What's New in CPR & DNR?

CPR (Cardiopulmonary Resuscitation) means an effort to *restart* heart and breathing if they both stop.

DNR (Do Not Resuscitate) means that if heart and breathing stop, the patient does *not* want to be revived.

This pamphlet gives no medical or legal advice. It gives information to discuss with medical and spiritual advisors and family. Sources[1] at medfacts.globe1234.com 8/9/2019

Video story: Aim camera at ▣ to see John, 62, being revived, hospitalized, and talking to the BBC.[2]

CPR in hospitals saves **26%** of patients when their heart stops[3] They leave hospitals alive. Success varies from 40% in WY to 20% in NY.[4] **CPR outside hospitals** saves **16%** of patients, if someone sees them collapse.[5] The best counties save more.[6]

For comparison, widely used heart medicines save 1% (statins) to 12% (beta blockers) of those treated.[7]

Minds usually stay the same. After CPR, up to 1% more survivors are in comas than before CPR (most people come out of comas[8]). 5%-10% more need help with daily life. 5%-21% more decline mentally, but stay independent.[9]

We accept similar risks from surgery: delirium after 30%-60% of surgeries, longer term mental decline after 10%-30%, and strokes after 4%-10% of heart surgeries.[10]

Injuries happen to 13% of CPR survivors: broken sternum or ribs (9%), lung injury (3%), internal bleeding (3%).[11] Bones heal in 1-2 months.[12] Cartilage also breaks, and sounds like breaking bones.[13] Injuries rarely hurt care; only 1% are life-threatening.[14]

Many groups have the *same* survival after CPR as the US average: hospitalized nursing home patients,[15] patients aged up to 85 or with 1-2 illnesses, heart failure, diabetes, ICD or pacemaker, or in ICU.[16] Others survive *half to two thirds* as well as average: patients at nursing homes,[17] over 90, those with 3-8 big illnesses,[18] cancer, pneumonia, on dialysis, sepsis, liver or brain damage.[19] Some call CPR futile, but American Heart Association (AHA) guidelines say these survival rates are not futile.[20]

CPR involves pressing down on the chest 2 to 2.4 inches, 1.7 to 2 times per second (♪*ah ah ah ah stayin' alive*♫[21]), while patient lies on a hard surface (not a bed). Mouth-to-mouth is optional. No interruptions except for AED. Untrained people can give CPR.[22] 911 centers guide you.[23] Hire a trainer for parties, so your friends learn CPR well, to save you and each other![24] Even families of high risk patients rarely get CPR training.[25]

AEDs (automated external defibrillators) are easy to use. They guide you and safely shock the heart to restart it.[26] Many public places have AEDs.[27] Some nursing homes and assisted living do too, an important criterion if you want CPR.[28]

Patients need a few days to recover, with medicine, cooling the body, imaging arteries, a breathing tube for oxygen, etc.[29] (Breathing tubes are also used for pneumonia and surgery, much more than for CPR.[30])

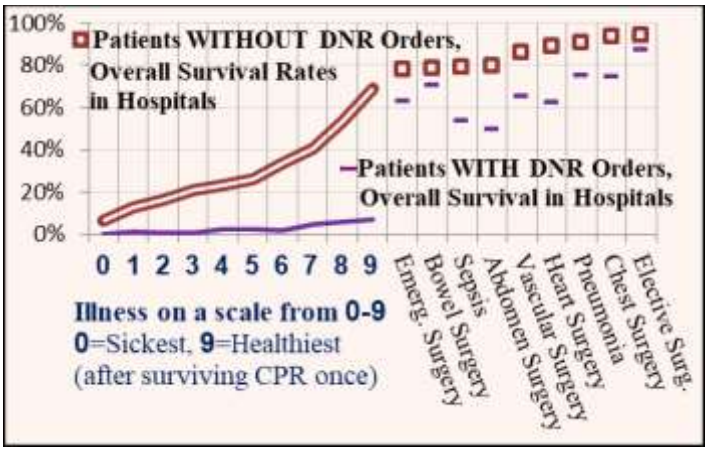
Organ donation of kidneys and liver is allowed after CPR.[31] 180,000 people die each year from sudden cardiac arrest.[32] These could donate: no age limit.[33] A 92-year old donated his liver to save a 69-year old. 400 people over 80 have donated livers.[34] Sign up at OrganDonor.gov.

Patients have many goals,[35] **and they matter.** DNR may support goals of less treatment, not being a burden, avoiding aging.[36] CPR may support activity, time with people, reaching milestones, closing one's affairs. Either can support dignity.[37] People who want to die at home[38] may want CPR if they collapse away from home.

Watching CPR on a loved one (video ▣ p.1) comforts families.[39] 59% of CPR survivors live over a year, usually mentally alert; 44% live over 3 years.[40]

Patients need to be thorough in telling doctors their goals, from getting through the day, to walking, going to church, gardening, sports, etc, since doctors adjust care to match your goals.[41] Many doctors reduce care if they think goals are too high to reach, or goals are so low you already reach them.[42] Goals and preferences change.[43]

People who have DNR orders get fewer diagnostic tests, antibiotics, transfusions, operations, stents, and less dialysis.[44] Doctors know that many DNR patients want less curative care, and more comfort care.[45] Many doctors "make assumptions to avoid a discussion with patients about end-of-life preferences."[46] 60% of US surgeons do not offer, to patients on DNR, operations like bypass, heart valves, or removing tumors.[47] Fewer DNR patients survive hospital stays, whatever their illness (graph[48]).



Up to 94% of the healthiest patients without DNR orders survive, and 6% of the sickest.[49] About 1/6 of the sickest needed under 4 minutes of CPR, and 1/6 over 37 minutes.[50]

Surgeons ask to suspend DNRs to operate.[51]

Medical offices ask for emergency contacts. These contacts need a form signed by you to see medical records, speak for you, and get 2nd opinions. (*Medical representative* forms are free online;[52] tell *Medicare* too.[53]) You can name 1 or 2 others to see records too, such as siblings, so they can get information. Contacts need good hearing, clarity, tact,[54] free time, and your trust.[55] Let them use their judgment or give them *Advance Directives* or a *Living Will*.[56] Many staff assume (without reading) that advance directives in your medical record, mean no curative care,[57] or may ignore it.[58] So directives are safer with your emergency contact than in hospital records.

You get CPR unless a **doctor signs a DNR order** (or *POLST-Physician Order for Life-Sustaining Treatment* or similar[59]). People may not realize a DNR order goes right into effect.[60] If your wishes depend on future events, you can tell your representative to get one later if needed. Hospitals can have or lose a DNR order without you knowing.[61] Check it if you are hospitalized. You can tell doctors to cancel a DNR any time.

Signatures from you or a doctor must be accessible, along with allergies, illnesses, prescriptions, doctors' and contacts' phones. Some can be taped to your driver's license or ID. Medics look for a state-approved bracelet[62] and ID. Signed forms can also be on the refrigerator, and online, at a web address shown on your bracelet or ID.[63]

Scenarios: What do you want, if the following situations happen next week, and your heart and breathing stop?[64] Many people want to **pray** and **discuss these issues** with others who are comfortable listening and discussing fears and the meaning of death.[65] Half the dying feel restless and confused;[66] worry is normal. When you're ready, answer for your **current** health. You can always change.	A. Do you want CPR?	B. Do you want CPR to continue until you get to an operating room, if someone can use your organs?	C. Do you want DNR, and expect most doctors will reduce other treatments too?	D. Do you want DNR and try to insist that all doctors give you full treatments except CPR?
1. Your heart stops next week in a hospital, while you have a heart monitor on, so nurses know immediately.				
2. Your heart stops next week in an office or mall, near an AED machine. An off-duty medic sees you collapse.				
3. You're in a car accident next week. Your heart stops from the impact.[67]				
4. Your heart stops next week where you live. A relative or friend who knows CPR sees you collapse.				
5. Your surgeon wants permission to give CPR during and right after an operation you want, if your heart stops.				
6. CPR revives you in a hospital, and you still have your mental abilities. Doctors often ask the next day if you want to change to DNR, though guidelines say to wait 3 days,[68] and to consult a brain specialist.[69] If you say CPR, you may leave the hospital alive. If you say DNR, you'll probably die in the hospital.[70]	If you choose DNR in 1-4, ask a doctor to sign an order. You will decide 5-6 when the time comes. If you choose DNR in 7-10, tell your representative. On issues like 7-10, many people give their representatives flexibility.[75] You can write that in.			
7. You drift into dementia without updating your DNR choice. You're never lucid, so cannot decide for yourself. You laugh and joke with family or other patients.				
8. You drift into dementia without updating your DNR choice. You're never lucid, so cannot decide for yourself. You groan at all music, TV or other stimulation. You rarely speak or recognize anyone.				
9. You're in a car accident next week, and go into a coma. Like "the vast majority" of coma patients, your eyes open in 2-3 weeks.[71] 70% of coma patients with specialized care show "accurate yes/no communication or object use" in an average of 16 weeks. 60% regain decision-making ability after 14 more weeks. Most of these go home to live partly or entirely independently.[72] Neurologists say the term *"permanent vegetative state" is no longer accurate*.[73] Right now you cannot say your preferences, so your representative(s) must decide your CPR/DNR status until you can decide.				
10. Do you want different actions on 7-9, while you cannot make your own decisions: a. If doctors estimate you have less than __ weeks to live? b. If pain doctors[74] cannot control your pain?				

Quotes from People who Chose CPR[76]

(Goodreads.com/quotes covers life and death)

I want to donate organs. Thousands of people are waiting for kidneys and livers. Keep up the CPR until I revive or you get me to an operating room, if you can use my organs.[77]

I like life…life has been very good to me.

The first thing I thought of was my daughter, then I said, yes…yes, resuscitate me.

I said you just do what you have to do to keep me alive. Because there is a lot that I want to do.

I would want to be resuscitated. If I didn't, then why would I come to the hospital?

I don't want to be on a machine for the rest of my life. I would consider anything that could be done within 3 months.[78]

Jessica was asked by 3 different doctors [about DNR]... This caused great distress... They stressed the trauma several times and... that as there is no cure for her cancer so why fight to live... she cried because she felt under pressure to give in... they were not listening to her... "It's pointless coming back I won't change my mind"... it happened again by two different doctors over the next couple of days.[79]

I'm 98. I had CPR when I was 92. If they do CPR again it may not work. It may break bones. But if they don't do CPR I'll be dead. Try it. Medical procedures can be messy, but they don't scare me. They don't hurt my dignity. Stop asking! I think my life is worthwhile, don't you?

Eight patients per 1,000 have cardiac arrest. CPR hurts 1/8 of them, so chance of injury from CPR is 1 in 1,000. DNRs reduce care for 1/3 of patients. So harm from DNR is **300 times** as likely as from CPR.[80]

Not if I'm gonna be like frozen if they resuscitate me, you know what I mean? PHYSICIAN: OK, but in the moment, we often don't know that. So, do you want us to give it like the best try we can–PATIENT: Oh yeah.[81]

Quotes from People who Chose DNR[82]

I'm 93. I'm not doing anyone any good, and I believe in Heaven. I have a DNR which the ambulance ignored. I wish they had let me die.

I can't stand up by myself out of bed, I need help with everything so what's the sense to try to keep on living?

If I only have 3 more months, I don't really want to have any more pain.

I wouldn't take the machine that would keep me going for a period of time.

It causes hardship for my family.

If I'm going to live on a machine, somebody will have to look after the machine, and I don't think that's fair.

It bothers me that society is paying all this money to stay alive.

I don't want to be kept artificially alive…when the body cannot sustain you, you are dead.

If I'm dying, let me die. You can't change something that is irrevocable.

The doctor convinced me CPR would break all Dad's ribs. Dad recently broke two ribs and probably wants CPR. But his kidneys are shot, so reviving him only offers 4-6 weeks. He'd want that time to enjoy his memories and his family, but I agreed to the DNR for him.[83]

Among young doctor trainees, 88% say they will want DNR when they become terminally ill.[84]

Among retired doctors, in their seventies, 90% wanted DNR if they had "irreversible brain damage."[85] That survey was done in 2002. Now brain damage is not usually seen as irreversible.[86]

Advocates for People with Disabilities Say People Adapt, and It Takes Time[87]

"[P]atients, having absorbed negative attitudes about disability and likely unaware of medical, technological and financial resources, don't realize they may be able to live satisfying lives... They and the medical providers who advise them often have had no exposure... Two, three months after an injury, you cannot be making an informed decision... You just don't have the experience yet." Many movies[88] show how people adjust to disabilities.

[1-88] Notes give more information on each topic, at medfacts.globe1234.com

The following notes are at DNR.globe1234.com, not in the 4-page printed pamphlet. This website also shows videos of CPR, successful and not.

[1] Background for this pamphlet:

- The source notes here are broader than just what is needed to document the facts in the pamphlet. Extra information here lets people explore each topic.
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- **Links to the papers go to free copies whenever possible. For other papers, you can search for the title at https://scholar.google.com , and any free copies are listed there in the right column.** Scholar.Google includes free collections like ResearchGate and Academia, but not Sci-Hub. If you find a free copy not listed here, please tell info@globe1234.com
- 2016 Jordan et al. say two thirds of patients want to **learn about DNR from a pamphlet**, and it needs to cover survival rate, risks and mechanics of CPR: ASSOCIATIONS WITH RESUSCITATION CHOICE: DO NOT RESUSCITATE, FULL CODE OR UNDECIDED *Patient Education and Counseling* https://www.sciencedirect.com/science/article/pii/S0738399115301440#sec0110
- 2018 Navar et al. say a **bar graph is more motivating** to patients than a pictograph: INFLUENCE OF CARDIOVASCULAR RISK COMMUNICATION TOOLS AND PRESENTATION FORMATS ON PATIENT PERCEPTIONS AND PREFERENCES *JAMA Cardiology* https://jamanetwork.com/journals/jamacardiology/fullarticle/2711641
- 2018 Breu inspired this pamphlet by noting that CPR always has better (lower) death rate than DNR, and what matters to people is not the death rate, but level of injuries and ability to talk to families *after* CPR:, CLINICIAN-PATIENT DISCUSSIONS OF SUCCESSFUL CPR—THE VEGETABLE CLAUSE *JAMA Internal Medicine* https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2697393
- 2019 Saver et al. justify showing survival as percents, not number needed to treat, since percents are easier to compare among groups. "benefit per hundred... more readily facilitates comparisons because it expresses the treatment effect magnitude using a uniform (100) and familiar (from percentages) denominator" NUMBER NEEDED TO TREAT CONVEYING THE LIKELIHOOD OF A THERAPEUTIC EFFECT. JAMA Guide to Statistics and Methods, 2019 https://jamanetwork.com/journals/jama/fullarticle/2724456
- 2006 Ewanchuk and Brindley give a brief history of CPR and DNR policies ETHICS REVIEW: PERIOPERATIVE DO-NOT-RESUSCITATE ORDERS – DOING 'NOTHING' WHEN 'SOMETHING' CAN BE DONE *Critical Care* https://ccforum.biomedcentral.com/articles/10.1186/cc4929

Images are free of copyright:

- Drawing of CPR: https://commons.wikimedia.org/wiki/File:Cardiopulmonary_Resuscitation_Adult.jpg
- Drawing of woman: https://catalog.niddk.nih.gov/catalog/imagelibrary/detail.cfm?id=416

Readability:

- Flesch-Kincaid Grade Level: 5.9 (sixth grade)
- Flesch Reading Ease: 72.9 (text scale), *fairly easy*
- http://www.readabilityformulas.com/freetests/six-readability-formulas.php
- https://www.online-utility.org/english/readability_test_and_improve.jsp

Author:

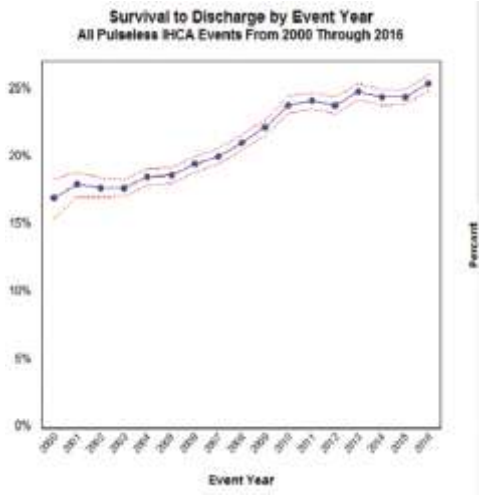
Paul Burke, A.M. is an expert in data analysis, and analyzes health care issues from the patients' perspective. He has managed and analyzed data for Congress' Office of Technology Assessment, the UN Development Program, the Census Bureau, and chaired the committee on member surveys for a health care cooperative with 100,000 members. He has an undergraduate degree in Mathematics, and a Master's degree in Interdisciplinary Urban

Studies, both from Brown University. He has led seminars at the University of California-Berkeley, Columbia University, Fordham University, Venezuela's National Council on Human Resources, and the International Labor Statistics Center of the US Department of Labor.

[2] **True video of the CPR, not actors**. This video was made for a BBC TV show, *Real Rescues*, Series 4, Episode 6, broadcast 9 Nov 2009. BBC rides with emergency vehicles to film what happens, and gets permission later to broadcast it. https://Youtu.be/nxpYuVr53zQ and https://www.bbc.co.uk/programmes/b00nz0nc

John Ellsworth, who was resuscitated, is a grandfather of 6, a retired seaman, in Southampton, England. He spent 4 days in intensive care, and got an implanted defibrillator. https://www.dailyecho.co.uk/news/5045923.pcso-brought-me-back-to-life/ His goal when he recovered was to travel with his wife.

[3] **Survival of 26,178 patients who got CPR in hospitals** in 2017: **page e381** "*Survival to hospital discharge was 25.6%*" and **page e390** "*Survival to hospital discharge... 25.6*" in: "HEART DISEASE AND STROKE STATISTICS—2019 UPDATE" *Circulation* https://www.ahajournals.org/doi/10.1161/CIR.0000000000000659
Trend graph of in-hospital cardiac arrest (IHCA) on p.e392:

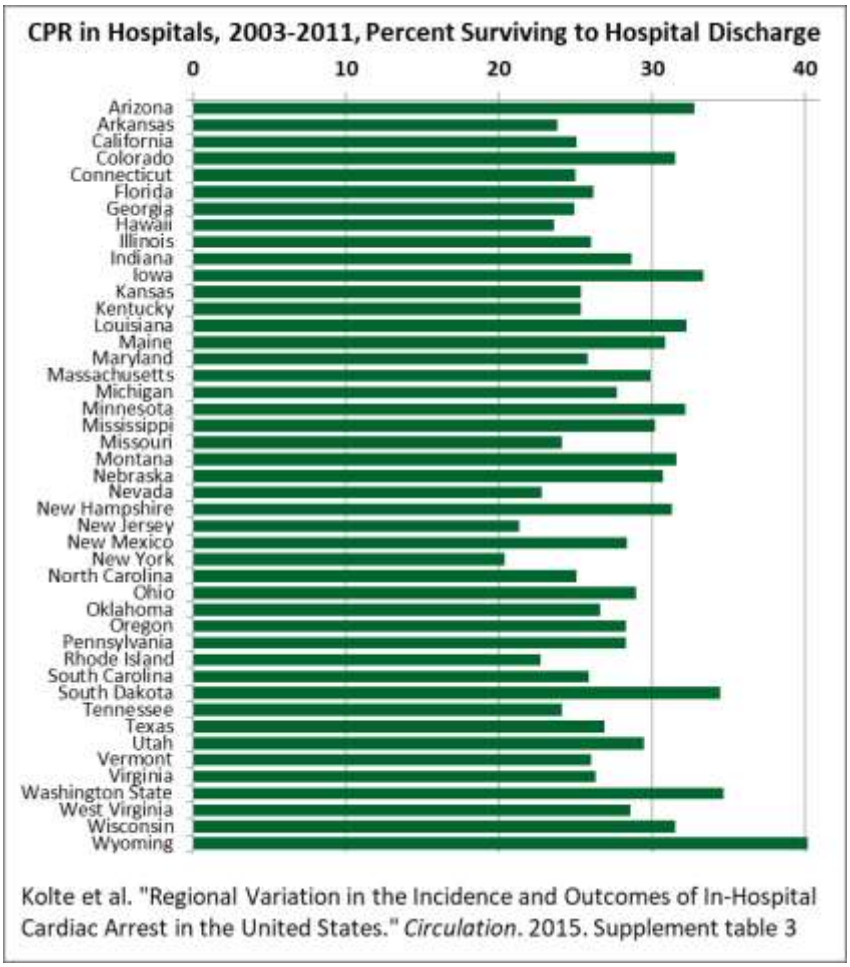


Trying CPR is cheap, $185 under Medicare; it is procedure code 92950. Further care costs much more, but is only done on the living, or to save organs for transplant.

[4] **State variations: 2015 Kolte et al. data on 838,465 patients 2003-11** in hospitals. REGIONAL VARIATION IN THE INCIDENCE AND OUTCOMES OF IN-HOSPITAL CARDIAC ARREST IN THE UNITED STATES. *Circulation*. Supplement table 3: https://www.ahajournals.org/doi/suppl/10.1161/CIRCULATIONAHA.114.014542

State	Risk-Adjusted Survival (%)				
USA	**24.7**				
Wyoming	40.2	Utah	29.5	Maryland	25.8
Washington	34.7	Ohio	29.0	Kansas	25.4
South Dakota	34.5	Indiana	28.7	Kentucky	25.4
Iowa	33.4	West Virginia	28.6	California	25.1
Arizona	32.8	New Mexico	28.4	North Carolina	25.1
Louisiana	32.3	Oregon	28.3	Connecticut	25.0
Minnesota	32.2	Pennsylvania	28.3	Georgia	24.9
Montana	31.6	Michigan	27.7	Missouri	24.1
Colorado	31.5	Texas	26.9	Tennessee	24.1
Wisconsin	31.5	Oklahoma	26.6	Arkansas	23.8
New Hampshire	31.3	Virginia	26.3	Hawaii	23.6
Maine	30.9	Florida	26.2	Nevada	22.8
Nebraska	30.7	Illinois	26.0	Rhode Island	22.7
Mississippi	30.2	Vermont	26.0	New Jersey	21.3
Massachusetts	29.9	South Carolina	25.9	New York	20.4

Alaska and North Dakota excluded, since each had less than 100 patients with CPR



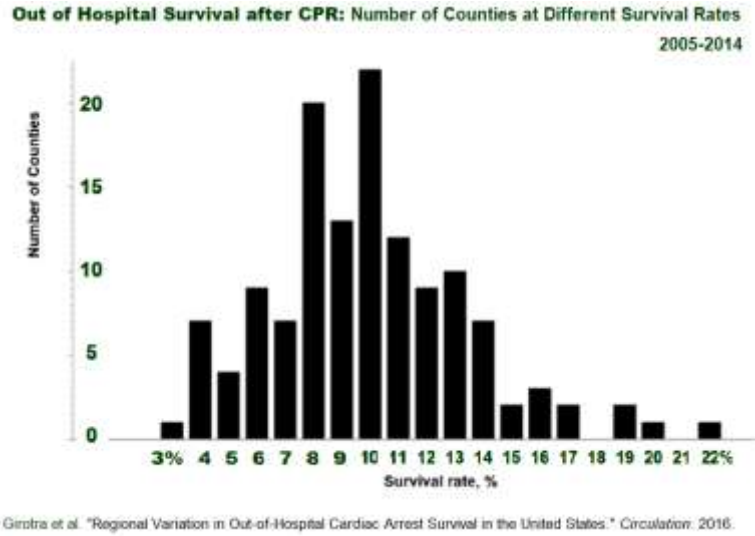
2018 Nallamothu et al. "Resuscitation teams at top-performing hospitals demonstrated the following features: dedicated or designated resuscitation teams; participation of diverse disciplines as team members during IHCA; clear roles and responsibilities of team members; better communication and leadership during IHCA; and in-depth mock codes." How Do Resuscitation Teams at Top-Performing Hospitals for In-Hospital Cardiac Arrest Succeed? *Circulation.* https://www.ahajournals.org/doi/full/10.1161/CIRCULATIONAHA.118.033674

2018 Okubo et al. In different ambulance companies, survival ranged from under 2% to over 20%. Variation in Survival After Out-of-Hospital Cardiac Arrest Between Emergency Medical Services Agencies *JAMA Cardiology.*https://jamanetwork.com/journals/jamacardiology/fullarticle/2704017

2008 Peberdy et al. Survival in a large sample of hospitals 2000-2007 ranged from 22% for CPR at 3pm to 13% at 4am, so there is room for improvement. In operating rooms where staff are focused on patients, survival averaged 37% in the day and 17% at night. Survival on weekend days was closer to nighttime survival than to weekday survival.Survival From In-Hospital Cardiac Arrest During Nights and Weekends. *JAMA* https://jamanetwork.com/journals/jama/fullarticle/181485

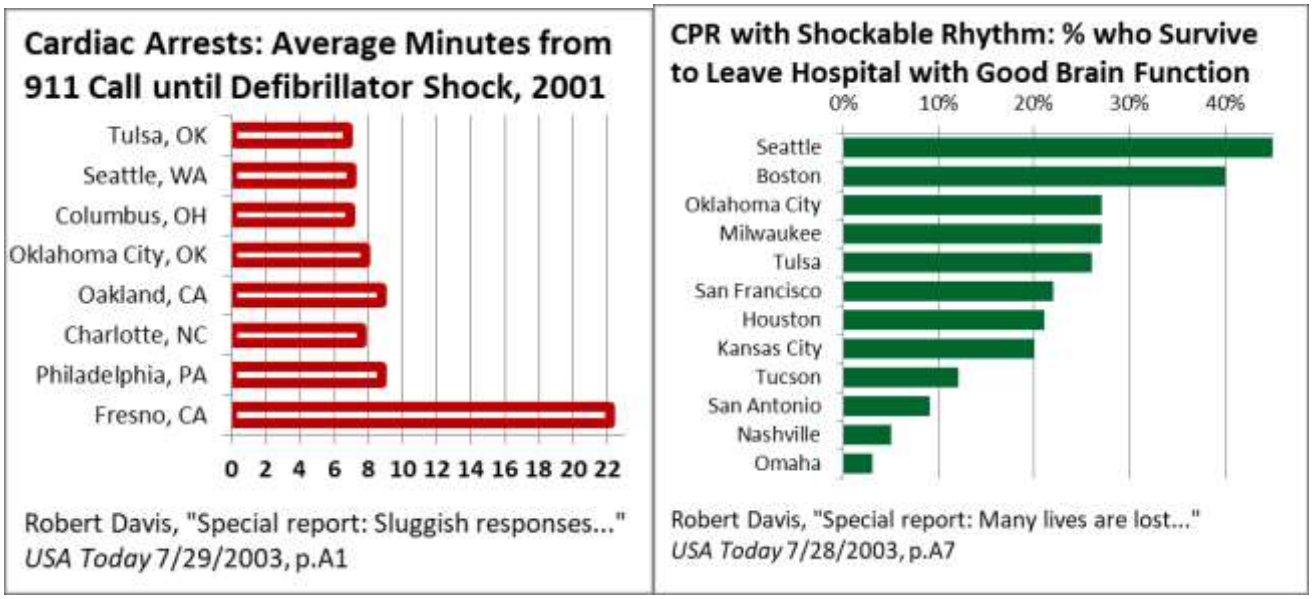
[5] **Survival of 37,155 patients who got CPR outside hospitals** in 2017 "*Bystander witnessed... (16.1)... 911 Responder witnessed... (18.1)*": https://mycares.net/sitepages/uploads/2018/2017%20Non-Traumatic%20National%20Survival%20Report.pdf

[6] **Some places have better survival than average** outside hospitals: **2016 Girotra** et al. found a range of survival from 3% to 22% in different counties for CPR performed in 2005-14. Regional Variation in Out-of-Hospital Cardiac Arrest Survival in the United States. *Circulation*. https://www.ahajournals.org/doi/full/10.1161/CIRCULATIONAHA.115.018175



2003 Davis wrote heart-rending articles in *USA Today* about 911 calls for cardiac arrest, and unnecessary delays. He found a range of response times and outcomes in different cities in 2001. Delays were caused by lack of monitoring, and the mismatch between recruiting people as firefighters, though most calls are medical, so staff resisted and delayed on the medical calls. Building codes have cut the number of fires, but staff still think of themselves as firefighters. Robert Davis describes heroic management efforts to improve medical service, and sad tales of lives suddenly cut short, from slow response.

- SPECIAL REPORT: MANY LIVES ARE LOST ACROSS USA BECAUSE EMERGENCY SERVICES FAIL ; TURF WARS BETWEEN AMBULANCE, FIRE CREWS CAUSE DEADLY DELAYS July 28, 2003, p.A6, with numbers corrected on July 29
- SPECIAL REPORT: SLUGGISH RESPONSES TO EMERGENCIES LET PATIENTS DIE; PRECISE MEASURES OF EMS RESPONSE TIMES CAN SAVE LIVES July 29, 2003, p.A1
- THE METHOD: MEASURE HOW MANY VICTIMS LEAVE THE HOSPITAL ALIVE July 28, 2003, p.A7
- DOCTORS IN CHARGE RARELY CALL THE SHOTS ; MOST MEDICAL DIRECTORS IN BIG CITIES LACK THE POWER TO IMPROVE THE SYSTEM July 29, 2003, p.A9
- ONE CITY SAVES LIVES, OTHERS FAIL TO LEARN ; AGGRESSIVE LEADERSHIP BRINGS SWIFT RESPONSE TO MEDICAL EMERGENCIES July 30, 2003, p.D1



2017 Mell et al. EMERGENCY MEDICAL SERVICES RESPONSE TIMES IN RURAL, SUBURBAN, AND URBAN AREAS, *JAMA Surgery*. https://jamanetwork.com/journals/jamasurgery/fullarticle/2643992 found:

Response times for all ambulance calls, from call to arrival on scene, in 2015 for 485 EMS agencies in US

	Average	25th Percentile	50th	75th	90th
Urban	7.0	4	6	9	12
Suburban	7.7	4	6	10	14
Rural	14.5	8	13	19	26

2005 Bill Dedman at the *Boston Globe* similarly counted **fire** response times, for each fire department in the US 1986-2002, which may correlate with medical response times in those years. Hopefully they're faster now:

- Detail on Massachusetts towns http://archive.boston.com/news/specials/fires/
- Less detail on 20,000 US fire companies http://site.votewell.net/fire.xls

[7] **Drug researchers** count the number of deaths in people taking each medicine, compared to the number of deaths among similar people in control groups. The difference in deaths is the number of lives saved by taking the medicine, per hundred patients. Most people don't die either way, and medicines only stop some of the deaths. Those are the lives saved by the medicine.

Heart Medicines	5-year Risk of Death, Per 100 Patients		Lives Saved by Taking Each Medicine for 5 Years, per 100 Patients
	Control Group	Intervention Group	
Statins (deaths from all causes)*	2.8	2.2	0.6
Statins (deaths from coronary heart disease)**	4.4	3.4	1.0
Angiotensin II receptor blocker (ARB)	40.5	36.3	4.2
Angiotensin receptor neprilysin inhibitor vs. enalapril (ARNI)	36.7	31.9	4.8
Angiotensin-converting enzyme inhibitor (ACE inhibitor)	43.8	38.3	5.5
Mineralocorticoid receptor antagonist (MRA)	35.8	29.3	6.5
Cardiac resynchronization therapy (CRT)	32.4	25.4	7.0
Implantable cardioverter defibrillator (ICD)	36.1	28.9	7.2
Angiotensin receptor neprilysin inhibitor vs. imputed placebo	41.3	31.9	9.4
Beta blocker	42.3	30.4	11.9

*Statins 2008 study: https://www.nejm.org/doi/10.1056/NEJMoa0807646

**Statins 2005 meta-analysis: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(05)67394-1/fulltext

Other medicines are summarized in a 2018 multi-university report: **2018 Srivastava** et al.. ESTIMATED 5-YEAR NUMBER NEEDED TO TREAT TO PREVENT CARDIOVASCULAR DEATH OR HEART FAILURE HOSPITALIZATION WITH ANGIOTENSIN RECEPTOR-NEPRILYSIN INHIBITION VS STANDARD THERAPY FOR PATIENTS WITH HEART FAILURE WITH REDUCED EJECTION FRACTION - AN ANALYSIS OF DATA FROM THE PARADIGM-HF TRIAL *JAMA CARDIOLOGY*. https://jamanetwork.com/journals/jamacardiology/fullarticle/2716298 The specific Table 3 is at: https://jamanetwork.com/data/journals/cardiology/0/hbr180027t3.png

Another standard reference on the Number you Need to Treat to save one patient (NNT) covers many diseases. It summarizes that Statins save 1 of every 83 patients taking statins (1.2%) from death: http://www.thennt.com/nnt/statins-for-heart-disease-prevention-with-known-heart-disease/ Same source says statins also save 1 in 39 (2.6%) from non-fatal heart attack and 1 in 125 (0.8%) from stroke.

2016 Boston Globe report on statins quotes the same 1 saved for every 83 patients with known heart disease, so lives saved=1.2%: https://www.statnews.com/2016/06/15/medication-number-needed-to-treat/

A British source on NNT - Number Needed to Treat is http://www.bandolier.org.uk/band50/b50-8.html

2016 Prasad et al. say cancer screening, saves few or no lives. WHY CANCER SCREENING HAS NEVER BEEN SHOWN TO "SAVE LIVES"—AND WHAT WE CAN DO ABOUT IT *British Medical J.* https://jeannelenzer.com/s/BMJ-Prasad-Why-cancer-screening.pdf

[8] **Recovery from comas**: **2009 Katz** et al. study of patients during 2003 – 2008. NATURAL HISTORY OF RECOVERY FROM BRAIN INJURY AFTER PROLONGED DISORDERS OF CONSCIOUSNESS: OUTCOME OF PATIENTS ADMITTED TO INPATIENT REHABILITATION WITH 1–4 YEAR FOLLOW-UP *Progress in Brain Research* https://www.sciencedirect.com/science/article/pii/S0079612309177075

- "The natural history of recovery from brain injury typically consists of a period of impaired consciousness, a subsequent period of confusion and amnesia, followed by a period of post-confusional recovery of function... The transition from coma to VS [vegetative state], which occurs within 2-3 weeks in the vast majority of survivors..." Then **72%** emerged from Minimally Conscious State (MCS), and **58%** emerged from Confusional State/Post-traumatic Amnesia (CS/PTA) "by latest follow-up. It took significantly longer for patients admitted in VS (means: MCS, 16.43 weeks; CS/PTA, 30.1 weeks)... The transition from the MCS to the next stage, labeled CS/PTA is marked by the Aspen work group criteria of accurate yes/no communication or object use..."
- **Further stages of recovery** from the same study: **Partly independent:** "**43%** patients achieved household independence (ability to be left alone for 8 h"). **Entirely independent:** "**22%** returned to work or school, **17%** at or near pre-injury levels... "
- "Most of these outcome studies were performed with patients admitted to hospital-level rehabilitation facilities with specialized programs... In the United States, public and private payers for health services have traditionally considered persons with prolonged impairments of consciousness inappropriate candidates for active rehabilitation assessment and treatment and they are often denied admission to hospital- level rehabilitation facilities... "

Permanent Vegetative State no longer accurate: 2018 guidelines on disorders of consciousness: "Given the frequency of recovery of consciousness after 3 months in patients in nontraumatic VS/UWS [vegetative state/unresponsive wakefulness syndrome], and after 12 months in patients with traumatic VS/UWS (including some cases emerging from MCS [minimally conscious state]), use of the term permanent VS should be discontinued." **2018 Giacino** et al. PRACTICE GUIDELINE UPDATE RECOMMENDATIONS SUMMARY: DISORDERS OF CONSCIOUSNESS. *Neurology*. http://n.neurology.org/content/91/10/450.long

2016 Tong et al had similar findings in an earlier study. FUNCTIONAL NEUROLOGIC OUTCOMES CHANGE OVER THE FIRST SIX MONTHS AFTER CARDIAC ARREST *Critical Care Medicine* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5115936/

New brain pathways can form to bring patients out of comas:

- 2018: https://www.flintrehab.com/2018/can-the-brain-heal-itself-after-a-stroke/
- 2006: https://www.sciencedaily.com/releases/2006/12/061223092924.htm
- 2006: https://www.newscientist.com/article/dn9474-rewired-brain-revives-patient-after-19-years/

[9] Mental abilities after CPR in hospitals:

1% more survivors were in comas than before CPR. 5% more needed help with daily life. 5% more declined while staying inde¬pen¬dent. . Based on 12,517 survivors from US national data 2000-2009, the most recent study. Appendix shows survivors' CPC mental levels after CPR, and estimates of CPC before CPR from family and medical notes. A surprising number of those reports showed more mental problems before CPR, so figures here reflect net change, not gross change. Hospitals have improved CPR, so these rates are not likely to have deteriorated since 2009.

Survivors, by CPC Mental Level	Patients at This Level before Cardiac Arrest	Patients at This Level at Discharge	Net Change	As % of Survivors
1. Not significant mental problems	7,678	6,251	-1,427	-11%
2. Mental problems, independent	3,329	3,920	591	5%
3. Dependent on others	1,142	1,816	674	5%
4. Coma	368	530	162	1%
Total	12,517	12,517		

Source: **2012 Chan** et al. A VALIDATED PREDICTION TOOL FOR INITIAL SURVIVORS OF IN-HOSPITAL CARDIAC ARREST *Archives of Internal Medicine.*
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3517176/bin/NIHMS424599-supplement-Appendix.doc

- Definition of CPC mental levels: https://web.archive.org/web/20180126203858/http://www.fda.gov/ohrms/dockets/ac/05/briefing/2005-4100b1_03_CPC%20Scale.pdf
- Earlier, smaller study of 2000-2008 patients did not distinguish between severe and minor decline, and found 14% of survivors who had lived in nursing homes before hospitalization declined after in-hospital CPR, and 16% of those not living in nursing homes: Abbo et al, 2013. CARDIOPULMONARY RESUSCITATION OUTCOMES IN HOSPITALIZED COMMUNITY-DWELLING INDIVIDUALS AND NURSING HOME RESIDENTS BASED ON ACTIVITIES OF DAILY LIVING. *J. of the American Geriatric Society.* http://www.ncbi.nlm.nih.gov/pubmed/23311551

CPR is not the only procedure with risk of mental decline. Operations for heart surgery and hip replacement leave ½ to ¾ of patients delirious for some amount of time, and some with reduced cognitive function later:

- Saczynski et al. COGNITIVE TRAJECTORIES AFTER POSTOPERATIVE DELIRIUM *NEJM* 2012. https://www.nejm.org/doi/full/10.1056/NEJMoa1112923 and
- Witlox et al. 2013. THE NEUROPSYCHOLOGICAL SEQUELAE OF DELIRIUM IN ELDERLY PATIENTS WITH HIP FRACTURE THREE MONTHS AFTER HOSPITAL DISCHARGE *International Psychogeriatrics* https://www.researchgate.net/publication/236653087

Mental abilities after CPR outside hospitals: patients from 2007-11 in Copenhagen: one more patient of every 200 was in a coma after CPR. 10% more patients began to need daily help. 21% more declined while staying independent. **Søholm et al. 2014** RESUSCITATION OF PATIENTS SUFFERING FROM SUDDEN CARDIAC ARRESTS IN NURSING HOMES IS NOT FUTILE *Resuscitation* https://www.resuscitationjournal.com/article/S0300-9572(13)00842-3/fulltext

[10] **Surgery side effects:** Data are quoted from the first reference. The others confirm the numbers.

- **2018 Hood** et al. REVIEW ARTICLE, PERI-OPERATIVE NEUROLOGICAL COMPLICATIONS, *Anaesthesia* https://onlinelibrary.wiley.com/doi/epdf/10.1111/anae.14142
- **2018 Evered** et al. RECOMMENDATIONS FOR THE NOMENCLATURE OF COGNITIVE CHANGE ASSOCIATED WITH ANAESTHESIA AND SURGERY—2018, *Anesthesiology* http://anesthesiology.pubs.asahq.org/data/journals/jasa/937574/20181100.0-00013.pdf
- **2018 Safavynia** et al AN UPDATE ON POSTOPERATIVE DELIRIUM: CLINICAL FEATURES, NEUROPATHOGENESIS, AND PERIOPERATIVE MANAGEMENT *Current Anesthesiology Reports* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6290904/
- **2015 Mashour** et al. NEUROLOGICAL COMPLICATIONS OF SURGERY AND ANAESTHESIA *British J. of Anaesthesia.* https://academic.oup.com/bja/article/114/2/194/293595

[11] **Physical injuries:** 13% overall, including 9% with broken bones, in 2009-12, from CPR outside hospital, MN and WI: **2015 Boland** et al. CHEST COMPRESSION INJURIES DETECTED VIA ROUTINE POST-ARREST CARE IN PATIENTS WHO SURVIVE TO ADMISSION AFTER OUT-OF-HOSPITAL CARDIAC ARREST, *Prehospital Emergency Care*. https://www.ncbi.nlm.nih.gov/pubmed/25076024

Oschatz 2001. 12% Compression injuries, 8% broken bones in 1997-99, published 2001: CPR in and out of hospitals, Vienna: CARDIOPULMONARY RESUSCITATION PERFORMED BY BYSTANDERS DOES NOT INCREASE ADVERSE EFFECTS AS ASSESSED BY CHEST RADIOGRAPHY. *Anesthesia and Analgesia.* https://www.ncbi.nlm.nih.gov/pubmed/11429353

[12] **Ribs heal:** https://www.nhs.uk/conditions/broken-or-bruised-ribs/

https://healthcare.utah.edu/the-scope/shows.php?shows=0_vtl3zc38

[13] **Cartilage:** http://heartsavercpromaha.com/cpr-review---keeping-it-real.html

http://emtlife.com/threads/cpr-breaking-bones.23116/

[14] **Life-threatening:** 1% in 2009-12, published 2015: CPR outside hospital, MN and WI: Boland 2015. CHEST COMPRESSION INJURIES DETECTED VIA ROUTINE POST-ARREST CARE IN PATIENTS WHO SURVIVE TO ADMISSION AFTER OUT-OF-HOSPITAL CARDIAC ARREST. *Prehospital Emergency Care.*
https://www.ncbi.nlm.nih.gov/pubmed/25076024

[15] **Survival of nursing home residents** whose heart stops in a hospital is average (see table below).

[16] Survival to Hospital Discharge	Group's Survival Rate	Overall Survival in Study	Group Rate as Fraction of Overall	Survival Updated to Current Levels	Sample Size	Patient Data	Sources. More details are in notes above
Current Total, Outside Hospitals, Adults	10%	10%	1.0	10%	79,356	2018	
Outside Hospitals, Adults where Bystander used AED, not in health facility or nursing home	35%	10%	3.3	35%	1,349	2018	mycares.net
Outside Hospitals, Witnessed Adults, with or without AED	16%	10%	1.6	16%	39,976	2018	
Outside Hospitals, Unwitnessed Adults	4%	10%	0.4	4%	39,378	2018	
OUTSIDE HOSPITALS, MULTIPLE CONDITIONS, King County WA, excluding Seattle							
4-8 Major health conditions	18%	34%	0.5	9%	98	99-03	
3 Major health conditions	24%	34%	0.7	12%	125	99-03	
2 Major health conditions	33%	34%	1.0	16%	211	99-03	Carew pubmed.gov/17309904
1 Major health condition	35%	34%	1.0	17%	323	99-03	
0 Major health conditions	43%	34%	1.3	21%	286	99-03	
OUTSIDE HOSPITALS, AT NURSING HOMES							
Nursing homes	4.3%	10.4%	0.4	4%	9,105	2018	
Nursing homes	4.1%	10.4%	0.4	4%	8,655	2017	
Nursing homes	4.4%	10.8%	0.4	4%	6,477	2016	
Nursing homes	4.4%	10.6%	0.4	4%	5,695	2015	
Nursing homes	4.5%	10.8%	0.4	4%	4,786	2014	
Nursing homes	5.0%	10.8%	0.5	5%	3,713	2013	mycares.net
AED used by staff or bystander in nursing home or health facility	9.5%	10.4%	0.9	10%	3,809	2018	
	10.1%	10.4%	1.0	10%	3,329	2017	
	12.2%	10.8%	1.1	12%	2,229	2016	
	10.0%	10.6%	0.9	10%	1,887	2015	
	11.4%	10.8%	1.1	11%	1,422	2014	
Nursing homes, group homes, and assisted living, King Co. (exc. Seattle)	4%	na	na	na	218	99-00	Becker pubmed.gov/12879377
Nursing homes, Denmark, live 30 days	2%	5%	0.4	na	2,516	2001-14	
Nursing homes, Denmark, best case: witnessed, bystander CPR, AED before hospital, live 30 days	8%	23%	0.3	na	135	2001-14	Pape pubmed.gov/29425977
Nursing homes, Denmark, ROSC	12%	13%	0.9	na	2,516	2001-14	
Nursing homes, Copenhagen	9%	17%	0.6	9%	245	2007-11	Søholm pubmed.gov/24269866
Nursing homes, Rochester, ROSC	19%	20%	1.0	15%	42	98-01	Shah pubmed.gov/17352981
Current Total, Inside Hospitals	**26%**	26%	1.0	26%	22,960	2016	2018 update pubmed.gov/2938620
INSIDE HOSPITALS, MULTIPLE CONDITIONS, Deyo-Charlson score, higher means higher burden of chronic illness							
3-33 highest burden of chronic illness	16%	18%	0.9	23%	94,608	92-05	
2	19%	18%	1.0	27%	116,401	92-05	Ehlenbach pubmed.gov/19571280
1 low burden	19%	18%	1.0	27%	145,627	92-05	
0 lowest burden	19%	18%	1.0	26%	77,349	92-05	
INSIDE HOSPITALS, NURSING HOME RESIDENTS IN DIFFERENT YEARS							

Nursing home or other not home	17%	19%	0.9	22%	34,342	2001-10	Merchant et al.
Nursing home residents	11%	16%	0.7	17%	2,845	2000-08	Abbo pubmed.gov/23311551
Nursing home residents, mental CPC=3, dependent	9%	16%	0.5	14%	1,299	2000-08	
Skilled nursing facility	12%	18%	0.6	16%	10,924	92-05	Ehlenbach pubmed.gov/19571280
INSIDE HOSPITALS, INDIVIDUAL CONDITIONS							
Mental problems (CPC=3), dependent	10%	16%	0.6	16%	4,251	2000-08	Abbo pubmed.gov/23311551
Advanced Cancer*	10%	18%	0.5	14%	6,585	2006-10	Bruckel, pubmed.gov/28763260
Cancer or blood disease	10%	19%	0.5	14%	16,640	2001-10	Merchant ahajournals.org/doi/suppl/10.1161/JAHA.113.000400
Liver insufficiency/failure	10%	19%	0.5	13%	10,154	2001-10	
Septicemia	11%	19%	0.5	14%	21,057	2001-10	
Dialysis	12%	19%	0.6	16%	5,135	2001-10	
Pneumonia	14%	19%	0.7	19%	18,277	2001-10	
Respiratory insufficiency	16%	19%	0.8	21%	57,054	2001-10	
Congestive heart failure	19%	19%	1.0	26%	40,362	2001-10	
Diabetes	20%	19%	1.0	27%	41,154	2001-10	
Pacemaker/ICD (implanted cardioverter defibrillator)	20%	19%	1.1	27%	10,386	2001-10	
INSIDE HOSPITAL, LOCATION OF CARE							
Intensive care unit	18%	19%	0.9	24%	81,176	2001-10	Merchant ahajournals.org/doi/suppl/10.1161/JAHA.113.000400
Monitored, other than ICU	25%	19%	1.3	33%	30,100	2001-10	
Unmonitored	15%	19%	0.8	20%	22,899	2001-10	
Age 90+, ECG-monitored, live 30d	27%				355	2007-15	Hirlekar et al, Sweden, pubmed.gov/28736324
Age 80-89, ECG-monitored, live 30d	29%				2,237	2007-15	
Age 70-79, ECG-monitored, live 30d	40%				2,609	2007-15	
INSIDE HOSPITALS, PATIENT TRAITS							
Black race	15%	19%	0.8	20%	27,246	2001-10	Merchant et al
<$15k median income, patient zip code	13%	18%	0.7	19%	10,626	92-05	Ehlenbach pubmed.gov/19571280
$15-$30,000 median in patient's zip	18%	18%	1.0	25%	87,164	92-05	
Patients' ages 90 or older, Sweden	15%				1,008	2007-15	Hirlekar et al, Sweden, pubmed.gov/28736324
Patients' ages 80-89, Sweden	20%				5,156	2007-15	
Patients' ages 70-79, Sweden	28%				5,232	2007-15	
Patients' ages 90 or older, USA	12%	18%	0.7	17%	34,069	92-05	Ehlenbach pubmed.gov/19571280
Patients' ages 85-89	15%	18%	0.8	21%	62,530	92-05	
Patients' ages 80-84	17%	18%	0.9	24%	91,471	92-05	
Patients' ages 75-79	19%	18%	1.0	27%	98,263	92-05	
Patients' ages 70-74	21%	18%	1.1	29%	84,353	92-05	
Patients' ages 65–69	22%	18%	1.2	31%	63,299	92-05	
INSIDE HOSPITALS, INITIAL HEART RHYTHM BEFORE CPR							
Ventricular fibrillation (quiver) / ventricular tachycardia (rapid beat)	38%	19%	2.0	51%	27,653	2001-10	Merchant ahajournals.org/doi/suppl/10.1161/JAHA.113.000400
Stopped (asystole)	13%	19%	0.7	17%	46,856	2001-10	
Pulseless electrical activity	14%	19%	0.7	19%	53,965	2001-10	
Other	24%	19%	1.3	32%	7,422	2001-10	

*Bruckel et al. said cancer survival was "under 10%." Their figure was 9.6%, which rounds to 10% here.

Cancer was also studied by Champigneulle et al.in Paris. In 2015 they reported survival after patients entered ICUs, not overall. Cancer patients had the same ICU mortality and 6-month mortality as matched non-cancer patients. https://pubmed.gov/25917260

[17] ***Inside* nursing homes,** there are annual US national data, and earlier data for Denmark and a few cities (see table above). Most US nursing homes lack defibrillators, so your choice of nursing home affects your chance of resuscitation. Since *hospital* CPR saves 17% - 22% of nursing home residents (also in table above), many could do better if their nursing homes had AEDs.

- **2007 Fisher** et al. found that in 2004, 1 of 13 nursing homes in Boston had a defibrillator, 2 of 13 in Omaha, 4 of 38 in Philadelphia, and 8 of 24 in Seattle: LACK OF EARLY DEFIBRILLATION CAPABILITY AND

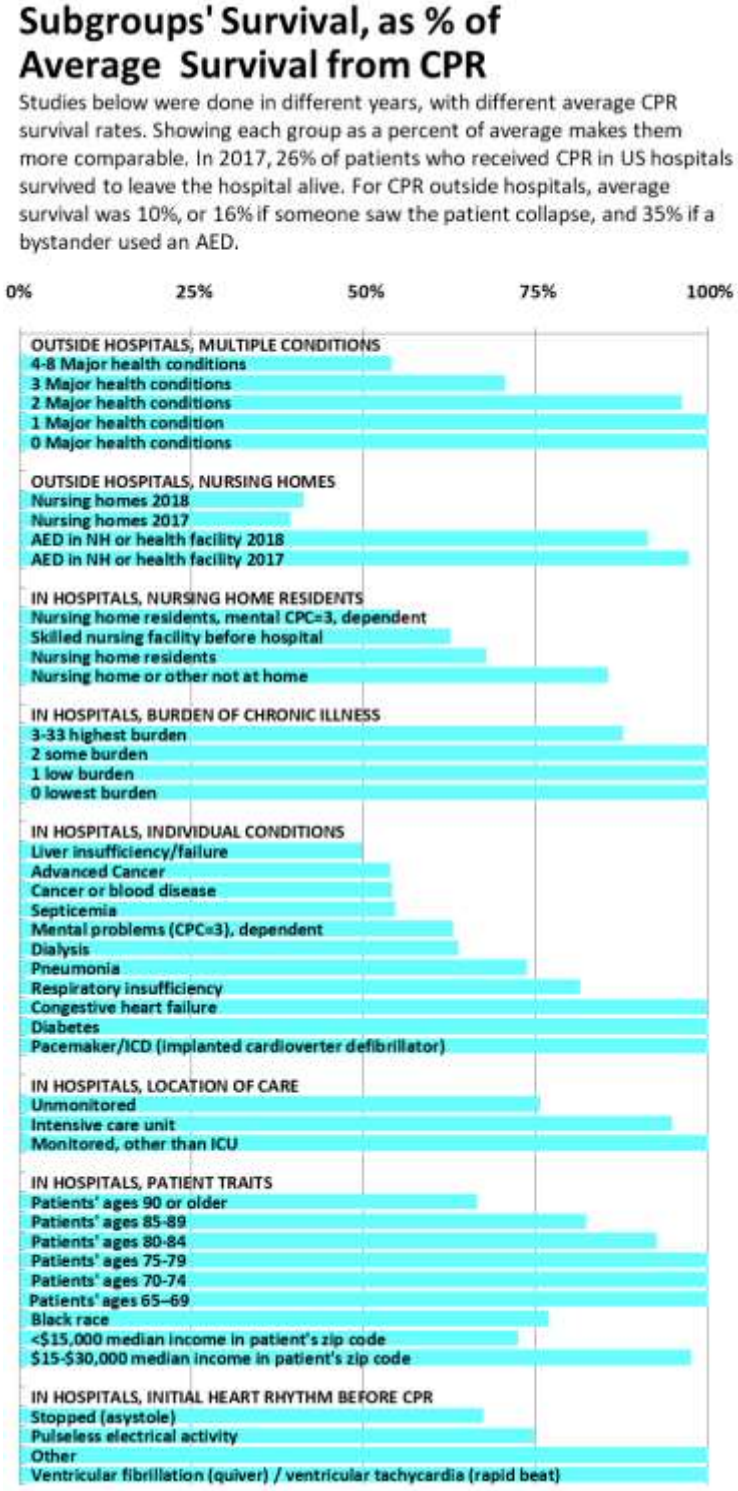
AUTOMATED EXTERNAL DEFIBRILLATORS IN NURSING HOMES. *J. of the American Medical Directors Association.* https://pubmed.gov/17619041

- **2018 Pape** et al. tracked 2,516 patients with CPR attempts in nursing homes in Denmark 2001-14, and 24,483 whose CPR was in neither nursing homes nor hospitals. 2% survived 30 days after CPR in nursing homes, 5% from elsewhere. They do not report survival to hospital discharge. If someone saw the collapse, started CPR, and they got AED before the hospital, 8% survived 30 days after CPR in nursing homes, 24% from elsewhere. Return of spontaneous circulation (ROSC) happened before reaching the hospital among 12% of nursing home residents with data available, 13% from elsewhere. Quick CPR and AEDs are important. In the overall study period, 1.1% of CPR attempts used an AED before EMS arrived. AEDs began to spread in Danish nursing homes around 2009, but by 2014 there were still only 211 AEDs, among 1,400 nursing home addresses (p.3 https://www.dst.dk/ext/velfaerd/Imputering). SURVIVAL AFTER OUT-OF-HOSPITAL CARDIAC ARREST IN NURSING HOMES – A NATIONWIDE STUDY *Resuscitation*. https://www.sciencedirect.com/science/article/pii/S0300957218300704
- **2014 Søholm** et al, covers part of the same time period, with 245 patients from 2007-11 in Copenhagen. They found survival after CPR in nursing homes at 9%, which was six tenths as high as the 17% in the community outside nursing homes. They did not report on AEDs, but the Danish national numbers above show AEDs were rare: RESUSCITATION OF PATIENTS SUFFERING FROM SUDDEN CARDIAC ARRESTS IN NURSING HOMES IS NOT FUTILE *Resuscitation* https://www.resuscitationjournal.com/article/S0300-9572(13)00842-3/fulltext
- **2006 and 2007 Shah** et al., is an older study of 42 patients in nursing homes 1998-2001 in Rochester NY. They recommend "an optimized system of care, which includes **immediate CPR and defibrillation, must be tested**." They did not measure survival to hospital discharge. They found return of spontaneous circulation (ROSC) and 1-year survival not statistically different for people in and out of nursing homes. Before 911 arrived, no one had AED and only 2/3 had CPR. Yet their hearts re-started (ROSC) at the same rate (19%) as others in Rochester (20%). Only one nursing home even owned an AED. The authors say more patients would survive with AEDs and CPR, which is what Denmark found in Pape's article. Survival at 1 year was 2%, not different statistically from 5% survival of others in Rochester. 2006 copy: CARDIAC ARRESTS IN SKILLED NURSING FACILITIES: CONTINUING ROOM FOR IMPROVEMENT? *J. of American Medical Directors Association* https://www.sciencedirect.com/science/article/pii/S1525861005006481 Same paper was in the same journal 2007: https://www.sciencedirect.com/science/article/pii/S1525861006006128
- **2003 Becker** et al., An equally old study in 1999-2000 in King County WA (excluding its major city, Seattle) found 4% survival where 911 responders gave CPR among residents of nursing homes, group homes and assisted living. This was the only study to cover assisted living or group homes. They do not say how residents were in each type of home, and they had no comparison to residents outside long term care. They did not report if AEDs were used. RESUSCITATION OF RESIDENTS WITH DO NOT RESUSCITATE ORDERS IN LONG-TERM CARE FACILITIES. *Prehospital Emergency Care* https://pubmed.gov/12879377
- Other studies are much older, with data from the 1980s and early 1990s:
- **1996 Benkendorf** et al. covers 182 CPR attempts in 1989-93 in Oakland County MI, a large suburban county outside Detroit. None survived to hospital discharge. OUTCOMES OF CARDIAC ARREST IN THE NURSING HOME: DESTINY OR FUTILITY? *Prehospital Emergency Care* https://www.tandfonline.com/doi/abs/10.1080/10903129708958790
- **1993 Duthie** et al. covers 195 CPR attempts in 1986-89 in Milwaukee, 5% survived to hospital discharge. UTILIZATION OF CARDIOPULMONARY RESUSCITATION IN NURSING HOMES IN ONE COMMUNITY: RATES AND NURSING HOME CHARACTERISTICS. https://Pubmed.gov/8463524
- **1992 Awoke** et al. cover 45 CPR attempts in 1987-90 at the Soldiers' and Airmen's Home in Washington DC. None survived to hospital discharge. OUTCOMES OF SKILLED CARDIOPULMONARY RESUSCITATION IN A LONG-TERM-CARE FACILITY: FUTILE THERAPY? https://pubmed.gov/1587977

- **1990 Applebaum** et al. covers 117 CPR attempts in 1987 in Baltimore, 2% survived to hospital discharge, THE OUTCOME OF CPR INITIATED IN NURSING HOMES**.** Pubmed.gov/2312998
- **1986 Kaiser** et al. covers 32 CPR attempts in a NY long term care facility. 16% lived over 30 days. J. of Am. Geriatrics Society p.909, SURVIVAL AFTER CARDIOPULMONARY RESUSCITATION IN A LONG TERM CARE INSTITUTION. https://onlinelibrary.wiley.com/toc/15325415/1986/34/12

[18] **Multiple conditions:** **2007 Carew** et al. study of CPR outside hospitals **1999-2003,** in King County, WA (excluding Seattle); survival to hospital discharge, as shown in table above: CHRONIC HEALTH CONDITIONS AND SURVIVAL AFTER OUT-OF-HOSPITAL VENTRICULAR FIBRILLATION CARDIAC ARREST *Heart* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1955210/

[19] **Groups surviving half to two thirds as well as average:** Sources in table above.



Also **2019 Pun** et al. found that dialysis centers do not always provide CPR, and half the time provide AED. Results are better when they do: OUTCOMES FOR HEMODIALYSIS PATIENTS GIVEN CARDIOPULMONARY RESUSCITATION FOR CARDIAC ARREST AT OUTPATIENT DIALYSIS CLINICS, *J. of the Am, Society of Nephrology* https://jasn.asnjournals.org/content/30/3/461 Summary at https://www.healio.com/nephrology/chronic-kidney-disease/news/online/%7B99f1ee44-07f1-43d9-841b-8bbddf5d3aa1%7D/cpr-increases-survival-but-is-underused-by-dialysis-staff-efforts-vary-among-clinics

[20] **Futility** in **AHA/ECC Guidelines** since 2010: "An objective criterion for medical futility was defined in 1990 for interventions and drug therapy as imparting a <1% chance of survival.[13] Although this criterion may be controversial, it remains a basis for current futility research." https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-3-ethical-issues/?strue=1&id=3-2

2007 Burns and Truog trace 3 approaches in the recent history of futility and in legal cases on it:

1. Definitions, such as less than 1% success, or long term dependence on medical care. The authors note lack of societal agreement on 1%, or that dependence is wrong, especially when cases go to court.
2. Procedures, where (a) doctors decide futility on grounds which seem appropriate to them, (b) their hospital colleagues on an ethics committee endorse or overrule their view, and (c) patients can appeal to court or transfer to another hospital if they disagree. The authors note the lack of (or erroneous) information on prognosis, and the lack of due process or equality between patients and hospitals, where the committee is "a group that is virtually indistinguishable from the clinicians themselves." The lack of definitions and evidence gives discretion to doctors without making clear how patients and surrogates can convince them otherwise.
3. Communication improvements, which are used in business negotiations between equals, such as generating a variety of options, getting outside (non-hospital) mediators and second opinions. The authors recommend that if there is still an impasse, the hospital should do what the patient or surrogate wants, except in rare cases where the hospital can prove to a court that a surrogate is harming a patient, so the court can appoint a new surrogate to negotiate with.

   FUTILITY: A CONCEPT IN EVOLUTION, *Chest* https://www.sciencedirect.com/science/article/pii/S0012369215524768

2013 Rubin and Courtwright criticize the concept and procedures of futility:

- "health-care providers are notoriously unreliable in predicting general clinical outcomes, including death. For example, Meadow et al 10 found that 16% of patients in the ICU who every member of the care team agreed would die during their hospitalization survived to discharge... "
- "substantial variability among individual health-care provider assessments of whether ongoing treatment was futile, suggesting that whether a patient is referred to a medical futility process depends as much on individual provider factors as the patient's medical condition."
- "it is likely that racial minorities are overrepresented in procedural medical futility cases. 12-15 Without further data on the factors that lead providers to invoke medical futility procedures, we do not know whether the use of these procedures is arbitrary; unrelated to actual medical prognosis; or, more seriously, inappropriately biased by patient or surrogate sociodemographic characteristics."
- "majority of HEC members had no formal education in bioethics or clinical ethics, only about one-half of HECs usually or always see the patients for whom they were consulted... there is limited information on the evidentiary standards these committees use to reach their decisions."
- "Of the three available studies on the outcomes of futility procedures taken to completion, committees recommended limiting or withdrawing life-sustaining treatment in 70%, 79%, and 91% of cases... by the end of the 10-day waiting period [in Texas]... 5% improved to the point that ongoing treatment was no longer deemed futile [and 34% had no data on outcomes]."
- "decisions currently are being made opaquely, arbitrarily, or not at all."

- The authors recommend basing futility on peer-reviewed studies. MEDICAL FUTILITY PROCEDURES: WHAT MORE DO WE NEED TO KNOW? *Chest*. https://www.sciencedirect.com/science/article/pii/S0012369213607503

2016 Bosslet et al. Written decisions are rare, but are helpful to force careful thinking about reasons, and to guide future decisions. UK gives more authority to doctors, while US and Canada give more authority to patients and their representatives. Ontario's Consent and Capacity Board usually sides with doctors in overruling patient representatives, and publishes its reasons. UK's Court of Protection makes some public decisions. REASON-GIVING AND MEDICAL FUTILITY: CONTRASTING LEGAL AND SOCIAL DISCOURSE IN THE UNITED STATES WITH THE UNITED KINGDOM AND ONTARIO, Canada *Chest.* https://www.sciencedirect.com/science/article/pii/S0012369216502487?dgcid=raven_sd_recommender_email

2016 Reese quotes doctors: "Prolonging survival by weeks to months is meaningful for some, while minimizing the financial burden to the family is meaningful to others." "Futile care is inappropriate and does not meet professional responsibility standards for proper ethical conduct" "I wouldn't recommend it but might not be able to refuse the family's request" MEDSCAPE ETHICS REPORT: LIFE, DEATH, AND PAIN. https://www.medscape.com/features/slideshow/ethics2016-part2#page=12

2014 Kane quotes doctors: "I am an ER doc. If the patient has a pulse, nothing is futile unless there is an advanced directive or power of attorney to tell me otherwise." "Futile is a relative term! If the patient lives a few more months and his family can interact with him in a positive way, but he still dies of his disease, that is not futile." "I have done so in the past, patient survived fatal liver failure and fully recovered. Miracles happen." "I never recommend life-sustaining therapy that I believe to be futile, or provide services when family refuses to withdraw care and wants ongoing treatment. It is very difficult." "I would usually not recommend but would give if family or nursing care felt it was helpful." "I will sometimes offer a short course (generally time limited) of aggressive therapy even if I expect it to be futile to help family members to feel confident that all was done in the care of their loved one." "I would recommend or give life-sustaining therapy over a short period of time to allow the family members to accept the inevitable outcome and/or allow distant family members to come say their goodbyes." "If it would make a family member feel better and know that everything that could be done, was done...I would recommend it." "This is not helpful for anyone, and is one of the reasons that healthcare costs are so high." MEDSCAPE ETHICS REPORT: LIFE, DEATH, AND PAIN. https://www.medscape.com/features/slideshow/public/ethics2014-part1?src=wnl_edit_specol#5 and https://www.medscape.com/features/slideshow/public/ethics2014-part1?src=wnl_edit_specol#6

2014 Swetz et al. defend the concept of futility, though acknowledging problems:

- "American Medical Association... determined that “a fully objective and concrete definition of futility is unattainable.”... Kwiecinski8 commented that “most physicians now know it [futility] when they see it.” "
- "Survival rates exceeded the predicted rates by a significant margin, with 23% surviving to hospital discharge... prognostic scoring systems are increasingly used to attempt to predict the clinical course of the sickest patients, they still are unable to determine when an individual therapy is futile... these models may predict mortality reasonably well at a population level but tend to be less effective for individual patient prognostication."
- "The hope for an extremely improbable favorable outcome (sometimes perceived as a miracle outcome), although not a commonly articulated sentiment of patients or surrogates, nevertheless can enter into the decision making of physicians, many of whom have during their careers witnessed or heard about one of these rare events."
- Swetz et al say that the 11% of ICU patients who got "futile" care got only 3.5% of total care costs, so they receive less than a quarter as much care as average.
- Swetz et al cite a court case that care may not be denied to patients because of their disabilities.
- "When physicians and hospitals have withdrawn support against family wishes, courts have typically sided with the medical professionals.43 However, when medical professionals have preliminarily sought support

for their decisions before stopping life-sustaining treatments, the courts have more often sided with families."

- "When physicians and ethics committees are employed by the same institution, it may be difficult for the ethics committee to be unbiased... ethics committees are ill equipped with sufficient medical knowledge to have life and death decision making in their hands"
- "unilateral withdrawal of life-sustaining measures of disputed efficacy is almost never morally or ethically justified given several concerns about what defines due process, who actually is defining futility, and the many opportunities for conflicts of interest to creep in."
- TEN COMMON QUESTIONS (AND THEIR ANSWERS) ON MEDICAL FUTILITY *Mayo Clinic*. https://www.mayoclinicproceedings.org/article/S0025-6196(14)00163-3/fulltext

2013 Truog and White. "It is exceedingly rare for surrogates in ICUs to request treatments that are strictly futile (ie, stand *no chance* of achieving their intended goal). Instead, disputes generally arise from requests for treatments that stand at least some chance of accomplishing the patient's goal but for which the clinician believes... the low likelihood of benefit or the high cost... clinicians vary substantially in their attitudes and practices regarding what sorts of treatments should be provided" FUTILE TREATMENTS IN INTENSIVE CARE UNITS *JAMA Internal Medicine*. https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1735891

2014 Field et al. Systematic review says: "Commonly used words are not explicitly defined in the studies or in daily practice, such as quality of life, futility or frailty, or terms like 'in the best interest'.": SYSTEMATIC REVIEW OF INTERVENTIONS TO IMPROVE APPROPRIATE USE AND OUTCOMES ASSOCIATED WITH DO-NOT-ATTEMPT-CARDIOPULMONARY-RESUSCITATION DECISIONS *Resuscitation.* https://www.resuscitationjournal.com/article/S0300-9572(14)00726-6/abstract

Early warning systems (EWS, MEWS, VIEWS, NEWS) have limited ability to identify patients who will do well or poorly: **2014 Alam** et al. THE IMPACT OF THE USE OF THE EARLY WARNING SCORE (EWS) ON PATIENT OUTCOMES: A SYSTEMATIC REVIEW *Resuscitation* https://pubmed.gov/24467882

[21] **Music to keep the beat of CPR:** American Heart Association recommends *Stayin' Alive* by the Bee Gees, *Crazy in Love* by Beyoncé, *Hips Don't Lie* by Shakira, and *Walk the Line* by Johnny Cash. https://www.shopheart.org/hands-only-cpr-know-and-go-cards-25-pack

[22] **Encouragement for untrained people to give CPR:** https://www.mayoclinic.org/first-aid/first-aid-cpr/basics/art-20056600 and https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-5-adult-basic-life-support-and-cardiopulmonary-resuscitation-quality/?strue=1&id=4-6

- Example of a 21-year old car mechanic who gave CPR though untrained. The patient survived well enough to be released by the hospital the same day: https://tucson.com/news/local/tucson-man-helps-save-woman-with-cpr-he-learned-from/article_e00d2ccf-534f-55da-a12e-f4a6d11d7cc0.html

[23] **911 dispatchers:** https://newsroom.heart.org/news/more-cardiac-arrest-victims-could-survive-with-dispatcher-cpr-instruction-rescue-breaths-for-children and https://www.911.gov/project_telecommunicatorassistedCPR.html

[24] **Hiring a CPR trainer.** The life you save will probably be someone you know and love. Think how happy you will be if training arranged by you helps one friend save another. The trainer will need to bring manikins and a simulated AED to practice with.

- You can ask a fire department, ambulance service, hospital or school if they can lend manikins and a trainer who will come for payment or a donation.
- CPR teachers offer to come train your guests in some areas:
    - California, **Los Angeles** and **Orange** Counties: http://yourcprparty.com/ and https://www.surefirecpr.com/cpr-party/ and http://www.codebluemedcpr.com/
    - California, **Fresno**: https://www.cprfresno.com/featured/cpr-parties.html

- **Florida**, southeast: https://www.cprflorida.net/cprparty
- **Oregon**, northwest: http://www.cpr-works.com/pedcpr
- **Pennsylvania,** eastern: http://www.preciousminutestraining.com/cpr-courses/parties/

- The Red Cross will bring CPR and AED training to companies for a fee, so you can ask them to come to your party. https://www.redcross.org/take-a-class/train-my-employees
- American Heart Association has training centers which can connect you with instructors they have trained. https://ahainstructornetwork.americanheart.org/AHAECC/classConnector.jsp?pid=ahaecc.classconnector.home
- American Heart Association has kits to help people teach CPR. You will need a mannikin (borrowed or bought) for each trainee.
  - Kits for home use. One for adults, another for infants: https://www.shopheart.org/education?cat=29 and https://laerdal.com/us/products/simulation-training/resuscitation-training/adult-child-cpr-anytime/ and https://cpr.heart.org/idc/groups/ahaecc-public/@wcm/@ecc/documents/downloadable/ucm_496574.pdf
  - Kit which schools use to train students https://cpr.heart.org/AHAECC/CPRAndECC/Training/CPRInSchoolsTrainingKits/UCM_473191_CPR-In-Schools-Training-Kits.jsp
  - Kit to help university groups train their members. They suggest facilitators can be nursing or other medical students and health centers. https://cpr.heart.org/AHAECC/CPRAndECC/Programs/CPRInSchools/UCM_484652_University-Toolkits.jsp

[25] **CPR training not routine** for high risk patients' families: **2008 Bardy** et al. did show CPR training videos every 3 months to high risk patients, and said "such education is not reflective of real-world instruction after" heart attack. It resulted in resuscitation for 12% of all witnessed home deaths, and for 19% of witnessed home deaths with shockable rhythm. HOME USE OF AUTOMATED EXTERNAL DEFIBRILLATORS FOR SUDDEN CARDIAC ARREST, *NEJM* https://www.nejm.org/doi/full/10.1056/NEJMoa0801651

[26] **AED basics:**

- **Description of AED process**: https://www.redcross.org/take-a-class/aed/using-an-aed/aed-steps
- **Description of brands** available; Pages 14-29 describe models. Pages 30-31 show which models tell you when you need to go slower, faster, deeper, shallower, or give you beeps for the rhythm: https://www.aedsuperstore.com/resources/aed-buyers-guide/
- **ECG** and other information is stored by some or all AEDs. For all brands, the ECG can be downloaded, usually by infrared IrDA, to a computer with compatible software. It can be sent by encrypted email or fax to the hospital, if the Emergency Department's email or fax is stored with the AED. AEDs also log events, for later review by the site hosting the AED, to find any lessons to be learned. https://guide.aedbrands.com/implementation-guide
- **Automatic emailing of the ECG** as a PDF to the hospital emergency department and elsewhere is offered by Philips "Data Messenger" software ($215, pp. 23-26, 40 of 2015 manual, "Document part number: 453564532871", https://manualzz.com/download/40539746). The ECG can be emailed as a PDF even to hospitals and other recipients which do not have Philips software. The PDF can have a password if the recipient will know what the password is. Other brands have not responded on how they export ECGs to hospitals. Messenger gets ECGs in different ways from different Philips HeartStart models (pp.19-20):
  - HS1 and FRx by infrared,
  - FR2 and XL by SD card,
  - XL+ by USB drive,
  - FR3 by Bluetooth or SD card,

- MRx by Bluetooth, SD card or Ethernet cable.

- **A review site**, http://www.ecg-quiz.com/guidelines/aed-defibrillator/ , lists examples of data stored by different AEDs. Most use infrared data transfer (IrDA, faster and more secure than wifi or Bluetooth). The receiving computer needs compatible software and an IrDA port built in, or an IrDA adapter plugged into a USB port.
  - Philips HeartStart HS1 First Aid Defibrillator stores first 15 minutes of ECG and the entire incident's events. Infrared transfer to computers with compatible software. $1,354
  - Philips HeartStart FR3 AED stores "several hours" of ECG (and audio if desired), of the current and all previous patients on a removable SD data card until it is full or erased. The card can be read by moving the card to a computer with Philips software (at the AED site or at the hospital). The owner can also buy a Bluetooth option to transfer data to computers with compatible software. $2,520 https://www.aedsuperstore.com/pdf/philips-heartstart-fr3-aed-manual.pdf
  - ZOLL AED Plus stores 50 minutes of ECG and CPR data. If audio recording option is installed and enabled, 20 minutes of audio recording, ECG, and CPR data. If audio recording is disabled, 7 hours of ECG and CPR data. Infrared transfer to computers with compatible software. $1,995
  - Physiocontrol LIFEPAK CR PLUS 1 stores 20 minutes of ECG, Event log report and summary with waveform segments. Infrared transfer to computers with compatible software. $2,195
  - Physiocontrol LIFEPAK 1000 stores 40 minutes of ECG for the most recent patient and a summary for the next most recent patient, which is then erased when a 3rd patient is connected. Infrared transfer to computers with compatible software. https://www.physio-control.com/uploadedFiles/products/defibrillators/product_data/operational_manuals/LP1000_Operations_Manual_3205213-002.pdf
  - Physio-Control Lifepak CR2 stores 60 minutes of ECG for the 2 most recent patients. Can transfer by wifi and internet to EMS before and after EMS arrival, if EMS uses Lifepak products. Otherwise by wifi or USB cable to computer with compatible software. AED has wifi always on to monitor maintenance needs, which makes it susceptible to hacking. https://www.aedsuperstore.com/pdf/physio-control-lifepak-cr2-aed-brochure.pdf

- **AHA/ECC guidelines** for defibrillators: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-7-adult-advanced-cardiovascular-life-support/?strue=1&id=5-2-1-1

- **Summary of state and federal laws** on AEDs: http://www.ncsl.org/research/health/laws-on-cardiac-arrest-and-defibrillators-aeds.aspx Other summaries of state laws on AEDs:
  - detailed citations of state laws: https://www.aedbrands.com/resource-center/choose/aed-state-laws/
  - comparison chart of state laws: https://www.aedsuperstore.com/aedlaws
  - Federal Good Samaritan protection for AEDs *excludes* health professionals acting within the scope of their license and job, 42 USC 238q(b)(2): https://law.onecle.com/uscode/42/238q.html

- **Story of the entrepreneurs who developed portable AEDs** in 1992, with FDA approval and airline adoption in 1996: **2003 Davis,** TO SAVE LIVES, INVENTORS HAD TO CHANGE MINDS; DEFIBRILLATOR'S STORY SHOWS TRIALS, REWARDS OF TECH START-UPS *USA Today* July 30, 2003, p.B1

[27] **AED Locations:** The *"PulsePoint Respond"* app shows a **map** of AEDs in communities which pay to participate. The *"Staying Alive"* app covers more areas, though it is incomplete and unverified. (Other countries have public maps http://www.heartsafe.org.uk/AED-Locations and https://aedlocations.co.nz/ and https://tappenbeck.net/osm/maps/deu/index.php?id=1029).

2008 Bardy et al. evaluated AEDs in homes of high risk patients. Only 1.5% suffered arrests at home, with someone there to help, over an average of 3 years follow-up. Control and AED groups watched CPR training videos every 3 months, and almost the same number were resuscitated in both groups: 12%-13% of witnessed home deaths, 19% of witnessed home deaths with shockable rhythm in control group, 26% in AED group,

apparently no statistical difference. So the authors could not show any benefit of AEDs at home. The total deaths were very low because of the good care they got in the study. HOME USE OF AUTOMATED EXTERNAL DEFIBRILLATORS FOR SUDDEN CARDIAC ARREST, *NEJM* https://www.nejm.org/doi/full/10.1056/NEJMoa0801651

[28] **Lack of an AED** is a signal the nursing home or assisted living is not thorough in providing CPR. States rarely seem to require AEDs in nursing homes or assisted living: https://www.aedsuperstore.com/aedlaws.

It would help clients if someone creates a list of senior housing with AEDs. It is hard to match the small maps from the *PulsePoint Respond* and *Staying Alive* apps with locations of nursing homes, so phone calls to inquire are the only approach.

- A 2004 survey found that 1 of 13 nursing homes in Boston had a defibrillator, 2 of 13 in Omaha, 4 of 38 in Philadelphia, and 8 of 24 in Seattle: Fisher et al. 2007, LACK OF EARLY DEFIBRILLATION CAPABILITY AND AUTOMATED EXTERNAL DEFIBRILLATORS IN NURSING HOMES. *J. of the American Medical Directors Association.* https://www.jamda.com/article/S1525-8610(07)00207-1/fulltext
- Patients can buy their own defibrillators (for example aedbrands or aedsuperstore below), but nursing homes and assisted living facility staff may have policies against allowing or using them.
- **2013 Centers for Medicare & Medicaid Services** says that **skilled and custodial nursing facilities must have staff certified in CPR** onsite at all times if they accept Medicare or Medicaid patients. They must start CPR when needed, unless an advance directive or DNR order says not to. The rule does not mention AEDs. MEMO# 14-01-NH CARDIOPULMONARY RESUSCITATION (CPR) IN NURSING HOMES *CMS Survey & Certification Group* https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions-Items/Survey-and-Cert-Letter-14-01.html
- **2017 Hackler**. An assisted living association shows which states require **CPR-certified staff in assisted living**, and how many such staff, updated in 2017: STATE COMPARISON OF STAFFING LEVELS *Argentum* https://www.argentum.org/wp-content/uploads/2017/07/State-comparison-of-Staffing-levels.pdf
- Assisted living facilities may have policies not to train staff in CPR, and not to start it until 911 responders arrive. For example Allen's articles cited below say California does not let non-health care staff honor DNRs (e.g. housekeeping or dining room aides), so assisted living providers often do not train them, and do not let them give CPR, to avoid intruding on the many residents who prefer DNR. Allen 2013 recommends disclosure of such policies before a resident moves in.
- California requires an AED in some big new buildings built since 2017 (or with $100,000 renovations). They include institutions and residences with 200 or more occupants, except they exclude apartment buildings (Health+Safety Code, HSC 19300), hospitals and skilled nursing facilities (HSC 19300(d)(2) and 1250(a/b/c/f)): https://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=HSC&sectionNum=19300. That implies each big new custodial nursing home will have an AED.

Discussion of nursing home and assisted living policies:

- **2006 Shah** et al., "an optimized system of care, which includes **immediate CPR and defibrillation, must be tested**." In their study of 42 patients in 1998-2001 in nursing homes in Rochester, NY, no patient had AED before 911 responders came, and only 2/3 had CPR, yet their hearts re-started (ROSC) at the same rate (19%) as others in Rochester (20%). The study did not report survival to hospital discharge. Only one nursing home even owned an AED. The authors say more patients would survive with AEDs and CPR. Survival at 1 year was 2%, not different statistically from 5% survival of others in Rochester (This was 20 years ago, when survival was much worse than now). CARDIAC ARRESTS IN SKILLED NURSING FACILITIES: CONTINUING ROOM FOR IMPROVEMENT? *J. of American Medical Directors Association* https://www.jamda.com/article/S1525-8610(06)00612-8/fulltext

- **2013 Laskowski-Jones** editorial, REFUSING TO GIVE CPR: SHOULD POLICY TRUMP COMMON SENSE? in *Nursing,* https://journals.lww.com/nursing/Fulltext/2013/05000/Refusing_to_give_CPR__Should_policy_trump_common.2.aspx

- General press coverage: https://newoldage.blogs.nytimes.com/2013/04/11/when-independence-means-youre-on-your-own/ and https://www.forbes.com/sites/howardgleckman/2013/03/06/the-cpr-death-at-glenwood-gardens-what-really-happened-and-five-lessons-you-should-learn

- **2013 Allen**, CPR IN ASSISTED LIVING - REVISITING A COMPLEX CARE ISSUE. *Geriatric Nursing*. https://www.sciencedirect.com/science/article/pii/S0197457213001304 and Allen, 2010, CPR IN ASSISTED LIVING: NOT AS SIMPLE AS IT SEEMS. *Geriatric Nursing.* https://www.sciencedirect.com/science/article/pii/S0197457210004878 For his statement that California does not let non-health care staff honor DNRs (e.g. housekeeping or dining room aides), Allen cites the California Assisted Living Association (CALA), not state law. He may mean Probate Code sec.4782, which only protects from liability "A health care provider who honors a" DNR: https://law.onecle.com/california/probate/division-4.7/part-4/index.html The general Good Samaritan law in California does not protect paid staff: Health+Safety Code sec.1799: https://law.onecle.com/california/health/1799.102.html CALA has a discussion for members only: http://caassistedliving.org/members/resources/CPR_in_AL.pdf

- **2008 Hickman** et al. listed several aspects of state laws on DNR and Advance Directives as of 2005-6: THE POLST (PHYSICIAN ORDERS FOR LIFE- SUSTAINING TREATMENT) PARADIGM TO IMPROVE END-OF-LIFE CARE: POTENTIAL STATE LEGAL BARRIERS TO IMPLEMENTATION, *J. of law, medicine & ethics* http://www.polst.org/wp-content/uploads/2013/02/survey+of+laws+article_1.pdf

- **1999 Sabatino** surveyed state laws: SURVEY OF STATE EMS-DNR LAWS AND PROTOCOLS *J. of Law, Medicine & Ethics* https://journals.sagepub.com/doi/abs/10.1111/j.1748-720X.1999.tb01465.x

- **1997 Kane** and Burns surveyed nursing homes in Wisconsin in 1994 about CPR in 1993. 27% had policies of not starting CPR, though most of these, 23%, would call 911. They averaged 1 CPR attempt per 166 beds per year. CARDIOPULMONARY RESUSCITATION POLICIES IN LONG-TERM CARE FACILITIES. *J. of Am. Geriatrics Society*. https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1532-5415.1997.tb04500.x

[29] Care after CPR:

- 2015 AHA/ECC Guidelines (*American Heart Association Guidelines for CPR & Emergency Cardiovascular Care*)**:** https://eccguidelines.heart.org/index.php/tables/2010-multiple-system-approach-to-post-cardiac-arrest-care/

- https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-8-post-cardiac-arrest-care/?strue=1&id=4-1

- Sometimes a patient can be released quickly. This woman was released the same day she got CPR, January 2019: https://tucson.com/news/local/tucson-man-helps-save-woman-with-cpr-he-learned-from/article_e00d2ccf-534f-55da-a12e-f4a6d11d7cc0.html

- If a patient recovers in the ICU, s/he may need special care after the hospital to transition from the stress of the ICU: **2019 Kuehn** CLINICS AIM TO IMPROVE POST-ICU RECOVERY. *JAMA*, https://jamanetwork.com/journals/jama/fullarticle/2726865

When talking to patients, doctors often emphasize invasive aspects of CPR, such as breathing tubes and electric shock, which they do not mention for other health care, such as surgery's use of breathing tubes, cutting, cauterizing, and powerful drugs.

- **2017 Young** et al. DISCORDANCE OF PATIENT-REPORTED AND CLINICIAN-ORDERED RESUSCITATION STATUS IN PATIENTS HOSPITALIZED WITH ACUTE DECOMPENSATED HEART FAILURE *J. of Pain and Symptom Management*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5373999/

- "As you probably know, there are a number of things that doctors can do to try to revive someone whose heart has stopped beating, which usually includes a machine to help breathing. Thinking of your current condition, what would you want your doctors to do if your heart ever stops beating? Would you want your doctors to try to revive you, or would you want your doctors not to try to revive you?."

- **2008 Deep** et al. DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling*. http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf
  - "As you may know, there are a number of things doctors can do to try to revive someone whose heart has stopped beating, which usually includes a machine to help breathing. Thinking of your current condition, what would you want doctors to do if your heart ever stopped beating?"
  - A patient says the doctor "talked about using the paddles to get it going... we did not talk about if they did CPR."
  - A doctor asked another patient, "If something were to happen to your heart, if it were to stop beating, would you want us to shock it? Or if something were to happen and you stopped breathing and we were to put a tube in your throat and put you on life support, would you be okay with that?"

Machines to help CPR: AHA guidelines have a short summary at:

- https://eccguidelines.heart.org/index.php/tables/appendix-2015-guidelines-update-part-6-recommendations/
- with explanation and research citations at: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-6-alternative-techniques-and-ancillary-devices-for-cardiopulmonary-resuscitation/
- **Machines for compressions**: machines can compress the chest, maybe not as well as people, but can be better in a moving ambulance or with over-tired rescuers. Some ambulance companies use them extensively, some a little, most not at all: 2017 summary of 2016 research: https://www.acepnow.com/mechanical-cpr-devices-tied-worse-outcomes/?singlepage=1 Regions Hospital in St. Paul, MN, used one for 2 ¾ hours, and Tim Franko walked out of the hospital alive. https://www.youtube.com/watch?v=oziyPVZWoSs
- One hospital recommends machine compressions as standard practice in hospitals, since hospital beds, even with a board, are too yielding for good CPR: 2017 Nielen + de Minkelis EARLY, INSTEAD OF LATE, AUTOMATED CHEST COMPRESSIONS FOR IN-HOSPITAL CARDIAC ARREST *Resuscitation*. https://www.resuscitationjournal.com/article/S0300-9572(17)30040-0/fulltext
- **Measure CO_2** ($ETCO_2$) in exhalations to monitor CPR quality: https://www.ems1.com/capnography/articles/18746048-5-things-to-know-about-capnography-in-cardiac-arrest/
- **Compression feedback devices** show speed and depth of manual compression. They may help, but not if they delay start of compression: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-5-adult-basic-life-support-and-cardiopulmonary-resuscitation-quality/?strue=1&id=7-1 and https://pubmed.gov/24215730
- **Valve to restrict airflow**: "impedance threshold device" in the patient's mouth restricts airflow into lungs. While this may seem unwise, it leaves more vacuum in the chest to help blood flow from veins to the heart, which can be more important than airflow. Major random trial found no effect, 2011: https://www.nejm.org/doi/full/10.1056/nejmoa1010821 but there may be benefit when combined with good quality compressions, 2016: https://pubmed.gov/27616594
- **Pumping blood outside the body**: Extracorporeal CPR (ECPR), Extracorporeal membrane oxygenation (ECMO), Emergency cardiopulmonary bypass (ECPB), Etracorporeal Life Support (ELSO): Places where it is done: https://www.elso.org/Membership/CentersbyCategory.aspx

- **2017 Thiagarajan** et al. *Extracorporeal Life Support Organization Registry International Report 2016* has total counts: https://journals.lww.com/asaiojournal/fulltext/2017/01000/Extracorporeal_Life_Support_Organization_Registry.11.aspx#O10-11
- **2018 Holmberg** et al. Systematic review of 25 studies: EXTRACORPOREAL CARDIOPULMONARY RESUSCITATION FOR CARDIAC ARREST: A SYSTEMATIC REVIEW *Resuscitation*. https://pubmed.gov/30063963
- **2009 Thiagarajan** et al. Worldwide survival rates 1992-2007: EXTRACORPOREAL MEMBRANE OXYGENATION TO SUPPORT CARDIOPULMONARY RESUSCITATION IN ADULTS *Annals of Thoracic Surgery.* https://www.annalsthoracicsurgery.org/article/S0003-4975(08)02748-3/pdf
- **2012 Kagawa** et al. Description of work in Japan to give ECMO and PCI during CPR. *Circulation*. https://pubmed.gov/22899771

[30] **Breathing tubes' usefulness:** In a 2002 study about 5,000 patients in 1998, 2% of breathing tubes were for cardiac arrest, 14% for pneumonia, 21% post-operatively.No data on tubes used during operations. **2002 Esteban** et al. CHARACTERISTICS AND OUTCOMES IN ADULT PATIENTS RECEIVING MECHANICAL VENTILATION. *JAMA*. https://jamanetwork.com/journals/jama/articlepdf/194560/jce10020.pdf

Patients can also live productively and happily for years on a breathing tube, or indeed with a feeding tube. Videos give the best sense of how this is possible and what the people involved enjoy: http://aaa.globe1234.com

[31] **Organ donations and chance to say goodbye:** **2015 AHA/ECC Guidelines**: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-8-post-cardiac-arrest-care/?strue=1&id=11

2015 European guidelines say, "After stopping CPR, the possibility of ongoing support of the circulation and transport to a dedicated centre in perspective of organ donation should be considered." https://ercguidelines.elsevierresource.com/european-resuscitation-council-guidelines-resuscitation-2015-section-11-ethics-resuscitation-and-end/fulltext

The above guidelines say patients with return of spontaneous circulation (**ROSC**) can donate **all organs**.

- ROSC without survival is present in 38% of CPR attempts *in* hospitals: https://jamanetwork.com/journals/jamacardiology/fullarticle/2647084
- ROSC without survival is present in 22% of CPR attempts *outside* hospitals: https://mycares.net/sitepages/uploads/2018/2017%20Non-Traumatic%20National%20Survival%20Report.pdf
- Donating all organs means up to 8 organs if desired: https://www.bendbulletin.com/home/5703805-151/how-can-one-organ-donor-save-eight-lives
- Patients who had CPR donate 1,000 of the *30,000* organs transplanted each year, and an average of 3 organs are taken from each patient who donates organs: 1999-2011 data published 2013: https://www.ncbi.nlm.nih.gov/pubmed/23949474
- Organs transplanted per year *34,000* in 2016-18; *22,000-29,000* per year in 1999-2011: https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#
- Donations can be taken from 40% of patients who have ROSC and later become brain dead: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5069310/
- In Spain, "A quarter of deceased donors are people with devastating brain injuries put on organ-preservation treatment as part of their end-of-life care. In many countries they are sent instead for palliative care and lost as donors." **2019**. LIVING WILLS, KIDNEY DONORS ARE WANTED, DEAD OR ALIVE, SINCE THERE ARE NOT ENOUGH OF EITHER KIND, DONATION NEEDS TO BE BETTER ORGANISED. *Economist*. https://www.economist.com/international/2019/04/13/kidney-donors-are-wanted-dead-or-alive

ROSC patients also have a **chance to say goodbye** to loved ones: 2018 paper: https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2697393

[32] **180,000 deaths per year from cardiac arrest**: this just counts deaths in hospitals. **Page e378** of https://ahajournals.org/doi/abs/10.1161/CIR.0000000000000659 shows 180,000 out-of-hospital cardiac arrests treated by EMS (18% die in hospital=32,000), and 209,000 in-hospital cardiac arrest (74% die in hospital=155,000)

[33] **Video about donation:** https://youtu.be/r7vYIm29XAY

- Pre-register at: https://www.organdonor.gov/register.html
- No age limit: https://www.organdonor.gov/about/donors/seniors.html A third of donors are over 50, 7% over 65, though most people that age think they cannot donate: https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#
- Example of detailed organ donation procedures: https://www.onelegacy.org/docs/DonorManual_080110.pdf
- List of organ procurement organizations, by state: https://www.organdonor.gov/awareness/organizations/local-opo.html

[34] **Older organ donors:**

- 92-year old liver donor: https://www.organdonor.gov/statistics-stories/donation-stories/carlton-liver-donor.html
- 84-year old liver donor: https://youtu.be/V7LZ-HMzK4M
- **2019 Haugen** et al. counted 400 liver transplants from people 80 or older in 2003-16. By the end of the period, recipients from older donors were dying at the same rate, 11% within a year, as recipients from younger donors. Deaths within 5 years were slightly higher from older donors: 23% vs. 21%.Graft loss was slightly higher from older donors: 15% vs. 11% in a year, 27% vs. 24% in 5 years. ASSESSMENT OF TRENDS IN TRANSPLANTATION OF LIVER GRAFTS FROM OLDER DONORS AND OUTCOMES IN RECIPIENTS OF LIVER GRAFTS FROM OLDER DONORS, 2003-2016 *JAMA Surgery* https://jamanetwork.com/journals/jamasurgery/fullarticle/2724358
- Editorial decrying surgeons at the top of the waiting list rejecting passable livers, since they know they will get another chance soon. **2019 Waits + Englesbe** FIXING THE PROBLEM OF DISCARD OF LIVERS FROM OLDER DONORS *JAMA Surgery* https://jamanetwork.com/journals/jamasurgery/fullarticle/2724352

[35] **Patients' many goals:** Many goals cannot be addressed by DNR or advance directives, but can be addressed by doctors and family.

- **2012 Brunner-LaRocca** et al studied patients with chronic heart failure (CHF)
    - "At baseline, 74% of the patients were not willing to trade any survival time for excellent health" and at month 18, the percent had grown to 87% unwilling to have a shorter life in order to avoid symptoms."
    - The authors explain that some treatments for CHF shorten life expectancy while reducing symptoms "such as inotropic agents or opioids" and other treatments extend life expectancy, "such as internal cardioverter-defibrillators (ICD)", so patient preferences matter, though this can be a stressful question.
    - "Patients with CHF are willing to address their end-of-life preferences, often value longevity even at older age, but individual preferences are impossible to predict and may change over time, reinforcing the value of listening to patients to provide relevant insight and individualize care.34 Openness and communication about prognosis, trajectories, and realistic treatment possibilities engender hope and allow patients to plan for their future."

- The sample consisted of elderly patients with heart failure, with severe symptoms, other diseases, and whose quality of life was "significantly reduced." END-OF-LIFE PREFERENCES OF ELDERLY PATIENTS WITH CHRONIC HEART FAILURE *European Heart J.* https://academic.oup.com/eurheartj/article/33/6/752/441148

- **2008 Stevenson** et al. did a similar study of patients with heart failure. In hospitals, 49% were not willing to trade much survival time for "excellent health" (zero or 1 month). Six months later, 70% were unwilling to trade much survival time for "excellent health" (zero to 2 months). Many increased their preference for longer life over health, while few shifted to preferring health over longer life. CHANGING PREFERENCES FOR SURVIVAL AFTER HOSPITALIZATION WITH ADVANCED HEART FAILURE *J. of the Am. College of Cardiology.* http://www.onlinejacc.org/content/accj/52/21/1702.full.pdf
- **2000 Steinhauser** et al. surveyed 340 VA patients with advanced chronic illnesses in 1999. They asked about 44 goals, and found 34 were held by over 70% of patients.
  - Having a doctor comfortable talking about the patient's spiritual beliefs, death and fears were goals of 50%, 86% and 90%.
  - Physical touch was a goal of 86%.
  - Prayer and being at peace with God were goals of 85% and 89%.
  - Helping others was a goal of 88%.
  - Being mentally aware was a goal of 92%.
  - Having someone who will listen, knowing what to expect physically and having a nurse they are comfortable with were goals for 95%, 96% and 97% of patients.
  - Being mentally alert was almost as important to patients as avoiding pain. Less than 2/3 of doctors had that goal, so sometimes give too much pain medicine near the end of life.
  - Some other goals mattered to much smaller groups of patients: dying at home was a goal for 35% of patients, getting all possible treatments was a goal of 48%, talking about the meaning of death was a goal of 58%.
  - As in Reinke's 2013 paper (below) being with pets was important to many veterans, 37%.
  - The paper was: FACTORS CONSIDERED IMPORTANT AT THE END OF LIFE BY PATIENTS, FAMILY, PHYSICIANS, AND OTHER CARE PROVIDERS *JAMA*. https://jamanetwork.com/journals/jama/articlepdf/193279/JOC00645.pdf
  - A later, version with less complete rankings, more quotes, and summary of other research on doctors' over-optimistic advice, is **2001 Steinhauser** et al, PREPARING FOR THE END OF LIFE: PREFERENCES OF PATIENTS, FAMILIES, PHYSICIANS, AND OTHER CARE PROVIDERS *J. of Pain and Symptom Management* https://www.jpsmjournal.com/article/S0885-3924(01)00334-7/pdf
  - They started with focus groups, described (with questions used) in **2000a Steinhauser** et al. IN SEARCH OF A GOOD DEATH: OBSERVATIONS OF PATIENTS, FAMILIES AND HEALTH CARE PROVIDERS. *Annals of Internal Medicine*. https://annals.org/aim/fullarticle/713475/search-good-death-observations-patients-families-providers
- **2013 Reinke** et al. surveyed 362 veterans with chronic obstructive pulmonary disease (COPD) in 2004-7 in the Seattle area. The most common goals included:
  - for 86% having health costs taken care of,
  - for 85% being unafraid of dying,
  - for 83% laughing and smiling,
  - 80% discussing end of life care with doctors,
  - 79% avoiding strain on loved ones,

- 77% spending time with spouse or partner.
- Almost half said it was very important to spend time with their pets: 47%.
- Only a little over half said breathing easily or controlling pain were very important (53% and 60%).
- The paper was: PREFERENCES FOR DEATH AND DYING AMONG VETERANS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE (Tables 2 and 3) *Am. J. of Hospice & Palliative Medicine* https://pubmed.gov/23298873

- **Methods**:
  - Steinhauser analyzed and reported each of the 44 items separately.
  - Reinke said they used a 28-item PADD (preferences about death and dying) survey, but cited a paper on a 31-item QODD (quality of death and dying) survey: **2001 Patrick** et al. EVALUATING THE QUALITY OF DEATH AND DYING. *J. of Pain and Symptom Management*.
  - **2005 Engelberg** et al. similarly said it used PADD, but cited QODD in a survey of hospice patients' goals (CORRESPONDENCE BETWEEN PATIENTS' PREFERENCES AND SURROGATES' UNDERSTANDINGS FOR DYING AND DEATH).
  - **2002 Curtis** et al. validated one summary total of 27 QODD items for surveys of bereaved family members (sample was too small to develop subscores, and they dropped 4 items inapplicable to half the sample: time with spouse, with pets, resolving bad feelings, attending events), in A MEASURE OF THE QUALITY OF DYING AND DEATH: INITIAL VALIDATION USING AFTER-DEATH INTERVIEWS WITH FAMILY MEMBERS. *J. of Pain and Symptom Management* https://www.jpsmjournal.com/article/S0885-3924(02)00419-0/fulltext
  - **2009 Downey** et al similarly used this summary approach, ignoring minority goals, no matter how strongly desired, in surveys of patients and families, which they called PADD:. SHARED PRIORITIES FOR THE END-OF-LIFE PERIOD. *J. of Pain and Symptom Management.* https://www.jpsmjournal.com/article/S0885-3924(08)00381-3/fulltext
  - **2010 Downey** et al. did find 4 subscores in QODD ratings by bereaved family members, and developed a 17-item version: THE QUALITY OF DYING AND DEATH QUESTIONNAIRE (QODD): EMPIRICAL DOMAINS AND THEORETICAL PERSPECTIVES. *J. of Pain and Symptom Management* https://www.jpsmjournal.com/article/S0885-3924(09)00737-4/fulltext
  - **2013 Curtis, Downey and Engelberg** call attention to the limits of QODD, which they developed, including that it does not measure the dying person's values. THE QUALITY OF DYING AND DEATH IS IT READY FOR USE AS AN OUTCOME MEASURE? *Chest*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3566992/
  - **QODD has been translated** to Spanish https://www.sciencedirect.com/science/article/pii/S1462388918300048 , German https://www.jpsmjournal.com/article/S0885-3924(15)00253-5/fulltext and Dutch https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3566992/

- Hospice organizations may **oversimplify** goals, picking a few which hospice can address, rather than the many which it cannot:
  - http://cascadebusnews.com/changing-goals-end-life/
  - time, peace, and comfort
  - https://casahospice.com/determing-your-end-of-life-goals/
  - My goal is to die without pain and in peace.
  - My hope is that my family is taken care of after I am gone.
  - I want to leave this world without any anger or regrets.
  - Casa Hospice says, "These resolutions emphasize the quality of our life . They emphasize respect-ting our dignity and individuality, our beliefs, and they give us comfort in the final phase of life."

- A literature review did not show much additional US research: **2017 Meier** et al. DEFINING A GOOD DEATH (SUCCESSFUL DYING): LITERATURE REVIEW AND A CALL FOR RESEARCH AND PUBLIC DIALOGUE *Am. J. of Geriatric Psychiatry* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4828197/
- **2015 Mockford** et al. "Patients were reported as focusing on life-sustaining therapies rather than long term goals" DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) ORDERS: A SYSTEMATIC REVIEW OF THE BARRIERS AND FACILITATORS OF DECISION-MAKING AND IMPLEMENTATION *Resuscitation* http://www.repository.heartofengland.nhs.uk/1052/1/gavin%20download.pdf
- People who plan to keep living balance dozens of important goals and subgoals such as: https://www.stageoflife.com/Portals/0/MyLifeRewards/Store/Stage_of_Life_Goal_Setting.pdf and https://www.forbes.com/sites/christinawallace/2016/12/24/the-personal-balanced-scorecard/#5f2d08c15a65
- **1988 Danis** et al. is an old, unique, study of ICU patients' willingness to have a second stay in an ICU if needed.
    - 74% of survivors, and 67% of families of non-survivors, were willing for the patient to go to an ICU again if it would extend life by as little as a month.
    - "quality of life, particularly when considered as a factor in deciding whether to forego life-sustaining treatment, should only be judged by patients themselves."
    - Willingness to go to ICU again was widespread at all levels of "sickness-related dysfunction" and all levels of psychological well-being, and of life satisfaction, as reported by the patients. It was widespread for all categories of "age, sex, income level, educational level, or marital status" or level of social contact. It was widespread regardless of "length of stay in the intensive care unit, APACHE II score [predicted survival], and [extent of ICU use, measured by] charges for intensive care"
    - The authors recognize the "harsh aspects of intensive care," but hypothesize that patients also have "positive responses to the attention, concern, and information provided" as well as to the extension of life.
    - The patients were in ICUs in Chapel Hill, NC in 1983. PATIENTS' AND FAMILIES' PREFERENCES FOR MEDICAL INTENSIVE CARE *JAMA* https://jamanetwork.com/journals/jama/article-abstract/373361

[36] **Discussion of goals of avoiding aging and burdens.** **2014 Van Dusen** et al. THE CONVERSATION. *Atlantic*. https://www.theatlantic.com/magazine/archive/2014/12/the-conversation/382249/ More general surveys of goals are in

- **2000 Steinhauser** FACTORS CONSIDERED IMPORTANT AT THE END OF LIFE BY PATIENTS, FAMILY, PHYSICIANS, AND OTHER CARE PROVIDERS *JAMA*. https://jamanetwork.com/journals/jama/articlepdf/193279/JOC00645.pdf and
- **2013 Reinke**, PREFERENCES FOR DEATH AND DYING AMONG VETERANS WITH CHRONIC OBSTRUCTIVE PULMONARY DISEASE (Tables 2 and 3) *Am. J. of Hospice & Palliative Medicine* https://pubmed.gov/23298873

[37] **Dignity**: **2016 Ackerman** discusses several types of dignity in a section on "Death with Dignity" at the end of her article: CURRENT LAWS PERMITTING ASSISTED SUICIDE ARE MORALLY INDEFENSIBLE *Vox.* https://www.vox.com/the-big-idea/2016/11/21/13693016/assisted-suicide-referendums-philosophy

[38] **35% want to die at home**, according to **2000 Steinhauser**, above. However care can be burdensome at home according to: **2017 Srivastava**, DYING AT HOME MIGHT SOUND PREFERABLE. BUT I'VE SEEN THE REALITY *The Guardian* https://www.theguardian.com/commentisfree/2017/may/01/dying-at-home-terminally-ill-hospital

[39] **Family benefits of watching resuscitation,** literature review:**2018 Leske** et al. FAMILY PRESENCE DURING RESUSCITATION AFTER TRAUMA *J. of Trauma Nursing*. https://pubmed.gov/28272181

- **2015 Goldberger** et al. study of 2007-10 patients: Hospital policies allowing family presence do not affect survival, slightly lengthen CPR by 1.4 minutes, and slightly cut time before defibrillation. FAMILY PRESENCE DURING RESUSCITATION AND PATTERNS OF CARE DURING IN-HOSPITAL CARDIAC ARREST *Circulation*. Cardiovascular quality and outcomes https://pubmed.gov/25805646

[40] Live 1, 2 or 3 years: Chan et al. March 14, 2013 based on data 2000-2008: *Long-Term Outcomes in Elderly Survivors of In-Hospital Cardiac Arrest* NEJM http://www.nejm.org/doi/full/10.1056/NEJMoa1200657

There are some signs among cancer patients showing when death is likely within 3 days (though the signs are not universal), and CPR may not be useful if some of these signs have been present, such as no pulse at the wrist, certain kinds of breathing, less than 100 ml of urine in the past 12 hours, decreased responses to stimuli, inability to close eyelids. There are no comparable studies for non-cancer patients.

- **2014 Hui** et al. Tables 1 and 4, CLINICAL SIGNS OF IMPENDING DEATH IN CANCER PATIENTS *The Oncologist.* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4041673/
- **2015 Hui** et al. Tables 1 and 2 BEDSIDE CLINICAL SIGNS ASSOCIATED WITH IMPENDING DEATH IN PATIENTS WITH ADVANCED CANCER: PRELIMINARY FINDINGS OF A PROSPECTIVE, LONGITUDINAL COHORT STUDY *Cancer*. https://onlinelibrary.wiley.com/doi/pdf/10.1002/cncr.29048
- **2018 Reid** et al. does not focus on the last 3 days. It includes measures which are present months in advance. Table 3 A SYSTEMATICALLY STRUCTURED REVIEW OF BIOMARKERS OF DYING IN CANCER PATIENTS IN THE LAST MONTHS OF LIFE; AN EXPLORATION OF THE BIOLOGY OF DYING *PLOS One.* https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0175123

[41] Doctors' probing for goals:

- **2015 Mockford** et al. "Time for discussion ranged from a median of 1 min to 10 min... Physicians often allowed insufficient time for patients to express, discuss or follow up their views, or questions in person" DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) ORDERS: A SYSTEMATIC REVIEW OF THE BARRIERS AND FACILITATORS OF DECISION-MAKING AND IMPLEMENTATION *Resuscitation* http://www.repository.heartofengland.nhs.uk/1052/1/gavin%20download.pdf
- **2015 Dunlay** et al "hospitalization is a suboptimal time to begin these discussions, as physical and mental constraints may limit thoughtful decision-making." A SURVEY OF CLINICIAN ATTITUDES AND SELFREPORTED PRACTICES REGARDING END-OF-LIFE CARE IN HEART FAILURE *Palliative Medicine*. http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.991.3696&rep=rep1&type=pdf
- **2004 Fagerlin** et al. "the conversations are ordinarily short, vague, and tendentious. In the Tulsky study, for example, doctors only described either 'dire scenarios... in which few people, terminally ill or otherwise, would want treatment' or 'situations in which patients could recover with proper treatment.'[46]" ENOUGH: THE FAILURE OF THE LIVING WILL, *Hastings Center Report,* https://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf
- **2017 Young** et al. "discussion of resuscitation preferences on admission to the hospital is amongst a host of issues addressed in a short amount of time.... resident physicians, nurse practitioners, and physician assistants are often responsible for entering orders for resuscitation preferences on hospital admission and may lack competence in facilitating these discussions." DISCORDANCE OF PATIENT-REPORTED AND CLINICIAN-ORDERED RESUSCITATION STATUS IN PATIENTS HOSPITALIZED WITH ACUTE DECOMPENSATED HEART FAILURE *J. of Pain and Symptom Management*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5373999/
- Some doctors believe it is their job to nudge patients toward the doctors' goals. 2013. UPENN RESEARCHER GUIDES PATIENTS 'GENTLY' TOWARD END OF LIFE GOALS https://www.lifemattersmedia.org/2013/06/upenn-researcher-guides-patients-gently-toward-end-of-life-goals/

[42] **Doctors limit care based on your goals.** Many doctors reduce care if the patient's goals are too high to reach, or goals are so low the patient already reaches them. Patients need to express their hierarchy of goals, from get¬ting through the next hour or year, to their dreams.

- **2014 Misak** et al "what course of care will best achieve goals agreed upon by clinicians and patients." MEDICAL FUTILITY: A NEW LOOK AT AN OLD PROBLEM *Chest* https://www.sciencedirect.com/science/article/pii/S0012369215515389
- **2014 Armstrong** et al. MEDICAL FUTILITY AND NONBENEFICIAL INTERVENTIONS: AN ALGORITHM TO AID CLINICIANS *Mayo Clinic*. https://www.mayoclinicproceedings.org/article/S0025-6196(14)00793-9/fulltext:
  - "the preeminent place of patient values in determining the benefit or burden imposed by medical interventions."
  - "clarify the values of the care team and patient so that the manner in which a given intervention may align or conflict with those values and goals can be discussed and a decision about how to manage the questioned intervention can be made."
  - "realistic and patient-centered goals are pivotally important because they serve as the end against which the means are measured. Provided the medical intervention can move toward at least 1 goal, the intervention should be used if the risks to the patient do not outweigh the benefit expected... Persistent stalemate regarding the treatment goals or the alignment of those goals with available clinical options and the patient's values will require further discussion."
  - "resolution strategies aim to improve communication, clarify values, and align goals, values, and prognosis... open and clear communication at the end of life can be difficult, and clinicians often lack the training for these types of discussions."
  - They suggest "outside assistance" if there is an impasse, but define it as "the hospital ethics committee or a patient affairs group" both of which would be internal and allied with doctors"
- **2014 Swetz** et al "We believe that futility is best adjudicated by determining the clinical benefit of an intervention or lack thereof and how this affects the goals of care." Later in the paper they give a life and death example, "If Wanglie's case had occurred in Texas... mechanical ventilation would likely have been withdrawn because it could not restore the patient to health, which was the goal of the critical care... the [Minnesota] institution saw the respirator as 'non-beneficial' because it would not restore [Wanglie] to consciousness. In the family's view, however, merely maintaining life was a worthy goal, and the respirator was not only effective toward that end, but essential." TEN COMMON QUESTIONS (AND THEIR ANSWERS) ON MEDICAL FUTILITY *Mayo Clinic*. https://www.mayoclinicproceedings.org/article/S0025-6196(14)00163-3/fulltext
- **2013 Truog** and White. "treatments that are strictly futile (ie, stand *no chance* of achieving their intended goal). Instead, disputes generally arise from requests for treatments that stand at least some chance of accomplishing the patient's goal." FUTILE TREATMENTS IN INTENSIVE CARE UNITS *JAMA Internal Medicine*. https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1735891
- **2012 Dunlay** and Roger 2 doctors at the May Clinic say in an editorial what patients' goals should be. "As the end of life nears, the goals of care should also change, and the alleviation of adverse symptoms becomes the most important objective." LIVING AND DYING WITH HEART FAILURE: IT'S TIME TO TALK *European Heart J* https://academic.oup.com/eurheartj/article/33/6/689/441492
- **2008 Burns** and Truog say "complex medical aspects of a patient with a critical illness must be integrated with considerations of the patient's values and preferences, but this requires communication skills that are far more sophisticated than those taught in medical school around the basic medical interview." FUTILITY: A CONCEPT IN EVOLUTION, *Chest* https://www.sciencedirect.com/science/article/pii/S0012369215524768
- **2008 Deep** et al. "ensure we provide treatment in accordance with the patient's goals of care". DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling*.

http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf

[43] **Disability paradox:** people accept disabilities which they thought they would not. Also see Brunner-LaRocca and Stevenson, above.

- **2018 Dresser**, "negative stereotypes that influence advance choices about dementia care... they can only guess what they might want and need as a person with dementia.[9]... empirical research shows that people living with intellectual disabilities experience a better quality of life than nondisabled people think they do.[11] ADVANCE DIRECTIVES AND DISCRIMINATION AGAINST PEOPLE WITH DEMENTIA *Hastings Center Report* *https://onlinelibrary.wiley.com/doi/full/10.1002/hast.867*
- **2017 Nothelle** et al.. Geriatricians say "it is vanishingly rare that a patient reports to us a preference to be dead," no matter how badly disabled the patient is: http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2613950
- **2016 It's Not Yet Dark** (movie). Ruth Fitzmaurice, wife of a man with ALS (Lou Gehrig's disease, or MND-Motor Neuron Disease) says at minute 37:08 "With each stage, you mourn the loss of it. But then - you have a cry. We cried a lot. You have a cry and then you pick yourself up and you move on. And that's the surprising thing to realize that you can suffer that much and mourn the loss of something, and yet wake up the next day, and still have the strength to keep going. And that's a really powerful thing because you begin to really believe in yourself and you begin to believe in each other." https://www.imdb.com/title/tt5433330/
- **2010 Sudore** and Fried. "problems with prediction, adaptation, extrapolation, and on the nature of surrogate decision-making. Individuals have difficulty predicting what they would want in future circumstances because these predictions do not reflect one's current medical, emotional, or social context... [shift] the focus away from asking patients to make what are often premature treatment decisions based on incomplete or hypothetical information." REDEFINING THE "PLANNING" IN ADVANCE CARE PLANNING: PREPARING FOR END-OF-LIFE DECISION MAKING *Annals of Internal Medicine*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2935810/
- **2004 Fagerlin** et al., "Even patients making contemporary decisions about contemporary illnesses are regularly daunted by the decisions' difficulty. How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?... Seventy-seven percent of the subjects changed their minds at least once when given the same case scenario but a different description of the intervention.'[51] At first, they stated fatuously general desires in absurdly general terms... the demand for specificity forced patients to address more questions than they could comprehend." ENOUGH: THE FAILURE OF THE LIVING WILL, *Hastings Center Report,* https://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf

[44] **Less care for patients with DNR:**

- **2018 Graham** summary: "doctors and nurses receive little if any training in understanding and interpreting living wills, DNR orders and Physician Orders for Life-Sustaining Treatment (POLST) forms." https://elderlawnews.blog/2018/08/14/you-may-have-signed-a-living-will-but-scary-mistakes-can-happen-at-the-er/
- **2017 Fendler** et al. study of 2006-12 patients: "DNR status adoption for other medical conditions is associated with *lower rates of guideline-adherent treatment* and higher mortality.3[2014, 4 2008]–5[1999] This suboptimal care may be due to clinicians misinterpreting DNR preferences and thus not providing other appropriate therapeutic interventions (e.g., *intensive care unit transfer or blood transfusion*)6[1998],7[2002] or unwarranted pessimism about prognosis in patients made DNR thus leading to a "self-fulfilling prophecy" of poor outcomes.8" ASSOCIATION BETWEEN HOSPITAL RATES OF EARLY DO-NOT-RESUSCITATE ORDERS AND FAVORABLE NEUROLOGICAL SURVIVAL AMONG SURVIVORS OF IN-HOSPITAL CARDIAC ARREST https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5747564/ https://onlinelibrary.wiley.com/doi/abs/10.1002/msj.20076

- **2016 Horwitz** commentary: "early [DNR] orders receive less-aggressive treatment overall, including potentially critical interventions, such as *blood transfusions, cardiac catheterizations, cardiac bypass surgery, and operations for surgical complications*.4[2013-Richardson],5[2012-Scarborough] In fact, one study6[2004] of patients with intracerebral hemorrhage found that hospitals with more early DNR patients provided so much less-aggressive care (eg, *fewer intubations, craniotomies, ventriculostomies, and cerebral angiographies* overall) that the odds of death for these patients vs non-DNR patients were higher than at other hospitals. However, this was not the case in the study of Walkey et al3[2016] in which DNR patients had slightly lower mortality at hospitals with more early DNR patients [though overall mortality was higher, 12.8 vs. 11.9]. Other studies7[2015] have shown that DNR patients have higher mortality at all levels of severity of illness, which in theory should not be the case since DNR status should be relevant only in catastrophic situations." IMPLICATIONS OF INCLUDING DO-NOT-RESUSCITATE STATUS IN HOSPITAL MORTALITY MEASURES *JAMA Internal Medicine* https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2474399

- **2016 Sarkari** et al. study of 116,873 patients in 2010-2011 with sepsis in California: 46.3% death rate with DNR order; 21.2% without. Those with DNR also had "lower performance of critical procedures including *central venous line* (37.6% vs 50.7%), *mechanical ventilation* (32.6% vs 41.4%), *hemodialysis* (6.3% vs 13.1%), and *major operating room procedure* (6.2% vs 15.5%)" "Early in the course of hospitalization, aggressive intervention such as central venous line placement in shock and mechanical ventilation for acute respiratory failure can be life-saving in critically ill septic patients" IMPACT OF EARLY DO-NOT-ATTEMPT-RESUSCITATION ORDERS ON PROCEDURES AND OUTCOMES OF SEVERE SEPSIS *J. of Critical Care* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5967875/

- **2015 Angus** editorial from JAMA: argues for limiting care in patients with poor health, even though some survive; treats DNR order as symptom of generally limiting care: SUCCESSFUL RESUSCITATION FROM IN-HOSPITAL CARDIAC ARREST-WHAT HAPPENS NEXT? https://jamanetwork.com/journals/jama/fullarticle/2442916 He praises DNR orders within 12 hours after CPR, although **2010** and **2015** AHA/ECC Guidelines said "there are no clinical neurologic signs, electrophysiologic studies, biomarkers, or imaging modalities that can reliably predict death or poor neurologic outcome (eg, Cerebral Performance Category of 3, 4, or 5) within the first 24 hours after cardiac arrest... 63% of patients who survived an [in-hospital cardiac arrest] were given a [DNR] status, and 43% had medical interventions actively withdrawn. These patients... experienced death after withdrawal of life support in a time frame that was inadequate to allow thorough examination." https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-3-ethical-issues/?strue=1&id=7-1

- **2015 Olson+Schwarze.** comment on 2012 Scarborough, below: "patients in the 'DNR' group were by and large elderly with many serious comorbidities who had already shown interest in limiting aggressive and potentially burdensome medical treatment as evidenced by their DNR advance directive... as the clinical course unfolds and complications ensue, less aggressive treatment may be more in line with patient goals" FAILURE-TO-PURSUE RESCUE: TRULY A FAILURE? https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4085137/ A reply is at 2015 Scarborough et al. REPLY TO LETTER: "FAILURE-TO-PURSUE RESCUE: TRULY A FAILURE?". https://www.ncbi.nlm.nih.gov/pubmed/26164434

- **2013 Speicher** et al. study of 2005-09 patients "decision makers—patients, their families, and their physicians—must be counseled on surgical expectations preoperatively and be made aware of the significantly increased perioperative risks involved when a DNR order exists." EXPECTATIONS AND OUTCOMES IN GERIATRIC PATIENTS WITH DO-NOT-RESUSCITATE ORDERS UNDERGOING EMERGENCY SURGICAL MANAGEMENT OF BOWEL OBSTRUCTION *JAMA Surgery* https://jamanetwork.com/journals/jamasurgery/fullarticle/1558108

- **2013 Richardson** et al. study of 2002-10 patients: "DNR patients were less likely to undergo *cardiac catheterization or stenting* (1.1% vs. 4.3%), *ICD/pacemaker* placement (0.1%vs.1.1%), and *transfusion* (7.6% vs.11.2%) (all $p < 0.0001$). Patients with early DNR orders were less likely to survive to transfer or hospital discharge (5.2% vs. 21.6%) and had a shorter length of stay (median 1 day vs. 2 days, Q3 2 days vs. 4 days)... We also found that the over-whelming majority of patients with early DNR order placement die in the hospital without discharge to home or hospice, most commonly within one day of admission. This may help guide providers and families as to what to expect following this decision" THE IMPACT OF EARLY DO NOT

RESUSCITATE (DNR) ORDERS ON PATIENT CARE AND OUTCOMES FOLLOWING RESUSCITATION FROM OUT OF HOSPITAL CARDIAC ARREST *Resuscitation* https://www.sciencedirect.com/science/article/pii/S0300957212007502

- **2012 Scarborough** et al., study of 2005-10 patients: "DNR patients from the matched cohort had a significantly higher postoperative mortality rate than non-DNR patients (36.9% vs 22.3%, P < 0.0001) despite having a similar rate of major postoperative complications (42.1% vs 40.2%, P = 0.38). DNR patients in the propensity-matched cohort were much *less likely to undergo reoperation* (8.3% vs 12.0%, P = 0.006) than non-DNR patients and were significantly more likely to die in the setting of a major postoperative complication (56.7% vs 41.4%, P = 0.001)." The study identified patients who had a DNR order any time within 30 days before emergency general surgery: "acute appendicitis, intestinal obstruction, gallbladder disease, intestinal ischemia, ventral hernia, intestinal perforation, diverticular disease, groin hernia, gastroduodenal ulcer, and colorectal malignancy... the propensity-matching algorithm that we used resulted in a smaller cohort of non-DNR patients that seemed to be very well matched to DNR patients for all of the patient- and operation-related variables that were available for risk adjustment." FAILURE-TO-PURSUE RESCUE: EXPLAINING EXCESS MORTALITY IN ELDERLY EMERGENCY GENERAL SURGICAL PATIENTS WITH PREEXISTING "DO-NOT-RESUSCITATE" ORDERS**.** https://www.ncbi.nlm.nih.gov/pubmed/22868360 and https://www.medscape.com/viewarticle/769702
- **2011 Yuen** et al. summary: "many providers inappropriately alter treatment plans for patients with a DNR order without discussion with the patient or surrogate.39[2002] In one survey of 155 medicine and surgery residents, 43% would withhold blood products and 32% would *not give antibiotics* to a patient with a DNR order.40[2005] Some believe that *diagnostic tests should not be ordered* when a patient is 'DNR.' This may be due to misunderstanding the scope of DNR orders by some providers. Still, other providers intentionally apply DNR orders broadly because they either assume that patients with DNR orders would also prefer to abstain from other life-sustaining treatments or believe that other treatments would not be medically beneficial.39 They make assumptions to avoid a discussion with patients about end-of-life preferences because of the lack of time or discomfort with having the conversation.41[2000]" HOSPITAL DO-NOT-RESUSCITATE ORDERS: WHY THEY HAVE FAILED AND HOW TO FIX THEM https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3138592/
- **2010 Lund and Samant.** Cancer doctors and nurses in the Ottawa Hospital Cancer Centre who were given a description of a patient and told there was a DNR order "were more than twice as likely to agree that aggressive care should not be provided" as those given the same description without a DNR order. "Eleven percent of nurses and physicians agreed that DNR was synonymous with 'Comfort Measures.' " INTERPRETATION OF DO-NOT-RESUSCITATE (DNR) ORDERS AMONG ONCOLOGY HEALTH CARE PROFESSIONALS AND THE POTENTIAL FOR THESE ORDERS TO INFLUENCE CARE FOR MEDICAL ISSUES UNRELATED TO RESUSCITATION. *J. of Clinical Oncology.* https://ascopubs.org/doi/abs/10.1200/jco.2010.28.15_suppl.9078
- **2010 Fritz** et al. survey of doctors in a British hospital: Most doctors said DNR orders reduced how often nurses contacted the medical team (84%-90%), and frequency of nursing observations (72%). Half thought DNR reduced fluids given (52%). 40% thought DNR increased pain relief given, while 10% thought DNR reduced pain relief. "it is clearly common for the DNAR order form to be misinterpreted by both doctors and nurses to mean that care should be reduced; thus, the concern is that patients with DNAR orders may be receiving substandard care... Second, the perception that those with DNAR orders receive substandard care is pervasive... This widespread belief may lead to doctors being less willing to fill out DNAR order forms on patients, even in circumstances where they do not think attempted CPR would be appropriate, for fear of diminishing the overall level of care that the patient receives." INTERPRETATION AND INTENT: A STUDY OF THE (MIS)UNDERSTANDING OF DNAR ORDERS IN A TEACHING HOSPITAL *Resuscitation* https://www.sciencedirect.com/science/article/pii/S0300957210003096
- **2008 Smith** et al. summary: "DNR orders are often broadly applied to other therapies.7–12... Another study surveyed primary and cross-covering residents of patients with DNR orders and found that residents intended to withhold a variety of other therapeutic interventions, that in half of these instances there was no chart documentation to that effect, and that there was little agreement between primary and cross-covering residents regarding which therapies to withhold.8 Several retrospective chart reviews have found that patients in hospitals and long-term-care facilities with DNR orders receive fewer life-prolonging treatments, even after

controlling for age, functional status, and severity of illness.10,11 A cross-sectional survey mailed to medical residents and attending physicians, consisting of 3 patient scenarios followed by 10 treatment decisions that included or did not include a DNR order, found that physicians significantly agreed or strongly agreed to initiate *fewer interventions* when a DNR order was present versus when a DNR order was absent. In addition, patients with a DNR order were *less likely to be transferred to an intensive care unit or to be intubated*, and their physicians had a decreased willingness to draw *blood cultures, perform central line placement, or give blood transfusions*.12" DO NOT RESUSCITATE DOES NOT MEAN DO NOT TREAT: HOW PALLIATIVE CARE AND OTHER MODALITIES CAN HELP FACILITATE COMMUNICATION ABOUT GOALS OF CARE IN ADVANCED ILLNESS https://onlinelibrary.wiley.com/doi/abs/10.1002/msj.20076

[45] **Many DNR patients want less curative care:** **2012 Fromme** et al. Half of Oregon patients with DNR orders who filled out a POLST wanted only comfort care, and 7% wanted full care. The rest wanted various limits on care, so blanket assumptions are not reliable. POLST REGISTRY DO-NOT-RESUSCITATE ORDERS AND OTHER PATIENT TREATMENT PREFERENCES *JAMA*. https://jamanetwork.com/journals/jama/fullarticle/1104816

[46] **Doctors' assumptions:**

- **2011 Yuen** et al. "They make assumptions to avoid a discussion with patients about end-of-life preferences because of the lack of time or discomfort with having the conversation." HOSPITAL DO-NOT-RESUSCITATE ORDERS: WHY THEY HAVE FAILED AND HOW TO FIX THEM https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3138592/
- **2015 Olson** et al. "patients in the 'DNR' group... had already shown interest in limiting aggressive and potentially burdensome medical treatment as evidenced by their DNR advance directive... as the clinical course unfolds and complications ensue, less aggressive treatment may be more in line with patient goals" FAILURE-TO-PURSUE RESCUE: TRULY A FAILURE? https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4085137/ A reply is at 2015 Scarborough et al. REPLY TO LETTER: "FAILURE-TO-PURSUE RESCUE: TRULY A FAILURE?". https://www.ncbi.nlm.nih.gov/pubmed/26164434
- **2019 Barnato** and Vergo (palliative doctors at Dartmouth) report that **doctors' terminology causes great confusion** in decisions on CPR and other treatments: "In the 1990's, however, the term "resuscitation" increasingly began to appear in the medical literature to describe strategies to treat people with reversible conditions, such as IV fluids for shock from bleeding or infection. As the medical terminology surrounding treatments designed to intervene before arrest might occur increasingly appropriated the term "resuscitation"" from its origin in CPR, the meaning of DNR became ever more confusing to health-care providers... Eliminating the term DNR and replacing it with "no CPR" would make it more transparent to patients, families and providers what, exactly, is being withheld." THE TERM 'DO NOT RESUSCITATE' SHOULD BE LAID TO REST *The Hill*. https://thehill.com/opinion/healthcare/442188-the-term-do-not-resuscitate-should-be-laid-to-rest
- **2018 Marco** et al. **confirm the blending of terms** described by Barnato and Vergo above. They conducted a survey about "Do Not Resuscitate" orders and defined the term "*resuscitative efforts*" to include treatment for:

Allergic reaction	Blood clot to the lungs (pulmonary embolism)	Suicide attempt
Bleeding ulcer	Cancer causing collapsed lung	Surgery for appendicitis
Foreign body in throat	Sepsis (infection in the blood)	Surgery for broken hip
Gunshot wound	Severe car accident with critical injuries	
Pneumonia	Surgery for aortic aneurysm rupture	

Three physician-authors, the journal editor, and the peer reviewers all considered treatment of these 13 conditions as "*resuscitative efforts*", which means people could think Do Not *Resuscitate* orders restrict treatment of the 13 conditions. "ADVANCE DIRECTIVES IN EMERGENCY MEDICINE: PATIENT PERSPECTIVES AND APPLICATION TO CLINICAL SCENARIOS" *Am. J. of Emergency Medicine* https://www.sciencedirect.com/science/article/pii/S0735675717306496 They asked what patients thought, but results are not generalizable, since patients gave their personal beliefs about what "should" happen in each circumstance, not what the law requires. It was not clear if they were answering about CPR or about other treatments applicable in each circumstance. It was also not clear if they were answering for themselves or for some hypothetical person with a DNR. The questionnaire asked:

"Do you believe a DNR order should apply in these circumstances: [list of circumstances]:

- YES, DNR Order applies. Resuscitative efforts should NOT be done.
- NO, DNR Order does not apply. Resuscitative efforts SHOULD be done."

- **2001 Steinhauser** et al. indicates bias: a nurse derides CPR when "this person had no hair and one breast." The researchers (PhDs and MDs) agreed with the nurse. Perhaps the nurse and researchers were younger, and scorned life with cancer, but lack of hair and breast does not make death or DNR a necessary choice. PREPARING FOR THE END OF LIFE: PREFERENCES OF PATIENTS, FAMILIES, PHYSICIANS, AND OTHER CARE PROVIDERS *J. of Pain and Symptom Management* https://www.jpsmjournal.com/article/S0885-3924(01)00334-7/pdf

[47] **Surgeons and DNR:** 2**013 Schwarze** et al. publication on surgeons denying operations "with a greater than 1% operative mortality or significant morbidity such as renal failure, major stroke, paralysis or long-term ventilator dependence.[10, 11]": SURGEONS EXPECT PATIENTS TO BUY-IN TO POSTOPERATIVE LIFE SUPPORT PREOPERATIVELY: RESULTS OF A NATIONAL SURVEY *Critical Care Medicine.* http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3624612/pdf/nihms-454691.pdf

Cited the following to identify risky operations, based on data 1994-99: **2001 Finlayson and Birkmeyer,** OPERATIVE MORTALITY WITH ELECTIVE SURGERY IN OLDER ADULTS *Effective Clinical Practice* http://ecp.acponline.org/julaug01/finlayson.pdf

[48] **Small graph** comparing death rates for people with and without DNR. (Scarborough, Speicher and Richardson have already been described above. The other studies are described more below the table.)

Illness Severity 2015 Fendler et al. study of 2006-12 patients in hospitals. Their deciles from healthiest to sickest, are reordered in this graph to go from sickest to healthiest: ALIGNMENT OF DO-NOT-RESUSCITATE STATUS WITH PATIENTS' LIKELIHOOD OF FAVORABLE NEUROLOGICAL SURVIVAL AFTER IN-HOSPITAL CARDIAC ARREST. https://jamanetwork.com/journals/jama/fullarticle/2442939

Emergency Surgery 2012 Scarborough et al., study of 2005-10 patients: FAILURE-TO-PURSUE RESCUE: EXPLAINING EXCESS MORTALITY IN ELDERLY EMERGENCY GENERAL SURGICAL PATIENTS WITH PREEXISTING "DO-NOT-RESUSCITATE" ORDERS**.** https://www.ncbi.nlm.nih.gov/pubmed/22868360

Bowel Surgery (obstructed bowels) 2013 Speicher et al. study of 2005-09 patients "EXPECTATIONS AND OUTCOMES IN GERIATRIC PATIENTS WITH DO-NOT-RESUSCITATE ORDERS UNDERGOING EMERGENCY SURGICAL MANAGEMENT OF BOWEL OBSTRUCTION *JAMA Surgery* https://jamanetwork.com/journals/jamasurgery/fullarticle/1558108

Sepsis 2016 Sarkari et al. study of 116,873 patients in 2010-2011 with sepsis in California IMPACT OF EARLY DO-NOT-ATTEMPT-RESUSCITATION ORDERS ON PROCEDURES AND OUTCOMES OF SEVERE SEPSIS *J. of Critical Care* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5967875/

Abdomen Surgery (exploratory laparotomy) 2011 Kazaure et al. study of 2005-8 patients. About 160 DNR patients had ex-laps. HIGH MORTALITY IN SURGICAL PATIENTS WITH DO-NOT-RESUSCITATE ORDERS. *Archives of Surgery* https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1107763

Vascular Surgery 2015 Aziz et al. study of 2005-10 patients in hospitals: THE INFLUENCE OF DO-NOT-RESUSCITATE STATUS ON THE OUTCOMES OF PATIENTS UNDERGOING EMERGENCY VASCULAR OPERATIONS https://www.sciencedirect.com/science/article/pii/S0741521415000889#bib5

Heart Surgery 2013 Maxwell et al study of 2005-10 patients. 2,678 DNR patients had heart surgery. PERIOPERATIVE MORBIDITY AND MORTALITY OF CARDIOTHORACIC SURGERY IN PATIENTS WITH A DO-NOT-RESUSCITATE ORDER. *PeerJ* https://peerj.com/articles/245/

Pneumonia 2016 Walkey et al. study of 2011 patients: ASSOCIATION OF DO-NOT-RESUSCITATE ORDERS AND HOSPITAL MORTALITY RATE AMONG PATIENTS WITH PNEUMONIA https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2474401

Chest Surgery 2013 Maxwell et al study of 2005-10 patients. 3,129 DNR patients had chest surgery. PERIOPERATIVE MORBIDITY AND MORTALITY OF CARDIOTHORACIC SURGERY IN PATIENTS WITH A DO-NOT-RESUSCITATE ORDER. *PeerJ* https://peerj.com/articles/245/

Elective Surgery 2018 Brovman et al. study of 2012 patients. 459 matched pairs of DNR and non-DNR patients had elective surgery. POSTOPERATIVE OUTCOMES IN PATIENTS WITH A DO-NOT-RESUSCITATE (DNR) ORDER UNDERGOING ELECTIVE PROCEDURES. *J. of Clinical Anesthesia* https://www.sciencedirect.com/science/article/pii/S0952818018301855

	Patients with		Study	
	DNR	Full Code	(cites above)	Patients
Survive with good mental ability, after in-hospital CPR left them with best prognosis 0-10 (CASPRI score)	7%	69%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 11-12	6%	53%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 13-14	5%	40%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 15-16	2%	34%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 17-17	2%	26%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 18-19	3%	23%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 20-20	1%	21%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 21-22	1%	16%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with prognosis 23-26	1%	13%	2015 Fendler	2006-12
Survive with good mental ability, after in-hospital CPR left them with worst prognosis 27-44	0%	6%	2015 Fendler	2006-12
Survive with good mental ability, Total, after in-hospital CPR	2%	31%	2015 Fendler	2006-12
Survive to transfer or hospital discharge, Total, after out-of-hospital CPR	5%	22%	2013 Richardson	2002-10
Survive, after emergency general surgery	63%	78%	2012 Scarborough	2005-10
Survive 30 days after obstructed bowel surgery	70%	79%	2013 Speicher	2005-09
Survive 30 days after exploratory laparotomy (abdomen surgery)	50%	80%	2011 Kazaure	2005-8
Survive 30 days after emergency vascular surgery	65%	86%	2015 Aziz	2005-10
Survive heart surgery to hospital discharge	63%	89%	2013 Maxwell	2005-10
Survive sepsis hospitalization	54%	79%	2016 Sarkari	2010-11
Survive pneumonia hospitalization, sum of two lines below	75%	90%	2016 Walkey	2011
Survive chest surgery to hospital discharge	75%	94%	2013 Maxwell	2005-10
Survive 30 days after elective surgery	87%	94%	2018 Brovman	2012
Survive 30 days after emergency surgery	65%	82%	2011 Kazaure	2005-8
Survive 30 days after non-emergency surgery	83%	95%	2011 Kazaure	2005-8
Survive 30 days after major surgery	88%	95%	2011 Saager	2005-8
Survive 30 days after vascular surgery	79%	87%	2015 Siracuse	2007-10
Survive in hospitals where <8.9% of pneumonia patients go DNR in first 24 h in hospital	64%	89%	2016 Walkey	2011
Survive in hospitals where >22.3% of pneumonia patients go DNR in first 24 h in hospital	77%	92%	2016 Walkey	2011
Receive ICD/pacemaker placement	0.1%	1.1%	2013 Richardson	2002-10
Receive cardiac catheterization or stenting	1%	4%	2013 Richardson	2002-10
Receive blood transfusion	8%	11%	2013 Richardson	2002-10
Have reoperation, to fix problems from initial operation	8%	12%	2012 Scarborough	2005-10
Successful weaning from mechanical ventilation	85%	90%	2015 Aziz	2005-10
Graft success after emergency vascular surgery	91%	98%	2015 Aziz	2005-10

- **2018 Brovman** et al. study of 2012 patients. 459 matched pairs of DNR and non-DNR patients had elective surgery. "DNR patients, as compared with non-DNR patients, have increased post-operative mortality but not morbidity, which may arise from unmeasured severity of illness or transition to comfort care in accordance with a patient's wishes. The informed consent process for elective surgeries in this patient population should include a discussion of acceptable operative risk." POSTOPERATIVE OUTCOMES IN PATIENTS WITH A DO-NOT-RESUSCITATE (DNR) ORDER UNDERGOING ELECTIVE PROCEDURES. *J. of Clinical Anesthesia* https://www.sciencedirect.com/science/article/pii/S0952818018301855

- **2017 Walsh** et al. study of 2007-13 patients. "DNR patients were still found to have increased incidence of postoperative mortality (odds ratio 2.54" This study is not in the table above or graph, since survival rates were not given for DNR and comparable patients without DNR, just the odds ratio. DO-NOT-RESUSCITATE STATUS IS ASSOCIATED WITH INCREASED MORTALITY BUT NOT MORBIDITY *Anesthesia & Analgesia* https://www.ingentaconnect.com/content/wk/ane/2017/00000125/00000005/art00016

- **2017 Beverly** et al. study of 2007-13 patients with hip fracture surgeries performed in patients with preexisting DNR status: "30-day postoperative mortality ... emergency (21.4%) and nonemergency (16.4%) ... elective (19.6%) and nonelective (18.3%)... For patients with DNR status, both emergent and non-emergent hip surgery carries high mortality, greatly exceeding rates predicted for that patient by American College of Surgeons NSQIP risk calculators." This study is not in the table or graph, since comparable numbers were not given for DNR and non-DNR patients, just DNR patients. COMPARISON OF POSTOPERATIVE OUTCOMES IN ELDERLY PATIENTS WITH A DO-NOT-RESUSCITATE ORDER UNDERGOING ELECTIVE AND NONELECTIVE HIP SURGERY *Geriatric Orthopaedic Surgery & Rehabilitation* https://journals.sagepub.com/doi/10.1177/2151458516685826

- **2016 Walkey** et al. study of 2011 patients: Hospitals ranked by percent of pneumonia patients classed as DNR in first 24 hours of hospital stay:

  Death rates in hospitals with early DNR >22.3%: All: 12.8% (DNR 22.9, CPR 8.2),

  Death rates in hospitals with early DNR <8.9%: All:11.9% (DNR 36.1, CPR 10.6).

  ASSOCIATION OF DO-NOT-RESUSCITATE ORDERS AND HOSPITAL MORTALITY RATE AMONG PATIENTS WITH PNEUMONIA https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2474401

- **2015 Fendler** et al. study of 2006-12 patients: Controlling for prognosis, patients who stayed CPR survived to hospital discharge 8 to 33 times as often as patients of the same condition, who got DNR designation within 12 hours after successful CPR (table 2) ALIGNMENT OF DO-NOT-RESUSCITATE STATUS WITH PATIENTS' LIKELIHOOD OF FAVORABLE NEUROLOGICAL SURVIVAL AFTER IN-HOSPITAL CARDIAC ARREST. *JAMA* https://jamanetwork.com/journals/jama/fullarticle/2442939

- **2015 Aziz** et al. study of 2005-10 patients: "DNR patients were more likely to have higher rates of graft failure (8.7% vs 2.4%; adjusted $P < .01$) and failure to wean from mechanical ventilation (14.9% vs 9.9%; adjusted $P < .001$)... DNR status was associated with a 2.5-fold rise in 30-day mortality (35.0% vs 14.0%; 95% confidence interval, 1.7-2.9; adjusted $P < .001$)." THE INFLUENCE OF DO-NOT-RESUSCITATE STATUS ON THE OUTCOMES OF PATIENTS UNDERGOING EMERGENCY VASCULAR OPERATIONS https://www.sciencedirect.com/science/article/pii/S0741521415000889#bib5

- **2015 Siracuse** et al. study of 2007-10 patients, 1,538 matched pairs, vascular surgery. This is not in the graph, since it overlaps with Aziz, which covers more years. IMPACT OF "DO NOT RESUSCITATE" STATUS ON THE OUTCOME OF MAJOR VASCULAR SURGICAL PROCEDURES *Annals of Vascular Surgery* https://www.sciencedirect.com/science/article/pii/S0890509615005658

- **2015 Jawa** et al. study of trauma patients on Long Island, NY in 2008-13. Regression shows "5.2-fold increased odds of mortality" if patient had DNR, controlling for other conditions. This is not in the table or graph, since comparable numbers were not given for DNR and non-DNR patients, just odds ratio. PREADMISSION DO NOT RESUSCITATE ADVANCED DIRECTIVE IS ASSOCIATED WITH ADVERSE OUTCOMES FOLLOWING ACUTE TRAUMATIC INJURY *Am. J. of Surgery.* https://www.sciencedirect.com/science/article/pii/S0002961015003207

- **2013 Maxwell** et al study of 2005-10 patients. 3,100 thoracic surgery patients with DNR were matched to 12,000 without. 2,700 cardiac surgery patients with DNR were matched to 11,000 without. "Tremendous financial and operational resources (including the labor of surgical, anesthesia, perfusion, nursing, and operating room technical staff, equipment and medication costs, postoperative intensive care and supportive services) are devoted to the types of cardiothoracic operations used to define our study cohorts. If "failure to pursue rescue" after making the decision to undergo a major surgical intervention plays a role in explaining the substantial elevation in postoperative mortality in this population, we believe it suggests unwise resource utilization. Perhaps even more importantly, thousands of DNR patients may be exposed to the discomfort and risk of highly invasive procedures that have a diminished prospect of a good outcome if they are not coupled with a range of certain aggressive postoperative interventions." PERIOPERATIVE MORBIDITY AND MORTALITY OF CARDIOTHORACIC SURGERY IN PATIENTS WITH A DO-NOT-RESUSCITATE ORDER. *PeerJ* https://peerj.com/articles/245/
    - **2011 Kazaure** et al. study of 2005-8 patients. 4,128 DNR surgery patients were matched to 4,128 without. Two thirds had general surgery and a quarter had vascular surgery. Scarborough and Brovman have more recent data for emergency and elective surgery respectively, but Kazaure also shows specific data on abdomen surgery (exploratory laparotomy). HIGH MORTALITY IN SURGICAL PATIENTS WITH DO-NOT-RESUSCITATE ORDERS. *Archives of Surgery* https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1107763
    - **2011 Saager** et al. study of 2005-8 patients. 2,199 DNR patients were matched to 2,199 without. This study is not in the graph, since it overlaps Kazaure, which has more patients and Scarborough, which has newer data. PRE-EXISTING DO-NOT-RESUSCITATE ORDERS ARE NOT ASSOCIATED WITH INCREASED POSTOPERATIVE MORBIDITY AT 30 DAYS IN SURGICAL PATIENTS. *Critical Care.* https://journals.lww.com/ccmjournal/Abstract/2011/05000/Pre_existing_do_not_resuscitate_orders_are_not.16.aspx A critique compares the 2015 Saager and Kazaure papers which used the same data and similar methods: 2011 DNR PATIENTS AND OUTCOMES OF SURGERY: TWO PAPERS, SAME DATA, DIFFERENT RESULTS *Skeptical Scalpel* http://skepticalscalpel.blogspot.com/2011/04/dnr-patients-and-outcomes-of-surgery.html

[49] **Patients with prognosis of highest risk** for early death after CPR (CASPRI score 27-44): 6% survived if they continued to classify themselves as full code (CPR), none if they chose DNR. **2015 Fendler** et al. study of 2006-12 patients after CPR in hospital: ALIGNMENT OF DO-NOT-RESUSCITATE STATUS WITH PATIENTS' LIKELIHOOD OF FAVORABLE NEUROLOGICAL SURVIVAL AFTER IN-HOSPITAL CARDIAC ARREST *JAMA* https://jamanetwork.com/journals/jama/fullarticle/2442939

[50] **Revival after long CPR:** Most patients in each study did not get long CPR. If they had, more could have lived. In fact many patients had very short CPR, under 10-15 minutes. A nonprofit recommends 30 minutes of CPR (http://takeheartamerica.org/save-a-life-toolkits/public-lay-rescuers/cardio-pulmonary-resuscitation/). The pamphlet's statements about a sixth pf patients are based on the 2015 Fendler study, and there are several other studies with similar findings:

- **2015 Fendler** et al. study of 2006-12 patients: "Time to ROSC (minutes), mean ± SD 5.7 ± 7.3 [in healthiest decile] 20.3 ± 16.5 [in sickest decile]" Mean plus or minus a standard deviation (SD) in the sickest decile is therefore 3.8 or 36.8 minutes. A sixth of the patients would be at least one standard deviation above the mean, and a sixth at least one standard deviation below, if CPR times were a normal bell-shaped curve. Since they are not, this pamphlet says the number of patients reviving before 4 minutes or after 37 minutes is each "*About* 1/6." Fendler et al. do not report median or distribution of CPR length given to those who died. Table e3 of Supplement: ALIGNMENT OF DO-NOT-RESUSCITATE STATUS WITH PATIENTS' LIKELIHOOD OF FAVORABLE NEUROLOGICAL SURVIVAL AFTER IN-HOSPITAL CARDIAC ARREST *JAMA* https://jamanetwork.com/journals/jama/fullarticle/2442939
- **2017 Reynolds** et al. study of 2000-12 patients who had CPR in hospitals and did *not* survive. Most did not have long enough CPR to give them a full chance of revival. 24% of these received less than 13 minutes of CPR, before the hospital gave up on them. Only 25% had 28 minutes or more. This study, unlike most, did not report on those who did revive. DURATION OF RESUSCITATION EFFORTS FOR IN-HOSPITAL CARDIAC ARREST BY PREDICTED OUTCOMES: INSIGHTS FROM GET WITH THE GUIDELINES *Resuscitation.* https://www.resuscitationjournal.com/article/S0300-9572(16)30595-0/fulltext

- **2016 Reynolds** et al. study of 2007-10 patients who had CPR outside hospitals: 42 minutes of CPR needed to revive 99% of those who were revived. Median CPR given to those who died was 23.4 minutes. (Discriminatory in only counting survival of those without mental disabilities): ASSOCIATION BETWEEN DURATION OF RESUSCITATION AND FAVORABLE OUTCOME AFTER OUT-OF-HOSPITAL CARDIAC ARREST: IMPLICATIONS FOR PROLONGING OR TERMINATING RESUSCITATION. *Circulation*. https://pubmed.gov/27760796
- **2016 Nagao** et al. study of 2005-12 patients who had CPR in Japan, outside hospitals: 40-45 minutes of CPR needed to revive 99% of those who were revived. Median CPR given before arrival at hospital, to those who died, was 31 minutes, and they show the distribution; they do not report length of subsequent in-hospital CPR. Japanese medics are required to continue CPR until the patient revives or reaches a hospital, giving these longer times: DURATION OF PREHOSPITAL RESUSCITATION EFFORTS AFTER OUT-OF-HOSPITAL CARDIAC ARREST. *Circulation*. https://pubmed.gov/26920493
- **2012 Goldberger** et al. study of 2000-2008 patients in hospitals found an eighth of patients who revived needed over 30 minutes of CPR. Among patients with no pre-existing disorder, a fifth needed over 30 minutes to revive (their table 1). These findings (eighth and fifth) underestimate the potential, since only 26% of patients who did *not* survive had over 30 minutes of CPR, only 54% had over 20 minutes, and 16% had less than 10 minutes, so most of them did not get enough time to have a full chance of revival. The biggest benefits of long CPR were for patients initially with no heartbeat (asystole or pulseless electrical activity, PEA). Mental abilities were the same in patients who needed longer CPR as those who revived faster: DURATION OF RESUSCITATION EFFORTS AND SURVIVAL AFTER IN-HOSPITAL CARDIAC ARREST: AN OBSERVATIONAL STUDY, *Lancet* https://pubmed.gov/22958912 Their reply has links to comments: https://pubmed.gov/23399066
- **2012 Nolan** + Soar: editor in chief of *Resuscitation* summarizes Goldberger, above, "Prolonged resuscitation efforts can result in high-quality survival. If the cause of cardiac arrest is potentially reversible, it might be worthwhile to try for a little longer." DURATION OF IN-HOSPITAL RESUSCITATION: WHEN TO CALL TIME? https://pubmed.gov/22958913
- **Methods:** All studies report actual survival from generally short periods of CPR (median under 25-31 minutes), so they give minimum levels of survival. Maximum survival if everyone had longer CPR could be estimated from a **Life Table**, in the same way people estimate life expectancy. At each minute, among patients who were still getting CPR, the ROC-PRIMED study shows the fraction who revived and lived to leave the hospital in 2007-10. A Life Table could combine this sequence of fractions to estimate total survival with longer periods of CPR. The members of the sample change from minute to minute. But similarly when Life Tables calculate a country's life expectancy, survival rates at each age are calculated from different people, born in different years. ROC-PRIMED data are at https://biolincc.nhlbi.nih.gov/studies/rocprimed/?q=primed
- **2018 Andersen** et al. methods paper gives other ways to reduce bias in studies of resuscitation, from truncation of good practices by revival, and truncation of harmful practices by death: *"*RESUSCITATION TIME BIAS"-A UNIQUE CHALLENGE FOR OBSERVATIONAL CARDIAC ARREST RESEARCH *Resuscitation.* https://pubmed.gov/29425975
- **2016 Youness** et al. Discusses case studies of patients with very long resuscitation. REVIEW AND OUTCOME OF PROLONGED CARDIOPULMONARY RESUSCITATION *Critical Care Research and Practice* https://pubmed.gov/26885387

2015 European Guidelines (subject to update in 2020): EUROPEAN RESUSCITATION COUNCIL GUIDELINES FOR RESUSCITATION 2015SECTION 11. THE ETHICS OF RESUSCITATION AND END-OF-LIFE DECISIONS. *Resuscitation*. https://ercguidelines.elsevierresource.com/european-resuscitation-council-guidelines-resuscitation-2015-section-11-ethics-resuscitation-and-end/fulltext The following are quoted from the guidelines:

- 88% of patients who achieved sustained ROSC did so within 30 min.[77] As a rule, resuscitation should be continued as long as VF [ventricular fibrillation] persists. Asystole [no heartbeat] for more than 20 min during ALS [advanced life support] in the absence of a reversible cause is generally accepted as an

indication to abandon further resuscitation attempts [Goldberger, above, found 30% of asystole survivors needed more than 20 minutes for ROSC (7,024 of 23,158, table 1)]. However, there are reports of exceptional cases that do not support the general rule, and each case must be assessed individually...

- The decision to start or discontinue CPR is usually more challenging outside a hospital... it has been argued that success rates of less than 1% still justify the resuscitation effort.[78, 81, and 82] Institutional guidelines for the Termination Of Resuscitation (ToR) in the pre-hospital environment are very much needed to reduce unwanted variability in this decision-making...
- Some EMS systems use just that one component, the absence of pre-hospital return of spontaneous circulation (ROSC), as the criterion to terminate resuscitation and this clearly may exclude potential survivors for transportation.[78, 83, 84, 85, 86, and 87]
- Patients with refractory cardiac arrest, with ongoing CPR during transport to hospital, used to have a very poor prognosis.[88 and 89] In a moving vehicle, manual CPR may be difficult and the use of mechanical devices may be considered. As advanced rescue therapies and specific circumstances-related interventions become more widely available and success rates are improving, defining which patients might benefit from these becomes crucial.[90, 91, and 92]
- *Withholding or withdrawing CPR* Healthcare professionals should consider withholding or withdrawing CPR in children and adults when:
    - the safety of the provider can no longer be sufficiently assured;
    - there is obvious mortal injury or irreversible death [ROLE];
    - a valid and relevant advance directive becomes available;
    - there is other strong evidence that further CPR would be against patient's values and preferences or is considered 'futile';
    - asystole for more than 20 min despite ongoing ALS, in the absence of a reversible cause.
- After stopping CPR, the possibility of ongoing support of the circulation and transport to a dedicated centre in perspective of organ donation should be considered."

[51] Suspend for operations:

2006 Ewanchuk and Brindley give an extended discussion of why surgeons want to suspend DNR during operations and for some time afterwards, and how hard it is morally and physically to honor DNR wishes during an operation. They can mistrust the quality of the DNR conversation, prognoses given, etc. They note "anaesthesiologists are accustomed to adjusting preoperative orders in order to optimize patients for surgery. Furthermore, the rationale for and events leading up to the writing of the DNR order will be questioned. When was the order last updated? Why was it written? With whom was it discussed? By whom was it written? Was accurate prognostic information provided to the patient? Did the patient actually possess an illness commonly regarded as terminal? To what extent did the clinician influence the eventual decision? This final question is especially pertinent, given the disparity in opinions among physicians regarding the prognosis of various conditions [4,11]." ETHICS REVIEW: PERIOPERATIVE DO-NOT-RESUSCITATE ORDERS – DOING 'NOTHING' WHEN 'SOMETHING' CAN BE DONE *Critical Care* https://ccforum.biomedcentral.com/articles/10.1186/cc4929

2018 Belcaid et al. said that in their Ottawa hospital, most patients' limits on resuscitation were ignored in the operative notes (13 of 19). This was 6 months after a reminder letter went to all anesthesiologists emphasizing the policy of documenting limits on care for operations. DOCUMENTATION OF PERIOPERATIVE RESUSCITATION STATUS FOR NON-ELECTIVE SURGICAL PATIENTS *J. of Clinical Anesthesia.* https://www.sciencedirect.com/science/article/pii/S0952818018307074

2012 Scott and Gavrin. "To properly inform a patient and 'reconsider' the DNR status before palliative surgery, a long, exhaustive, and ideally multidisciplinary conversation with the patient, patient's surrogate decision maker, primary care physician, surgeon, and anesthesiologist must take place. Such a meeting is often impossible in clinical practice. Nonetheless, any conversation, even one that is not ideal, may suffice provided one addresses the

patient's goals and values in the context of the procedure." "There is a common misunderstanding that patients who have enrolled in hospice also have given up the desire for resuscitation. Designating oneself as DNR is not necessary for hospice care." PALLIATIVE SURGERY IN THE DO-NOT-RESUSCITATE PATIENT: ETHICS AND PRACTICAL SUGGESTIONS FOR MANAGEMENT. *Anesthesiology Clinics.* https://www.anesthesiology.theclinics.com/article/S1932-2275(12)00002-X/abstract

2013 Speicher et al. study of 2005-09 patients "decision makers - patients, their families, and their physicians—must be counseled on surgical expectations preoperatively and be made aware of the significantly increased perioperative risks involved when a DNR order exists." EXPECTATIONS AND OUTCOMES IN GERIATRIC PATIENTS WITH DO-NOT-RESUSCITATE ORDERS UNDERGOING EMERGENCY SURGICAL MANAGEMENT OF BOWEL OBSTRUCTION *JAMA Surgery* https://jamanetwork.com/journals/jamasurgery/fullarticle/1558108

2014 Byrne et al. summarize 8 organizations' guidelines for re-opening DNR discussions before and after an operation. The authors recommend both surgeon and anesthesiologist discuss wishes with the patient, and they can refuse to participate if they are dissatisfied with limits the patient imposes. The authors recommend repeated discussions during recovery, on the hospital floor, and before discharge, without considering the emotional and physical burden of repeated discussions. RECONSIDERING DO-NOT-RESUSCITATE ORDERS IN THE PERIOPERATIVE SETTING. *J. of PeriAnesthesia Nursing* https://www.sciencedirect.com/science/article/pii/S1089947214000331

2002 Waisel et al. suggest good policies for discussing DNR preferences before an operation. GUIDELINES FOR PERIOPERATIVE DO-NOT-RESUSCITATE POLICIES *J of Clinical Anesthesia* https://www.sciencedirect.com/science/article/pii/S0952818002004014 They also summarize legal cases on DNR. The cases are old, but one could Shepardize (https://legal-dictionary.thefreedictionary.com/Shepardize) them to find more recent cases. Waisel et al said courts were unwilling to penalize hospitals for resuscitating people who had DNR, since "continued living was not a compensable injury."

[52] State laws on medical representatives: https://statelaws.findlaw.com/health-care-laws/durable-power-of-attorney.html

- Most people have discussed their wishes with a spouse or children if applicable, but have not always put permission in writing. More have discussed with a lawyer than with a doctor: http://journals.sagepub.com/doi/pdf/10.1177/2333721417741978

[53] Medicare has its own form to let Medicare discuss and disclose your information to your emergency contact: https://www.cms.gov/Medicare/CMS-Forms/CMS-Forms/CMS-Forms-Items/CMS1193148.html

Veterans Affairs has a similar form, https://www.va.gov/vaforms/medical/pdf/10-5345%20fill.pdf and an advance Directive form to designate a representative and other preferences https://www.va.gov/vaforms/medical/pdf/vha-10-0137-fill.pdf

[54] Skills needed by emergency contacts:

- **2010 Sudore** and Fried. "Given the extreme stress experienced by patients and/or surrogates (13) and the frequent absence of a prior relationship with the clinician at the time a decision must be made (63), it is unlikely that patients and surrogates will be able to communicate effectively without some form of preparation (2,13)." REDEFINING THE "PLANNING" IN ADVANCE CARE PLANNING: PREPARING FOR END-OF-LIFE DECISION MAKING *Annals of Internal Medicine*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2935810/
- **2011 Lim** et al. Table 1 has 10 questions to cover before surgery. DOCTOR-PATIENT COMMUNICATION, KNOWLEDGE, AND QUESTION PROMPT LISTS IN REDUCING PREOPERATIVE ANXIETY - A RANDOMIZED CONTROL STUDY. *Asian J. of Surgery.* https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1369-7625.2005.00354.x
- **2001 Brown** et al. The second page has 17 questions to ask about cancer. Most apply to other major diseases. PROMOTING PATIENT PARTICIPATION AND SHORTENING CANCER CONSULTATIONS: A RANDOMISED TRIAL. *British J. of Cancer.* https://www.nature.com/bjc/journal/v85/n9/pdf/6692073a.pdf?origin=ppub
- **2005 Bolman** et al. Table 1 has 16 questions to ask about heart disease. Most apply to other diseases. It cites a 2001 paper which says the questionnaire had 49 items in Dutch, but does not provide most of them.

LONG-TERM EFFICACY OF A CHECKLIST TO IMPROVE PATIENT EDUCATION IN CARDIOLOGY *Patient Education and Counseling.* https://www.researchgate.net/profile/Catherine_Bolman/publication/8078632

- **2017 Arthur** et al. The last page has 25 questions, primarily about palliative and end of life care, with a few on medications. PERCEPTION OF HELPFULNESS OF A QUESTION PROMPT SHEET AMONG CANCER PATIENTS ATTENDING OUTPATIENT PALLIATIVE CARE. *J. of Pain and Symptom Management.* https://www.jpsmjournal.com/article/S0885-3924(16)30367-0/fulltext
- **2003 Clayton** et al. The last 3 pages show over 100 questions about palliative care, medications, prognosis, effects on daily life, etc; some need to be asked repeatedly over time: ASKING QUESTIONS CAN HELP: DEVELOPMENT AND PRELIMINARY EVALUATION OF A QUESTION PROMPT LIST FOR PALLIATIVE CARE PATIENTS. *British J. of Cancer* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2376858/ This was so widely respected, that it was translated to French: **2012 Fouquet** et al. ADAPTATION EN LANGUE FRANCAISE D'UN LIVRET DE QUESTIONS À DESTINATION DES PATIENTS ATTEINTS DE CANCER ET DE LEURS PROCHES, DANS LE CADRE D'UNE CONSULTATION EN SOINS DE SUPPORT ET SOINS PALLIATIFS EN ONCOLOGIE *Bulletin du Cancer.* https://www.sciencedirect.com/science/article/pii/S0007455115304367

[55] Medical staff may ignore family instructions. **2018 Martin**. Medscape surveyed physicians:

- 45% end care when they want to, even if the family wants further care
- 34% end care when the family asks, even if the doctor thinks the patient may recover. This 34% is up from 28% in 2014. Only 19% refuse the family's instructions to end care, down from 22%. 48% say "it depends"
- 27% in 2014 said they would end care for a newborn if they thought s/he would have a "terrible" quality of life (not asked in 2016-2018)
- 12% think some patients are taken off life-support too soon.
- 20% under-treat pain since they fear trouble from the government, up from 9% in 2014 and 6% in 2010
- They surveyed 5,000 US doctors in 2018, 7,500 in 2016, 17,000 US doctors and 4,000 European doctors in 2014, 10,000 in 2010, probably US.

- MEDSCAPE ETHICS REPORT: LIFE, DEATH, AND PAIN. https://www.medscape.com/slideshow/2018-ethics-report-life-death-6011014
- **2016 Reese** MEDSCAPE ETHICS REPORT: LIFE, DEATH, AND PAIN. https://www.medscape.com/features/slideshow/ethics2016-part2
- **2014 Kane** MEDSCAPE ETHICS REPORT: LIFE, DEATH, AND PAIN. https://www.medscape.com/features/slideshow/public/ethics2014-part1
- **2010 Kane** PHYSICIANS' TOP 20 ETHICAL DILEMMAS https://www.medscape.com/features/slideshow/public/ethical-dilemmas

[56] Contents of Living Wills:

- **2008 Deep** et al. When a patient rejected "life support" or the possibility of a vegetative state, several physicians interpreted this as DNR. What these patients seem to be requesting is a time-limited trial of intensive care – a valid option often unrecognized by the physicians" DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling.* http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf
- **2018 Ollove.** "Palliative sedation" is a term for enough pain medicine to prevent consciousness, while hastening death. Doctors may or may not acknowledge to family members that they are raising pain medicines to this level. Patients and family members may or may not want it. DOES PALLIATIVE SEDATION EASE SUFFERING DURING END-OF-LIFE CARE? *PBS News Hour* https://www.pbs.org/newshour/health/does-palliative-sedation-ease-suffering-during-end-of-life-care
- **2011 Braun** et al. said "All physicians reported interpreting requests to 'do everything' as a 'red flag', a sign to more thoroughly explore what 'everything' meant to the patient or family." Caucasian doctors said such

families "might be in denial." Hispanic and African American doctors said such requests could show suspicion of doctors. THE PHYSICIAN'S PROFESSIONAL ROLE IN END-OF-LIFE DECISION MAKING: VOICES OF RACIALLY AND ETHNICALLY DIVERSE PHYSICIANS *Patient Education and Counseling.* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2891864/

- **2011 American Bar Association** says doctors don't have to obey directives if they think an instruction is "medically inappropriate." "Advance directive laws merely give doctors and others immunity if they follow your valid advance directive." MYTHS AND FACTS ABOUT HEALTH CARE ADVANCE DIRECTIVES http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fact_hc_ad.authcheckdam.pdf
- **2005 American Bar Association** recommends putting organ donation wishes in Advance Directives, and deciding if you want to allow an autopsy for research or diagnosis: AFTER DEATH DECISIONS TO THINK ABOUT NOW https://www.americanbar.org/content/dam/aba/administrative/law_aging/tool5.pdf
- **1991 Lynn** "a durable *power of attorney* is quite valuable... having that *person properly designated* can ease a great deal of administrative and legal concerns... a person who never wants to be in a particular hospital again, or to have a particular treatment again, or to be treated for pain, might well benefit by carefully documenting this preference. [italics added] WHY I DON'T HAVE A LIVING WILL. *Law, Medicine and Health Care,* https://www.researchgate.net/profile/Joanne_Lynn/publication/21259748
- **Federal law** requires: "42 CFR 489.102 (a) Hospitals... nursing facilities, home health agencies... are required to: (1) Provide written information to such individuals concerning—(i) ...the right to... advance directives..." which are defined as "42 CFR 489.100 living will or durable power of attorney." A lawyer says this rule is almost never enforced: http://medicalfutility.blogspot.com/2012/03/psda-requires-disclosure-of-futility.html

Critiques of living wills:

- **1991 Lynn** directs Altarum Institute's Program to Improve Eldercare, https://www.nhpf.org/speakerbio_joannelynn
    - I do not have a living will because I fear that the effects of having one would be worse, in my situation, than not having one: How could this be? A living will of the standard format attends to priorities that arc not my own, addresses procedures rather than outcomes, and requires substantial interpretation without guaranteeing a reliable interpreter...
    - All too commonly, someone who has a living will is assumed to have requested hospice-type care including a 'Do not resuscitate' order, to prefer not to use intensive care, and to have refused curative treatments...
    - How is a person to write a living will that would ask for his family to seek divine guidance in prayer, or to ensure that her death is as dramatic and public as the rest of her life has been?...
    - I, for example, would hope that my family would be emotional about the choices to be made, not simply concerned with the application of my advance directives to my situation...
    - The other group who refuse to be involved in advance directives includes those who simply want to be able to live in the moment and to have a community and family that is trustworthy about making future choices... I, and surely some other patients, prefer family choice over the opportunity to make our own choices in advance. The patient himself or herself may well judge the family's efforts less harshly than he or she would judge his or her own decisions made in advance or by the professional caregivers. I have had a number of seriously ill patients say that their next of kin will attend to some choice if it comes up...
    - Families are those who grieve for the patient's suffering and death... and about whom the patient most likely would have had the most concern. Somehow to imagine that the society could, or should set up systems that remove the family from decision-making is almost outrageous...
    - common requirement in durable powers of attorney and proxy statutes that there be one solo decision-maker designated. For many families, making a unitary designation is contrary to the

family's history of making conjoint decisions and imposes the possibility of generating an unnecessary discord, as someone must be granted disproportionate authority...

  - WHY I DON'T HAVE A LIVING WILL. *Law, Medicine and Health Care,* https://www.researchgate.net/profile/Joanne_Lynn/publication/21259748

- **2010 Sudore** and Fried. "Individuals have difficulty predicting what they would want in future circumstances because these predictions do not reflect one's current medical, emotional, or social context." The authors see a need to shift "the focus away from asking patients to make what are often premature treatment decisions based on incomplete or hypothetical information." REDEFINING THE "PLANNING" IN ADVANCE CARE PLANNING: PREPARING FOR END-OF-LIFE DECISION MAKING *Annals of Internal Medicine*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2935810/
- **2004 Fagerlin** et al. ENOUGH: THE FAILURE OF THE LIVING WILL, *Hastings Center Report,* " 'absolutely, hopelessly ill' or 'actively dying.' Until patients crossed this threshold, ADs were not seen as applicable." https://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf
- **2000 Lynn**, "Most people, however, have ambiguous prognoses throughout the time that they live with their fatal illness. For instance, on the day before death, the median prognosis for patients with heart failure is still a 50% chance to live 6 more months, because patients with heart failure typically die quickly from an unpredictable complication like arrhythmia or infection.[37] Often, a chronically ill patient can "hold on" for a long time, until a complication overwhelms his or her fragile reserves. Good care at the end of life will have to include long-term care for the very sick, since no method can target only those patients who are sure to die soon.[38]" LEARNING TO CARE FOR PEOPLE WITH CHRONIC ILLNESS FACING THE END OF LIFE" JAMA, https://jamanetwork.com/journals/jama/article-abstract/193267
- **2014 Council of Europe** defines "end of life" very narrowly as "a situation in which the main purpose of any medical treatment is palliative, focusing on the quality of life or, at the very least, the control of symptoms that are liable to impair the quality of the end of a patient's life." http://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168039e8c5

[57] Living wills misinterpreted as reduced care

- **2012** In a survey of 732 residents, fellows and attending physicians, 78% incorrectly classed a patient as DNR if she had a living will with instructions which only applied in terminal illness; only 22% correctly classed her as full code. If the patient's health situation was also described, clarifying she did not have terminal illness, the incorrect (DNR) answers went down to 57%. If "Full Code" was explicitly written on the living will, 33% still incorrectly classed the patient as DNR, based on instructions which would only apply in terminal illness, which she did not yet have. Because of these misinterpretations, 45%-40% made incorrect treatment decisions : **Mirarchi et al.** TRIAD III: NATIONWIDE ASSESSMENT OF LIVING WILLS AND DO NOT RESUSCITATE ORDERS *J of Emergency Medicine,* https://www.jem-journal.com/article/S0736-4679(11)00853-5/pdf
- **2015** 42% of first responders ignored the DNR order in a hypothetical POLST calling for DNR and full treatment. Even 17% ignored the DNR order in a POLST calling for DNR and comfort measures only. The POLSTs confused them more than a simple order for DNR or full code: **Mirarchi et al.** TRIAD VII: DO PREHOSPITAL PROVIDERS UNDERSTAND PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT DOCUMENTS? *J. of Patient Safety* http://www.iremsc.org/symposium/Symp%20Documents/2016%20Symp/Presentation%20PDFs/POLST%20Study%20TRIAD%20VII.pdf
- **2018** " 'Don't resuscitate this patient; he has a living will,' the nurse told the doctor... 'Do everything possible,' it read, with a check approving cardiopulmonary resuscitation. The nurse's mistake was based on a misguided belief that living wills automatically include "do not resuscitate" (DNR) orders." https://elderlawnews.blog/2018/08/14/you-may-have-signed-a-living-will-but-scary-mistakes-can-happen-at-the-er/

- **2017 Pedraza** et al. Researchers treated any completion of an Advance Directive as a request to die at home or on hospice: ASSOCIATION OF PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT FORM USE WITH END-OF-LIFE CARE QUALITY METRICS IN PATIENTS WITH CANCER *J. of Oncology Practice.* http://ascopubs.org/doi/pdf/10.1200/JOP.2017.022566

- **2013 Smith** et al. Researchers recommend following "previously expressed preferences" when "benefits of intervention... weak or unlikely / Burdens strong or likely" which mistakenly implies these "previously expressed preferences" would always be for non-intervention. Last page of: WHEN PREVIOUSLY EXPRESSED WISHES CONFLICT WITH BEST INTERESTS. *JAMA Internal Medicine*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3741042/

- **2012 Scott and Gavrin.** "There is a common misunderstanding that patients who have enrolled in hospice also have given up the desire for resuscitation. Designating oneself as DNR is not necessary for hospice care." PALLIATIVE SURGERY IN THE DO-NOT-RESUSCITATE PATIENT: ETHICS AND PRACTICAL SUGGESTIONS FOR MANAGEMENT. *Anesthesiology Clinics.*

[58] Medical staff may ignore Living Wills

- **2017 Nothelle** and Finucane. "state statutes sharply restrict the circumstances in which clinicians may forgo life-sustaining treatment on the basis of a living will... Living will laws tend to assume that preferences expressed in advance may be changed in the event of dementia" STATES WORSE THAN DEATH. *JAMA Internal Medicine*. https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2613950

- **2019 Hannibal** Pregnant women's directives on withdrawing life support have limited or no effect under many state laws. STATE LAWS ON PREGNANCY AND HEALTH CARE DIRECTIVES *Nolo*. https://www.nolo.com/legal-encyclopedia/state-laws-pregnancy-health-care-directives.html

- **2010 Silveira** et al. A nationally representative survey in the US found that two thirds of people who died 2000-2006 had advance directives before they died, but confirmed these were not always followed. Among **incapacitated** patients who had left instructions:
    - Only 10 patients wanted all care possible; 5 got it but 5 did not.
    - 425 patients did not want all care possible; 395 got what they requested, but 30 got full care.
    - 14% of representatives said problems came up in trying to follow the written instructions.
    - They surveyed next of kin for 3,764 people over 60 who died in 2000-2006 (random sample which represented 12 million deaths). Some advance directives named a representative, some gave instructions, some did both. ADVANCE DIRECTIVES AND OUTCOMES OF SURROGATE DECISION MAKING BEFORE DEATH *New England J. of Medicine* https://www.nejm.org/doi/full/10.1056/NEJMsa0907901

[59] State formats of DNR bracelets vary: https://www.americanmedical-id.com/dnr or https://www.stickyj.com/blog/does-my-state-honor-dnr-jewelry/ or http://caringadvocates.org/store/index.php?main_page=index&cPath=2

[60] When DNR is in effect:

2015 update, Pennsylvania Department of Health "effective when it is signed by the attending physician" https://www.health.pa.gov/topics/Documents/EMS/Sample%20Out-Of-Hospital%20DNR%20Order.pdf

2013 Mental Health Legal Advisors Committee. Massachusetts list of court cases before 2013 on when judges need to decide about DNR orders: LEGAL GUIDE TO DO NOT RESUSCITATE (DNR) ORDERS http://mhlac.org/wp-content/uploads/2018/10/legal_guide_dnr.pdf

2018 Marco et al. Eight of 21 patients in one hospital who actually *had* a DNR believe they "should" be revived if they have a cardiac arrest.

Marco et al. also surveyed 250 patients who did *not* have a DNR. Results are not generalizable, since patients gave their personal beliefs about what "should" happen in each circumstance, not what the law requires. It was not clear

if they were answering about CPR or about other treatments applicable in each circumstance. It was also not clear if they were answering for themselves or for some hypothetical person with a DNR. The questionnaire asked:

"Do you believe a DNR order should apply in these circumstances: [list of circumstances]:

- YES, DNR Order applies. Resuscitative efforts should NOT be done.
- NO, DNR Order does not apply. Resuscitative efforts SHOULD be done."

The paper used the term "*resuscitative efforts*" to cover far more than CPR. It included treatment for: Allergic reaction, Bleeding ulcer, Blood clot to the lungs (pulmonary embolism), Cancer causing collapsed lung, Foreign body in throat, Gunshot wound, Pneumonia, Sepsis (infection in the blood), Severe car accident with critical injuries, Suicide attempt, Surgery for aortic aneurysm rupture, Surgery for appendicitis, Surgery for broken hip. Three physician-authors, the journal editor, and the peer reviewers all considered treatment of these 13 conditions as "*resuscitative efforts*", in the patient surveys about DNR.

"ADVANCE DIRECTIVES IN EMERGENCY MEDICINE: PATIENT PERSPECTIVES AND APPLICATION TO CLINICAL SCENARIOS" *Am. J. of Emergency Medicine* https://www.sciencedirect.com/science/article/pii/S0735675717306496

[61] **DNR Discrepancies** in hospital:

- **2017 Young** et al.
  - 34% of 166 patients who wanted DNR orders did not have them. 10% of 213 patients who wanted to be full code actually had DNR orders. This was at the Mayo Clinic in 2014-2016. The study did not identify whether causes were miscommunication, doctors who forgot the instructions, or patients who changed their minds without telling doctors.
  - They did say, depressingly, about this life or death medical order, "discussion of resuscitation preferences on admission to the hospital is amongst a host of issues addressed in a short amount of time.... resident physicians, nurse practitioners, and physician assistants are often responsible for entering orders for resuscitation preferences on hospital admission and may lack competence in facilitating these discussions."
  - DISCORDANCE OF PATIENT-REPORTED AND CLINICIAN-ORDERED RESUSCITATION STATUS IN PATIENTS HOSPITALIZED WITH ACUTE DECOMPENSATED HEART FAILURE *J. of Pain and Symptom Management*. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5373999/
- **2012 Brunner-LaRocca** et al "For 390 patients with distinct CPR preferences, patient preferences (as answered to the study question) differed from the hospital records 32% of the time (n = 126; Figure 4). No predictors for disagreement could be identified." END-OF-LIFE PREFERENCES OF ELDERLY PATIENTS WITH CHRONIC HEART FAILURE *European Heart J.* https://academic.oup.com/eurheartj/article/33/6/752/441148
- **2008 Deep** et al. 28 doctor-patient pairs were interviewed separately in Kentucky in 2006.
  - "In 6 of the 28 interview dyads (21%) there were discrepancies about the resulting outcome of the discussion. Two patients had no recollection of speaking with their physician about this topic despite passing a screening test for memory and orientation... In four cases the preferences stated by the patient during the research interview differed from those perceived by the physician. Two patients (7% of total) who desired resuscitation had orders limiting their care because the physician interpreted the discussion differently. Two patients (7% of total) who did not want resuscitation lacked DNR orders."
  - "Several patients and surrogates stated they would accept resuscitation but not "life support" implying they perceive a difference between the two. Interestingly many of the physicians did not make this distinction. When a patient rejected "life support" or the possibility of a vegetative state, several physicians interpreted this as DNR. What these patients seem to be requesting is a time-limited trial of intensive care – a valid option often unrecognized by the physicians"

- "resident physicians... report they are rarely observed having discussions about CPR and infrequently receive feedback about their performance... Residents in this program had received no formal training on end-of-life communication."
- DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling*. http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf

[62] **95% of emergency responders look for a bracelet:** https://www.americanmedical-id.com/faq State laws may let them honor the bracelet without seeing a doctor's signature, if the state approved the bracelet issuer: https://www.americanmedical-id.com/dnr or https://www.stickyj.com/blog/does-my-state-honor-dnr-jewelry/ or http://caringadvocates.org/store/index.php?main_page=index&cPath=2

[63] **Online storage of medical signatures**, including state standards for DNR bracelets: http://globe1234.org/online.htm

Engrave medical bracelet with custom information. This may not meet state standards for a DNR bracelet, but it works to provide other information: https://www.etsy.com/search?q=engraved%20bracelet%20medical%20id

[64] **Disability group says to show multiple scenarios:** **2013 Coleman** FULL WRITTEN PUBLIC COMMENT: DISABILITY RELATED CONCERNS ABOUT POLST *Institute of Medicine's Committee on Approaching Death* http://notdeadyet.org/full-written-public-comment-disability-related-concerns-about-polst

Scenarios inspired by those for intubation at: https://ars.els-cdn.com/content/image/1-s2.0-S002561961300270X-mmc1.pdf, which is the appendix of: **2013 Jesus** et al. PREFERENCES FOR RESUSCITATION AND INTUBATION AMONG PATIENTS WITH DO-NOT-RESUSCITATE/DO-NOT-INTUBATE ORDERS, *Mayo Clinic Proceedings*. https://www.sciencedirect.com/science/article/pii/S002561961300270X

[65] **What many people want:** **2000 Steinhauser** et al. surveyed 340 VA patients with advanced chronic illnesses in 1999.

- Talking about the meaning of death was a goal of 58%.
- Prayer and being at peace with God were goals of 85% and 89%.
- Having a doctor comfortable talking about the patient's spiritual beliefs, death and fears were goals of 50%, 86% and 90%.
- Having someone who will listen was a goal for 95%.

FACTORS CONSIDERED IMPORTANT AT THE END OF LIFE BY PATIENTS, FAMILY, PHYSICIANS, AND OTHER CARE PROVIDERS *JAMA*. https://jamanetwork.com/journals/jama/articlepdf/193279/JOC00645.pdf

[66] **Restless, agitated and confused** - "Terminal restlessness" or "Terminal agitation" affects:

- half the dying: **Western Australia Dept. of Health** https://www.healthywa.wa.gov.au/Articles/U_Z/Understanding-the-dying-process
- 13%-88% of the dying, p.1; drugs account for 30%-50% of cases, p.2; placebos better than some drugs, p.4; delirium is main cause of terminal sedation, p.4: **2016 Hosker & Bennett** DELIRIUM AND AGITATION AT THE END OF LIFE *BMJ* http://eprints.whiterose.ac.uk/101456/1/16.157.pdf

[67] **Traffic accidents** were the leading cause of cardiac arrest among emergency admissions in 2005 in Taiwan. Some appear to reach ROSC, though Taiwanese survival is low: **2012 Chien** et al. CAUSE ANALYSIS OF INJURY-RELATED OUT-OF-HOSPITAL CARDIAC ARREST IN THE ELDERLY *Intl. J of Gerontology*. https://core.ac.uk/download/pdf/81988190.pdf

[68] **DNR conversations after CPR**

- DNR after CPR *in* hospitals, 2006-12 data: **2015 Fendler** et al. ALIGNMENT OF DO-NOT-RESUSCITATE STATUS WITH PATIENTS' LIKELIHOOD OF FAVORABLE NEUROLOGICAL SURVIVAL AFTER IN-HOSPITAL

CARDIAC ARREST. *JAMA*. https://jamanetwork.com/journals/jama/fullarticle/2442939 and https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5747564/

- **2015 Angus** editorial from JAMA: argues for limiting care in patients with poor health, even though some survive; treats DNR order as symptom of generally limiting care; praises DNR orders within 12 hours after CPR: SUCCESSFUL RESUSCITATION FROM IN-HOSPITAL CARDIAC ARREST-WHAT HAPPENS NEXT? https://jamanetwork.com/journals/jama/fullarticle/2442916,
- DNR after CPR *outside* hospitals, 2002-10 data in **2013 Richardson** et al. THE IMPACT OF EARLY DO NOT RESUSCITATE (DNR) ORDERS ON PATIENT CARE AND OUTCOMES FOLLOWING RESUSCITATION FROM OUT OF HOSPITAL CARDIAC ARREST *Resuscitation*. https://www.sciencedirect.com/science/article/pii/S0300957212007502

Guidelines against such conversations:

- **2010** and **2015** AHA/ECC Guidelines said "there are no clinical neurologic signs, electrophysiologic studies, biomarkers, or imaging modalities that can reliably predict death or poor neurologic outcome (eg, Cerebral Performance Category of 3, 4, or 5) within the first 24 hours after cardiac arrest... 63% of patients who survived an [in-hospital cardiac arrest] were given a [DNR] status, and 43% had medical interventions actively withdrawn. These patients... experienced death after withdrawal of life support in a time frame that was inadequate to allow thorough examination." https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-3-ethical-issues/?strue=1&id=7-1
- **2005** guidelines said "prognosis for adults who remain deeply comatose (Glasgow Coma Scale Score _5) after cardiac arrest can be predicted with accuracy after 2 to 3 days": https://www.ahajournals.org/doi/pdf/10.1161/CIRCULATIONAHA.105.166551
- which is part of full guidelines at: https://www.ahajournals.org/toc/circ/112/24_supplement
- **2000** AHA/ECC Guidelines similarly said "prognosis for adults who remain deeply comatose (Glasgow Coma Scale Score _5) after cardiac arrest can be predicted with accuracy after 2 to 3 days" https://www.ahajournals.org/doi/10.1161/circ.102.suppl_1.I-12#d3e500
- **1992** AHA/ECC Guidelines said "The prognosis for adults in persistent vegetative state following cardiac arrest can be predicted with high accuracy after 3 to 7 days." https://jamanetwork.com/journals/jama/fullarticle/400799

[69] **Need for specialist in brains and comas:** 2018 guidelines on disorders of consciousness: **2018 Giacino** et al. PRACTICE GUIDELINE UPDATE RECOMMENDATIONS SUMMARY: DISORDERS OF CONSCIOUSNESS. *Neurology*. http://n.neurology.org/content/91/10/450.long

[70] **DNR after CPR probably die** in hospital: "the over-whelming majority of patients with early DNR order placement die in the hospital without discharge to home or hospice, most commonly within one day of admission. This may help guide providers and families as to what to expect following this decision", 2002-10 data in **2013 Richardson** et al. THE IMPACT OF EARLY DO NOT RESUSCITATE (DNR) ORDERS ON PATIENT CARE AND OUTCOMES FOLLOWING RESUSCITATION FROM OUT OF HOSPITAL CARDIAC ARREST *Resuscitation*. https://www.sciencedirect.com/science/article/pii/S0300957212007502

[71] **Coma patients' eyes open:** **2009 study of recovery** from coma during 2003 - 2008: "The transition from coma to VS, which occurs within 2-3 weeks in the vast majority of survivors, is marked by spontaneous eye opening." **2009 Katz** et al. NATURAL HISTORY OF RECOVERY FROM BRAIN INJURY AFTER PROLONGED DISORDERS OF CONSCIOUSNESS: OUTCOME OF PATIENTS ADMITTED TO INPATIENT REHABILITATION WITH 1–4 YEAR FOLLOW-UP *Progress in Brain Research* https://www.sciencedirect.com/science/article/pii/S0079612309177075

[72] **Study of recovery from coma** during 2003- 2008: **2009 Katz** et al. NATURAL HISTORY OF RECOVERY FROM BRAIN INJURY AFTER PROLONGED DISORDERS OF CONSCIOUSNESS: OUTCOME OF PATIENTS ADMITTED TO INPATIENT REHABILITATION WITH 1–4 YEAR FOLLOW-UP *Progress in Brain Research* https://www.sciencedirect.com/science/article/pii/S0079612309177075

- "The natural history of recovery from brain injury typically consists of a period of impaired consciousness, a subsequent period of confusion and amnesia, followed by a period of post-confusional recovery of function... The transition from coma to VS [vegetative state], which occurs within 2-3 weeks in the vast majority of survivors..." Then **72%** emerged from Minimally Conscious State (MCS), and **58%** emerged from Confusional State/Post-traumatic Amnesia (CS/PTA) "by latest follow-up. It took significantly longer for patients admitted in VS (means: MCS, 16.43 weeks; CS/PTA, 30.1 weeks)... The transition from the MCS to the next stage, labeled CS/PTA is marked by the Aspen work group criteria of accurate yes/no communication or object use..."
- **Further stages of recovery** from the same study: **Partly independent:** "**43%** patients achieved household independence (ability to be left alone for 8 h"). **Entirely independent:** "**22%** returned to work or school, **17%** at or near pre-injury levels..."
- "Most of these outcome studies were performed with patients admitted to **hospital-level rehabilitation facilities with specialized programs**... In the United States, public and private payers for health services have traditionally considered persons with prolonged impairments of consciousness inappropriate candidates for active rehabilitation assessment and treatment and they are often denied admission to hospital- level rehabilitation facilities... "

[73] **Permanent Vegetative State no longer accurate:** 2018 guidelines on disorders of consciousness: "Given the frequency of recovery of consciousness after 3 months in patients in nontraumatic VS/UWS [vegetative state/unresponsive wakefulness syndrome], and after 12 months in patients with traumatic VS/UWS (including some cases emerging from MCS [minimally conscious state]), use of the term permanent VS should be discontinued." **2018 Giacino** et al. PRACTICE GUIDELINE UPDATE RECOMMENDATIONS SUMMARY: DISORDERS OF CONSCIOUSNESS. *Neurology*. http://n.neurology.org/content/91/10/450.long

New brain pathways can form to bring patients out of comas:

- 2018: https://www.flintrehab.com/2018/can-the-brain-heal-itself-after-a-stroke/
- 2006: https://www.sciencedaily.com/releases/2006/12/061223092924.htm
- 2006: https://www.newscientist.com/article/dn9474-rewired-brain-revives-patient-after-19-years/

Specialist center in Germany rehabilitated woman who had been comatose 28 years in non-specialist care: 2019 Embury-Dennis. WOMAN WAKES UP FROM VEGETATIVE STATE AFTER 28 YEARS. *The Independent* https://www.independent.co.uk/news/world/middle-east/woman-coma-vegetative-state-wakes-up-munira-abdulla-germany-uae-a8881081.html

[74] **Board-certification of pain doctors** covers more knowledge about pain assessment, and drug- and non-drug treatments: http://www.abpm.org/outline than palliative care doctors, who have more on death, grief, communication, ethics, psychosocial and spiritual issues: http://www.abim.org/pdf/blueprint/HPM-CERT-Blueprint.pdf

[75] **Flexibility for medical representatives:**

- **2018 Veterans** Affairs Advance Directive 2018 revision. Section D asks if patients want their preferences "to serve as a general guide" or "to be followed strictly." https://www.va.gov/vaforms/medical/pdf/vha-10-0137-fill.pdf
- **2014 Rid et al.**, survey of 1169 patients in 2009-11 in George Washington University Hospital, Washington DC. For 88% having the family involved was one of the goals to balance. 10% said their most important goal was having their family help the doctors make treatment decisions. 39% said the most important goal was getting the treatments they themselves wanted, or avoiding treatments they did not want. PATIENTS' PRIORITIES FOR TREATMENT DECISION MAKING DURING PERIODS OF INCAPACITY: QUANTITATIVE SURVEY *Palliative & Supportive Care* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5535787/

- **2011 Sharma** et al. interviewed 52 patients with pancreatic cancer or ALS at Johns Hopkins Hospital. Looking into the future when they might be unconscious, 44% of patients would want their own preferences followed; 37% wanted decisions based equally on their wishes and what the family thinks best; 19% wanted whatever the family thinks best. When conscious, 35% wanted to make their own decisions; 59% wanted to share decision-making with family (so more wanted a shared decision, when they could speak up); 6% wanted the family to decide. FAMILY UNDERSTANDING OF SERIOUSLY-ILL PATIENT PREFERENCES FOR FAMILY INVOLVEMENT IN HEALTHCARE DECISION MAKING *J. of General Internal Medicine* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3138973/

- **2008 Berger** et al., "placing trust in their surrogates", SURROGATE DECISION MAKING: RECONCILING ETHICAL THEORY AND CLINICAL PRACTICE, *Annals of Internal Medicine* *http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.691.1213&rep=rep1&type=pdf*

Older papers on the benefits of flexibility, and the impossibility of clear, useful advance directives are:

- **2012 Kelly** et al. SYSTEMATIC REVIEW: INDIVIDUALS' GOALS FOR SURROGATE DECISION-MAKING. Summarizes 9 studies 1992-2003, showing about half of patients wanted their preferences strictly followed, sometimes after forming the preferences in a discussion with family. The rest wanted their representatives to have complete or partial flexibility *J. of Am. Geriatrics Society* https://pdfs.semanticscholar.org/89f9/f79f22b587d51f111ecaeac37643cd2504ed.pdf

- **2004 Fagerlin** et al. ENOUGH: THE FAILURE OF THE LIVING WILL, *Hastings Center Report,* https://www.thehastingscenter.org/pdf/publications/hcr_mar_apr_2004_enough.pdf

- **1991 Lynn** WHY I DON'T HAVE A LIVING WILL. *Law, Medicine and Health Care,* *https://www.researchgate.net/profile/Joanne_Lynn/publication/21259748*

[76] Patient reasons for choosing CPR:

- Most of these come from: **2011 Downar** et al. WHY DO PATIENTS AGREE TO A "DO NOT RESUSCITATE" OR "FULL CODE" ORDER? PERSPECTIVES OF MEDICAL INPATIENTS https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3101966/

- There are more in **2011 Anderson** et al., CODE STATUS DISCUSSIONS BETWEEN ATTENDING HOSPITALIST PHYSICIANS AND MEDICAL PATIENTS AT HOSPITAL ADMISSION *J. of General Internal Medicine* https://link.springer.com/article/10.1007/s11606-010-1568-6

- There are also more in **2018 Marco** et al. Table 3 has quotes from patients. "ADVANCE DIRECTIVES IN EMERGENCY MEDICINE: PATIENT PERSPECTIVES AND APPLICATION TO CLINICAL SCENARIOS" *Am. J. of Emergency Medicine* https://www.sciencedirect.com/science/article/pii/S0735675717306496

- There are a few in **2008 Deep** et al. DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling*. http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf

[77] 2018 Waiting lists for organs: https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/#

- 2015 AHA/ECC Guidelines on organ donations: https://eccguidelines.heart.org/index.php/circulation/cpr-ecc-guidelines-2/part-8-post-cardiac-arrest-care/?strue=1&id=11

[78] 3-month trial:

2018 Marco et al. Table 3 has this and other quotes from patients. "ADVANCE DIRECTIVES IN EMERGENCY MEDICINE: PATIENT PERSPECTIVES AND APPLICATION TO CLINICAL SCENARIOS" *Am. J. of Emergency Medicine* https://www.sciencedirect.com/science/article/pii/S0735675717306496

[79] Pressure from repeated requests to accept DNR is described at

https://community.macmillan.org.uk/cancer_experiences/general_cancer_discussions/f/general_cancer_discussions-13/3463/resuscitation-arguments-for-and-against

[80] **Odds of harm from DNR:** updated from a first aid and CPR instructor's comments at: https://www.quora.com/Are-there-any-reasons-not-to-sign-a-DNR-do-not-resuscitate-form-in-case-of-a-terminal-illness.

- Cardiac arrest happens 8 times per1,000 hospital admissions: **page e378**: "HEART DISEASE AND STROKE STATISTICS—2019 UPDATE" *Circulation* https://www.ahajournals.org/doi/10.1161/CIR.0000000000000659

[81] **Give it the best try we can**: **2011 Anderson** et al, CODE STATUS DISCUSSIONS BETWEEN ATTENDING HOSPITALIST PHYSICIANS AND MEDICAL PATIENTS AT HOSPITAL ADMISSION *J. of General Internal Medicine* https://link.springer.com/article/10.1007/s11606-010-1568-6

[82] **Patient reasons for choosing DNR:**

- Most of these come from: **2011 Downar** et al. WHY DO PATIENTS AGREE TO A "DO NOT RESUSCITATE" OR "FULL CODE" ORDER? PERSPECTIVES OF MEDICAL INPATIENTS https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3101966/
- There are more in **2011 Anderson** et al., CODE STATUS DISCUSSIONS BETWEEN ATTENDING HOSPITALIST PHYSICIANS AND MEDICAL PATIENTS AT HOSPITAL ADMISSION *J. of General Internal Medicine* https://link.springer.com/article/10.1007/s11606-010-1568-6
- There are also more in **2018 Marco** et al. in Table 3. "ADVANCE DIRECTIVES IN EMERGENCY MEDICINE: PATIENT PERSPECTIVES AND APPLICATION TO CLINICAL SCENARIOS" *Am. J. of Emergency Medicine* https://www.sciencedirect.com/science/article/pii/S0735675717306496
- There are a few in **2008 Deep** et al. DISCUSSING PREFERENCES FOR CARDIOPULMONARY RESUSCITATION: WHAT DO RESIDENT PHYSICIANS AND THEIR HOSPITALIZED PATIENTS THINK WAS DECIDED? *Patient Education and Counseling*. http://www.academia.edu/download/43322831/Discussing_preferences_for_cardiopulmona20160303-28644-1if1m6g.pdf

[83] **Son choosing against father's wishes:** Described by

- **2012 Ackerman**: http://www.startribune.com/to-what-lengths-to-prolong-life/161996495/
- **2012 Klein** http://time.com/735/the-long-goodbye/

[84] **Doctor trainees' expectations of DNR:** In a 2013 simulation, young doctor trainees said that **if they were terminally ill** they would choose DNR. This was widely mis-reported that doctors of all ages already have DNR orders: **2014 Periyakoil** et al. DO UNTO OTHERS: DOCTORS' PERSONAL END-OF-LIFE RESUSCITATION PREFERENCES AND THEIR ATTITUDES TOWARD ADVANCE DIRECTIVES *PLOS One* https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0098246

[85] **2002 data on retired doctors** from Johns Hopkins study: **2008 Wittink** et al. STABILITY OF PREFERENCES FOR END OF LIFE TREATMENT AFTER 3 YEARS OF FOLLOW-UP: THE JOHNS HOPKINS PRECURSORS STUDY *Archives of Internal Medicine* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2596594/

[86] **2018 guidelines on disorders of consciousness:** **2018 Giacino** et al. PRACTICE GUIDELINE UPDATE RECOMMENDATIONS SUMMARY: DISORDERS OF CONSCIOUSNESS. *Neurology*. http://n.neurology.org/content/91/10/450.long

[87] **Disability advocates say:** **2007 Ostrom**. SOME FAVOR SLOWER RIGHT TO DIE FOR PARALYZED *Seattle Times.* https://www.seattletimes.com/seattle-news/health/some-favor-slower-right-to-die-for-paralyzed/

Disability paradox: Most people with any kind of disability find meaning, often more than before their disability. When studies interview people with and without disabilities, they rate their quality of life equally highly. People grieve and adapt, in the same way they grieve and adapt after loss of a spouse, as shown in the following studies:

- **Living with brain damage:**

- 2018, six stories: https://www.theguardian.com/global/2018/dec/09/life-after-brain-damage-the-survivors-story
- Summary of many studies: https://www.cmu.edu/dietrich/sds/docs/loewenstein/misimaginingUnimaginable.pdf
- "When well, a patient may not think they wish any intensive or invasive treatments; when faced with the stark reality of death they may reconsider. **2015 Mockford** et al. DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR) ORDERS: A SYSTEMATIC REVIEW OF THE BARRIERS AND FACILITATORS OF DECISION-MAKING AND IMPLEMENTATION *Resuscitation* http://www.repository.heartofengland.nhs.uk/1052/1/gavin%20download.pdf
- **Nothelle et al. 2017. Geriatricians say** "it is vanishingly rare that a patient reports to us a preference to be dead," no matter how badly disabled the patient is: http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2613950
- **Patients with Locked In Syndrome**: **2011 Bruno** et al. A SURVEY ON SELF-ASSESSED WELL-BEING IN A COHORT OF CHRONIC LOCKED-IN SYNDROME PATIENTS: HAPPY MAJORITY, MISERABLE MINORITY *BMJ Open* https://bmjopen.bmj.com/content/1/1/e000039.full.pdf
- **2018 Dresser**, "negative stereotypes that influence advance choices about dementia care... they can only guess what they might want and need as a person with dementia.[9]... empirical research shows that people living with intellectual disabilities experience a better quality of life than nondisabled people think they do.[11] ADVANCE DIRECTIVES AND DISCRIMINATION AGAINST PEOPLE WITH DEMENTIA *Hastings Center Report* *https://onlinelibrary.wiley.com/doi/full/10.1002/hast.867*

[88] **Videos** of CPR attempts and training are at http://medfacts.globe1234.com

Videos by patients who use various types of **equipment** to enjoy productive lives (service animals, oxygen, feeding and breathing tubes, speech assistance, dialysis) are at http://aaa.globe1234.com/

Movies about living with disabilities are at

- https://themighty.com/2015/02/oscar-nominated-films-that-got-disease-and-disability-right/
- http://disabilityhorizons.com/2015/10/top-10-films-featuring-disability/
- https://www.ranker.com/list/best-disability-movies-list/all-genre-movies-lists
- https://en.wikipedia.org/wiki/Category:Films_about_disability

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These notes are at medfacts.globe1234.com, not in the 4-page printed pamphlet. That website also shows videos of CPR, successful and not.

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