

What to say and what not to say: A resident's guide to having meaningful conversations with your patients

Using code status discussions as a framework for all conversations

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TABLE OF CONTENTS

Why is this important?	3
Words Matter in Risk Interpretation	3
<i>Introduction</i>	<i>3</i>
<i>“There are three kinds of lies: lies, damned lies and statistics.”</i>	<i>3</i>
<i>A Real Life Example</i>	<i>4</i>
<i>How Do We Interpret Statistics?</i>	<i>4</i>
An example for the everyday: End of Life decisions	5
<i>Introduction</i>	<i>5</i>
<i>The Basic Data on Outcomes of CPR.....</i>	<i>5</i>
<i>A Typical Case</i>	<i>6</i>
<i>Video link: https://plotagon.com/310199</i>	<i>6</i>
<i>The Reflection.....</i>	<i>6</i>
<i>Common Statements From Patients, and Ideas of How to Respond</i>	<i>7</i>
<i>I want everything done.</i>	<i>7</i>
<i>Only if it’s reversible (aka for a day or two).....</i>	<i>8</i>
<i>I want CPR, but I don’t want to be on life support.</i>	<i>8</i>
<i>I just don’t know.....</i>	<i>8</i>
Shared Decision Making Model.....	10
<i>Choice Talk.....</i>	<i>10</i>
<i>Option Talk</i>	<i>11</i>
<i>Decision Talk.....</i>	<i>11</i>
Applying Shared Decision Making to Other Conversations	12
Conclusions	12
Appendix 1	14

Why is this important?

Maybe you have had a conversation that didn't go so well (we all have). Maybe it was an angry patient. Maybe you blurted out something that didn't sit well with the patient (however true it may have been). Maybe you were asked to have a conversation with a patient that you weren't comfortable with. Or maybe you came to an agreement with a patient but you weren't convinced they had actually understood the conversation. And hopefully you've had some conversations go extremely smoothly. While all of those situations will continue to occur, we hope to make the difficult situations less frequent by increasing the effectiveness of your communication skills.

This manual is not meant to be a comprehensive review of the literature. It's meant for you (residents) to get a taste of common pitfalls in communication, and get a few strategies to use when having conversations with patients. It's meant to get you thinking about how you communicate with your patients and learning to be conscientious about the conversations that you have. Over time you will develop your own strategies based on what works for you and your patients, and hopefully this will get you started on a good path.

Words Matter in Risk Interpretation

Introduction

"There are three kinds of lies: lies, damned lies and statistics."

Even the most honest and well-intentioned tend to use the numbers that look more impressive based on their goals: it's human nature. Not to mention the publication bias towards positive papers⁶ and the influence of industry, which profits on our clinical decisions. When we receive information from what we consider to be a reliable source (such as a high impact factor journal or a presentation from staff) we often take them at face value, as it's difficult to have your critical appraisal hat on 24 hours a day. It is important, however, to try to view the statistics with a cautious eye.

We all strive to provide the best care for our patients, which most of us consider to be evidence-based medicine. *If we misrepresent the statistical evidence to our patients (and ourselves for that matter), are we still practicing the spirit of evidence-based medicine?* And since patient autonomy is held above all else in our current climate of medical care, it seems crucial to be able to give patients unbiased evidence on which to base their decisions on.

Absolute versus relative risks, survival rates versus mortality rates, number needed to treat or to harm; while all may be accurate, how they are presented will influence our understanding of the issue at hand.

A Real Life Example

In 1995, a post-market analysis suggested that women taking third-generation oral contraceptives (OCPs) were at a 100% increased risk of thrombosis compared to those taking second-generation OCPs.

This relative risk increase of 100% was presented to the public via a press conference. Understandably then, a lot of women were scared and stopped taking the pill. This led to an **estimated 13 000 additional abortions in the UK that year**⁷, a procedure which came with significant additional risks, complications, and mental distress. While the increased relative risk presented was accurate, the baseline risk of thrombosis in those taking second-generation OCPs is 1 in 7000. Thus, doubling the risk (or a relative risk increase of 100%) only changes the risk of thrombosis to 2 in 7000. That is an absolute risk increase of 0.014% (or 1 in 7000).

When presented at a doubling of risk, you can understand the reaction. That is the power of changing the way risks are presented. As such, **it is important that we, as providers, understand that the way we present risk influences how it is interpreted.**

How Do We Interpret Statistics?

There are many studies examining how physicians and patients alike understand risk. A 2005 systematic review and meta-analysis put these together and confirmed what a lot of smaller studies suggested: that **presentation matters**⁸! Generally, relative risks are interpreted more favorably than are absolute risks or number needed to treat. Interestingly, when absolute risk or the baseline rate is presented **with** the relative risk, the relative risk is more appropriately interpreted.

Other studies suggest that using natural statistics (such as 1 in 100), rather than conditional statistics (1%) are more intuitive for people to understand, and also easier to convert between absolute and relative risks⁹.

The nitty-gritty: Converting between statistics

Absolute risk reduction = Rate of outcome (with intervention – without intervention)

Risk of thrombosis: $2/7000 - 1/7000 = 1/7000$
(0.014%)

Number Needed to Harm/Treat = $1 \div$ absolute risk

Number of people taking 3rd generation OCP need to cause 1 additional thrombosis event = $1 \div (1/7000) = 7000$

Relative Risk reduction = Rate of outcomes (with intervention \div without intervention)

Relative risk of thrombosis on 3rd generation OCP = $(2/7000) \div (1/7000) = 2$ (doubled risk)

How can we avoid these common pitfalls?

- ↳ Be aware that these techniques are used and be critical of what you see, hear and read
- ↳ Know how to do the calculations back and forth so even if they aren't provided, you can calculate them! (There are lots of online calculators to help with this)
- ↳ If you are given only relative risks, ask the presenter or search for the baseline absolute risk so you can form your own opinions based on complete information

While we as physicians are responsible for knowing and understanding the numbers we present to our patients, our data sources don't make it easy. Consider how the journals we often consider to be the most reliable, such as JAMA, BMJ, the Lancet, NEJM, Annals of Internal Medicine and the Journal of the National Cancer Institute, present their statistics. In an examination of the research articles published in those journals in the 11 month period between June 2003 and May 2004, **less than half presented an absolute risk** anywhere in the paper to accompany the relative risk used to convey the positive result¹⁰. And even when all of the relevant statistics were there, **the rate of benefit was often presented as a relative risk and the adverse event rate presented as an absolute risk**, potentially skewing your interpretation of the risk-benefit balance towards the intervention.

An example for the everyday: End of Life decisions

Introduction

We have 'the code conversation' on a daily basis with patients, yet we receive almost no training on how to do it! Hopefully this quick introduction will give you the basics to develop your own style.

The Basic Data on Outcomes of CPR

Did you know that on television, 77% of people survive a cardiac arrest¹¹? A survey of the general public demonstrated that the average predicted survival rate was 65%¹². It's no wonder patients often balk at our conversations around do-not-resuscitate orders; I would take those odds! As might be expected, the real statistics show a range of values depending on many variables, most of which we instinctively think about such as functional status, comorbidities and age. The following are rate of survival *to discharge* (not of immediate survival) of *in-hospital* cardiac arrests.

- ↳ **All comers: 17-18% survival rate¹⁻³**
 - Survival rate with good neurological function ~10% (58% of survivors³)
- ↳ Metastatic Cancer: 0-5% survival rate²
- ↳ Dependent (from a nursing home or dependent on any ADLs): 3% survival rate²

In addition to considering death, quality of life needs to be addressed with patients. Having received resuscitation in hospital has an important functional consequence for survivors. I often tell my patients that resuscitation is not a benign treatment, and that most people have some functional impairment upon survival. In fact, in a very large cohort study (>12,000) of those who underwent resuscitation in hospital, 84% of survivors previously lived at home. After surviving resuscitation, only 52% were functionally capable of returning home³. Considering that this is a section on presenting statistics, the opposite wording should also be considered: without resuscitation, 100% of patients will remain dead, or that 90% of patients will pass away despite attempting resuscitation.

In 2013 there was a calculator published that validated 13 variables that influenced survival rates, that is free to use online¹³. The calculator is useful as a tool for your own edification about what variables are relevant to survival, but also may be useful in more difficult conversations or when patients want a more personalized number than the “all-comers” survival rate (<http://www.gofarcalc.com/>).

There have been multiple studies suggesting patients are able to understand basic statistics and adjust their thought process accordingly. To prove this, 287 elderly patients in a geriatric practice were informed about the generic all comers’ probability of survival (above). When armed with this information, the rate of opting for CPR went from 41% to 22%. When given a rate of 0-5% survival for those with chronic disease with life expectancy of <1 year, CPR rate went from 11% to 5%¹⁴. This suggests that giving patients concrete numbers during code status discussions helps patients to make informed decisions.

A Typical Case

Mrs Lewis is an 81 year old female, retired real estate agent, presenting to the ED with shortness of breath and fever. Past medical history includes hypothyroidism, hypertension, paroxysmal atrial fibrillation, and type 2 diabetes mellitus (controlled on oral agents). She currently lives at home independently with no extra supports needed from home care.

Video link: <https://plotagon.com/310199>



(Full text of the conversation can be found in [Appendix 1](#))

The Reflection

This example conversation went far more smoothly than most of these kinds of conversations do in real life. The goal of this example was not to suggest that all of your conversations should look like this, but rather to give you an illustration of the shared decision making model (see [here](#) for details on the model) and to show you an ideal. Below we discuss some of the techniques that were used in the example.

It seems an obvious statement that different patients require different approaches. This could mean that the education level or cognitive status of the patient warrants more or less detail in the conversation. Mrs. Lewis has at least a grade 12 education, and thus appropriate level of language and detail was utilized. Other considerations include level of illness, both acute and chronic. In this case of Mrs. Lewis, the resident was using their expertise to suggest to the patient what they thought was most reasonable – DNR and no ICU. If in this example, Mrs. Lewis was instead a well 60 year old who comes in with a GI bleed secondary to NSAID use the conversation would look much different than if she was an 80 year old with metastatic cancer, which would again be different if she was a 74 year old with a few comorbidities coming in with sepsis. It is extremely important to gauge the conversation based on your earlier assessments and the information about the patient that you have available.

It is additionally important to be aware of framing in these conversations. Remember the section on stats – 90% mortality comes across differently than 10% survival. While not explicitly stated in the conversation, the words and descriptors are used to guide the patient. This approach can be seen as coercive – leading the patient to a decision without explicitly telling the patient you are directing them. The other way to look at it is taking what the patient expressed as their priorities, and using your knowledge to help their choices fit their priorities. It is extremely difficult, perhaps impossible without extensive counseling training, to phrase these conversations without some bias. ***What is most important is that we are cognizant that our word choice has the capability of guiding patients.*** For example, in this conversation use of the phrase “allow you to rest peacefully” has a certain connotation that may be considered to lead the patient in one direction. If instead it was phrased as “do nothing” it may lead the patient in another direction. Word choice has consequences for interpretation, and we need to consider this when having crucial conversations like code status discussions.

As your experience grows and you advance in your training and become staff, your comfort and certainty in providing suggestions and recommendations will evolve and with it, how this conversation unfolds will mature.

Hopefully this example gives you some vocabulary and questions to get you started on developing your own style. Just remember that every patient has different life experiences and levels of knowledge about healthcare that will influence how the conversation will go!

Common Statements From Patients, and Ideas of How to Respond

I want everything done.

Everything means different things to different people. It is important to clarify what that would look like in the patient’s mind and address any misconceptions. Receiving CPR or not is very different from receiving medical care or not. Sometimes a statement like “we would continue with the medical plan as we have discussed irrespective of your decision about CPR” can help to

clarify the common misconception that DNR = Do Not Treat. Other statements that might be useful in response to this can be “some people choose to allow a natural death if their heart were to stop completely and others may want all aggressive and heroic measures to attempt to restart their heart.”

Only if it's reversible (aka for a day or two)

This one's a difficult one – and that's exactly what I tell patients. We can never know if the illness will be reversible or if it will be a short stay in the ICU (they broke our crystal balls when we got into medicine). All jokes aside, this could be a reasonable option, but there is no clear way to document this on most standard resuscitation forms. What you can do, however, is document this conversation on your admission note after clarification with the patient.

For example, ask the patient “So you would be willing to be on a breathing machine and require the ICU for a short trial period. If you do not improve enough to be taken off the machines by day 3, we should, after discussion with your loved ones, take you off the machines and allow the illness to take its course, likely resulting in your death.” Then you document that exact conversation in their chart and it can then help to guide future discussions. I believe this documentation is especially important because it is very difficult for families to decide to discontinue care, and having this very clearly outlined in the chart can save families from the burden of making this agonizing decision.

I want CPR, but I don't want to be on life support.

This one is a common offender, and often comes from misinformation and misunderstanding about semantics. The problem here is that in order to properly address this you need time – which is often precious when these conversations are being had (i.e. at 3am when your energy is seriously fading). The ideal is to explore what is so acceptable about CPR and not acceptable about life support and see if clarification and education can overcome this opposition.

The other concern that may need to be addressed is that resuscitation is a package deal – you need to consent to the whole thing: CPR, shocks, ventilator and ICU stay. If we were to not intubate and ventilate during resuscitation, it would be like cleaning your bathroom without any cleaning products – it looks like you're doing something, but in truth you accomplish very little.

I just don't know

Sometimes the patient is confused on admission and the emergency department is not the best place for this conversation. If this is the case, best to document based on previous wishes (if available) or default full code AND ensure that the receiving team knows that another attempt should be made to have the conversation with the patient/SDM.

Alternatively, the patient may be overwhelmed by an emotionally charged conversation, and here would be the appropriate spot in shared decision making to ask permission to give your opinion based on the numbers and the patient's comorbidities as well as their expressed priorities. This may also be a good place to use the GO-FAR calculator for survival rates for that specific situation (click here - [GO-FAR](#)). Additionally, giving them an information pamphlet that they can read when they are feeling more ready to think about the topic may be a useful way to overcome this roadblock (available for download on the intranet at LHSC at <https://intra.lhsc.on.ca/ethics/other-resources/resources-patientsfamily>). If that's the case you can give them the reading material and revisit the topic the next day (again in this case, a default form should be completed and the patient informed that until a decision is made, the default is full).

Shared Decision Making Model

There are many different models of communication in the literature, and like many things, are more or less trendy (or have had different decades of prevalence in clinical practice). You have probably witnessed senior physicians use at least a few different communication styles in your experience thus far. The paternalistic strategy was predominant until a few decades ago, when the pendulum swung in the opposite direction to the informed decision making model (physician gives information without bias or opinion and the patient makes the decision). More and more literature in the last 15-20 years is focused on what might be considered a happy medium: the shared decision making model. While the hundreds of papers using this terminology have significant differences in the exact definition⁴, there are important similarities that have led to some guiding principles to be used. In 2012 a model was proposed that suggests a procedure that guides the outline below, and was used in the¹⁵. We present this model in hopes that you can use it as a framework for conducting difficult conversations – just as we did for our [sample conversation](#) above.

Essential elements include:

- ↳ Explaining the *issue* and the *options*.
- ↳ Discussing the positives and negatives of the different options.
- ↳ Getting the patient to express their values.
- ↳ The physician explaining their recommendation or experience.
- ↳ Ensuring comprehension and making a decision^{4,5}

Choice Talk

Summarize the problem. Then let the patient know that **there are choices** – often multiple reasonable choices, of which the “better” choice may depend on the individual patient. It needs to be clear to the patient that there is **not a wrong choice**. It is also important at this stage to express the **uncertainty of outcomes and side effects**. Phrases like those outlined in the box can help normalize the uncertainty that is inherent in medicine, a fact that patients often underestimate.

Phrase suggestions for Choice Talk:

“There is good information about how these treatments differ that I’d like to discuss with you”

“Different treatments have different consequences, some of which will matter more to you than to other people, some less.”

“It is difficult to predict who will have positive outcomes or intolerable side effects”

Option Talk

In today's world of google, it is incredibly important to check the patient's baseline understanding. Using phrases like those outlined in the box check to make sure you answer and address what they know so far, dispel any myths they may have encountered, and make sure that the discussion of particulars starts on a clean slate. **Initially listing the options and afterwards describing each** allows your patient to prepare themselves for the details.

Phrase Suggestions for Option Talk

"What have you read or heard about _____?"

"Active surveillance" rather than "watch and wait" is more dynamic.

It is also important to **describe each option in relative terms** to the other options (similarities and differences), in order to help patients digest the large amounts of information you are giving them. It is here that you could present the **risks and benefits** of the treatment options, and where the careful presentation of statistics would occur ([Click here](#) to go to section on risks). When all of the information is presented, you need to **summarize and check again for comprehension** of the facts. If available for your particular discussion, a decision aid or information pamphlet could be given to the patient at this point.

Decision Talk

Here is where you as the physician can ask an open-ended question and give your tired voice box a break! At this point you want to explore **their values and priorities**. From their stated preferences, you can then have them **express a decision** between the stated options. If their choice of the options does not match their stated goals and preferences, you can explore the opposing dichotomy with them to see if an option that matches your understanding of their values is there.

It would be here, at the request of the patient, that it would be appropriate to guide the patient or to **express your opinion about the best option** for that patient based on expertise and your knowledge of the patient's preferences.

Then you should be **moving towards making a decision**

with the patient about a way forward – whether that is a decision on a treatment plan now, or plans to reconvene to make a treatment decision after the patient can deliberate and discuss with their loved ones. In certain situations it may be appropriate to let your patient know that even if a decision is made, it can be revisited in the future.

Decision Talk Phrase suggestions

"What matters most to you?"

"Are there health states that would be intolerable to you?"

"Keeping in mind the preferences you just described to me, which of the options appeals to you?"

"After all this discussion, do you have any thoughts about what option you would like to pursue?"

"How does that treatment option allow you to prioritize _____?"

Applying Shared Decision Making to Other Conversations

The shared decision making model applies to all treatment decisions with patients, and is thought to be the ideal. I'm sure you can picture this sort of model informing conversations about anticoagulation for stroke prevention in atrial fibrillation, or different chemo regimens in oncology clinics in addition to our example on code status discussions.

Just remember the basics:

- Ensure the premise for the conversation is clear
- Present the different options initially
- Then present in more detail outlining the:
 - Similarities and differences
 - Pros and cons of the options
- Elicit patient priorities/values
- Explore how those priorities can be met by the options presented
- If appropriate, discuss your suggestions and opinions
- Move towards making a decision together

Conclusions

There is tons of research and resources out there if you are interested in getting some more information about the topics outlined above. The reference list below is in no way comprehensive, but could provide a start to your reading if you are interested. If you have any questions at all, please don't hesitate to contact me, Rachel Kyle, at rkyle2014@meds.uwo.ca!

Also please feel free to share this document to whomever may be interested. The more people read it the better our collective communication skills will be!

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Appendix 1

The following is the text version of the mock conversation in the video

Dr. PGY1: Hello again Mrs. Lewis. I would like to discuss something that is difficult to talk about, but that we ask everyone who stays with us in the hospital, no matter their age or health.

Mrs. Lewis: Oh my, that doesn't sound good.

Dr. PGY1: We do not expect this to happen, however we need to know what you would want us to do if you were to get much sicker so that in this unlikely event, we can give you the treatment you want. There are several treatment options that I would like to discuss with you, and each has different negative consequences. The acceptability of these risks are different for each person. **Have you ever thought about the kind of medical treatments you would want if you were to get sicker?**

Mrs. Lewis: It's a bit of a morbid question. But I've been in hospital a few times and you always ask it, so I have thought about it a little, but I'm not really sure what I want.

Dr. PGY1: That's no problem. There are two parts to the discussion that I would like to tackle separately. The first is about if we were to walk into your room and find your heart not beating and your lungs not breathing – that means you have passed away naturally. There are two options in this case: 1. Understand that you have died either from your illness or another unexpected event and allow you to rest peacefully or 2. Attempt to bring you back to life with aggressive and heroic measures including CPR and life support. This treatment plan means breaking ribs, placing a breathing tube in your throat, shocking your heart with electricity and transferring you to the intensive care unit on a ventilator. On average, out of every 10 people that receive this treatment, one to two would live to be discharged from hospital, and all of those will experience some level of functional decline, meaning you won't be as well as you were prior to this illness.

Mrs. Lewis: Oh my gosh. Nobody ever told me those details! Knowing that information I don't think its something I would want.

Dr. PGY1: Okay, I understand and that seems reasonable. The second part of this conversation is about if your illness is getting worse in hospital and our current level of medical care is not enough to get you over your illness. There are different levels of invasive care that we can provide, from intensive in the ICU with machines breathing for you and medications supporting your blood pressure, all the way to only offering medications related to symptoms without any goal of prolonging life. These options, and all those in between, have pros and cons, and which level of care you choose will depend on what your priorities are. **Mrs. Lewis, is there a state of health or functioning that you would consider unendurable?**

Mrs. Lewis: I live at home by myself right now, and that is extremely important to me. I think that having to go to a nursing home or coming in and out of hospital a lot would be worse than dying. I've had a good life, I'm 81 you know.

Dr. PGY1: Considering what you just told me about your priorities, what do you think about the level of care you would want if your health were worsen while you are in hospital?

Mrs. Lewis: Well I'm pretty sure I don't want to be on life support, but I would like to continue with other treatments.

Dr. PGY1: Sometimes when people don't want to be on life support we have less invasive options that we can try. We can use medications such as antibiotics by the IV or by mouth, machines like bipap that support your breathing while allowing you to be awake and alert, and generally avoid treatments that can cause pain or require sedating medications. With these treatments we attempt to minimize short term suffering while still treating your acute illness. Additionally, since you are able to communicate with us while receiving these treatments, we can include you in all treatment decisions.

Mrs. Lewis: That sounds reasonable, I would be okay with that.

Dr. PGY1: Okay, I'm going to repeat my understanding of our discussion, and you let me know if my understanding is correct. If we were to find you passed away, you would want us to leave you be, and if you were getting sicker, we would not go to the ICU and we would not put you on life-support. Otherwise, we would continue with our treatment plan.

Mrs. Lewis: That sounds like what I want.

Dr. PGY1: Also important for you to know is that if after reflection or discussions with your family, if you change your mind or have questions, we can always revisit the conversation. If you are interested, we do have a patient information pamphlet that I could give to you that outlines some of the issues we have discussed.

Mrs Lewis: Great, thank you.

Dr PGY1: You're welcome Mrs Lewis, I'll come check on you later.