Clinical forecasting: Towards a sociology of prognosis

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A B S T R A C T

Much of our understanding of prognosis in clinical settings comes from end-of-life situations but prognostication is also a concern in chronic illnesses. Parents of children living with seizures wonder what the future holds: will the child outgrow their seizures, or will they remain a part of their child's life? Based on video recordings of clinic consultations between pediatric neurologists and families, we examine how clinicians convey a child's prognosis. We find that neurologists mainly communicate the prognosis indirectly through the goals they set for the child, the time frame of attaining these goals, and the uncertainties they highlight regarding the attainability of the goals. By modulating goals and erring on the side of optimism, clinicians maintain a collaborative relationship even if the prognosis turns increasingly dire.

1. Introduction

What does the future hold for children diagnosed with seizures? Those children may follow a wide range of trajectories: from seizures that are outgrown as the child ages without further impairments, recalcitrant seizures that are barely controllable with medications, to uncontrollable seizures even after drug and surgical interventions (Jafarpour et al., 2018). The optimal outcome is to remain seizure free without medications, but for some children this goal remains out of reach. The future comes into focus over clinic visits as clinicians observe test results, seizure intensity and frequency, response to drugs, patient and parent preferences, and medication side effects. Consequently, during consultations, neurologists, parents, and patients navigate where on a scale of treatability the child falls. We argue that this kind of prognostication occurs indirectly through hints about the kind of future that can be anticipated and helps families to balance hope and maintain a therapeutic working relationship.

This analysis expands an emerging sociology of prognosis (Christakis, 1999). Most of the literature on prognosis deals with end-of-life discussions, even though prognoses also matter greatly for chronic conditions with variable or uncertain outcomes. At stake is how disease will disrupt anticipated futures and what futures are still attainable (Bury, 1982). Scholars have repeatedly found that even when clinicians have a good idea of what future awaits the patient, they avoid explicit prognostication. Typically, a prognosis is only implied by the diagnostic process and treatment steps (Christakis, 1997). Even when they prognosticate, clinicians favor giving positive prognoses and couch bad news in evasive euphemisms. They report fearing that a negative

prognosis will become a self-fulfilling prophecy and may torpedo the therapeutic partnership. Clinicians aim to prepare patients and their relatives for a possible turn for the worse without giving up hope for improvement. This optimistic bias greatly rests on how clinicians present clinical uncertainties, using the fact that outcomes are not predetermined as a means of maintaining hope.

Our contribution is threefold. First, we extend the literature on prognosis to the arena of chronic conditions. Clinicians reveal what quality of life and limitations to expect through indirect clues rather than direct prognoses. As in end-of-life discussions, this is a delicate task because clinicians must balance expectations with incentives to continue a long-term care relationship. Second, we identify indicators used to convey a prognosis. We will argue that clinicians tip their hand about the kind of future possible for the child based on three sets of clues: discussions of goals, timing of when these goals are achievable, and degree of certainty that the goals may be reached. Third, these three elements cluster together to indirectly convey prognostic trajectories. Clinicians differentiate between fixable, treatable, and manageable trajectories. A fixable future suggests that the child has a chance of remaining seizure and medication free; treatable implies that the seizures are possibly controlled with the continued use of medications; and manageable conveys that seizures may still be reduced but are likely going to be part of the child's future even with aggressive medication regimens. To communicate these trajectories, clinicians modulate the goals, timing, and certainties to set expectations for each family. Thus, they suggest attainable goals for all patients but these goals differ, allowing physicians to justify ongoing treatment and maintain a working relationship regardless of the kind of trajectory the child is on.

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2. A sociology of prognosis

Christakis (1997) showed that although historically prognosis was a prominent concern of medical expertise for a wide range of conditions, forecasting a patient's future has become marginalized in contemporary health interactions, subsumed in discussions of diagnosis and treatment. At a time when physicians had little control over the natural course of disease and many patients died, reading the patient for "grave" or "worrisome" signs remained an important part of physicians' training. When once fatal conditions turned chronic, however, the focus shifted to accurate diagnosis and tailoring treatments. Prognosis has become mainly relevant when the patient no longer follows an expected trajectory and the physician needs to account for idiosyncratic or individualistic factors that may signal a turn for the worse. The default expectation is that once a patient is correctly diagnosed and treatments implemented, the patient will hopefully improve, therefore rendering prognostic talk largely redundant.

Early medical sociological work highlighted that clinicians kept patients in the dark about prognostic knowledge. Thus, Glaser and Strauss (1965) built their typology of awareness contexts of dying on what patients knew about pending end-of-life (see also Sudnow, 1967). Davis noted that clinicians held insights about children's future after polio from parents, even though they were quite confident in what to expect. Roth (1963) analyzed how parents in a tuberculosis sanitorium read clues from fellow patients when clinicians avoided talking to them about their future. Peräkylä (1991) observed that clinicians used evasion to maintain hope for patients undergoing bone marrow transplantations. More recent studies show that although there may now be institutional incentives to prognosticate, –particularly at the end-of-life – clinicians tend to remain evasive in offering a prognosis. Thus, Lutfey and Maynard (1998) still found that clinicians shroud terminal cancer prognoses in vague and euphemistic language with allusions rather than direct statements and focus on what can still be done treatment wise. Work on the interactional organization of medical encounters consistently also finds that whereas most visits have diagnoses and/or treatment recommendation delivery slots, no phase of the visit is dedicated to discussing prognoses (Heritage and Maynard, 2006).

Clinicians' reluctance to prognosticate is rooted in concerns that articulating a bad prognosis may render it a self-fulfilling prophecy (Christakis, 1999) and sabotage the patient-clinician relationship (Antelius, 2007). They fear that telling patients about pending death may sap them of any hope to live and may initiate an isolating social death, where relatives and care providers treat the patient as already passed away. Maintaining hope, especially in cancer care where a positive outlook has received therapeutic traction (Good et al., 1990), is closely related to residual uncertainty in how the patient will respond to treatments (Gofton et al., 2018; Mattingly, 2010). Clinicians rarely consider an outcome predetermined and retell stories of patients beating the odds (Chambliss, 1996) or of outlier patients, either doing worse or better than the statistical norm. Consequently, prognostication is often optimistically biased: clinicians are more forthcoming with positive than negative prognoses, and they add silver linings to bad news (Stivers and Timmermans, 2017). Additionally, "cultivating hope" gives clinicians the opportunity to pursue further therapeutic steps (Russ and Kaufman, 2005). Patients and their relatives also show ambivalence towards receiving bad prognostic news: there is both a desire to know what they are in for and a need to believe in improvement to keep fighting (Russ and Kaufman, 2005). Excessive optimism, however, may undercut the clinical partnership if patients and relatives suspect that physicians are "sugarcoating" (Nyborn et al., 2016). Clinicians and patients then collaboratively, but with different levels of authority (Surbone, 2000), hold prognoses at bay to maintain hope for a positive outcome and to maintain belief in additional therapeutic steps.

Prognoses are also important for patients with chronic diseases who may wonder what their future holds. Certain conditions, such as developmental disabilities, congenital disorders, psychiatric diseases, and neurological ailments have a broad spectrum of symptomatic manifestations that range from mild to serious, even if not life-threatening. While a prognosis may be implied by a diagnosis and treatment protocol that sets a general expectation, the question remains whether *this specific patient* will follow the prognostic mold (Adams et al., 2009). At stake is the level of disability and the quality of life a patient and relatives may expect. Although few studies have examined prognosis for non life-threatening conditions, clinicians and patients face similar challenges such as managing clinical uncertainty, navigating hope and despair, and maintaining a long-term clinical relationship (Farber et al., 2018). For instance, in a study of nursing home patients with acquired brain damage, the staff lost patience with those who gave up, and insisted on the creation of a narrative of change with uncertain endings, thus preserving the possibility of improvement (Antelius, 2007). At a broader level, the notion of biographical disruption (Bury, 1982) suggests changes in future biography after chronic illness in light of a past self.

If clinicians tend to avoid direct prognostication about illness, how do parents and patients come to know clinicians' views of likely future trajectories? We extend an investigation of prognostication into pediatric neurology to examine how clinicians provide families with a sense of the future for their child with epilepsy. We show prognoses are not delivered directly the way that diagnoses and treatment recommendations typically are. Rather, they are brought into the treatment discussion through invocations of what kinds of goals are possible, the timing for achieving these goals, and the certainty with which families can conceive of these goals.

3. Data and methods

We draw from 132 video recordings of clinic visits for a child with seizures involving 123 families with one of 13 pediatric neurologists in a large Western US University level 4 (highly specialized) based outpatient clinics. The families were 43% white; 38% Latino; 13% Asian and 6% African American with just 1 family claiming "Other." Sixteen percent had a high school degree or less; 40% had completed some college or had an associate degree; 28% had a college degree; and 17% had attended graduate school. Families were generally earning at least $80 K per year (52%) with 12% earning less than $20 K, and 36% earning between $20 K and $80 K per year. Most families spoke English as their primary language (82%). The mean age of their child with epilepsy was 9.5 years (ranging from 0 to 23) and 51% of these children were boys. All study procedures were Institutional Review Board approved. Families provided written informed consent and completed a short demographic survey.

In terms of analysis, we coded video data following the principles of abductive analysis in which researchers code in light of existing theory with an aim of making theoretical innovations (Tavory and Timmermans, 2014) to distinguish the broad categories of treatability conveyed in the consultation in light of the sociological literature on prognosis. We began with a holistic approach to coding the data, identifying all cases in which a physician talked about the condition in a way that indicated it was or was not likely to be "treatable." Hallmarks of this were talk of stopping medication and/or seizures (or not). As we explain below, we excluded cases where all indicators were that the condition was untreatable. The next stage of analysis involved looking for indications that the condition was very likely to be treatable versus less likely to be treatable. We identified three clusters of cases on the continuum of how likely the condition is to be treatable. Each cluster shares commonalities and differs from the other two categories in how clinicians talk about the condition and treatment in terms of goals, time-frames and certainty. We then reviewed each case within these clusters ("fixable", "treatable," and "manageable") for talk of goals, time-frames, and certainty. Thus, in what follows, we argue that clinicians rely on these three dimensions to convey where on a prognostic continuum a child with epilepsy resides.