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New Terms of Engagement
Bart Windrum's Definitions: Baselines for Overcoming Obstacles to Dying in and at Peace

Definitions Introduction

Right definitions are the foundation of engagement. Language matters because it frames our worldview. Language underlays our assumptions and expectations (however dubious having either may be…)…especially when we're vulnerable, in a situation in which effectiveness requires right thinking. It's too easy to lose the first week of some hospitalization in a state of passive uncertainty, unsure about both what is happening and what isn't happening. And if it's a 3-week terminal hospitalization (the typical and average US duration), that's a week we can't afford to lose. Reclaiming language is a vital first step in orienting ourselves to fulfill the role that medicine urges us to take on: advocating for our hospitalized loved one.

When a loved one is hospitalized or dying, our goals are simple: safe emergence from the hospital or a peaceful demise as it unfolds over months, closing weeks, and final days. During each of my parents' three-week terminal hospitalizations I learned the hard way that disorientation at the onset can compound, becoming multiple instances of harm, and even death (my father's death was precipitated by acquiring a hospital-caused superbug infection, MRSA, through a wrong-sized urinary catheter).

As the first week of each hospitalization wore on we couldn't believe some things that were happening, and we couldn't believe many things were not happening. It took us almost a full week—both times!—to begin waking up to the fact that what we were experiencing was not as we'd been led to believe by medical advertising (both historic and contemporary to the hospitalization) and the by very language used to discuss medical matters.

Subsequently, as I began pondering all the failures—my own, my family's, medicine's, our society's—the first problem I identified had to with expectations of receiving care. That led me to ask what "care" means.

The words we use and what they mean set our trajectory through a medical event, be that a mid-life surgery or dying and death. Words express concepts, identify situations, and frame our viewpoints

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and behaviors. When they're wrong, we suffer. Right language sets the stage for our experience. So let's set some terms right.

Care vs. Treatment and Care Team vs. Treatment Group

I no longer use 'care' and 'care team.' I wish every patient-family would stop using them, too (I can't even get my fellow patient activists to follow suit; after all the term 'care' is embedded in the label 'healthcare'). We know what care is—we learned it from our parents and provide it to our loved ones. I have come to call it 'mom and apple pie care'. Hospitals provide treatment. Here's my full definition of what hospitals provide. It's based on multiple hospital experiences:

> *Hospitals provide bodily repair services under the direction of independent physician-scientists and nurse-monitoring on some schedule.*

Medicine proffers to us that it delivers care. It does not. It uses 'care team' to describe how groups of providers on your case function.'Team' implies coordination under a leader. You might be surprised to learn, if you haven't yet experienced, how uncoordinated medical services can be. 'Treatment group' is an apt descriptor of what actually occurs. Medicine has a name for breakdowns in care/coordination: discontinuity. The fact that this name exists testifies to the prevalence of the condition it describes. But the term fails to convey what patient-families experience because of discontinuity. In my repeated experience that's shock and harm.

I'm happy to use 'care' and 'care team' once I've had felt experiences of them in a given situation. These identifiers must be earned in each context.

Do not think I'm being mean. I'm not; I'm being plain. It's tempting to let medicine's claim to 'care' skew our perceptions. Let's be honest: most of us care about who we are, what we do, and how we do it. Medicine does not own the notion or essence of 'care', and it is not disrespectful to reclaim it based on common sense and everyday experiences. When medicine fails its own aspirations to care that doesn't mean that we have to prop up what is too often a fiction. On the other hand, providers' work conditions can be daunting; we can offer a helping hand as advocates for our loved ones. And when medical providers truly manifest and deliver care, recognize them for it.

Prognosis vs. Forecasting

'Prognosis' is "the likely course of a disease or ailment." To 'forecast' is "to predict or estimate a future event or trend." Forecasting guides us by outlining a possible future. During hospitalization

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that'd be roughly five day's time. Prognosis is actually a subset of forecasting. The goals of forecasting include adequate disclosure with adequate lead time, the ability to plan, decide, and execute, and to reduce the likelihood of patient-family destabilization due to the shock that often accompanies news of next steps that have not been forecast. During my parents' terminal hospitalizations and other family members' mid-life hospitalizations we experienced a complete absence of forecasting which might easily have been provided. Had it, unnecessary risk and profound moments of shock and harm would not have occurred. Those moments destabilized us, and will destabilize you and your family should you experience them.

Perhaps you can sense how 'care' and 'forecasting' are related.

Wash vs Disinfect

"Please wash your hands" is the phrase suggested over and over again to try to guide medical providers toward compliance with a simple procedure that has been known for centuries to reduce infections. But it's the wrong phrase because it's inaccurate; hand washing is not the issue, disinfecting is. Hand washing is a procedure to disinfect. Infection is the danger. A request to wash can be brushed aside; a request to disinfect is a professional one that precisely targets the problem and risk.

Windrum's Matrix of Dying Terms™

We say we want to die in peace—meaning at home. We set that off against the awful opposite—tubed and wired up in an ICU (intensive care unit). We use these two extremes to express the universe of dying possibilities, but they don't. We are profoundly wrong, oversimplifying pathways to dying in our complex world.

Windrum's Matrix of Dying Terms is a moderately complex work that—for the first time—both identifies and names the range of dying situations ahead of all of us in the 21st century.

Windrum's Matrix is a tool. It's not hard to understand but does take some time to study. I identified sixteen distinct dying situations (to which we bring our varied circumstances). Sixteen is not a magic number, it emerged as I worked the interesting problem of identifying and neutrally naming dying situations that are common throughout the medicalized world.

Read up on Windrum's Matrix of Dying Terms at www.AxiomAction.com/matrix.

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Persient

The patient safety and empowerment world has pondered and gone back and forth about what to call people in need of medical treatment. Folks have flirted with ‘consumer’. The goal is to utilize language that puts the focus on the person and their personhood rather than medicine or one’s role as a patient (a dubious thought but it’s implied daily). Hence persient [pers (ē)ənt] derived from person and patient. The ‘s’ places the emphasis on personhood whereas a ‘t’ would place the emphasis on patienthood, and persient is close enough to ‘patient’ so as to represent a minor lingual change. Risky business, coining and introducing new language—yet new words are added to language every year (and sanctioned for inclusion in the dictionary). Feel free to use persient (and let people know you heard it from me). Persient: a person in need of medical attention.

Guest Definition: Nequamitis

From Joel Selmeier,* this fascinating suggestion: Nequamitis. *Nequam* is Latin for worthless, good for nothing, or bad. *Itis* is a suffix derived from Greek meaning inflammation. Nequamitis refers to systemic harm emanating from other than innocent human error. This is relevant because today it’s well documented that medical error is the 3rd leading cause of death in America, behind heart failure and cancer and ahead of every other cause of death.** Joel uses surgical precision in naming a condition afflicting medicine using the language that medicine uses.

* www.patient-safety.com/nequamitis.html
** www.jopm.org/opinion/commentary/2013/04/24/it’s-time-to-account-for-medical-error-in-“top-ten-causes-of-death-charts

The Importance of Using Right Language

Medicine has told us for some years now to bring at least one advocate along when hospitalized (ideally you want a team because it’s a 24/7 job and we ought not be alone in-hospital). It really doesn’t tell us why (too scary) or how (too complicated). Right language, neutrally expressed to accurately portray events and situations, helps us orient ourselves both emotionally and cognitively to our role as advocates for our hospitalized loved ones. Right language, right framing, are baselines for everything I offer in my presentations, the Overcoming the 7 Deadly Obstacles to Dying in Peace webinars and seminars, *Notes from the Waiting Room: Managing a Loved One’s (End of Life) Hospitalization*, and *How to Efficiently Settle the Family Estate*.

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