

Healthy as a trout – as delicate as a dragon-fly

TRAVAIL CRÉATIF / CREATIVE WORK

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Résumé

Les hôpitaux de réadaptation offrent un contraste saisissant entre le personnel, qui est en grande partie jeune, en forme et en bonne santé, et les patients, qui ont subi des événements importants, souvent brutaux, qui changent leur vie. Comblers le fossé entre ces deux mondes n'est pas facile, mais il peut aussi être difficile de concilier les valeurs des patients hospitalisés avant une blessure ou une maladie à ceux qui sont la voie de la guérison. Ceux qui travaillent dans la médecine de réadaptation promeuvent souvent un modèle de processus de consentement parce qu'ils comprennent que les patients avec des blessures fraîches peuvent avoir besoin de temps pour adapter leurs valeurs à leur nouvelle vie. Malgré cette compréhension, il peut être un défi de déterminer la meilleure façon de respecter l'autonomie du patient, tout en aidant ces mêmes patients à apprécier quelques-unes des limites de leurs capacités. La rédaction du récit personnel qui suit, tiré de ma propre expérience d'éthicienne de soins de santé et un patient réticent, m'a donné un meilleur aperçu de ces perplexités. Cette réflexion explore mon changement d'approche dans ma pratique professionnelle – et surtout dans ma vision de l'autonomie du patient – à la lumière de ma propre expérience avec la dépression post-partum.

Mots clés

réadaptation, autonomie, modèle de processus de consentement, dépression post-partum, éthicien

Summary

Rehabilitation hospitals provide a striking contrast between young, fit and largely able-bodied staff and patients who have experienced significant, often sudden, life-changing events. Bridging the gap between these worlds is not easy, but it can also be difficult to reconcile the values that the patients held before injury or illness with those that have begun to emerge on the road to recovery. Those working in rehabilitation medicine often endorse a process model of consent because they understand that patients with fresh injuries may need time for their values to adapt to their new lives. Despite this understanding, it can be a challenge to understand how best to respect patient autonomy whilst helping those same patients to appreciate some of the limits on their abilities. Drafting the following personal narrative, drawn from my own experience as a healthcare ethicist and reluctant patient, gave me greater insight into these perplexities. This reflection explores my changing approach to my professional practice – and especially my view of patient autonomy – in light of my own experience with post-partum depression.

Keywords

rehabilitation, autonomy, process-model of consent, post-partum depression, ethicist

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None to declare

Preamble

What follows is a brief meditation on the evolution of my own thinking about the nature of autonomy. This was a change initiated by personal experience rather than conscious deliberation, but I suspect that it could not have been wrought any other way.

Rehabilitation facilities routinely admit patients who have experienced life-events and undergone changes that present significant challenges to their self-understandings: an injured athlete may resist the knowledge that his independence depends largely on the efforts of others; an impatient patriarch might unexpectedly appreciate the gentle ministrations of those whose opinions he'd previously devalued; and an introverted academic might strain to read staff badges following an injury that has impaired his intellect. Paraphrasing an old lawyers' expression, we might say that "we must take our patients as we find them", and it would be a grave error to overlook their individuality as we seek to obtain consent to treatment, or to offer the supports that may be of benefit to them.

I offer the example of my own experience with the healthcare system to illustrate the value of well-placed questioning, and to invite reflection on the ways that our assumptions about a patient's needs and capacities might mislead. I believe that because I worked in a hospital setting, and presented myself as one who was independent, competent and resilient, that my healthcare providers were inclined to believe that I had little need of information or empathy. Indeed, one of my treating physicians spent nearly the whole of our clinical encounter peppering me with questions about my work and its relation to my studies in moral philosophy. I was grateful to be treated as a colleague, it certainly helped to mask my distress, but his approach may have reinforced my illusions of invincibility and reluctance to seek help.

The lessons I draw from my experience are not novel or profound, but I do hope that this glimpse of an insider's perspective might alert some others who might be inclined to rely too heavily on a patient's glib assurances when these might be motivated by self-protective strategies fostered by anxiety, pride or fatigue.

Personal narrative text: *Healthy as a trout –as delicate as a dragon-fly*

I work in a rehabilitation hospital and am reminded daily that a cardiac event, a spinal cord injury or a brain aneurism (to name but a few possibilities) can change a life within moments. Our patients work hard, harder than I'd thought possible, at resuming lives that have been interrupted. The physicians and staff work hard, too. As one of my spiritual care colleagues frequently observes, rehab is an "emotional hard-hat zone".

It feels good to work here though. Rehab specialists are focussed on setting goals and measuring small victories. They celebrate shuffling steps and indistinct vocalisations and it's tough to feel self-pity in a context so imbued with a can-do disposition. I have a confession to make, however. I haven't always worked in rehab (I spent approximately ten years in acute care before assuming my current position) and I haven't always felt as resilient as I seem. Physically, I am, as a good Maritimer might say, "as healthy as a trout". I'm doing well psychologically too, but I have experienced three postpartum depressions (PPD) that have made it as clear as a Miramichi salmon stream that none of this can be taken for granted. Like salmon fighting against fierce currents, those of us engaged in rehabilitation know that we face a difficult and tenuous process.

My most recent experience of PPD caught me entirely by surprise. It made no sense as I had no newborn to provide context or compensation. I was working as the Director of Ethics in a large acute care hospital and discovered in the space of four short months, first, that I was pregnant and, second, that I had lost this unexpected blessing. I was in my mid-forties with two children in university and a third, finally, settling into elementary school. As long as my daily two hour commute was smooth, and the ICUs reasonably quiet, work life and home co-existed fairly peacefully.

Carrying a pager and a blackberry around the clock had distanced me from my own life, however, in ways that hadn't quite registered on my consciousness. On the morning of my "procedure" – my body refused to miscarry after the heartbeat was lost – I was incredulous when a helpful attendant insisted that I surrender my electronic devices. I was on-call, after all. As I hadn't been able to eat before

receiving anaesthetic I urged my husband to take me to breakfast directly after discharge so that I could push through the wobbliness and get back on task. He conceded (with some reluctance) and I promptly vomited in the restaurant parking lot.

I was saddened by the loss but swiftly acquired a puppy to fill the void. I thought I was tough. The months that followed were difficult. My husband stoically accepted the sleep disturbances and frequent “accidents” associated with our canine newborn. I was impatient, labile and unfocussed. Stress-induced alopecia provided occasion for gallows humour. I suggested that my hairdresser might prescribe a leave of absence, but uninterrupted work provided an island of control in an emotional life that roiled with anger and disappointment.

It took much longer to recognise what was wrong, and to seek treatment, than the four months that prompted my difficulties. A perceptive colleague, a family physician (and bioethicist) with health issues of his own, lit a beacon in the storm. We were engaging in “troubles talk” over a quiet dinner when he quietly contested my claim that I was doing well, “Have you considered...? Is it possible that...?” That brief exchange was instructive. That my senior colleague, and mentor, disagreed with my interpretations was not new. He was inclined toward a paternalism that was as familiar as it was provoking. What was new was my willingness to listen without protest and to take comfort in his certainty. Once my illness was identified I was able to seek a remedy – not a quick fix, mind you, although I would have liked one. It didn’t go swimmingly afterwards, but I was able to make a start on feeling better.

Few of us welcome platitudes like “it was for the best” or “these things happen for a reason” but the experience of loss and grief did provide me with some modest benefits. My subsequent encounters in the neonatal ICU made me feel, if not think, differently about the suffering of our families. I caught myself being attentive to the possibility that our clients might need supports in the months post-discharge and was less convinced (on the labour and delivery wards and well beyond them) that those who appeared in control had no need of solicitude or gentle enquiries and repeated prompts. Most importantly, I had direct experience of the dislocation and anxiety that can attend the patient role. In the rehabilitation environment we speak quite a lot about the “process model” of consent. We take treatment refusals seriously but we also know that checking in from time to time, and rephrasing our offers, may be particularly appropriate when a loss is sudden and unanticipated. My healthy-self embraced a muscular conception of autonomy. My postpartum-self appreciated a gentle parentalism more. Five years later I haven’t entirely sorted out my theoretical position, but I do know that a patient’s ability to present well in the presence of strangers should never be mistaken for certainty or health. Fragility comes in many guises.

Recommended readings

1. Kuczewski MG, Fiedler I. [Ethical Issues in Physical Medicine and Rehabilitation: Treatment Decision Making with Adult Patients](#). *Critical Reviews in Physical and Rehabilitation Medicine* 2005; 17(1): 31-52.
2. Lidz CW, Appelbaum PS, Meisel A. [Two models of implementing informed consent](#). *Archives of Internal Medicine*. 1988; 148 (6):1385-9.
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