The importance of interdisciplinary communication with patients about complex, chronic illnesses: our experiences as parents of a child with a craniopharyngioma

Our 4-year-old daughter Neva was diagnosed with a craniopharyngioma in the fall of 2013. Persistent headaches and a growth delay prompted our pediatrician to recommend a magnetic resonance imaging, and a 1.7-cm partially cystic mass was discovered. The tumor was largely confined to the sellar region, but showed potential for hypothalamic and optic nerve involvement. Blood work confirmed growth hormone deficiency and secondary hypothyroidism.

We needed to make treatment decisions quickly, with very little information. Craniopharyngiomas afflict about 2 in 100,000, and only 1/3 to 1/2 of these are childhood tumors (1), which are markedly different in their biology, treatment and prognosis (2, 3). Outcomes vary dramatically with tumor size and location and with patient age (3). Importantly, because the specifics of the initial disease presentation drive the treatment course, it is difficult to predict outcomes using retrospective statistical analyses (3, 4). As well, there has been a large shift from radical to conservative surgical approaches in recent years (5), making data on long-term sequelae less relevant to current interventions.

In sum, there was tremendous uncertainty around which treatment options made the most sense for Neva. As environmental biologists, we saw many parallels to challenges in our own disciplines: disentangling correlation from causation, the need for realistic and ethical studies, and difficulties with generating predictions against a changing technological landscape. We were unsurprised to find strong differences in opinion between experts, but we were not prepared for the ways in which such complex information was communicated to patients and families through serial appointments with specialists, rather than in collaborative, interdisciplinary discussions.

Indeed, our most challenging decisions all required an interdisciplinary understanding of costs and benefits. First, we debated the surgical approach: e.g., cyst drainage vs. an attempted gross total resection. We carefully weighed the risks associated with loss of endocrine function, neurological and optic damage, as well as tumor prognosis. But we were hampered by an inability to have a single, integrated conversation with the entire care team. The fact that we had individual meetings instead is understandable given the demands of balancing clinic days with the delivery of specialty care, but evidence within and beyond medicine shows that this siloed approach can lead to poorer outcomes (6, 7).

We faced similar post-surgical challenges in weighing the timing of growth hormone therapy (8) and the timing of radiation intervention (9). These decisions also required input from all of Neva’s specialists. And, over time, we transitioned to a model in which the entire care team did meet jointly with us, a change that improved both communication and the speed at which final decisions were reached. Open conversations that allow patients to ask questions that sit at the intersection of disciplines are essential to optimal decision making, especially when time is of the essence.

Cultural shifts in other professions show the value of engaging stakeholders in an interdisciplinary approach. A generation ago, many environmentally relevant fields tended to operate in isolation, but societal needs for better decision making contributed to a sea change. Today, experts in policy, natural science, humanities and economics not only work together to evaluate pressing environmental concerns, but do so in concert with affected stakeholders (10, 11). Importantly, these changes in professional culture not only arose from outside pressure but happened because of well-respected leaders within the fields pushing for change.

These same lessons and cultural shifts are clearly emerging in medicine (12) and have been formalized in a ‘systems thinking’ framework for interdisciplinary
approaches to health care (13). Positive outcomes of interdisciplinary training and education have been demonstrated (14) and, as evidenced by the broad participation in the Kraniopharyngeom meeting that motivated this special issue, are increasingly prioritized by practitioners. Interdisciplinary decision making has been shown to be highly effective for care related to a whole suite of medical issues, particularly cancers (15–17).

Despite this progress, interdisciplinary frameworks are not common practice in patient communication. And yet, ‘shared decision-making’ approaches with active patient involvement (18, 19) have been shown to improve health outcomes (20, 21). The role of the medical professional in the shared decision-making model is that of the expert (19). But, for rare and highly complex diseases like craniopharyngiomas, typically no true ‘experts’ exist; rather, a team of professionals is involved in decision making.

We argue that all of the relevant team members must then also engage in interdisciplinary, shared decision-making discussions with patients and families. Indeed, when prostate cancer patients met with a radiation oncologist and a urologist simultaneously, the vast majority found this approach ‘helpful’ or ‘very helpful’ in their decision making (22). More recently, Gonzalo et al. (23) advocated for the importance of interdisciplinary bedside hospital rounds (rather than interdisciplinary boardroom conferences) and identified associated challenges that need to be addressed to make this approach more feasible. We note that, while time burdens are sometimes cited as a barrier to interdisciplinary approaches, our experience suggests they would save practitioner time in the long run by dispelling persistent uncertainties and accelerating treatment decisions.

Finally, we stress that the potential benefits of interdisciplinary communication strategies with patients are widespread. Shared decision making has been termed the ‘pinnacle of patient-centered care’ (24), and in nearly every area of medicine, patients are increasingly involved with their care and decision making (25). Rising global chronic illness burdens also necessitate greater interdisciplinary care (26). Emphasizing protocols that foster a team-based approach to communication can improve both the efficiency and the quality of medical decisions, while best capturing the new spirit of patient-directed care.

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