary Resuscitation in the Elderly
Annals of Internal Medicine 1989;111:199-205

Nelson EC, Landgraf JM, Hays RD, Wasson JH and Kirk JW
The Functional status of Patients. How can it be measured in Physicians’ offices?
Medical Care 1990;28:1111-1126

Nichol G, Stiell IG, Hebert P, Wells GA, Vandemheen K and Laupacis A
What is the Quality of Life of Survivors of Cardiac Arrest? A Prospective Study
Academic Emergency Medicine 1999;6:95-102

O’Brien LA, Grisso JA, Maislin G, LaPann K, Krotki KP, Greco PJ, Siegert EA and Evans LK
Nursing Home Residents’ Preferences for Life-Sustaining Treatments
Journal of American Medical Association 1995;274:1775-1779
O’Keeffe S
Development and implementation of resuscitation guidelines; a personal experience
Age and Ageing 2001;30:19-25

O’Keeffe S, Redahan C, Keane P and Daly K
Age and Other Determinants of Survival After In-hospital Cardiopulmonary Resuscitation
Quarterly Journal of Medicine 1991;296:1005-1010

O’Keeffe, Noel J and Lavan JN
Cardiopulmonary Resuscitation Preferences in the Elderly
European Journal of Medicine 1993;2:33-35

O’Keeffe S, Ebell MH
Prediction of failure to survive following in-hospital cardiopulmonary resuscitation: comparison of two predictive instruments
Resuscitation 1994;28:21-25

Peatfield RC, Sillett RW, Taylor D and Mc Nicol MW
Survival after cardiac arrest in hospital
The Lancet 1977;1:1223-1225

Pope C and Mays N
Qualitative Research: Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research
British Medical Journal 1995;311:42-45

Pope C and Mays N
Qualitative Research in Health Care (2nd Edition) 1999
BMJ Books
ISBN 0-7279-1396-4

Potter JM, Stewart D and Duncan G
Living wills; would sick people change their minds?
Postgraduate Medical Journal 1994;70:818-820
Report of the Select Committee on Medical Ethics (1994)
House of Lords. London. HMSO

Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290

Re MB [1997] 2 FCR 541

Re T (Adult: Refusal of Treatment) [1992] WLR 782

Robertson GS
Making an advance directive
British Medical Journal 1995;310:326-238

Robertson GS
Resuscitation and Senility: a study of patient’s opinions
Journal of Medical Ethics 1993;19:104-107

Robertson JA
Second Thoughts on Living Wills
Hastings Center Report Nov-Dec 1991;6-9

Robinson GR and Hess D
Postdischarge survival and functional status following in-hospital cardiopulmonary resuscitation
Chest 1994;105(4):991-996

Robinson SM, Mackenzie-Ross S, Campbell Hewson GL, Egleston CV and Prevost AT
Psychological effect of witnessed resuscitation on bereaved relatives
Lancet 1998;352:614-617

Roine RO, Kajaste S and Kaste M
Neuropsychological Sequelae of Cardiac Arrest
Journal of the American Medical Association 1993;269:237-242
Ryan C
Betting your life; an argument against certain advance directives

Ryan CJ and Kaye M
Euthanasia in Australia – the Northern Territory Rights of the Terminally Ill Act

Saklayen M, Liss H and Markert R
In-Hospital Cardiopulmonary Resuscitation. Survival in one Hospital and Literature Review.
Medicine 1995;74(4):163-175

Saunders J
Who’s for CPR?
Journal of the Royal College of Physicians 1992;26:254-257

Sauve MJ, Doolittle N, Walker JA, Paul SM and Scheinman MM
Factors Associated With Cognitive Recovery After Cardiopulmonary Resuscitation
American Journal of Critical Care 1996;5:127-139

Prognostic implications of ventricular fibrillation in acute myocardial infarction: new strategies required for further mortality reduction
Heart 2000;84(3):258-261

Sayers GM, Schofield I and Aziz M
An analysis of CPR decision-making by elderly patients
Journal of Medical Ethics 1997;23:207-212

Schade SG and Muslin H
Do Not Resuscitate decisions: discussions with patients
Journal of Medical Ethics 1989;15:186-190
Schiff R, Rajkumar C and Bulpitt C
Views of Elderly People on living wills; interview study
British Medical Journal 2000;320:1640-1641

Schneider AP, Nelson DJ and Brown DD
In-Hospital Cardiopulmonary Resuscitation: A 30-Year Review
Journal of the American Board of Family Practice 1993;6:91-101

Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP and Langer RD
Effects of Offering Advance Directives on Medical Treatments and Costs
Annals of Internal Medicine 1992;117:599-606

Schonwetter RS, Teasdale TA, Taffet G, Robinson BE and Luchi RJ
Educating the Elderly: Cardiopulmonary Resuscitation Decisions before and after Intervention

Schonwetter RS, Walker RM, Solomon M, Indurkhya A, and Robinson BE
Life Values, Resuscitation Preferences, and Applicability of Living Wills in an Older Population
Journal of the American Geriatrics Society 1996;44:954-958

Seckler AB, Meier DE, Mulvihill M and Cammer BE
Substituted Judgement: How accurate are proxy predictions?

Sheikh JI and Yesavage JA
Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. In:
York: The Haworth Press 1986

Sheldon T
Holland decriminalises voluntary euthanasia
British Medical Journal 2001;322:947
Sidaway v Board of Governors of Bethlem Royal Hospital [1985] 1 All ER 643

Siegert EA, Clipp EC, Mulhausen P, Kochersberger G
Impact of advance directive videotape on patient comprehension and treatment preferences.
Archives of Family Medicine 1996;5(4):213-4

Silberfeld M, Nash C and Singer PA
Capacity to Complete an Advance Directive
The Journal of the American Geriatrics Society 1993;41:1141-1143

Singer PA
Disease Specific Advance Directives
Lancet 1994;344:594-596

Slevin ML, Stubbs L, Plant HJ, Wilson P, Gregory WM, Armes PJ and Downer SM
Attitudes to chemotherapy: comparing views of patients with cancer with those of doctors nurses and general public
British Medical Journal 1990;300:1458-1460

So HY, Buckley TA, and Oh TE
Factors affecting Outcome following Cardiopulmonary Resuscitation

Solomon NA, Glick HA, Russo CJ, Lee J and Schulman KA
Patient preferences for stroke outcome
Stroke 1994;25:1721-1725

Sommerville A
Remembrance of conversations past; oral statements about medical practice
British Medical Journal 1995;310:1663-5
Spangers MAG and Aaronson
The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease; A Review
Journal of Clinical Epidemiology 1992;45(7):743-760

Starr TJ, Pearlman RA and Uhlmann RF
Quality of life and resuscitation decisions in Elderly patients
Journal of General Internal Medicine 1986;1:373-379

Stewart K
Discussing cardiopulmonary resuscitation with patients and relatives
Postgraduate Medical Journal 1995;71(840):585-9

Stewart K, Abel K and Rai GS
Resuscitation decisions in a general hospital
British Medical Journal 1990;300:78

Stewart K and Bowker L
Might lead to a complaint for breach of confidentiality
British Medical Journal 1997;314:145

Stewart K, Spice C and Rai GS
Where now with Do Not Attempt Resuscitation (DNAR) Decisions?
Age and Ageing 2002 (in press)

Stewart K, Wagg A and Kinirons M
When can elderly patients be excluded from discussing resuscitation?
Journal of the Royal College of Physicians 1996;30(2):133-135

Stewart K, Wagg A and Kinirons M
Does audit improve DNR decision making?
Stolman CJ, Gregory JJ, Dunn D and Levine JL
Evaluation of patient, physician, nurse and family attitudes toward do not resuscitate orders
Archives of Internal Medicine 1990;150:653-658

Stolman NA, Glick HA, Russo CJ Lee J and Schulman KA
Patient Preferences for Stroke Outcomes
Stroke 1994;25:1721-1725

Strauss A and Corbin J
Basics of qualitative research; grounded theory procedures and techniques
Sage Publications 1990
ISBN 0-8039-3250-2

Streubert HJ and Carpenter DR
Qualitative Research in Nursing; Advancing the humanistic imperative
2nd edition (January 1999)
Lippincott Williams & Wilkins Publishers
ISBN: 0781716284

Sunnerhagen KS, Johansson O, Herlitz J and Grimby G
Life after cardiac arrest; a retrospective study
Resuscitation 1996;31:135-140

Swig L, Cooke M, Osmond D, Luce JA, Brody RV, Bird C and Luce JM
Physician responses to a hospital policy allowing then to not offer cardiopulmonary resuscitation
Journal of the American Geriatrics Society 1996;44:1215-1219

Taffet GE, Teasdale TA and Luchi R
In-Hospital Cardiopulmonary Resuscitation
Journal of the American Medical Association 1988;260:2069-2072

Taking Charge: Making Decisions for Later Life 1999
Benevolent Society and the Centre for Education and Research on Ageing
ISBN 0 7313 9812 2
Teno J, Lynn J, Wenger N et al (for the SUPPORT investigators)
Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self Determination Act and the SUPPORT intervention
Journal of the American Geriatrics Society 1995;45:500-507

Teno J, Lynn J, Connors AF et al (for the SUPPORT investigators)
The Illusion of End-of-Life Resource Savings with Advance Directives
Journal of the American Geriatrics Society 1997;45:513-518

Teno J, Licks S, Lynn J et al (for the SUPPORT investigators)
Do Advance Directives Provide Instructions That Direct Care?
Journal of the American Geriatrics Society 1997;45:508-512

Thel MC and O’Connor CM
Cardiopulmonary Resuscitation; Historical Perspective to Recent Investigations
American Heart Journal 1999;137:39-48

The Royal Australian College of Physicians
Ethics: A manual For Consultant Physicians
1992 (reprinted 1999)
ISBN 0 909783 29 2

Timmermans S
Sudden Death and the Myth of CPR
Temple University Press 1999
ISBN 1 56639 715 4

Tomlinson T and Brody H
Ethics and Communication in Do-Not-Resuscitate Orders
Tomlinson T and Czlonka D
Futility and Hospital Policy
Hastings Center Report May-June 1995, 28-35

Tresch D, Heudebert G, Kutty K, Ohlert J, VanBeek K and Masi A
Cardiopulmonary Resuscitation in Elderly Patients Hospitalized In The 1990s: A Favorable Outcome

Tunstall-Pedoe H, Bailey L, Chamberlain DA, Marsden AK, Ward ME and Zideman DA
Survey of 3765 cardiopulmonary resuscitations in British hospitals (the BRESUS study): methods and overall results
British Medical Journal 1992;304:1347-1351

Uhlmann RF and Pearlman RA
Perceived quality of life and preferences for life-sustaining treatment in older adults
Archives of Internal Medicine 1991;151:495-497

Uhlmann RF, Pearlman RA and Cain KC
Physicians’ and Spouses’ predictions of elderly patients’ resuscitation preferences.
Journal of Gerontology 1988;43(5):115-121

Wagg A, Kinirons M and Stewart K
Cardiopulmonary resuscitation: doctors and nurses expect too much

Wagner A
Cardiopulmonary Resuscitation in the aged. A prospective study

Ware JE, Kosinski M, and Keller SD
A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity
Medical Care, 1996;34(3):220-233
Ware JE, Kosinski M, and Keller SD
SF-12: How to score the SF-12 Physical and Mental Health Summary Scales

Watson DR, Wilkinson TJ, Sainsbury R and Kidd JE
The effect of hospital admission on the opinions and knowledge of elderly patients regarding cardiopulmonary resuscitation
Age and Ageing 1997;26:429-434

Weeks WB, Kofoed LL, Wallace AE and Welch HG
Advance Directives and the Cost of Terminal Hospitalization
Archives of Internal Medicine 1994;154:2077-2083

“Who Decides? Making decisions on behalf of mentally incapacitated adults”
A consultation paper issued by the Lord Chancellor’s Department
December 1997
ISBN 0-10-138032-1, Cm 3808

Wise J
Push to allow relatives to witness resuscitation
British Medical Journal 1996;313:899 (News, 12 October)

Withholding and Withdrawing Life-prolonging Medical Treatment. Guidance for decision making.
British Medical Association
BMJ Books 1999
ISBN 0 7279 1456 1
Website References

Age Concern
Pressure group for elderly in the UK
Includes link to EAGLE site (Exchange on Ageing, Law and Ethics)
http://www.ace.org.uk

British Geriatrics Society (BGS)
Including ethics special interest group
http://www.bgs.org.uk

British Medical Association (BMA)
Contains policy statements including latest DNR policy (2001) and consent/capacity
http://web.bma.org.uk

Department of Health (DoH)
Guidance on consent
http://www.doh.gov.uk

European Resuscitation Council (ERC)
Includes latest basic and advanced life support guidelines
http://www.erc.edu

General Medical Council
Contains ‘Good Medical Practice’ code of conduct new guidelines on withholding and withdrawing treatment (Aug 2002) and guidance on consent and competence
http://www.gmc-uk.org

Human Rights Act 1998

Interjurisdictional Committee on Guardianship and Administration Website (Australia)
http://www.ijcga.gov.au
http://www.open.gov.uk/lcd/family/mdecisions/indexfr.htm

National Council for Hospice Care
Various discussion and policy documents on ethics of palliative care including DNAR guidelines for hospices
http://www.hospice-spc-council.org.uk

National Service Framework for older people
Department of Health. Issued March 2001
http://www.doh.gov.uk/nsf/olderpeople.htm

Voluntary Euthanasia Society Website
http://www.ves.org.uk/ves/ves.htm

http://www.open.gov.uk/lcd/menincap/meninfr.htm
Chapter 10

Appendices
Appendix A Southampton Study Questionnaire (Chapter 2)

Information for participants

There is a lot of debate at the moment about what should happen if a patient has a "cardiac arrest", and I would like to ask you for your opinions. A cardiac arrest is where a patient's heart suddenly and unexpectedly stops beating (i.e. it does not mean the gradual slowing and weakening of the heartbeat in someone who is known to be dying). Nowadays it is sometimes possible to revive someone in this situation using cardiac massage (compressing the chest), drugs and electric shocks. Such resuscitation attempts are often unsuccessful, and they may revive only the heart and breathing but not the whole person. Therefore, this treatment is not given to all hospital patients. It may be withheld because of a very poor chance of success, or because it is considered kinder not to revive someone who has a serious incurable disease. Usually in this country it is the doctors who make this judgement, and very little is known about patients' own views.

We would therefore like to ask you some questions about your opinion on resuscitation and what things have influenced it. Your answers will be treated as strictly confidential. You may withdraw from the study at any stage if you wish and this will not affect your care in any way.
CPR PATIENT QUESTIONNAIRE
PART 1: Within 2 working days of admission

Subject number:
Age:
Sex:
Marital status:
Cultural origin:
Mental test score on admission: / 10
Barthel score on admission: / 20

Please answer the following questions by ticking the box or underlining your chosen answer as appropriate. Please ignore questions 9 and 10 (marked "**"); these will be completed by the investigators.

1. How satisfied are you with your recent quality of life? (tick)

   Totally unsatisfied [ ] 1
   Moderately unsatisfied [ ] 2
   Partly unsatisfied [ ] 3
   Partly satisfied [ ] 4
   Moderately satisfied [ ] 5
   Totally satisfied [ ] 6

2. How do you rate your health (for your age)? (underline)

   above average average below average

3. Are you living with?

   your spouse a friend residential home
   son/daughter alone nursing home
   other family warden-controlled flat
   other arrangement:

---

307
4. If you live alone, how much contact do you have with your family?
   less than once a week    more than once a week    none

5. How much social contact do you have outside home?
   frequent    infrequent    none

6. Do you look after a disabled person yourself?  Yes / No

7. Do you need any help with basic everyday activities?
   no          occasionally    usually

8. On a scale of 0 - 10, how dependant on other people are you?
   (0 = fully independent; 10 = dependent for everything)

Medical history

* 9. Current medical problem:

* 10. Principal background illnesses and disabilities:

11. How many times have you been in hospital before?
    none    1-5    6-10    >10
Previous experience

12. Have you ever been resuscitated? Yes / No / don't know
13. Do you remember what happened? Yes / No
14. Do you know what is actually done when someone is resuscitated? Yes / No
15. How did you learn about resuscitation?
   - through relatives/friends
   - through the media
   - first hand

Opinions about resuscitation

16A. If your heart were suddenly to stop beating in hospital would you want vigorous attempts to be made to revive you?
Yes / No / Not sure

17. Have you thought about this before? Yes / No

18A. Would you want this to be decided by your:
   self alone   family alone   doctor alone
   self and family/doctor jointly?

19A. Which of the following factors do you consider the most important for your choice?
   a) this illness?
   b) your usual state of health?
   c) life at home?
   d) the wishes of your family?
   e) religious beliefs?
   f) your age?
   g) your previous experience of resuscitation?
   h) other reasons:
20. Have you discussed this question with:
- your family? Yes / No
- your family doctor? Yes / No
- anyone else? Yes / No

If so, whom?

21. Have you ever been involved in a similar decision about a close relative? Yes / No

22A. Do you think you should be asked your wishes regarding resuscitation when you come into hospital? Yes / No

23A. Have you found this questionnaire stressful? Yes / No
PART 2: Within two days of discharge

Subject number:

Please answer the following questions by underlining/ticking the answers as appropriate.

16B. If your heart were suddenly to stop beating in hospital would you want vigorous attempts to be made to revive you?

Yes / No / Not sure

18B. Would you want this to be decided by your:

self alone family alone doctor alone
self and family/doctor jointly?

19B. Which of the following factors do you consider the most important for your choice?

a) this illness?

b) your usual state of health?

c) life at home?

d) the wishes of your family?

e) religious beliefs?

f) your age?

g) your previous experience of resuscitation?

h) other reasons:

22B. Do you think you should be asked your wishes regarding resuscitation when you come into hospital?

Yes / No

23B. Have you found this questionnaire stressful?

Yes / No

24. Are there any other comments you wish to make?
Appendix B. Winchester/ Newham Study Questionnaire (Chapter 4)

In recent years some patients have drafted Living Wills (also called advance directives) detailing their wishes for medical treatment if, at some stage in the future, they should become incapable of making decisions for themselves.

1. Did you know that some types of Living Will have legal force at present in the UK?
   Yes / No

   If you’ve answered “no” to question 1 then you do not have to complete any more of the questionnaire. Please return it to me in the envelope provided and I will send you your free copy of the BMA Booklet “Advance Statements about Medical Treatment”. Thank you for your help.

   If you’ve answered “yes” to question 1 then please answer questions 2 to 8 which refer to legally valid Living Wills (Advance Directives) in the UK.

2. To be legally valid a Living Will must be witnessed by a doctor.
   Yes/No/Don’t Know

3. To be legally valid a Living Will must be witnessed by a lawyer.
   Yes/No/Don’t Know

4. Doctors are legally obliged to give any treatment which a patient requests in a valid living will.
   Yes/No/Don’t Know

5. Doctors are legally obliged to withhold any treatment which a patient refuses in a valid living will.
   Yes/No/Don’t Know

6. Patients detained under the mental health act can make a legally valid living will in some circumstances.
   Yes/No/Don’t Know

7. Patients can legally nominate a relative or friend to make clinical decisions on their behalf in a living will.
   Yes/No/Don’t Know

Thank you for your help. Please return the questionnaire to receive your free copy of the BMA Booklet “Advance Statements about Medical Treatment”.

312
## ATTITUDES TOWARDS LIFE-SUSTAINING TREATMENTS OF OLDER PATIENTS FOLLOWING DISABLING STROKE

<table>
<thead>
<tr>
<th>INVITATION NUMBER</th>
<th>STUDY NUMBER</th>
<th>DATE</th>
<th>DOB</th>
<th>AGE</th>
<th>SEX</th>
<th>(Male = 0 Female = 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>STUDY NUMBER</td>
<td>DATE</td>
<td>DOB</td>
<td>AGE</td>
<td>SEX</td>
<td>(Male = 0 Female = 1)</td>
<td></td>
</tr>
<tr>
<td>DATE</td>
<td>DOB</td>
<td>AGE</td>
<td>SEX</td>
<td>(Male = 0 Female = 1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOB</td>
<td>AGE</td>
<td>SEX</td>
<td>(Male = 0 Female = 1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td>SEX</td>
<td>(Male = 0 Female = 1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### DATE OF STROKE

- DATE OF STROKE
- TIME SINCE STROKE (weeks)

### TYPE OF STROKE

- haemorrhage = 1 infarct = 2
- cortical left = 1 / right = 2 / subcortical = 3
- dysphasia (yes = 1 no = 0)
- dysphagia (yes = 1 no = 0 had NG Feeding = 3)
- inattention/perception (yes = 1 no = 0)
- TACI = 1 / PACI = 2 / LACI = 3 / POCI = 4 / PICH = 5

### CPR

- CPR For = 1 / DNR = 0 / NOT RECORDED = 2

### BARTHEL

- worst (Day 2 to 14)
- discharge

### TIME IN HOSPITAL (days)

### SCALES (now)

<table>
<thead>
<tr>
<th>BARTHEL</th>
<th>AMTS</th>
<th>GDS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

313
Thank you for letting me come and talk to you. You may know that many people have strong views about how they should be treated by doctors and hospitals when faced with serious illness. As you yourself have experienced serious illness you might well have some views on medical treatment. We are therefore particularly interested in your views.

I work as a doctor at the Radcliffe Infirmary but this research project is not directly connected with either your hospital doctor or your general practitioner. Your answers are confidential and will be known only to me. They will therefore have no effect on any treatment you receive at the hospital.

Please stop me at any stage if something is not clear and if you are not sure about any answer you can always answer don't know.

First of all I would like to ask you some general questions about you.

Do you have a partner?
Partner/Married = 3 / Divorced = 2 / Widowed = 1 / Single = 0

What was your/husbands occupation?

RESIDENCE?
Nursing Home = 3
Residential Home = 2
Own Home - alone = 1
Own Home - with others = 0

How much care do you receive?
None = 4
Informal help = 3
Nursing - more than twice/day = 2
- between = 1
- once/week or less = 0

Do you have a pet? What kind?
no = 0 / yes - dog = 1
- cat = 2
- bird = 3
- other = 4

314
How often do you see or speak to someone who is not directly caring for you?
- once a day = 4
- between once a day and once a week = 3
- once a week = 2
- less than once a week = 1

Do you feel lonely?
yes = 1 / no = 0 / don't know = 2

COOP Social support score
Quality of life score

If dysphasic stroke or apparent communication problems proceed to FAST.

Now I am going to ask you some questions about your attitude to medical treatment.

1.1 When a person’s heart or breathing stops there are some special techniques used to try and revive them?
This is called resuscitation. If you collapsed now, and there were people around who knew how to do resuscitation, would you want to have resuscitation?
yes = 1 / no = 0 / don't know = 2

2.1 I want to find out what you know about resuscitation. Can you tell me what is actually done to the patient during resuscitation?
- mouth to mouth
- chest compression
- intubation
- ecg monitoring
- drugs
- oxygen therapy
- iv drip/fluid
- DC shock (score )

2.2 Tell me what you think the success rate is for patients who have resuscitation. How often do you think the patient survives to leave hospital?
(show patient the linear analogue scale)
score 0 / 1 / 2 / 3 / 4 / 5 / 6 / 7 / 8 / unable to answer = 9

315
Now give a description of CPR including procedures used (as in first question). Quote success rate to discharge of around 10% depending on pre-arrest factors. In successful cases e.g. after a heart attack - life saving. Mention the following disadvantages.

- success rate only 5-10% to discharge i.e. 90-95% will die
- may keep you alive and in discomfort only to die a few days later (initial survival twice that at discharge)
- may leave you very disabled (1%)
- it means your relative will not be beside you at the moment of death

1.2 After our discussion would you want to have resuscitation if your heart stopped?

yes = 1 / no = 0 / don't know = 2

If different from 1.0

3.1 What do you think has changed your mind?

Show linear analogue scale again.

4.1 Most people would accept resuscitation if it were always successful. Would you personally accept resuscitation with a success rate of..

score 0 / 1 / 2 / 3 / 4 / 5 / 6 / 7 / 8 / unable to answer = 9

5.1 Doctors usually make the decision about whether or not resuscitation is to be used. If you were well enough do you think the doctor should routinely ask your opinion?

yes = 1 / no = 0 / don't know = 2

5.2 If you were too unwell to give your own opinion do you think your relatives should decide for you or should it be left to the doctors?

relatives = 1 / doctor = 0 / don't know = 2

6.1 Currently relatives are usually not allowed to be present during resuscitation attempts. Would you want your relatives to be present during an arrest procedure?

yes = 1 / no = 0 / don't know = 2

1.3 I now want you to think back to a year ago i.e. before your stroke. If I had asked you about resuscitation before your stroke do you think you would have wanted it?

yes = 1 / no = 0 / don't know = 2
7.1 Why do you think having the stroke has changed your mind?

8.1 Have you ever thought about any of these things before?
   yes = 1 / no = 0 / don't know = 2

8.2 Have you discussed any issues like these with your general practitioner .... or hospital doctor?
   yes - GP = 1
   yes - hospital doctor = 3
   yes - both = 4
   no = 0
   don't know = 2

8.3 Have you discussed any of these issues with anyone else in your family?
   yes = 1 / no = 0 / don't know = 2

8.4 Have you heard of an advance directive or living will? Have you thought about or actually made one?
   yes = 1 / no = 0 / don't know = 2
   yes - thought about = 3
   yes - made one = 4

9.0 Finally I would like to ask you about artificial feeding. After a stroke some patients cannot swallow normally and require feeding by a tube into their stomach in order to keep them alive. You may have seen this when you were on the ward. Many of these patients are unable to talk because the stroke has also paralysed their voice. Sometimes the tube is temporary but it might need to be permanent.

If you had another stroke that left you in this condition would you want the doctors to provide artificial (tube) feeding for you?
   yes = 1 / no = 0 / don't know = 2

10.0 Do you feel the same about other intensive treatments (eg dialysis, intensive care unit, artificial ventilation)?
    yes = 1 / no = 0 / don't know = 2 / mixed response = 3
That is the end of the questionnaire but I have to ask you a few more questions to test your memory as this is sometimes affected by stroke, please do not be offended.

Thank you for helping us with this project. It will give us important information about what patients think. May I remind you that your answers are entirely confidential? Have you got any questions? - If you want to speak to us again you can contact us, this letter gives you a phone number.
Appendix D. The Australian Study Questionnaire (Chapter 6)

Patient Information Sheet

LIVING WILLS AFTER STROKE

Living wills are statements made by patients about the kind of medical care they would want to receive if they became ill and were unable to express their wishes clearly at the time of their illness. Although there is a lot of interest in developing living wills it is still quite uncommon for them to be used in clinical practice and there is little research in this area.

This study was designed to look at a group of patients like yourself who have recently had a stroke to obtain their views about life-sustaining treatments. We are interested in your own personal views, how you make your decisions, and whether you feel differently about treatments over a period of time. Some people may find some of the questions distressing.

You have already been interviewed in hospital and we would now like to repeat the interview to see if any of your views have changed. You can drop out of the study at any time.

Any views you express will be kept in strictest confidence and will not be recorded in your medical notes or shared with any member of your health care team or your family doctor (GP). There is therefore no way that any views you express can effect your future medical treatment either in or outside the hospital.

Investigator ; Dr Sean Maher

Chief Investigator ; Lesley Bowker

Further information
This project has been approved by the Royal Perth Hospital Ethics Committee. Additional information is available from the Investigator (Tel: 9224 2750) or Clin Prof A Millar, Chairman of the Committee (Tel: 9224 2199).
**QUESTIONNAIRE 1** – Patient within 14 days of acute stroke

**ATTITUDES TOWARDS LIFE-SUSTAINING TREATMENTS OF OLDER PATIENTS FOLLOWING DISABLING STROKE**

<table>
<thead>
<tr>
<th>STUDY NUMBER</th>
<th>(1 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td></td>
</tr>
<tr>
<td>SEX</td>
<td>Male = 0 Female = 1</td>
</tr>
<tr>
<td>PARTNER</td>
<td>Married / Defacto = 3 / Divorced = 2 / Widowed = 1 / Single = 0</td>
</tr>
<tr>
<td>COME FROM</td>
<td>Nursing Home = 3 / Hostel = 2 / Own Home - alone = 1 / Own Home - with others = 0</td>
</tr>
<tr>
<td>DATE OF STROKE</td>
<td></td>
</tr>
<tr>
<td>TYPE OF STROKE</td>
<td>haemorrhage = 1 infarct = 2</td>
</tr>
<tr>
<td></td>
<td>cortical left = 1 / right = 2 / subcortical = 3</td>
</tr>
<tr>
<td></td>
<td>dysphasia (yes = 1 no = 0)</td>
</tr>
<tr>
<td></td>
<td>dysphagia (yes = 1 no = 0 had NG Feeding = 3)</td>
</tr>
<tr>
<td></td>
<td>inattention/perception (yes = 1 no = 0)</td>
</tr>
<tr>
<td></td>
<td>TACI = 1 / PACI = 2 / LACI = 3 / POCl = 4 / PICH = 5</td>
</tr>
<tr>
<td>?CPR</td>
<td>For = 1 / DNR = 0 / NOT RECORDED = 2</td>
</tr>
</tbody>
</table>

**MTS**

**BARTHEL**

**GDS**

**COMPETANCY SCORE** - G I BLEED

- CHEST INFECTION

**COOP**

- Social support

- Quality of life

320
I am a doctor in this hospital but I am not directly connected with either your care here. Your answers are confidential and will be known only to me. They will therefore have no effect on any treatment you receive at the hospital. Please stop me at any stage if something is not clear and if you are not sure about any answer you can always answer don’t know.

1.1 When a person’s heart or breathing stops there are some special techniques used to try and revive them? This is called resuscitation. If you collapsed now, and there were people around who knew how to do resuscitation, would you want to have resuscitation?
   yes = 1 / no = 0 / don’t know = 2

2.1 I want to find out what you know about resuscitation. Can you tell me what is actually done to the patient during resuscitation?
   - mouth to mouth
   - chest compression
   - intubation
   - ecg monitoring
   - drugs
   - oxygen therapy
   - iv drip/ fluid
   - DC shock

2.2 Tell me what you think the success rate is for patients who have resuscitation. How often do you think the patient survives to leave hospital?

Now give a description of cpr including procedures used (as in first question). Quote success rate to discharge of around 10% depending on pre-arrest factors. In successful cases e.g. after a heart attack - life saving. Mention the following disadvantages.

- success rate only 5-10% to discharge i.e. 90-95% will die
- may keep you alive and in discomfort only to die a few days later (initial survival twice that at discharge)
- may leave you very disabled (1%)
- it means your relative will not be beside you at the moment of death

1.2 After our discussion would you want to have resuscitation if your heart stopped?
   yes = 1 / no = 0 / don’t know = 2

If different from 1.0 3.1 What do you think has changed your mind?
5.1 Doctors usually make the decision about whether or not resuscitation is to be used. If you were well enough do you think the doctor should routinely ask your opinion?

   yes = 1 / no = 0 / don't know = 2

5.2 If you were too unwell to give your own opinion do you think your relatives should decide for you or should it be left to the doctors?

   relatives = 1 / doctor = 0 / don't know = 2

6.1 Currently relatives are usually not allowed to be present during resuscitation attempts. Would you want your relatives to be present during an arrest procedure?

   yes = 1 / no = 0 / don't know = 2

1.3 I now want you to think back to a year ago i.e. before your stroke. If I had asked you about resuscitation before your stroke do you think you would have wanted it?

   yes = 1 / no = 0 / don't know = 2

If different from 1.1 7.1 Why do you think having the stroke has changed your mind?

8.1 Have you ever thought about any of these things before?

   yes = 1 / no = 0 / don't know = 2

8.2 Have you discussed any issues like these with your general practitioner ....or hospital doctor?

   yes - GP = 1
   yes - hospital doctor = 3
   yes - both = 4
   no = 0
   don't know = 2

8.3 Have you discussed any of these issues with anyone else in your family?

   yes = 1 / no = 0 / don't know = 2

8.4 Have you heard of an advance directive or living will? Have you thought about or actually made one?

   yes = 1 / no = 0 / don't know = 2
   yes - thought about = 3
   yes - made one = 4
9.0 Finally I would like to ask you about artificial feeding. After a stroke some patients cannot swallow normally and require feeding by a tube into their stomach in order to keep them alive. You may have seen this when you were on the ward. Many of these patients are unable to talk because the stroke has also paralysed their voice. Sometimes the tube is temporary but it might need to be permanent.

If you had a stroke that left you in this condition would you want the doctors to provide artificial (tube) feeding for you?

yes = 1 / no = 0 / don’t know = 2

Thank you for helping us with this project. It will give us important information about what patients think. May I remind you that your answers are entirely confidential? Have you got any questions? If you want to speak to us again you can contact us, this letter gives you a phone number.

The Barthel Index, AMTS, GDS and COOP scores are identical to those used in the Oxford Project (see Appendix C). In addition the patients in the Australian Study also completed a Competency Test and the SF-12
QUESTIONNAIRE 2 – Follow-up interview in community

ATTITUDES TOWARDS LIFE-SUSTAINING TREATMENTS OF OLDER PATIENTS FOLLOWING DISABLING STROKE

STUDY NUMBER (2)

DATE

SITE OF INTERVIEW Hospital = 9, Nursing Home = 3, Hostel = 2, Own Home - alone = 1, Own Home - with other(s) = 0

DATE OF DISCHARGE

SCALES (now) BARTHEL

GDS

COMPETANCY SCORE - GI BLEED

- CHEST INFECTION

COOP - Social support

- Quality of life
Thank you for letting me come and talk to you. I am a doctor but this research project is not directly connected with either your hospital doctor or your general practitioner. Your answers are confidential and will be known only to me. They will therefore have no effect on any treatment you receive. Please stop me at any stage if something is not clear and if you are not sure about any answer you can always answer don’t know.

1.1 When a person’s heart or breathing stops there are some special techniques used to try and revive them? This is called resuscitation. If you collapsed now, and there were people around who knew how to do resuscitation, would you want to have resuscitation?

   yes = 1 / no = 0 / don’t know = 2

2.1 I want to find out what you know about resuscitation. Can you tell me what is actually done to the patient during resuscitation?

   - mouth to mouth
   - chest compression
   - intubation
   - ecg monitoring
   - drugs
   - oxygen therapy
   - iv drip/fluid
   - DC shock

2.2 Tell me what you think the success rate is for patients who have resuscitation. How often do you think the patient survives to leave hospital?

   __________ %

Now give a description of cpr including procedures used (as in first question). Quote success rate to discharge of around 10% depending on pre-arrest factors. In successful cases e.g. after a heart attack - life saving. Mention the following disadvantages.

   - success rate only 5-10% to discharge i.e. 90–95% will die
   - may keep you alive and in discomfort only to die a few days later (initial survival twice that at discharge)
   - may leave you very disabled (1%)
   - it means your relative will not be beside you at the moment of death

1.2 After our discussion would you want to have resuscitation if your heart stopped?

   yes = 1 / no = 0 / don’t know = 2

If different from 1.0 3.1 What do you think has changed your mind?
5.1 Doctors usually make the decision about whether or not resuscitation is to be used. If you were well enough do you think the doctor should routinely ask your opinion?
   yes = 1 / no = 0 / don't know = 2

5.2 If you were too unwell to give your own opinion do you think your relatives should decide for you or should it be left to the doctors?
   relatives = 1 / doctor = 0 / don't know = 2

6.1 Currently relatives are usually not allowed to be present during resuscitation attempts. Would you want your relatives to be present during an arrest procedure?
   yes = 1 / no = 0 / don't know = 2

1.3 I now want you to think back to a year ago i.e. before your stroke. If I had asked you about resuscitation before your stroke do you think you would have wanted it?
   yes = 1 / no = 0 / don't know = 2

If different from 1.1

7.1 Why do you think having the stroke has changed your mind?

8.2 Since we last spoke have you discussed any issues like these with your general practitioner ......?or hospital doctor?
   yes - GP = 1
   yes - hospital doctor = 3
   yes - both = 4
   no = 0
   don't know = 2

8.3 Have you discussed any of these issues with anyone else in your family?
   yes = 1 / no = 0 / don't know = 2

8.4 Have you heard of an advance directive or living will? .have you thought about or actually made one?
   yes = 1 / no = 0 / don't know = 2
   yes - thought about = 3
   yes - made one = 4
9.0 Finally I would like to ask you about artificial feeding. After a stroke some patients cannot swallow normally and require feeding by a tube into their stomach in order to keep them alive. You may have seen this when you were on the ward. Many of these patients are unable to talk because the stroke has also paralysed their voice. Sometimes the tube is temporary but it might need to be permanent.

**If you had a stroke that left you in this condition would you want the doctors to provide artificial (tube) feeding for you?**

yes = 1 / no = 0 / don't know = 2

Thank you for helping us with this project. It will give us important information about what patients think. May I remind you that your answers are entirely confidential? Have you got any questions? - If you want to speak to us again you can contact us, this letter gives you a phone number.
Patient Post-Interview Information Sheet

LIVING WILLS AFTER STROKE

Thank you very much for sharing your views with us. They provide valuable information about what patients think and this will help doctors with difficult ethical decisions.

Everything we have discussed will remain confidential and will not effect your future medical treatment.

If you have any worries or questions about what we have discussed please ring me.

I can be contacted during normal working hours on (08) 9224 2750.

Many thanks again.

Dr Sean Maher - investigator

Lesley Bowker - chief investigator
come into prisons and they say Oh I have turned to God. Yes, there is a reason why they turn to God because all of a sudden they realise they have taken a life and they aren’t God...... the time of the murder or the time that her husband was bashing her and he pulled out that knife and he stabbed her, he was God or she thought she had the power to be God.... And she killed him. Then all of a sudden they turned spiritual, you know, to God in the prison situation. They seem to realise - hey, I’ve done something wrong and so they are trying to repent for what they have done and everybody that does an action has a reaction, everybody, doesn’t matter who they are. If you steal a lolly, you feel guilty because you are not supposed to do it - now, who gave us those laws?

*S: When you say you are not God to make a decision, during Leslie’s interview you were saying that doctors should make the decision......

P: Yes....

*S: Can you explain that?

P: Right..... the doctors aren’t God. Right.... For one.... So nine times out of ten I believe, I believe, that they are going to make the decision to resuscitate. And I believe that they will make that decision because they aren’t God, they would be trying to save a life. Their dedication is to heal people, to help people, that is their dedication so if I was too far gone they could make the decision and say “well, look, this is useless, I can’t do anything for this person, now that decision they have to make..... but when there is a chance to be.... To help that person, yes, do it. If there is not going to be any chance whatsoever nobody would blame them for not doing it.

*S: When you say “when you are too far gone” - what are you saying there?

P: Too far gone is - say I’ve had a massive heart attack, I really had a massive heart attack but I am still hanging on by a thread but all my arteries...... and he knows by touching me that something is not going to happen - I am not responding or he has tried and he has put the electrodes ...... but nothing is happening - stop - you know why should he stress himself out or her or whoever it may be, why should they stress themselves out when they know in their own mind, in their educated mind, that it is not going to work but until that point that is part of their profession and as part of them being a humanbeing as well. I mean I have resuscitated people and
P: Well, when my number is in the frame is an old expression that goes back many years to 'why did that person die', 'why did that person get hit by that bus', his number was in the frame, he is ready to go! Spiritually I am not..... I don't go to church I haven't been to church for years but I still believe we are all put on this earth for a certain amount of time and that is it. Now whether that person was 2 years old when they died, or 70 years old - their number is in the frame. Their number is up, their time is up and that's how I relate to life. I am not afraid of death if it is going to happen, it is going to happen and all the resuscitation in the world won't save me but I want to try in case my number is not in the frame.

*S: So how is that number decided?

P: I don't know - it could be how we ever got here, how ever this planet was populated, how somebody or something has done that. I don't think it was a God or anything as big as a God - how do we know that a big asteroid is not going to hit us tomorrow? Well, not tomorrow, we would know by then but how do we know that one is not heading towards us right now - then all our numbers are in the frame, we are all going to go - the dinosaurs...... you know things happen, we are just a little speck of sand in a great big universe.

*S: You mentioned spirituality, can you elaborate on that?

P: Spirituality - well spirituality is how people have been brought up and how they accept it - what is it..... the hearafter. Now...... the hearafter you have it with the aboriginals, their dream time, that is very spiritual. Every nationality.....the jews, doesn't matter what creed, what religion, they have all got something spiritual about them, even the witches, they believe in something and everybody believes in something but a lot of us don't know what we believe in, so the easiest way to pass it on is to say there is a God or the spirits or whatever it is that we have been brought up to, to understand..... does that make sense?

*S: Yes. So how do you see the link between spirituality and resuscitation?

P: Right......I believe......this is my personal thought about it, is that if you are meant to live, if you are meant to live spiritually, you live, if you are not then your number is in the frame that's the end. So who is to say that you are not meant to live, who is it to say that I am going to drive that truck and knock you over and kill you......um...... Murderers...... all the murderers, as far as I am concerned, I have seen murderers
Appendix F Example of Printout of a single ‘node’ (Chapter 7)

This was node 3.1.1 (only 4 out of 17 pages included as an illustration)
/who decides about CPR/doctor/for doctor
*** Definition: positive attitudes to doctor as CPR decision-maker

ON-LINE DOCUMENT: interview
+++ Retrieval for this document: 143 units out of 928, = 15%
*decision about resuscitation?
++ Text units 32-35:
P: Well depends on the circumstances I guess
0
um... Whoever is there at the time of the...which
1 I suppose would be an emergency, the person who is
2 qualified to do it; in a hospital, the doctors etc
3 *should make that decision.
++ Text units 61-64:
P: Well I suppose if they are in hospital it
61 would be the doctors. I would think...the doctors or
62 the medical staff or both together, I would say.
63
*the track?
++ Text units 84-86:
P: I'd be very happy to leave it to the doctors
84 who... or whoever is in charge to make that
85 decision.
*for future reference.
++ Text units 110-128:
P: Well, what decision else would I make apart
110 from wanting to be...wanting the doctors to do their
111 best for me. I mean I'm not going to say um..."Oh
112 I wouldn't want them to do anything, they can just
113 leave me on a trolley and let me die". I am not
114 going to say anything like that! But if
115 anything... well if I have a stroke again for
116 instance, and I go to the hospital, I expect...I
117 would like the doctors to do the best that they can
118 for me. Whatever it is, it doesn't matter, to
119 get me right again... that's what I would like. And I
120 mean I may be unconscious. When I first had this
121 stroke I know I was very sick and I wasn't even
122 able to sit up or anything and I don't even
123 remember the first few days of hospital, I don't....
124 only little flashes of it, little bits and pieces
125 but not the whole time. So obviously the best was
126 being done for me and I would like the same thing no
127 matter what.
128
*Bill?
++ Text units 252-260:
P: I don't know... maybe. I don't know. I
252 really wouldn't want him to be worried over things
253 like that. No, I think I would just leave it to the
254 doctors. I think I would. Um... Yes I think so. I
255 would just leave it to the doctors. He would
256 probably like to know about things. He would want
257
to know if I was in hospital or whatever it was and everything but I don't think anything other than that.
*situation?
++ Text units 269-288:
P: No, I don't think so. I can't think of anything. There very probably is, depending on the severity of illness of people and things like that I suppose. The doctor may say "well if we resuscitate this person it is not going to do anything because the quality of life has gone or just about to go and this can happen, something else can happen because of it so it may be better to leave the person ". It could be that sort of thing you know but I think basically - I don't know of things like that so... It is hard for me to say that. But I suppose if I was really bad, if I had all sorts of things wrong with me or something very major and the doctors didn't think that it was going to do me any good, there was nothing going to be achieved from it rather than just leave me as I was or comfortable or whatever the term is, I think, well then we are getting back to the doctor's decision aren't we? So I think yes I think I would leave it to the doctor again that way.
*S: There is no right or wrong answer.
++ Text units 299-324:
life. I really don't but saying that I can understand where somebody is so ill and in so much pain and there was no so called light at the end of the tunnel for them except downright pain, more pain, more pain and misery and misery for everybody else I can understand doctors possibly wanting to do something like that and to allow the person a dignified death if you would like to call it that but it's....... Ah! I don't know...... but it's still stopping life anyway and I don't call it murder, I don't call it that but I do call it stopping a life or taking of a life - there is still life there no matter how hopeless it might be I suppose. But I don't know.... I don't like the thought of ...... I don't think doctors would anyway - would willy nilly just take a life. I mean they have a code ...... whatever the word is - to preserve life at all times etc. but I can understand that, you know, those sort of things.... I'd hate to have a loved one in so much pain and I believe we may get to a stage where you want the doctor to end the life - it is not so much I suppose of ending a life, it is ending the pain for them, the suffering and all that. Nobody wants to see people suffer. There again...... I don't know, I don't know......very hard to say, very hard....
*decide - 'no we will not resuscitate'.
++ Text units 330-342:
P: I would leave it to the doctor. If he thought it was in my interests or in the best interest of me not to be resuscitated, I would leave that to him. If he thought that, then fine... because I think if his answer was 'we are not going to resuscitate her' I think there would be very good reasons and I wouldn't be in a state to argue or anything because obviously I would be very close to death I would say and it could be the things where they say you are not thinking so much of saving a life but just ending all the suffering that's going on and to be resuscitating them would be a needless thing. I *no light at the end of the tunnel?* be advised... well I was advised about what was happening to him all the time there. They said... that's when they wanted me to go into the flat because they said that particular weekend he wouldn't - they didn't expect him to live but I just sort of had a feeling that he would. *want the doctor to make the decision?* be advised... well I was advised about what was happening to him all the time there. They said... that's when they wanted me to go into the flat because they said that particular weekend he wouldn't - they didn't expect him to live but I just sort of had a feeling that he would. *want the doctor to make the decision?* At that stage I couldn't have done anything like that. *decision or just means being told?* I would just like to know just what's going on. You know, what they are doing, or what can't be done or what should be done and how they thought he was going to react to different things. Like he had *thoughts and experience is about what doctors are?* Well, when you are sick you automatically ring for a doctor don't you? You know, because they are the ones who are supposed to know what's wrong with you and how to fix it up. Um... You virtually put your life in their hands, that's the way I look at it anyway. You virtually do and to hope that they are going to do the right thing. *resuscitation and things?* If I was to finish up like that...... I would be