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Saint Anthony's Fire and AIDS: two altarpieces and the oft-forgotten goals of medicine

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Sixteenth-century Isenheim, in what is now France, witnessed the anguish of those suffering from a mysterious disease called Saint Anthony's Fire (now commonly believed to be ergotism, caused by a fungus in rye flour). Often reaching epidemic proportions throughout the Middle Ages, this illness brought horrific suffering: nausea, vomiting, seizures, hallucinations, sores, gangrene and inflammation of nerve endings, making those afflicted by it feel as if their bodies were on fire. Sufferers would come to the Antonite monastery hospital seeking relief. To celebrate deliverance from this plague, the monks commissioned Matthias Grunewald to create an altarpiece for the monastery chapel. The [Isenheim Altarpiece](#) became one of the most important pieces of art of the Renaissance, a testament to the meaning and the mystery of suffering and the hope of redemption and restoration. Much scholarship has been directed toward the altarpiece in all of its complexity—both in its communication of doctrine and in its evocation of pain and isolation among those who suffered from Saint Anthony's Fire [1].

During the 1980s, AIDS spread throughout much of sub-Saharan Africa including the small fishing village of Hamburg, South Africa. It afflicted an estimated one-third of all adults in the Keiskamma River Valley. Those stricken with the disease were often isolated, dying in their parents' homes and then buried in cemeteries outside of town. Shame was strong, and the community remained silent—until 2002 when Dr. Carol Hofmeyr began to treat patients with HIV/AIDS. Hofmeyr and her husband, also a physician, worked to get AIDS medications to the area and established a hospice and treatment center in Hamburg. Hofmeyr, who studied art history, initiated a program to teach embroidery to local women, both for economic reasons and as a means of sharing their experiences of loss. After initial projects including a large tapestry depicting their region's history, the women began to plan their next project. Hofmeyr told the women about the Isenheim Altarpiece in France, which she had recently seen. The group considered how they might reinterpret it, and thus began the work of turning experience into embroidery (see figure 1) [2-4].



Figure 1. Keiskamma Altarpiece
By permission of the UCLA AIDS Institute.
Photo credit: Boza Ivanovic.

It took 130 women and several men approximately six months to finish the Keiskamma Altarpiece. Like the Isenheim, the Keiskamma Altarpiece is monumental, 13 feet tall and 22 feet wide, with three levels of panels. Also echoing the Isenheim Altarpiece, the three levels of the Keiskamma panels dramatically portray the sense of purpose and shared stories that drew the artists together. Hofmeyr describes the creation of the Keiskamma Altarpiece as a “turning point in our community’s relationship with HIV and AIDS...embod[ying] not just our fears and our losses but the slow restoration of hope in our community” [5].

“Be with me:” the sometimes forgotten goals of medicine

What turn-of-the 21st century Hamburg, South Africa, and turn-of-the 16th century Isenheim in Alsace Lorraine share—the experience of plague and their responses to it—informs, or should inform the goals and practice of medicine in a time where we increasingly look to technology for cure. In the broadest sense, the goals of medicine are to prevent or cure when possible and to care for patients when cure is not possible. When Grunewald created his altarpiece, the cause of Saint Anthony’s Fire was still unknown, and emphasis was placed on the alleviation of pain and transformation of suffering [6].

As knowledge in disease processes and technology has developed, however, the emphasis in medicine has shifted to cure [7]. This is obviously not a bad thing in and

of itself. Yet, one consequence of this shift has been the introduction of a clinical narrative of the patient that acknowledges neither the illness experience nor the relational aspect of human experience—a narrative that silences the voice of the patient [8]. The patient is objectified, becoming a body with an illness. Yet suffering is more than the physical presentation of an illness or disease. Thus, the clinical narrative eclipses the patient’s experience of suffering and its impact on her relationships. Isolated once by an illness, the patient is isolated again within the context of the patient-physician encounter.

Rita Charon puts this point so clearly: “Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses” [9]. What does it mean for a physician to accompany a patient through illness? Patient abandonment is discussed in its legal sense, but is it possible to abandon the patient without ever outwardly severing the patient-physician relationship? To the extent that medicine remains myopic in its focus on cure, I would answer yes.

“Let me speak:” narrative as integral to the healing process

How does a physician accompany his patients through illness? Not only do the Isenheim and Keiskamma altarpieces remind us of the often forgotten goals of alleviating and transforming patient suffering and accompanying the patient, they also suggest *how* the patient might be accompanied by illustrating the therapeutic value of telling one’s story. The altarpieces are narratives of illness, suffering, transformation and hope. Patients at the monastery hospital were brought into the chapel to see the altarpiece and pray or perhaps meditate. Although Grunewald may not have had St. Anthony’s Fire, his depiction was a keen acknowledgement of the patients’ suffering. With this sensitive portrayal and hope of transformation, the altarpiece was in essence the story of each patient that came before it.

Arthur Frank refers to the patient as a “wounded storyteller,” “trying to survive in a world that does not immediately make sense [10]. Narratives, an integral part of the healing process, are a response to this upheaval. Frank describes three types of illness narratives: restitution, chaos and quest. Restitution narratives often feature technology and the expectation of getting well. In contrast, chaos narratives seem to have no end or resolution. Quest narratives are concerned with gaining insight as illness becomes a means of personal transformation.

The restitution narrative fits well into a clinical paradigm that focuses narrowly on cure. As Frank notes, patients become ill, visit the doctor, follow recommended treatment and return to their everyday routines as if illness were a temporary detour from normal life. But what happens when suffering is extended or the prognosis uncertain or without hope? These situations are likely to invoke chaos narratives. And perhaps nowhere has this sense of isolation and loss of control been greater than in the experience of Africans with AIDS. The patient is disempowered in her own healing process. Denied time to reflect and form a narrative and unable to give voice to her experience, she surrenders control. Frank argues that “To deny a chaos story is

to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathetic relations of care” [11]. Likewise, Charon argues that physicians must develop “narrative competence” to absorb, interpret and respond to stories [12].

Failing to listen may cause a patient to withhold important information or may result in unfocused and more costly workups or even in incorrect diagnoses [13]. Honoring patient narratives can empower the patient and transform the meaning of suffering. It can improve quality of care and foster genuinely empathetic patient-physician relationships. But what happens when the patient, in physical or emotional illness, cannot speak?

“When I cannot speak, speak for me:” suffering and the relational aspect of healing and transformation

Serious or chronic illnesses can isolate the patient. A clinical paradigm that focuses too narrowly on cure only deepens this isolation. The Isenheim and Keiskamma altarpieces exemplify another way in which the often forgotten goals of medicine may be pursued: the transformation of suffering via the patient’s rejoining of community. The patients at the monastery hospital were welcomed into a community whose narrative not only identified affliction with the sufferings of Christ but also conveyed the possibility of the transformation of suffering into meaning.

This is not to say that meaning must be religious but that there is a spiritual aspect to human transcendence of suffering [14]. Frank’s description of the third kind of illness narrative, the quest, is helpful here. In quest narratives the patient is the hero, searching for a new understanding of the illness experience. In telling how she meets this challenge, the patient creates an ethical practice toward others through recollection, solidarity, commitment and inspiration. When the patient tells her story to correct a past wrong, she practices recollection. In practicing solidarity and commitment, she uses her story to speak along with fellow-sufferers. And in supplying an example of how one might meet this particular challenge, the patient provides inspiration [15].

Because the story-telling involves the other, the quest narrative serves as a means for the patient to rejoin the community of others. As illustrated by the Keiskamma Altarpiece, the story is told not only to create meaning for one’s self but also to speak alongside other community members who have suffered the devastation of AIDS in shared understanding. Those who had once lost their voices have found them. Those who cannot speak are spoken for. Once isolated in illness, those suffering have found their way to a home within their community.

Though the contexts of medicine may change, physicians will always need to attend to goals of alleviating and transforming suffering. Narrative medicine is the work of patient, physician and community. Developing capacities for listening to the stories that shape understanding of illness and suffering is both clinically and morally

required. Not only do the Isenheim and Keiskamma altarpieces exemplify how narratives might inform patient care, they are examples of the kinds of narratives to which we should attend. Whether found in museums, literature or at the patient's bedside, listening to such narratives has the potential to transform the practice of medicine.

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