

# Granularity: The Missing Link in Clinical Pathways

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**Most clinical pathways have not been designed to incorporate the full spectrum of the patient experience, which includes elements not immediately related to clinical considerations. Changing that requires a significant shift in how clinical pathways are thought about, how they are developed, and what stakeholders provide during development. In a recent article, Winston Wong, MD, commented: “We are missing the patient experience aim when we refer to clinical pathways.” We agree with this statement and offer our insights on this important issue. Suggestions on how we may be able to move toward clinical pathways that can serve as comprehensive decision support tools are also provided.**

Several years ago at a patient advocate’s meeting, I listened to a young woman talk about her metastatic triple-negative breast cancer (TNBC). She was very knowledgeable about her disease, her available treatment options, and her grim prognosis. For 20 minutes she talked calmly and objectively about her difficulties and the frustration of trying to identify and qualify for “the right” clinical trial for her. At the end, she put up a final slide. It was a shot of her 3 daughters, beautiful little girls all younger than 10 years, and said simply, “I will do anything, try any drug, put up with any side effect, if I can be there for my children.”

In his article, “Clinical Pathways: Are They Enough to Improve Cancer Care,”<sup>1</sup> Dr Wong talks about the Triple Aim of improving clinical outcomes, improving patient satisfaction, and controlling costs, and asks: “What is missing? We are missing the patient experience aim when we refer to clinical pathways.”

He is right, of course, but to date, most clinical pathways have not been designed to incorporate the patient experience. The algorithms and flowcharts rarely ever take into account what matters most to the people who are making decisions about their treatments. Changing that requires a

significant shift in how clinical pathways are thought about and put together, but it is one that reflects the actual nature of the decision-making process.

## PATHWAYS THAT ENCOMPASS QUALITY OF LIFE

In real life, every clinical encounter is more than just the sum of a person’s symptoms or medical status or a presentation of best medical evidence. Every time a patient sits down with a health care provider, there is an exchange between 2 people in which a wide range of very human factors influence the outcome. How old is the patient? What other medical conditions are present? Where is that person in the treatment process—at the beginning of a new diagnosis, 2 or 3 treatments into it, at the end with few or no effective options? What is important to this individual? Are they like the young TNBC patient willing to tolerate a high level of toxicity and participate in research studies, or are they more interested in living whatever is left of their lives with as few doctors, drugs, and side effects as possible?

If the goal is to make clinical pathways comprehensive, then these pathways must also encompass the quality-of-life matters that have an impact on a person’s ability to participate in a treatment plan. These include transportation issues, which tend to loom largely on patient surveys, lost job time, and childcare. It is also imperative to factor in financial burden. Patients are facing rapidly increasing copays and shared costs for their care as well as high costs for drugs. Serious illness also inevitably brings additional financial toxicity related to but not directly connected to the medical costs. All of these elements influence both the decisions patients make and their adherence to specific treatment programs. It is also important to note that these issues need to be not only built into the main pathway but also revisited repeatedly during the course of treatment.

As we have noted previously, not all pathways are created equal.<sup>2</sup> To achieve Dr Wong’s goal of pathways that serve as comprehensive decision support tools, the pathway has to be designed as a means of helping patients navigate

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through health care decisions based on safety and effectiveness—this includes clinical trials. Pathways designed to serve as “checklists” actually limit the exercise of clinical judgement and customization of care; they rely on rigid standardization and fail to meet the goal of serving as comprehensive support tools.

Too often, attempts to define pathways to get to a single “best option” are based on an unsubstantiated notion of an “average” patient. Each patient’s circumstances and experience are incredibly complex. This reality dictates the need for very granular pathways that incorporate multiple preference variables relevant to a patient’s outcomes and also multiple aspects of care like diagnostics, surgery, palliative care, etc, that similarly reflect the real-world decisions that patients must make based on best available evidence. When one or only a small number of factors serve as the central organizing principle of the pathway, there is little to no possibility that the treatment protocols produced from it will include patient experience or support shared decision making.

### MAKING PATHWAYS MORE GRANULAR

There are 2 practical ways to approach this issue. One is to design clinical pathways to accommodate the clinical and

biological diversity of individuals facing serious illnesses. This demands that the pathways leave room not only for the main body of the population under consideration but also for a variety of subpopulations. As treatment for many diseases becomes more personalized and sub-population specific, these more flexible pathways become more necessary.

The second way is to recognize that no clinical pathway should have 100% adherence. That in and of itself speaks to a lack of attention to individual needs and preferences, to over standardization and over reliance on financial outcomes as a measure of success. In addition, at the risk of repeating myself, if you want to represent the patient experience, you have to hear the actual voices of patients and include them in the process of designing, implementing, and evaluating pathways.

Standardization plays a critical role in achieving the triple aim of improving care, but, in order to be comprehensive, the pathway platform must be sufficiently granular to customize the outcomes for individual patients. ♦

### References

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