Dilemmas in Decision-Making about Resuscitation: A Focus Group Study of Older People

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Published in *Social Science and Medicine*, 2006, 62 7): 1579-1593.

Abstract

Cardiopulmonary resuscitation (CPR) may be used by default on patients suffering a cardiac arrest in hospital in the UK unless there is an order that specifies not to in the patient's notes. Guidelines recommend that the decision involves competent and willing patients or, in the case of incapacitation, their families. In practice, patient autonomy is often compromised. Ideally, discussion of preferences for end-of-life care should take place prior to hospitalisation. The majority of research on this topic has been conducted on hospitalised patients, so little is known about the views of older but healthy people about resuscitation decision-making. The present study was designed to address this gap. A series of 8 focus groups involving a total of 48 participants was conducted to explore people's views about the factors guiding resuscitation decision-making. A qualitative analysis, which emphasised the dilemmatic nature of CPR decision-making, identified two broad thematic dilemmas that subsumed six specific themes contributing to resolving the dilemmas: quality of life (medical condition, mental versus physical incapacity, age and ageing, and burden), and the involvement of others versus loss of autonomy (doctors and families). The dilemma underlying quality of life is that an acceptable quality of life after CPR cannot be assured. The dilemma underlying the involvement of others is that individual autonomy may be lost. The themes and sub-themes provide the basis for guiding these difficult discussions in advance of serious illness.

Key words: UK, Cardiopulmonary resuscitation, end-of-life care, life-sustaining treatments, older people, advance care planning.

Introduction

Medical advances include technologies to restore vital signs and prolong life. Although for some patients these technologies are greatly beneficial, for others they can result in additional and pointless suffering. Cardiopulmonary resuscitation (CPR) is one such technology. For hospitalised patients in the UK, CPR has evolved from an intervention reserved for those cases with a high probability of success to a policy of ‘CPR for all,’ unless an order not to resuscitate is in the patient’s notes. The existence of CPR and other life-prolonging technologies creates a dilemma for doctors, patients, and their families: for a given individual, is it in their best interest to employ this technology? The study reported here examines the views of groups of healthy older people on decision-making about end-of-life care, specifically the use of CPR.

In the UK, under guidelines from the British Medical Association (BMA, 2001) the ultimate responsibility for deciding whether or not to attempt resuscitation lies with the consultant or the general practitioner in charge of the patient’s care. The BMA guidelines advise that a ‘Do-Not-Attempt-to-Resuscitate’ (DNAR) order (i.e., an advance decision that CPR will not be attempted) should be discussed with competent patients (BMA, 2001). However information and discussion should not be forced on unwilling patients. In the event of incapacitation, family members should be consulted to act in the ‘best interest’ of the patient (BMA, 2001).

In practice, patients’ views about CPR for themselves are typically unknown because discussions about resuscitation rarely take place in UK hospitals (e.g. Keatinge, 1989; Landon, 2000). The patient may be unconscious, too ill or be otherwise incompetent and hence cannot participate in decision-making (e.g. Lo, 1991; Wenger, Kanouse, Collins, Liu, Schuster, Gifford et al., 1995). Moreover, medical professionals may be uncomfortable discussing these issues

with their patients because they do not want to cause emotional pain or be the bearer of bad news (Johnson, Pfeifer, McNutt, 1995; Marik & Zaloga, 2001; SUPPORT, 1995). As a result, decision-making in the hospital setting may compromise patient autonomy and self-determination. Therefore, advocates of advance care planning recommend that individuals discuss their wishes for end-of-life care with their doctors and their families when they are relatively healthy and competent. They may also choose to formalise their wishes by signing a living will. However, people typically do not have accurate knowledge about CPR and are therefore ill-equipped to make an informed decision (Gunasekera, Tiller, Clements, & Bhattacharya, 1986; Liddle, Grilleard, & Neil, 1994; Mead & Turnbull, 1995). Furthermore, in the UK, people have low knowledge about advance directives (Schiff, Rajkumar, & Bulpitt, 2000).

However, there are arguments against advance care planning. Healthy individuals may underestimate their desire to have medical intervention should they become ill (Ryan, 1996); and treatment preferences may change over time. Nevertheless, studies in the USA suggest that preferences are moderately stable over time (Ditto, Dank, Houts, Coppola, Smucker, Jacobson et al., 2003). Stability is greatest for invasive treatments such as CPR (Ditto et al., 2003); refusal of treatment is more stable than preferences to receive treatment (Carmel & Mutran, 1999a; Danis, Garrett, Harris, & Patrick, 1994) and prior completion of an advance directive is related to preference stability (Danis et al., 1994; Ditto et al., 2003). Investment of effort to complete an advance directive reflects a high degree of thought and commitment and thus decisions remain relatively resilient over time. Therefore, advance care planning may be considered as a process by which individuals arrive at relatively stable preferences for their end-of-life care.

Studies in the UK have generated inconsistent findings regarding hospitalised older patients' wishes for CPR attributable to several factors (e.g.. Hill, MacQuillan, Forsyth, & Heath, 1994; Gunasekera et al., 1986; Liddle et al., 1994; Morgan, King, Prajapati, & Rowe, 1994; Schiff et al., 2000). Some studies indicate that older people and women were more likely to forgo resuscitation (Lo, Saika, & Strull, 1985; Schonwetter, Walker, Kramer, & Robinson, 1994), whilst others show no such associations (Malloy, Wigton, Meeske, & Tape, 1992). Older people may be more likely to consider death as appropriate at the end of a natural life span (Phillips & Woodward, 1999; Rosenfeld, Wenger, & Kagawa-Singer, 2000). Patients with congestive heart failure and cirrhosis were more likely to prefer resuscitation than people with malignancies (Watchter, Luce, Heast, & Lo, 1989). SUPPORT (1995) conducted in the USA found that both the patient's diagnosis and their perception of the prognosis affected treatment preferences (Phillips, Wenger, Teno, Oye, et al., 1996). Functional disability, particularly mental dysfunction, has been associated with rejection of CPR (Gunasekera et al., 1986; Phillips & Woodward, 1999). In particular, the presence of Alzheimer's disease has been regarded as justification for the non-use of CPR (e.g. Resnick, Cowart, & Kubrin, 1998), and most patients wished to continue treatment only as long as they were cognitively intact (Cohen-Mansfield, Droge, & Billig, 1992). Several studies in the UK, USA and Canada have related quality of life to patients' preferences. Typically, patients would choose to prolong their lives only if they perceived their current quality of life as adequate (e.g. Ebell, Smith, Seifert, & Polinelli, 1990; Wilson, 1999).

Older patients' views show considerable diversity on who they believe should be responsible for the final decision regarding CPR. Frank, Heyland, Chen, Farquhar, Myers, & Iwassa's (2003) found that, across studies, the proportion of patients who wanted to be the sole

decision maker ranged from 19 - 92 %, whereas the proportion who wanted the decision to involve both themselves and medical professionals was 34 - 59 %. Studies in the UK suggest similar trends (e.g. Bruce-Jones et al., 1996; Gunasekera et al., 1986; Mead & Turnbull, 1995). Older people wish to include physicians because of their expertise, whereas families are granted authority based on their concern for the patient's well being (Rosenfeld, Wenger, & Kagawa-Singer, 2000). In their qualitative study, Seymour, Gott, Bellamy, Ahmedzai, & Clark (2004) found that older people living in the community in the UK wanted to have the opportunity to weigh the risks and benefits of a particular course of action in collaboration with clinicians, and they wanted their families to assume a degree of responsibility for representing the dying relative.

One potentially useful way of conceptualising the inconsistent findings from past research on CPR and advance care planning is to view these decisions as reflecting different forms of dilemmas. The fundamental dilemma underlying advance care planning is that it entails uncertainties, the nature and time of one's death and the preferences under those unknowable circumstances. However, advance care planning can anticipate and plan for likely scenarios. In dilemmas, the decision-maker is faced with a choice between costs and benefits that seem to be equally weighted. This choice is contemplated against a background of dilemmatic pre-conditions or contrary themes in society that is relevant to wider issues than any particular instance of decision-making (Billig, 1987; Billig, Condor, Edwards, Gane, Middleton, Radley, 1988). For the present study, the background of pertinent dilemmatic pre-conditions in Western society include the still prevalent but weakening taboo on discussions of death and dying versus the growing value placed on personal autonomy in medical decisions (Davis & Higginson, 2004; Seale, 2000; Timmermans, 1999). The dilemmatic nature of end-of-life decision-making in

general, and decisions regarding CPR in particular, was used as a conceptual framework for the present study.

The present study was conducted as part of a programme of research to develop communication tools to help patients and their families discuss end-of-life care among themselves and with their doctors. The aim of this particular study was to explore the perspectives on CPR decision-making of diverse groups of relatively healthy, non-hospitalised older people chosen to differ on education and income level, religion, and level of interest in and knowledge of the topic. Given the sensitivity of this research, and the need to learn directly from the people concerned about their views and their feelings, a qualitative approach was chosen. Focus groups have been used successfully to explore older people's perceptions of end-of-life care (e.g. Phillips & Woodward, 1999, Seymour, Bellamy, Gott, Ahmedzai, & Clark, 2003). Accordingly this method was chosen over individual interviews to create an opportunity for the easier expression and discussion; and provide a more supportive atmosphere (Kitzinger, 1995; Morgan, 1997).

The analysis of the discussions was conducted using Interpretative Phenomenology Analysis (IPA, Smith 1996) - a method by which the researcher identifies themes and generates a coherent interpretation of these themes. IPA was originally developed for analyzing semi-structured interview data, but more recently has been applied to focus group data (e.g., Dunne & Quayle, 2001; Flowers, Duncan, & Frankis, 2000). The dilemmatic nature of decision-making about life-prolonging technologies was used as a conceptual framework from which to develop the interpretative analysis.

Method

Participants and Recruitment

Eight focus groups (N = 48) were held with men and women over 65 years recruited from: Age Concern, two groups from the University of the Third Age (U3A), the Voluntary Euthanasia Society, a Roman Catholic Church group, a Residential Home, a Day Care Centre, and the Catenians Association (Catholic business and professional men).

Focus Group Guide

A semi-structured focus group guide was used to facilitate discussion on resuscitation and end-of-life care decision-making. The guide covered the following issues:

Healthcare challenges of ageing. To begin the discussion, the group was encouraged to talk generally about the challenges of ageing with respect to healthcare.

CPR and the DNAR order. These topics were introduced with a brief description drawn from BMA documents and a drawing of a patient undergoing CPR. Prompts included asking who should make this decision, what factors should be taken into account, and when is the best time to think about and make these arrangements.

Advance care planning. This topic was introduced by asking the group “How can individuals ensure that their dying process is in accordance with their wishes?” Where necessary, the researchers provided a short description of the living will. Prompts included why they would or would not choose to talk with their doctors, how easy it would be for them, and what problems they would anticipate when trying to have such a discussion. The same approach was used to generate discussion about raising end-of-life issues with family members and signing a living will. By this point, the group often spontaneously began to debate the pros and

cons of each of the methods of advance care planning, including members saying which method would be most suitable for them and the reasons for choosing one method over another.

Procedure

All the focus groups were facilitated by TV and TD and conducted in one of the participants' homes or in Age Concern premises. The discussion was audio-taped and subsequently transcribed verbatim. The discussion typically lasted about an hour and a half. At the end, participants were given a list of organisations that could provide help, information or counselling, and a condensed form of the information sheet by the Resuscitation Council (2002) describing CPR. They received £20 compensation for time and expenses. A one-page summary of the findings, and a leaflet to help older people and their families discuss end-of-life issues was sent to all participants at the completion of the study.

Analytic Strategy

Following IPA procedures, the transcripts were analysed for recurring themes with the aid of NVivo software (Smith, Osborn, & Jarman, 1999). The transcripts were read by TV and possible broad themes were identified. Emergent themes repeatedly found across and within focus groups were noted as recurrent themes. Similarly, TD read all the transcripts and generated emergent and recurrent themes. The two researchers discussed and agreed upon emergent themes, and then TV continued to examine the transcripts for connections among these recurrent themes by considering their context. Groups of related recurrent themes were organised under a master theme. Interpretations of the themes are illustrated by extracts from the transcripts. In the extracts, (...) indicates that material has been omitted, material in brackets () was added for clarification by the authors, and pseudonyms are used.

Results

Participant Characteristics

The number of participants in each focus group ranged from 5 - 7, with a mode of 6. In total, 20 men and 28 women participated. Most groups included both men and women, except for the Church group (all women) and the Catenians (all men). The majority of participants were under the age of 84 ($n = 45$) and had completed college ($n = 36$), although participants recruited from the Catenians were the most highly educated and those from the residential care the least. The majority of the participants ($n = 26$) were married or had a partner, while 12 participants were widowed. Participants from the University of the Third Age (group 2), from the Church and from Age Concern were more likely to live alone. Most of the participants were currently retired ($n = 41$), and described themselves as Christians ($n = 36$) and white ($n = 47$). Participants from the VES and Age Concern were more likely to describe themselves as having no religion. A large proportion of the participants had no long-term illness ($n = 31$), with the exception of participants recruited from residential care. The majority of the participants had not been hospitalised in the past 5 years ($n = 30$). Participants from the Catenians and residential care were more likely to have been hospitalised in the past 5 years. All participants described their current health status as fair to good, and no participant described his or her health as poor.

In sum, the focus groups represented a range of contextual factors that were expected to influence the themes to emerge in discussions. In particular, the groups represented different levels of religiosity, education, and interest in end-of-life decision-making.

Interpretative Analysis

The interpretative analysis revealed two overarching and related master themes reflecting the two dilemmas by which participants broadly conceptualised the resuscitation decision: the

individual's perspective on quality of life, and the involvement of others in the decision-making process. Within each master theme, several more specific recurrent themes were identified, and each was interpreted as a basis for resolving the dilemma underlying the resuscitation decision (see Table 1).

(Insert Table 1 here)

Quality of Life

Quality of life emerged as the central value underlying the dilemma of whether or not to apply a life-sustaining medical technology such as CPR. This broad theme emerged in some form in all the focus groups but was expressed most eloquently by the Catenians, who were the most highly educated group. They concluded that decisions regarding quality of life should be rational, arrived at by a process of weighing the pros and cons.

George: I think it's very difficult to judge when somebody has a quality of life, which isn't worth living. I don't think one can make judgements like that. On one hand you have to let nature take its course, and on the other, if there are techniques, machines available I think we should do something. Ultimately I suppose the decision has to be made, but it needs to be made very carefully.

(Catenians)

More generally, across the groups, CPR would be chosen only if the individual was enjoying an acceptable quality of life before CPR or could be reasonably expected to have an acceptable quality of life after CPR. The CPR decision became a dilemma when the individual's pre-CPR quality of life was not known, and/or the chances of survival and quality of life post-resuscitation could not be predicted. The definition of an acceptable quality of life in this context was an individual matter and therefore difficult for others to determine. However, quality of life was influenced by medical condition, physical versus mental disability, age, and

being a burden on others. Each of these influences emerged as a recurrent theme that could be used to address the dilemma.

Medical condition. Judgements of quality of life before CPR were based in part on the individual's health status. An individual with a terminal illness should not be resuscitated, but CPR should be attempted for acute conditions such as a heart attack in an otherwise healthy person. From this perspective, quality of life was defined in terms of how much more "good" life an individual could expect. For older people who had long-term illnesses, such as five of the participants in the Residential Care group, assessments of quality of life typically were based on medical condition.

Jean: If someone has had a plain heart attack they should try because if they resuscitate they could live longer. But if you have a terminal illness the rest of your body is not going to be able to cope with it.

Diana: Well I think it is a very difficult subject...because if I was very seriously ill and I was going to be terribly disabled physically or mentally if I lived much longer, I would not want resuscitation. The trouble is you can't really decide these things in advance ... Some people think 'life at any cost', I don't subscribe to that.

(Residential Care)

Using medical condition as a basis for the resuscitation decision is an attempt to resolve the dilemma that resuscitation may not result in acceptable quality of life post-CPR. Hence, for a terminally ill person, the risk is not worth taking. Similarly, for a person with much lower quality of life (which limited their daily activities) now compared to the past, life-prolongation is not attractive.

Mrs Adams: I feel, I don't want resuscitation, I am blind and because I can't cope any more

Mr Adams (husband): We have discussed it and we know exactly where we stand, the children know where they stand. It is in their hands more than anything. I mean, she (his wife), up to what, twelve years ago, maybe a bit longer, no-one could catch her (...). But her life now is sitting on her bed or in the wheelchair.

(Residential Care)

In contrast, for members of the Church group, assessment of quality of life was not as paramount as dying a 'natural death', leaving the decision to God. In the absence of any control, the dilemma is resolved by not thinking about death when healthy.

Edith: What we would call a natural happy death is what I want. If you are a terribly religious person, well dying is going to be lovely, because you are going to a better place.

Charlotte: You don't go around wondering what you're going to do if you get ill; it's the last thing in your mind. But if I'm unlucky enough to have a stroke and have a bad stroke and go down I would have to take my chances like the rest

Edith: I don't think I would necessarily want to be kept alive. If God wants you then he'll take you and if your work has not been done, you live a bit longer.

(Church Group)

Physical versus mental impairment. One important distinction for evaluating quality of life was whether an individual had physical or mental impairment. Mental incapacity, which was associated with being unable to communicate and having limited cognitive abilities, was considered much more threatening to quality of life. This was particularly important for the group recruited from the University of Third Age, where the emphasis on learning, education and retaining mental capacity was reflected in their views.

Emily: I think a lot depends on what sort of person you're going to be when you emerge again. If you're going to be as alert and as able as you were, but if you're going to be severely disabled either mentally or physically then perhaps a little more thought is necessary.

Anna: Well I think you need somebody who actually knows what you're going to be like when you have been resuscitated and if you're going to be an OK person then let's do it, but if you're not, just leave it.

Emily: If I felt I was going to be a cabbage afterward it's better, you know, to go quietly but if I felt I was reasonable, I don't say perhaps not as good as I used to be, but reasonable mentally etc, then I'd want to carry on.

(University of the Third Age)

However, for other groups, physical dysfunction was considered unacceptable and grounds for a DNAR. Members of the Voluntary Euthanasia Society commented:

George: I don't see the point in that situation of keeping me going just because they say that up here is something that is worthwhile saving.

Mark: Surely it's first of all that your mind is still working properly, because I think what most of us dread most is loss of the mind, more than physical function.

Richard: I personally couldn't bear to see myself in a mental state or in a chair, gradually slowly dying in front of my loved ones. I think it's appalling.

(Voluntary Euthanasia Society)

Age and ageism. Age was introduced as a basis for making a judgement about quality of life. Particularly relevant for older people (all participants recruited from the Day Care Centre were over the age of 70) was the position was that younger people's quality of life was intrinsically more valued than older people's.

Mary: Both my husband and I are in our 80s and feel that we've had a very good life and would not wish to be resuscitated to have a very limited life.

Heidi: But I think, if you get like you say 70's and 80s, let the person go.

Harry: (laughs) 'well, it depends how you feel, if there's a chance you'll survive another few years, but whose to know? I mean I think it's far better to try and save a younger person.

Margaret: I should think in his 30s, that's rather different from if you're in your 80s and you've had your life and a lot of your relatives have gone.

(Day Care Centre)

However, chronological age did not necessarily indicate poor quality of life, and too much emphasis on chronological age was seen as ageist. One member of the Residential Care group said: "And another thing that gets me, if you are over 70 'Geriatric patient'. Now is that for all people over 70, they are not all geriatric?"

Being a burden. Being a burden to one's family or to society indicated poor quality of life. The perception of burden was attributed to the perceived breakdown of the family, where younger family members no longer had the obligation or responsibility to look after their older relatives.

Audrey: "...even if you do have a very good family indeed, which I certainly have, there is still this anxiety that when you can no longer look after yourself what are you going to do?

Frank: But I think when you become a burden and you are not really able to do much for yourself, I mean the essential thing to me is to keep your dignity.

(Age Concern)

Older women were more likely to take perceptions of burden into account than older men, possibly because women typically take on more caregiving behaviours than men. In addition, comparisons with other continental European countries were made, where younger members of the family viewed looking after their older relatives as a responsibility rather than a burden.

Helen: ...as you have said on the Continent, they look after their kin much more in their family.(....) one of our biggest problems that we have lost families completely in this country. Some of us are lucky, but generally speaking families are something that, you know, they go. .(....). ...we grew up with the feeling that you didn't leave your family. You didn't have to concentrate on them, but you were responsible for them at some point maybe for keeping or taking care of your older relatives (....) But at least with some sort of sense of responsibility.

Audrey: I think I would long to have those expectations of the children, I really do.

Desiree: ... every generation owes something to the ones they follow, don't they in the perfect world.

(Age Concern)

A member of the Voluntary Euthanasia Society group summed up their discussion as follows.

Jade: ...a quality of life that enables sufficient health and enables you to be independent, I think this to me is very important. That you do you not want to become dependent, you do not want to be taken into care and institutionalised, that you want to be in charge and in command of your own life.

(Voluntary Euthanasia Society)

To summarise, one essential dilemma for older people contemplating CPR was the assessment of quality of life, which at the pre-CPR stage was often unknown and at the post-CPR stage difficult to predict. The general consensus was a ‘good’ quality of life qualified a person for resuscitation, whereas if a person had a ‘poor’ quality of life, they would rather forgo resuscitation. Poor quality of life was conceptualised as having long-term illnesses, having mental impairment at the pre-CPR stage or resuscitation resulting in mental impairment, being old and a burden or dependent on family and society. In contrast, a good quality of life was not having any terminal or life threatening illness, no mental dysfunction, younger age and being independent. Individuals differ in their definitions of an acceptable quality of life and use their personal circumstances to define this concept. These differences reflect their religious views, educational level, and their previous interest in the topic.

Involvement of Others in the Decision-making Process

The dilemma underlying this master theme concerns the risk of losing individual autonomy regarding resuscitation. Participants observed that the decision could be out of their control because at the time these decisions are made, they could be unconscious, too ill or incapacitated. Hence they needed to enlist the help of experts or loved ones to make this decision. The groups illustrated a diversity of views depending on their personal circumstances. For some, particularly for men, CPR should be a “medical decision” based on a “professional” and “objective view” (Catenians). Women were more likely to want to involve their family members “I would trust my family absolutely; I would leave it (the decision) to them” (Church

group). Members of the Residential Care group, most of whom had a long-term illness, were more likely to want their families involved: “The only people it concerns is you and your family” (Residential Care). Others were more likely to believe in personal autonomy: “Well, I think it should be only the patient's choice” (Day Care Centre).

Involving the doctor. Despite medical professionals having the ultimate responsibility for the CPR decision and being best equipped to make CPR decisions, they were seen as biased towards using life-prolonging technologies.

“... all the time there's a glimmer of hope, you've got to prolong life, I mean that is the doctor's oath isn't it, they must prolong life and if there's a chance you've got to do what you can” (Church Group).

Doctors were “afraid of letting it (death) happen,” indicating that death was looked on as failure in medical practice: “I've always been told that it's a black mark against them (doctors) if they lose a patient, so one wonders if it comes to the point they automatically bring you round. I think that worries me” (Voluntary Euthanasia Society).

Accordingly, involving the doctor in the CPR decisions was seen as more likely to swing the balance in favour of CPR. Various other reasons were given for why it was best to exclude medical professionals in the decision-making process.

Emily: I mean, it's hard enough thinking about these difficult issues without the added complication of contacting doctors and getting appointments and seeing different GP's every time one goes in.

Mary: Years ago you would phone up and you would have the same GP coming to you and he knew all about you.

Robert: I think the people to discuss it with, is your own family. No I wouldn't discuss it with my GP, sorry. I don't see how the GP and the doctor have anything to do with it at all. He is completely impartial, unless he has had a bad day ‘Oh let him die!’ (laughter)

(University of Third Age)

Sarah: If these decisions are made on the basis of whether a person can survive or not, isn't the doctor the best person to make these decisions?

Margaret: I guess he is. But I think it should be only the patients' choice. I think well if it's on a Doctor, I mean he's only human; he's got a conscience hasn't he? Now if he's got to make a decision on a person's life, what's he going to feel like afterwards? Did he make the right decision or not? It would prey on his mind for a very long time.

(Age Concern)

Involving the family. Participants perceived families as able to make decisions on the individual's behalf, and that their involvement would increase the likelihood that a person's wishes were adhered to.

Jean: Personally, I would rather my family know what I want to do... my notes might get muddled up with somebody else's or it might be a new doctor.

Sarah: I'd rather trust my family to know exactly and mine do. I have told them so many times and I would rather that than a doctor.

(University of Third Age)

However, another view was that the older person should make this decision for themselves without involving the rest of the family.

Edith: Well I don't think I would burden my family, but once I had made up my mind and say 'right I'm having this done... I don't think it's fair.

(Church Group)

Although some viewed the discussion with family members as an unfair burden on them, a participant from the University of the Third Age observed that informing a family member could be a relief for all concerned:

"I told my nephew, and he said: 'I'm so glad you've told me. Because if you hadn't, I'd have moved heaven and earth to keep you alive'. If you're the heir you've got to do

everything, unless you've got written (living will) or been told by your family member".

From yet another perspective, it was assumed that the family could be relied upon to know a person's wishes without having an explicit discussion.

Suzan: I'm very close to my family, and I know what I want, so I don't even have to tell them. I'm very close to my family, but I certainly don't think it's necessary to discuss these things with them.

(Church Group)

To summarise, the dilemma of involving others in the resuscitation decision was to risk losing personal autonomy versus relying on experts (doctors) or others who can be trusted (family). Involving the doctor was seen as essential as they were best equipped to offer a medical and professional assessment of the futility of CPR. However, they were seen as biased towards prolonging life, hence compromising the values of quality of life that were important to the patient. Family was trusted more than the doctor to act in the best interest of the patient concerned but this could place a burden on them.

Discussion

Despite the highly sensitive nature of the topic, the focus-group methodology yielded a diverse set of views on the resuscitation decision and related issues. Guided by IPA and a dilemmatic conceptual framework, the interpretative analysis of the transcripts identified two master themes that described two broad principles that should be used when making resuscitation decisions: appraisal of quality of life and involving others in the decision. Each of these principles encompassed a dilemma, and recurrent sub-themes that addressed these dilemmas.

The essential dilemma underlying quality of life as a guide to resuscitation decision-making is that quality of life may be unknown or unknowable. CPR offers the advantage of prolonging an acceptable quality of life, but this must be weighed against the disadvantage of prolonging or creating an unacceptable quality of life. The groups developed various positions on the definition of acceptable quality of life reflecting the contextual influences of each group's characteristics. Important elements of this definition were a person's current state of health, how it compared with past health, and the extent of mental versus physical incapacity. Personal circumstances and values were important when deciding which of these values to focus the decision on. For example, the VES group generated pro-DNAR views, while members from the Catenians advocated a rational, cost-benefit evaluation. Older participants in the Day Care group were more likely to take age into account whereas those with long-term illnesses, such as the Residential Care group, were more likely to take health and illness into account.

Two of the recurrent subthemes for quality of life were individual issues of medical condition and physical versus mental functioning. The other two subthemes originated in societal attitudes towards older people and their care. One theme reflected the societal value placed on youth, with younger people being considered more worthy candidates for CPR. Another theme reflected the societal problem of older people being a burden on the younger generation, indicating that CPR should be withheld if the person would become a burden. The subtext of these societal subthemes is that ageing is negative, and these two themes were well-expressed by the Day Care, the Age Concern and the VES groups, all of which provide settings for addressing various problems of ageing, illness, and death.

The emergence of quality of life as a major theme confirmed past research. Consistent with past research, participants considered health-related assessments of quality of life (present

health and physical and mental incapacity) when making decisions about life-prolongation (Carmel & Mutran, 1997b; Cicirelli, 1997; Ebell et al., 1990; Landon, 2000; Phillips & Woodward, 1999). In this respect, both older people and their doctors use the same principles to make CPR decisions (de Vos, Koster & de Hann, 1998) but may hold different positions on those principles. When considering CPR and advance care planning, the groups took into account not only physical and health-related aspects of quality of life but also emotional, psychological and social factors. Consistent with past research, the groups included psychosocial factors such as age when assessing quality of life (e.g. Gunasekera et al., 1986; SUPPORT, 1995) and burden (e.g. Schiff et al., 2000; Seymour et al., 2004).

The essential dilemma underlying the principle of involving others in the decision is that this may endanger individual autonomy. The groups discussed the various ways out of this dilemma. Involving doctors provides professional expertise and one solution is leaving the decision entirely to the doctor. However, the professional commitment to maintaining life, perhaps at almost any cost, could run counter to the high value placed on quality of life as a basis for making the decision. Involving one or more family members places a burden on them which can be avoided by a person making the decision independently: only informing the family or the doctor of the decision, rather than discussing it with them. Another solution is to believe that other family members intuitively know one's wishes without explicit discussion but this may make it difficult for family members to act in the patient's best interests. The resolutions to this dilemma did not appear to differ by group: rather all groups agreed that the decision was best understood in terms of each individual's personal circumstances.

This study added to past research in three ways. First, it demonstrated that similar issues emerged in groups of relatively healthy, community-dwelling older people as have been found

for older patients. Second, it extended past research that has noted the dilemmatic nature of resuscitation decision-making (e.g. Seymour, Gott, Clark, & Ahmedzai, 2003) by elaborating on the principles community-dwelling older people use to resolve these dilemmas. Billig's (1988) work on ideological dilemmas proved a useful way to interpret these discussions. The social and contextual views on ageing (such issues of personal autonomy and burden) and death and dying, formed the background of pertinent dilemmatic pre-conditions on which the CPR decision is based. Our study extended Billig's work by suggesting ways in which older people can think about these dilemmas and resolve them. Third, this study added to past findings by shedding light on inconsistencies found in past research over whether or not patients favour CPR (e.g. Hill et al., 1994; Liddle et al., 1994; Morgan et al., 1994; Schiff et al., 2000). The present findings suggest that there is a diversity of views because of the different weights given by individuals to the principles by which this decision is made. Non-representative sampling, such as recruiting participants from particular hospital wards or outpatient clinics, may inadvertently introduce a confound with the value placed on one or more of these principles.

A limitation of the present study sample was that, like previous studies, participants were not truly representative. The groups were selected to reflect a range of views, with the VES group representing the most favourable opinions regarding the use of the DNAR order. Participants were biased towards the more educated who may be more likely and willing to debate these issues in the form of dilemmas. The advantage of studying such people is that they are able to provide an articulate rendition of the way they think about this complex issue. Although the focus groups provided a supportive environment to discuss this sensitive topic, group discussions may generate different views compared with individual interviews. A useful direction for future research would be to determine the degree to which the various relevant

parties to the decision, including doctors and family members, use the same principles as those identified here. Another limitation was that much of discussion was hypothetical. Placed in a real dilemma, participants may behave quite differently. Further research is therefore needed to study actual end-of-life decision-making, perhaps by studying case histories of actual instances of advance care planning. A further but inevitable limitation was the failure to represent the views of people who were not willing to participate, such as those for whom death is a very distressing subject. Research on how to overcome culturally rooted reluctance to anticipate death and end of life care is needed to facilitate discussions with such individuals.

With these caveats in mind, the findings from this study suggest a possible approach to structuring end-of-life care discussions with those expressing interest in the topic. The dilemmas identified here provide questions to facilitate such a discussion. Older people could be invited to determine their own definition of an acceptable quality of life, based on their medical condition, extent of mental or physical impairment, age and level of independence. They could also develop a position on the involvement of others, based on their perception of personal autonomy. Because of the nature of the resuscitation dilemma, it is all too easy to avoid discussing or thinking about it and thus neglect making a decision. By developing a position with respect to the underlying principles upon which the decision rests, the decision itself may become clear. This would also allow doctors and family members to gain a perspective on the basis upon which these decisions were made, which could inform their decision-making for this person should any future need arise. Therefore, this conceptual framework could provide a basis for guiding these difficult decisions in advance of serious illness.

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Table 1: Master themes and sub-themes

Master themes	Subthemes
Quality of Life	Medical condition
	Physical and mental function
	Age and ageism
	Being a burden
Involvement of Others in the Decision-making Process	Involving doctors
	Involving family