

The art of medicine

Epistolary medicine

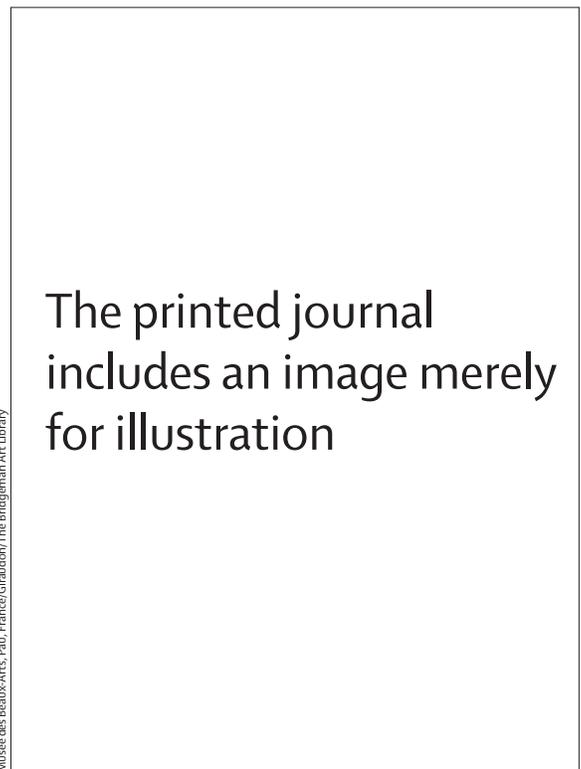
"When you have cancer, it seems like you lose parts of your identity—like in the fog of it you forget who you are, and it's really hard to find connections back to yourself. Writing to you has allowed me to reconnect with parts of myself that I had forgotten about or thought I had lost, so thank you for that." This note of gratitude was penned by a patient with cancer writing to a medical student. Intentionally, the two had never met face to face. Instead, they took part in a programme that embraces a philosophy of "slow communication", practising the art of dialogue to build rapport in a meaningful way.

Unlike many medical school exercises comprised of short exam room interviews where students take a patient's history, here the participants commit to taking the time to exchange thoughtful reflections about their attitudes regarding life around illness. They are participants in the Firefly Project, a component of Art for Recovery, at the UCSF Helen Diller Family Comprehensive Cancer Center. The project connects patients, medical students, and community teenagers through a monthly exchange of written correspondence and a collaborative creative project. Not emails, not twitters, not blog postings, but good old-fashioned letters sent through the post. All the participants agree that copies of letters will be held in an archive for the benefit of content analysis to

allow others to understand better how relationships come to be built through this means of communication. The aim is to give patients coping with life-threatening illness the opportunity to express their feelings through thoughtful writing, and to become teachers and mentors by sharing their experience. Students engage in a reflective dialogue to help them understand better patients' concerns, needs, and preferences in discussing their lives and illness, what the world of medicine is beginning to mean to them, and an opportunity to write about their own personal losses.

The Firefly Project was established 17 years ago and has enrolled over 900 correspondents who have exchanged thousands of letters. This archive of letters is a resource for analysing the art of doctor-patient communication and we have discovered certain themes and characteristic sentiments. Students find the time rewarding and patients show appreciation at being given an instrumental role as mentors in the journey of medical education. One patient wrote, "at times the shock of illness made me feel vulnerable to those who didn't understand 'the whole picture'. I was encouraged by the doctors who tried so hard to save me. I felt important enough to try my best too." As the project itself grew, it became notable that some teenagers, young students, and adult patients shared feelings of dependence, isolation, being misunderstood, and loneliness. Some students might not have had direct personal experience with sickness or dying, whereas others have lost a parent, grandparent, or friend. One student wrote to a correspondent: "My father passed away from cancer while I was in college. My dad's passing has affected my life in many ways, but I am thankful for the lessons I have learned from this experience." Patients, it became clear, wanted to give something back, to share the wisdom they gained through illness. "When patients step into the hospital or clinic", wrote one patient, echoing a sentiment expressed similarly by many others, "in some way it as though they have left their 'real' lives or identities outside the door—even though that isn't really true." When given the chance to reflect on, and respond to this comment, medical students have found new ways to talk about the effect of disease on their patients' lives. "Do you feel like there is some part of you that is immutable and cannot be altered by disease, or do you feel more fluid, so that experience is constantly molding your sense of self?" asked one student.

The tangibility of the letter is itself a special feature of the epistolary exchange. Philosophers and sociologists alike have related letter writing to a gift exchange. As one patient wrote in her first letter: "I am not a particularly private person and I am happy to discuss any and all aspects of my illness with you. Sharing experiences openly helps us stay connected with



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The Letter by Henri Lerolle

each other and helps us to keep our hearts open as we travel through challenges...and letters!" The receipt and possession of letters connects people in ways other exchanges might not. They hold the space of conversation in a uniquely artistic way, and the craft of letter writing becomes part of the ritual of slow communication. Indeed, it underscores the importance of the skill of composition, of paying attention to words, and reaching out in meditative ways to someone with whom one holds a respectful level of attention. To medical students, this stands in marked contrast to the SOAP (subjective, objective, assessment, plan) clinical note about a patient's condition where brevity is equated with efficiency and capability.

These letters become legacies of relationships and missives of education that contain insights about how we can build rapport and learn to talk about sensitive topics under trying circumstances. This is perceived by patients as a further benefit of participating in the project. "You asked what I hoped to get out of this experience," wrote one patient to a student, "I hope that I will have an impact on the way you practise medicine—that by knowing me more personally, it will help bring your whole self to your work—your heart and mind and spirit—so that each patient with whom you work feels that you see them as a person."

In examining the archive, we wanted to know what the letters can tell educators about the process of developing empathy and rapport between medical students and patients. Similar to the recent development of reflective journal writing in medical and nursing education, we believed that the written exchanges act as a pedagogical tool for enabling learning about the relationship between assumptions, attitudes, and practices of coping with disease. By analysing these letters, we sought to know what happens during organic and unpressured communication and what features might be useful for recommendations on how to navigate discussions of sensitive topics as part of medical education. We also wanted to find out if there are certain concerns about the illness experience or health care that are most prominent in patient communications, which may offer the potential to enhance our ability to engage with patients working through the progression of cancer diagnosis, treatment, and recovery.

What stood out the most to our readers was the prominence of concerns between patients and students alike about identity formation and modification in the face of life-transforming experiences. We found that for students, handling the pressures of medical education itself was a transforming experience that profoundly affected them and allowed them to understand how others struggle to express their feelings in trying times. "I am currently torn," wrote one student. "I am happy to be here but at times I find myself questioning whether I will be able to handle the rigors of medical school...[W]e call it the duck syndrome: on the surface of the water, outsiders see ducks gliding

around looking like they haven't got a care in the world, but underneath the water every duck is paddling ferociously to stay afloat." Like many students in training, she was beginning to glean a sense of how the professionalisation process imposes pressures on the way one manages time, personal commitments, knowledge, and attitudes about life dedicated to the complex arena of health care. And like most modern medical curricula, her coursework includes some instruction on what this world looks like from the patients' point of view. Yet as medical educators have widely reported, students find it difficult to balance a stance of professional neutrality and objectivity while not simultaneously depersonalising the clinical encounter and sometimes feeling dehumanised themselves in the process.

Patients often articulated ways that they feel a loss of identity owing to illness, surgery, or other aspects of a therapeutic regime. "Sometimes", a patient wrote, "I long for someone to just take care of me and tell me what to do—but that is not how MY journey has gone." In a representative comment, another correspondent described how "Physical illness seems to take you very far away from yourself". "But", she adds "in actuality it can't take you away from who you are at your core, your humanity, or soul. That core has tremendous resilience and a power all its own." This comment captures a shift in emotional and psychological focus about the self that we found was a common theme between correspondents. Not disease itself, or attitudes about the health-care delivery system, or visceral reactions to treatment, but the journey of rediscovery of oneself and reflecting on concerns about how others see the patient was what formed the heart of the exchange as the student-patient relationship bonded.

And this provides the message that we wish to share from what we learned about the art of slow communication. It is not necessarily what correspondents learned about each other but what they came to learn about themselves through reflection on their experiences that mattered most. A student wrote, "I have come to terms with death and dying perhaps more than your average 23 year old. Seeing people suffer is one of the downsides of medicine that I really fear. I also fear that one day I will become immune to it." The gift of the letter we believe opens up unique ways of understanding patients' self-identity and of developing medical students' sense of their own development as professional health-care providers.

Our research was supported by the University of California, San Francisco School of Medicine Dean's Summer Research Stipend.

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Further reading

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