

Nursing Facility Residents' Cardiopulmonary Resuscitation Decisions

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Abstract

Context: As many as one-quarter of all residents in nursing facilities have cardiopulmonary resuscitation (CPR) as a documented choice in the medical record, despite the likelihood of limited medical benefit in this setting.

Objectives: The aim of this study was to understand how nursing facility residents make decisions about CPR.

Methods: We used qualitative interviews to examine the perspectives of residents with a documented decision for CPR in the medical record. We then compared residents' views with those of healthcare providers who routinely conduct advance care planning (ACP) conversations in the nursing facility setting.

Results: Residents held misconceptions about CPR and/or exhibited an overall poor understanding of the relationship between their own health status and the likelihood of a successful CPR attempt. Although healthcare providers offer information and health education in an attempt to correct knowledge gaps, these efforts are not always successful or even accepted by residents. Resident viewpoints and priorities differed from healthcare providers in ways that affected communication about CPR.

Conclusions: Unrecognized differences in perception between providers and residents affect key aspects of ACP communication that can impact CPR decision making. ACP communication models and training should be designed not only to explore nursing facility residents' goals, values and preferences, but also to elicit any underlying differences in perception that may affect communication.

Keywords: nursing facility, cardiopulmonary resuscitation, communication, decision making, advance care planning

Summary Statement of Implications for Practice

What does this research add to existing knowledge in gerontology?

- This study shows that nursing facility residents may have a perception of their health status and/or prognosis that is vastly different from a healthcare provider's clinical assessment.
- Nursing facility residents may be grappling with psychosocial, emotional or existential issues related to decreasing functional status and other life changes and thus may have difficulty attending to discussions about prognosis and end-of-life treatments.

What are the implications of this new knowledge for nursing care with older people?

- If differences in perception of health status/prognosis between providers and residents are not recognized or addressed, residents will not have accurate information to make informed decisions about CPR and other end-of-life treatments.
- Efforts to offer education to assist in CPR decision-making may be unsuccessful if residents are distracted by other concerns or priorities.

How could the findings be used to influence policy or practice or research or education?

- Advance care planning in the nursing home setting must not only include efforts to assess a resident's understanding and knowledge about CPR, but should also be designed to elicit residents' perceptions regarding their health status and prognosis that affect decision making.

- Quality advance care planning uses a holistic approach that assists residents with reframing concerns and prioritizing needs.

Residents of nursing facilities typically live with advanced age, frailty, and multiple chronic health conditions. There are often questions about whether or not to provide life-sustaining treatments in response to an acute health status change, and residents are routinely approached about their preferences regarding resuscitation upon admission to a facility (see Patient Self-Determination Act, 1990). In the absence of a do-not-resuscitate (DNR) order, cardiopulmonary resuscitation (CPR) is the default option in nursing facilities in the United States. Although most residents opt for a DNR order, CPR remains a documented choice for 20-30% of residents (Mukamel, Ladd, & Temkin-Greener, 2013; Rahman, Bressette, Gassoumis & Enguidanos, 2016).

However, CPR survival rates among nursing facility residents are low, with estimates in the range of 1.5-2.0% (Pape et al., 2018; Shah, Fairbanks, & Lerner, 2007). Lower chances of survival after CPR attempts are associated with the presence of multiple chronic illnesses (Hirlekar et al., 2018; Carew, Zhang, & Rea, 2007). CPR necessitates mechanical ventilation in the hospital and may be associated with neurological impairment (Girotra et al., 2016) and traumatic injuries from chest compression (Kaldirim, et al., 2016; Kralj, Podbregar, Kejžar & Balažic, 2015).

In light of the low likelihood of benefit, it is difficult to understand why CPR is the intervention of choice for as many as one-quarter of nursing facility residents. Factors influencing decisions about resuscitation are not well understood (Messinger-Rapport & Kamel, 2005).

Decision-making about CPR is a part of advance care planning (ACP), a process for creating a shared understanding of a person's care goals, values, and treatment preferences to direct future care (Sinuff et al., 2015). Despite the large body of research on ACP, there is still no widely held consensus regarding what methods are most effective (Gilissen et al., 2018). Additional research is needed to understand the effective elements of ACP, especially in the nursing facility setting (Houben, Spruit, Groenen, Wouters & Janssen, 2014; Martin, Hayes, Gregorevic & Lim, 2016). For residents who choose CPR, it is unclear whether these decisions are a result of effective or ineffective ACP communication.

The aim of this study was to understand how residents of nursing facilities make decisions about CPR. Toward this end, we interviewed residents who had opted for CPR as well as healthcare providers who routinely conduct ACP in nursing facilities.

METHODS

The study was conducted between March and December 2018 after approval from the University Institutional Review Board.

Participants

We used criterion sampling (Kuzel, 1999) to select healthcare providers with at least one year of experience facilitating ACP conversations with nursing facility residents. We identified participants initially through professional networks in long-term care, and found subsequent participants using snowball sampling (Neutens & Rubinson, 2010).

Resident interviews were conducted in five urban nursing facilities. Eligible participants had been in a nursing facility for at least 45 days, were age 65 or older, had documentation in the medical record of a preference for CPR, and had been identified by facility staff as having the ability to make decisions. Staff assisted with exclusion of residents who were too frail, ill, or had

difficulties with communication, even if they were otherwise eligible. Because residents live with multiple chronic health conditions and limited functioning, diagnosis was neither an inclusion nor exclusion criterion.

Interview Procedures

Since this study involves complex communication phenomena, a qualitative approach was the method of choice. Qualitative interviewing is a flexible method that allows for an in-depth understanding of multiple perspectives within a particular context (Lindlof & Taylor, 2011). Prior to conducting interviews, the interview guide was pilot tested and revised accordingly. All resident interviews were conducted in person at the nursing facilities. Eight provider interviews were conducted in person and six were completed over the telephone. We audio recorded all interviews after receiving permission from participants and the recordings were later professionally transcribed. The interviews lasted approximately 30 minutes to 1 hour.

We asked healthcare providers to describe what they perceived as factors and conditions related to residents' decisions for CPR. We asked residents open-ended questions designed to explore their understanding of CPR and their health status and prognosis.

Data Analysis

Data collection and analysis were conducted simultaneously; as each interview was transcribed, we read through the entire transcript to gain an overall understanding of the data and to inform subsequent interviews (Corbin & Strauss, 1990). Using constant comparative methods, the first author conducted initial open coding on each transcript in line-by-line fashion to ensure an analysis that remained grounded in the data (Glaser & Strauss, 1990). The second author checked those interpretations, and any disagreements were resolved by consensus. Throughout this phase, we compared codes within the same interview as well as codes between interviews to look for similarities and differences. As we generated new codes, we reviewed and revised

previously coded transcripts. Once codes were stable and consistent, we used focused coding to apply the codes to all of the transcripts. During focused coding we wrote memos to raise the condensed codes to conceptual categories (Charmaz, 2014), and interviews continued until no new categories emerged.

RESULTS

A total of 14 healthcare professionals participated, including six nurses, two nurse practitioners, three social workers, one admissions director, and two physicians. All but one of the participants was female and only two individuals were non-White (Table 1). All participants routinely conducted conversations about CPR with residents and had between three and 37 years of experience. Six of the providers had completed training on evidence-based ACP communication models.

A total of 16 residents participated. They ranged in age between 66-88 years. Twelve were White and 4 were Black. Most were female and had education beyond high school (Table 2). All resident participants had a Brief Interview for Mental Status (BIMS) score in the range of 13-15, suggesting they were cognitively intact (Saliba et al., 2012). As an additional safeguard to ensure comprehension, we obtained informed consent using a “teach-to-goal” technique (Sudore et al., 2006) and excluded two residents during this process. Using this strategy, potential participants were asked five questions about the study after reviewing the consent form. They were provided targeted education for any missed items, and were allowed up to three attempts per item. Residents unable to demonstrate comprehension on all five items were excluded.

Resident vs. Provider Concerns

Although healthcare providers indicated that cognitively able residents have the right to make their own decisions, they also expressed unease about decisions for CPR in this population.

Providers used words like “horrible” and “traumatic” to describe the application of CPR in the nursing home. One provider spoke about a resident who maintained a CPR decision despite repeat hospitalizations and declining health:

Our concern was do we put somebody through needless pain? Our belief was that he would not survive it. CPR is painful. It’s distressing. In most cases it’s not successful. Do we do that? But because he said ‘yes’ [to CPR] then that’s what we did. Unfortunately, it was not successful (P7, nurse).

Resident statements, in contrast, showed minimal concern about CPR decisions. We asked one resident, “So, what are your thoughts about having CPR?” and the resident responded, “I don’t think anything of it really” (R10). In fact, although our goal was to engage residents in conversations about CPR, attention to this topic was regularly eclipsed by other concerns. For example, when we asked if there was anything that would cause a resident to change her mind about choosing CPR, her response indicated she was more focused on the prospect of being moved to another room in the facility:

I don't think so, uh uh. I might change my mind about coming here.

When we found out that they're giving us all new rooms, I was so upset, because I like this room. (R1)

When we asked questions of residents designed to assess their understanding of health status and prognosis, the responses almost always focused on concerns about the possibility of decreasing functional ability. We asked a resident what was her biggest health concern:

I have macular degeneration. That scares me the most. My right eye, I’m blind in, and the left one, I get a shot every five weeks. It’s kept it stable,

thank God. That's what I really, really worry about, that I'd be blind (R2).

For others, questions about health status evoked worries about loss of independence:

Resident: I dread the thought when I can no longer do for myself.

Interviewer: Do for yourself?

Resident: Like getting dressed and going to the bathroom and walking around. I hate the thought of when I lose those things. And if I have lost those things and I'm bedridden, I don't know what I would do. (R22)

Residents described multiple other concerns, primarily arising from or relating to the transition from independent living to institutionalization. Overall, we found that residents were much more focused on coping with the day-to-day challenges related to living life in a nursing facility than in discussing end-of-life treatment choices.

Offering Information vs. Avoidance

Healthcare providers we interviewed were aware that residents often had knowledge deficits, and described education as a primary strategy for facilitating decisions about code status:

We do have some that want to be full code, so we go through and explain to them what a full code means, what we'll do. (P4, nurse)

Providers also recognized that sometimes efforts to offer information are met with resistance and that even if accepted the information is not always effective in changing decisions. If this occurs, providers described waiting for future opportunities to provide information, when the resident seems 'ready':

Sometimes I know that they don't really understand, especially if they do not want any education. They just tell you they want everything [done],

so that's a situation where you have to let it go. Then you kind of have opportunities along the way to educate, to get beyond that. Sometimes you know that with time that might change. (P1, nurse)

Efforts to educate at intervals are related to providers' recognition that offering too much information at once can be problematic. One participant explained, "If there is any teetering, I just let them know that's fine, we can look at this later. Some people may not be ready to be bombarded with that." (P5, nurse)

In fact, the most difficult aspect of assisting residents with CPR decisions is that some individuals are simply not willing to engage in ACP discussions. "They don't want to talk about it or they keep putting it off. 'I'll do it when my daughter comes in.' 'I'll do it another day.' 'I don't feel like doing it today.' I think that's telling you something, too." (P2, nurse practitioner)

These observations were supported by our own encounters with residents who exhibited information avoidance during interviews. There were residents with obvious knowledge deficits who had no desire to receive information or to "worry about" health decisions:

Interviewer: So, what's going on with your kidneys?

Resident: I don't know if there's a name, truthfully I don't care, but not functioning at full capacity. I don't pay that much attention. I try and do my best just to function, without worrying about any of it, and that's what I do and it works fine. (R2)

Avoidance was a way to guard against information that this resident perceived as negative or overwhelming. We also encountered residents who would abruptly (and sometimes repeatedly) change the subject of conversation:

Interviewer: If you did have CPR what do you think your life would be like a month later?

Resident: I have no idea. I have a question. [Points to interviewer's hand] Is that a tattoo? (R10)

Of course these occurrences of selective attention could be due to distraction, but during several interviews they were frequent enough that it created a fairly effective barrier to deeper probing.

Lack of Understanding about CPR

Providers perceived a strong relationship between a resident's choice for resuscitation and a lack of understanding about CPR. A provider said, "When we have our conversations, you ask, 'Tell me what you know about CPR.' They can't explain it. They go, 'Isn't that when they push on your chest?' But sometimes that's the limit to what most people know." (P6, nurse) This lack of understanding was mirrored in our resident interviews:

Interviewer: So what do you know about CPR?

Resident: They put paddles on you to restart your heart. That's about it. (R10)

We also encountered knowledge deficits related to the effectiveness of CPR. Some residents estimated the chances of success of CPR as being high:

Interviewer: If ten people had CPR, how many do you think would get their heart restarted?

Resident: Probably at least half of them, maybe more. (R22)

Some providers recognized that a poor understanding of the chances of success of CPR was not improved by providing information in probabilistic terms. One provider said, "Unfortunately people don't have a very realistic picture. They don't understand the 3% [chance of success]. Just think about it. If your blood pressure medicine was effective 3% of the time,

would you take it? No.” (P8, physician) In fact, some residents did indicate that if there was any chance CPR might work, then they would like to try it. One resident said, “I told them to go ahead and try CPR on me, and if it don’t work, well, don’t repeat it.” (R13)

In talking to residents we found that some of the most profound knowledge deficits occurred in relation to the burdens of CPR:

Interviewer: How often would you say CPR works?

Resident: I think it works quite often, from what you see and hear.

Interviewer: If somebody here [nursing home] gets CPR, what's that person's life like a week later, if you were to guess?

Resident: I guess they'd be pretty happy, a week later. (R8)

Providers, however, were acutely aware of the burdens associated with CPR in this setting and were thus puzzled by some residents’ decisions. One provider tried to understand by imagining herself in the residents’ position:

I don't know, would I want to be like this my whole life? If I'm already dependent on people to transfer me, I can't eat anything because I'm going to aspirate, the only way I'm living is because I have a PEG tube. I look at it personally like, so if I was to go, would I want to be resuscitated to come back to this? (P4, nurse)

Lack of Prognostic Awareness

Responses from residents indicate that a choice for CPR may not only be related to knowledge deficits about resuscitation, but may also be associated with a disconnection between residents’ understanding of their overall health status (i.e., the presence of advanced age, frailty, chronic illness, and life expectancy), and the chances of surviving a CPR attempt.

This is in part based on information we collected prior to each interview which shows that residents do not necessarily perceive themselves to be in a state of poor health. Before each interview, we asked residents to rate their overall health on a five-point scale from poor to excellent. Surprisingly, 11 out of 16 residents indicated their health was ‘average’ or ‘very good,’ with only five rating their health as ‘poor.’ Review of the medical record showed that participants all had serious chronic illness and reduced functional ability requiring skilled care.

Some residents indicated that in their current state of health they thought CPR would be an appropriate choice (i.e., survivable), but that if their health became worse at some point in the future they would not wish to have CPR. One resident said, “If it happened today, I would say go ahead and do the CPR, just because I think I’d come out of it. But if it’s reached the point where it is a possibility that I’m not going to come out of it, I don’t want to be resuscitated.” (R22) Remarks such as the one above show how a resident’s poor understanding of their prognosis/illness trajectory can impact decisions about CPR.

When we directly asked, ‘Who should not have CPR?’ several residents responded that people who are very sick or dying should not have CPR:

Interviewer: Is there anything that would change your mind about your decision for CPR?

Resident: No.

Interviewer: Nothing?

Resident: No, unless I was too far gone.

Interviewer: Tell me what is ‘too far gone’? What does that look like for you, in your mind?

Resident: Like totally out of it, or dying. (R7)

Comments like the one above allude to a low prognostic awareness among some residents. Likewise, many of the providers expressed the opinion that CPR decisions were at times related to residents' lack of understanding of the chance of successful resuscitation given their health status and overall life expectancy. As one provider put it, "I think that's why they're choosing to stay full code. They want to stay full code because they can't understand the magnitude of what their condition is." (P4, nurse)

Don't Keep Me on Machines

Another unexpected aspect related to knowledge deficits emerged when residents spoke about what was acceptable to them in terms of quality of life. Although residents affirmed their CPR preference during the interview, many of those individuals also indicated that being 'kept alive on machines' for any length of time was unacceptable:

Interviewer: So what if this doctor said if you get CPR you're going to end up on a ventilator, probably not going to ever get off. What would you say?

Resident: Forget it.

Interviewer: Forget CPR?

Resident: If I'm not going to get off the ventilator, forget it. Just let me go. (R10)

These comments represent another gap in understanding the potential implications of receiving CPR. Some residents were not aware that if a heartbeat was restored after receiving CPR, it would necessitate the use of a ventilator and other supportive measures in a hospital intensive care unit.

DISCUSSION

Perhaps not surprisingly, this study identified a lack of knowledge about CPR as being associated with residents choosing CPR. Additionally, our interviews support the notion that CPR decisions in this population may be associated with low prognostic awareness on the part of residents.

The experienced and compassionate healthcare providers we interviewed were aware of these issues, but also indicated that at times their best efforts to bridge knowledge gaps are not successful. Thus, this study also suggests that the primary approach to this problem (offering information) may not always be an effective strategy.

Healthcare providers shared with us that if an initial attempt to educate a resident is rejected or does not result in a decision change from CPR to DNR, often the second-line response is to offer more information at periodic intervals, with the hope that the resident will become receptive at some future point in time. However, providers admit that at times even this ‘second-line’ strategy is unsuccessful.

It is possible that some residents may avoid engaging in discussions about CPR because their goal is to *maintain* uncertainty. While many persons seek information when facing health decisions to help reduce uncertainty, others may avoid information if there is an expected negative outcome (Hines, 2001). Avoiding information can allow some individuals to cope with distressing or overwhelming information and maintain feelings of hope or optimism (Babrow & Kline, 2000).

Other attempts to educate may fail if there are unrecognized differences in perceptions between provider and resident. For example, a provider may explain to a resident that CPR does ‘not work well in individuals with serious illness.’ However, if a resident perceives him or

herself as being in average or good health (as did most of our participants) the resident is likely to dismiss the information as not being applicable to his/her own situation.

Witte & Morrison (1995) observed that across cultures, people treat what they *perceive* to be the cause of their illness, not necessarily the actual cause. For example, if an individual believes that an evil spirit is invading the body and causing illness, a sorcerer may be asked to exorcise it. In the case of the residents we interviewed, some said that if the heart stopped beating, they would like to receive CPR in order to start the heart beating again. Their perception of the illness is that the heart has stopped, and so it is logical to request CPR to rectify the problem. What is needed is not more information about CPR, but clarification related to the resident's perception of the problem (i.e., a health condition that may result in cardiac arrest).

The residents in our study were strongly oriented toward concerns related to their present quality of life (especially functional ability) rather than about future treatment options. According to Hines (2001), individuals are more likely to focus on managing uncertainties they appraise as being most important. In a study of persons living with HIV/AIDS, participants described shifting to living more in the moment rather than concerning themselves with long-range planning (Brashers et al., 2000). This may be a way for persons who cannot achieve predictability in their lives to adapt to chronic uncertainty (Brashers, 2001). Although to some it might seem that life for an institutionalized older adult is routine in the extreme, as our interviews showed, for persons living in nursing facilities life can be anything but predictable. A strong orientation to the present may be a way for some residents to cope with chronic uncertainties related to the end-of-life.

Limitations

Perspectives of family members/surrogate decision makers were not included, and future studies with family members/surrogates may add a more complete understanding of this phenomenon. However, since research focusing on residents' perspectives has been neglected, we believe that comparing and contrasting the perspectives of residents and healthcare providers is of value.

Conclusion

By illuminating the perspectives of older adults in nursing homes this study suggests that current practices for conducting conversations about CPR (and ACP in general) may not always align with residents' needs. Since ACP is typically directed toward preparation for future medical care, it may be at odds with residents who prioritize their present emotional and functional concerns. Understanding that these concerns are a part of valid efforts at coping is crucial to avoid labeling residents as "death denying" (Zimmermann, 2007). When healthcare providers recognize the primary concerns of residents, they are in a unique position to facilitate end-of-life communication by supporting residents in prioritizing and reframing those concerns.

Furthermore, our study shows that unrecognized and unaddressed differences in perception between residents and providers can have a profound impact on CPR decisions. Before attempting to elicit a resident's goals, values, and preferences, healthcare providers must first understand how a resident's viewpoint may differ, especially in regard to health status and prognosis.

Finally, our study shows that some residents who have CPR as a documented choice in the medical record have knowledge deficits affecting CPR decision making. Perhaps the most troubling finding was that although interviewees affirmed their CPR preference during the

interviews, these same individuals also clearly stated that they had no desire to be put on 'machines.' Given this evidence, it is difficult to claim that these cases represent informed decision-making. Further work is needed to improve ACP communication to ensure that CPR decisions are truly informed and meet the needs and goals of nursing facility residents.

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Table 1. Provider Characteristics (N = 14)

Characteristic	Value
Sex	
Male	1
Female	13
Race	
White	12
Nonwhite	2
Occupation	
Nurse	6
Nurse Practitioner	2
Physician	2
Social Worker	3
Admissions & Marketing	1
Communication Training?	
Yes	6
No	8

Table 2. Resident Characteristics (N = 16)

Characteristic	Value
Sex	
Male	7
Female	9
Race	
White	12
Nonwhite	4
Education	
>High School	8
High School	4
<High School	4
Perceived Health Status	
Excellent	0
Very good	2
Good	2
Average	7
Poor	5