

The Crucible of Anorexia Nervosa

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ABSTRACT

Anorexia nervosa (AN) is a very serious condition because of the suffering and loss of life that it causes. However, the wishes of the people directly involved can be strongly opposed. The person with severe AN may not want treatment, yet her family beseeches professionals to unilaterally intervene and clinical teams are divided over the defensibility of involuntary hospitalization and treatment. The metaphor of a crucible is used in this paper to help identify how much is at stake and how much is in conflict when someone has AN. Frank (2004) cautions against ethical analyses that rely mostly on substantive principles or rules and institutional conflict resolution procedures. This paper applies his heuristic concepts of “ethics-as-substance” and “ethics-as-process” to a prototypical AN case to illustrate how process activities can expand understanding of, and responsiveness to, those who are living with this dire condition or those who are obligated to help.

Introduction:

Much has been written clinically about the serious eating disorder, anorexia nervosa (hereafter AN), which has one of the highest death rates of all psychiatric illnesses (Giordano 2003; Zhu & Walsh 2002). It seems that therapists’ use of forced hospitalization and feeding to rescue someone with severe AN prompted lawyers and ethicists to enter the debate, as evidenced by Rebecca Dresser and Norman Fost’s 1984 articles. Laws are socially sanctioned, penalty-bearing rules and regulations for individual and group behaviour in a community setting. On the other hand, ethics, as defined by Arthur Frank, is “the institutionalization of responding to troubles” (2004, 355).

AN clearly qualifies as a very troubling state for both the person who “has it” and those connected to her or him. The emotional toll is real, as shown by these comments: for the person: “it can make you feel you are being punished when you are [involuntarily hospitalized]” and “they were treating me like I was about ten [years old], and I was a vegetable” (Tan et al 2003, 640); for the family: “So how does a mother feel? Failed, useless, bad, stupid,

guilty, guilty, guilty” (Whitney et al 2005, 446) and “I just feel so helpless about it, I don’t know what to do anymore, I don’t know what to say” (Tan 639). And clinical teams often react with anger, mistrust, dislike, and fear of these clients (Brotman et al 2006; Surgenor 2003; Hébert & Weingarten 1991).

Based on these experiences, the metaphor of a crucible is fitting for having chronic, treatment refractory AN and responding to people with AN. In manufacturing or chemistry, a crucible is a device in which powerful forces are used to create, change or destroy very resilient materials. It is a vessel to bring together and contain such dynamics and it must be able to endure them. But crucibles are not limited to technology. Arthur Miller’s 1953 play, “The Crucible,” dramatizes the Salem witch trials wherein communal forces of public confession and religious absolutism counter individual forces of fidelity and honesty. As Judge Hathorne duly warns a petitioner, “We burn a hot fire here; it melts down all concealment” (78). Because these forces arise within the relatively young Salem community —itself a kind of bounded, phenomenological vessel—the forces’ potency endangers the community’s own survival.

In the case of AN, several strong ethical “forces” are at play. I believe these forces qualify as “ethics-as-substance,” a heuristic concept formulated by Frank (2004). Ethics-as-substance involves theories, principles, rules, and procedures to help make ethically sound decisions. Familiar examples include the theory of utilitarianism and virtue theory, the principles of truth telling and fairness, rules against patient abandonment and exploitation and institutional procedures for ethics consultation. Yet if substantive concepts are relied on exclusively, Frank foresees serious problems because they “miss something and what is missing eventually limits the force of ethics” (355). Accordingly, he recommends adding “ethics-as-process” as part of addressing everyday as well as crisis situations in healthcare. Ethics-as-process involves attitudes and approaches for responding ethically to other people. Examples include the attitudes of being non-judgmental and accepting uncertainty and approaches guided by imagination and existentialism.

This paper uses Frank’s two concepts to critique the reasoning and arguments commonly used in ethics-related discussions about AN. And the crucible metaphor is used by focusing on those most directly involved and the kinds of justifications typically offered for their actions: the person with AN, the family, the clinical team, and the community-at-large. This analysis is valuable because it shows how augmenting various substantive concepts with process

considerations improve ethical understanding of and responsiveness to a person with chronic AN.

To help ground the discussion in reality, assume that the situation-at-hand is much like that commonly described in the clinical literature: the young woman (e.g., 21 years old) has lived with AN for four years, been in different in-patient and outpatient therapy programs and has never sustained the weight gained from such interventions. Today, her body mass index is below 16 (18.5 to 24.9 is considered normal; NIH 2007) and the thinness of her face, hands and neck is clearly visible to others. Since she believes she is okay, she turns down suggestions to resume individual or group, in-patient or outpatient psychotherapy. Her parents and teenage brother are very worried and very exhausted by the chronicity and repeated regressions of their daughter and sister's illness.

From the Client's Perspective

Many writers justify this client's preference for her current situation by appealing to such substantive concepts as the theory of liberalism (Lester 1997; Silber 1989; Fost 1984) and the concepts of autonomy (Guarda et al 2007; Beumont & Carney 2003; Tan et al 2003; Gans & Gunn 2003; Draper 2000) and independence (Griffin & Berry 2003; Goldner 1989; Dresser 1984). Liberalism holds that what matters ethically are individual rights and freedoms. So as a starting point, she has the right to refuse recommended treatment and decide, without others' interference, how she wants to live. Patient autonomy, the counterbalance to professional and familial paternalism, focuses on conscientious choices someone makes to pursue his goals and interests. The young woman can therefore be held responsible and accountable for her decision. And at 21 years of age, she is an independent adult and so it is her life to live as she wishes.

However, these three substantive concepts are worrisome for some theorists. For instance, provocative phrases such as "dying with their rights on" (Treffert 1973) and "rotting with their rights on" (Appelbaum & Gutheil 1979) remind us that while rights are very important "means," attention must also be paid to the kinds of "ends" a person can hope for.

With respect to patient autonomy, it is sometimes treated as one of Charles Taylor's (1989) "hypergoods." A hypergood is something considered so important that it serves as "the standpoint from which [other goods] must be weighed, judged, decided about" (63). Gaylin and Jennings wrote *The Perversion of Autonomy* (2003) to argue against autonomy trumping all other relevant values and silencing other viewpoints. Sue Sherwin (1998) chose a different tack: she rehabilitated traditional Kantian autonomy by developing the concept of relational autonomy, wherein ongoing consideration of others' welfare and interests is required, important and normal.

Various feminist theorists (Sherwin; Donchin 2000; Nelson & Carse 1996; Gilligan 1982) and writers in disability studies (Smith 2001; Silvers 1999) dispute the traditional view of people being characterized as independent decision makers. They point to the reality of human experience. From cradle to grave, no matter how advantaged, educated, physically or mentally able a person

is, he relies on a host of other people and a host of people rely on him. Furthermore he is neither alone nor totally self-sufficient. Instead, he is interdependent. As a substantive concept replacing independence, interdependence reflects the ontological fact that humans have multiple temporal, asymmetrical, reciprocal and evolving interrelationships. Therefore substantive concepts for the young woman to use in examining her own situation should be revised to include alternative "ends," relational autonomy and interdependence.

How might ethics-as-process help assess the young woman's situation from her vantage point? In two ways, I think. Frank states that, "...almost all clinical troubles arise as consequences of prior decisions" (2004 356). Accordingly, it is important to ask: how did she come to be here, now, like this? Her history of having AN and all that she has been through informs who she is today. Therefore taking the time to learn from her, letting her voice be heard, and understanding her lived experience constitutes ethics-as-process or "the ongoing work of being ethical" (ibid). Tan's (2006, 2003) studies of patient and parents' experiences are one such example.

The second way begins with Frank's (1997) extensive work on the meaningfulness and identity-forming consequences of living with a long-term illness or not fully recovering from an illness. Rather than just focusing on the physiological consequences of rejecting or accepting clinical treatment, the young woman could ask herself, "Who [do] I become as a result of making this decision?" (2004, 357). When she studies the decisions she has made and questions her reasons for earlier choices, she is engaged in an ethical process of self-reflection and growth.

In summary, many writers employ ethically substantive concepts to defend an AN person's refusal of clinical treatment and care. Unfortunately, these concepts may be thin (i.e., rights alone), imperialistic (i.e., autonomy), or even inaccurate (i.e., independence). Fortunately, rehabilitated versions or substitutes have been developed. More recently, too, writers offer ethics-as-process approaches to deepen our engagement and understanding of the young woman.

From the Family's Perspective

Family requests for involuntary hospitalization and/or treatment usually are justified by four ethical concepts. First, love and fidelity motivate the young woman's parents' deep concern and fear for her well-being and her future and their ongoing efforts to access effective therapy. Complimenting this is the instinctive and socially expected parental duty to protect one's child from danger. The fourth concept is substitute decision making. When an adult is found to lack capacity for a treatment or admission decision, those who know him best and care about his welfare are good candidates to be responsible for his healthcare decisions. If there is no serious conflict of interest between the young woman and her parents, most institutional procedures for substitute decision-making will consider her parents the most appropriate SDMs if she is clinically deemed to lack the requisite capacity.

Substantive concepts are about what matters ethically. For themselves and for their daughter, the parents value her life and returning to more common activities and goals. But their daughter values something quite different. When more than one person is involved, different opinions should be expected as to what matters and how much. If the hope is for an outcome that everyone can, at a minimum, accept and still remain connected, then ethics-as-process is required.

Three processes are relevant to this situation. First, discussion as an ethics-related process is much more than communications, which can be one-way. To underscore the depth of this process, a favoured ethics term is “dialogue” which is meant to include sincerity, openness, mutuality and respect. Dialogue fails if participants retain isolationist positions or they vow never to be connected again.

Second, the family’s own history is important: over the four years, how have her parents and brother dealt with their daughter and sister having AN? The family unit qualifies as a crucible because it involves powerful forces: creating children and helping to mould them into capable and caring adults as well as children themselves impacting the parents’ parenting. Irrespective of what actually causes the young woman’s AN, her family’s reactions to her behaviours and her appearance are potent factors in its evolution. Family therapists and developmental psychologists’ work treating people with AN reflects the importance of familial experience (Giordano 2003; Gans & Gunn 2003; Tan et al 2003; Goldner 1989; Dresser 1984).

Third, people often ask for a decision-making framework for ethics and various ones have been developed (Pacquiao 2002; Devettere 2000; Jonsen et al 1982). Frameworks, however, can ignore the uncertainty and ambivalence attending most treatment decisions for serious illnesses and injuries. Ethics-as-process holds that the most important outcome is not a final decision, but instead “people coming to feel that how they acted was as good as it could have been” (Frank 2004, 355-6). In a study of parents of anorexic adolescents, Honey and Halse (2006) found that parents use various tactics to face their role in the situation:

We don’t go looking for a reason [anymore]. But I guess I’ll spend the next few years thinking, well, what if we’d done that differently or what if we’d done that differently. I guess you still, you still do. And that’s just, that’s just being a parent, isn’t it? It’s not, um, it’s not going to help you, and I guess just in time it, time will heal it (623).

Because her parents must decide between forced interventions (which, to be successfully administered, may require a lot of restrictions, ongoing surveillance, strong persuasion, and even physical restraints) and their adult daughter’s life-threatening preferences, they are faced with the kind of choice “people should never have to make” (Frank 2004, 355).

Just as identity is relevant for the young woman, so too for her parents. By having a daughter with AN, her parents might wonder, “Who do I become if I tolerate my child looking so neglected?” She looks the same as people pictured in charities’ advertisements for humanitarian aid to very poor and distant countries. Or people pictured in journalists’ reports about brutalizing wars. Or the parents might ask, “Who do I become if my child dies of a revers-

ible illness?” As Vialettes et al note, “They fear of delegating their responsibilities as parents, without control, to a third party” (2006 308). Applying Frank’s point to this fear, the parents might worry, “Who do I become if I insist strangers institutionalize, restrain, and make my daughter do what she hates most?” And what of the teenage brother:

You know [my son] and I went to pictures a lot. We went out to tea a lot. We’d spend a lot of time just going for a drive that, yeah. Just to be away from the situation. And then we’d come home and [my husband] would go out. So he could have time to regroup (Homey & Halse 2006, 624)

Pleas by families that their loved one be forcibly treated are often defended using various substantive ethical concepts. These concepts may not reveal all that is at stake when someone has chronic, treatment refractory AN. Using process notions such as dialogue, familial history, and familial identity can increase our understanding of the situation-at-hand as well as of the kinds of help each member truly needs and from whom.

From the Clinical Team’s Perspective

Several writers support clinical teams involuntarily hospitalizing and treating a person with AN whose life is in danger (Guarda et al 2007; Tan et al 2003; Giordano 2000; Draper 2000; Goldner 1989; Fost 1984; Dresser 1984). They justify their support with two substantive concepts. First, healthcare professionals have an *a priori* duty to rescue someone at risk of death. Second, as per the tenets of informed consent, they would not be required to honour the young woman’s refusal if they conclude she lacks the requisite capacity to decide.

Previous activities reflective of ethics-as-process have tempered the enduring professional duty to rescue. Sustained clinical and ethical debates on end-of-life situations have produced a general consensus that some people may conclude that not living their life is more desirable than continued living of their life, and that for some people, the burdens experienced from clinical interventions may greatly exceed the benefits (Giordano 2005; Draper 2000; Hébert & Weingarten 1991). An outcome of these past and often highly public discussions (e.g., Sue Rodriguez and her legal fight for physician-assisted suicide¹), high quality palliative care—wherein death is not fought against—is considered an important healthcare service.

Clearly, informed consent is a valuable ethical concept for healthcare. Yet for the case of AN, its potency is diluted somewhat because of the significant clinical uncertainty surrounding the epidemiology of AN. There are many hypotheses as to its cause(s): a psychiatric illness or delusion (Guarda et al 2007, Gans & Gunn 2003; Kaplan & Garfinkel 1999; Fost 1984), a desire to protest society’s expectations of women (Gans & Gunn 2003; Kaplan & Garfinkel 1999; Dresser 1984), a need to regain power or control (Tan et al 2003; Gans & Gunn 2003; Surgneor 2003; Lester 1997), a wish to master something difficult (Griffin & Berry 2003; Kaplan & Garfinkel 1999; Lester 1997), or a reliance on distorted values (Andersen 2007; Tan 2006, Giordano 2005; Beumont & Carney 2003). Moreover research on AN is difficult to conduct because

of its high morbidity and mortality rates. Not surprisingly, then, no single treatment has proven reliably beneficial (Garfinkel 2002; Kaplan 2002; Zhu & Walsh 2002). In other words, the “troubles” are even greater for those involved here.

From my experience, substantive ethical concepts often become clear only after understanding what is known clinically. When much remains uncertain or not known about the condition and available treatments, ethics-as-process is useful for figuring out how to move forward. Vialettes et al (2007) suggest clinicians try “modest tenacity;” in other words, continued participation in the crucible of AN. Yet over and above coping with clinical uncertainty, clinicians can react strongly to the symptomatic behaviours of AN. Surgenor (2003) and Hébert and

Weingarten (1991) describe the anxiety, fear, and frustration felt. Kaplan and Garfinkel (1999) elaborate further about the range and depth of clinicians’ negative reactions; for instance, disgust when told about vomiting and laxative use, and helplessness when the person refuses “the seemingly simple task of feeding [her]self to prevent death” (668). With the passage of time, if a clinician answers the Frank-ian question “Who am I becoming by continuing to work with this client?” with “I am becoming someone else,” the clinician is likely being damaged. Accordingly, the healthcare institution should help him by providing added resources, such as physical and responsibility relief via team rotations, emotional relief via psychological counselling, and “integrity relief” via ethics consultation. Even when clinical uncertainty renders reliance on substantive concepts tenuous, the process of involving other people “operationalizes” ethics in the guise of solidarity, caring and fairness.

From the Community’s Perspective

In *The Crucible* (1981), the community of Salem participates in the trial of John Proctor, either explicitly or implicitly. Criteria that apply to all members are established for determining which behaviours reflect being a witch, which statements qualify as legitimate accusations, and which procedures constitute a fair trial. The legal sanctioning of these criteria reflects explicit communal involvement. Since it is possible that prosecuting one man or woman could produce witchcraft accusations against many others,

Deputy Governor Danforth: “And do you know that near to four hundred are in the jails from Marblehead to Lyon, and upon my signature?”

Francis Nurse [a citizen]: “I-”

Danforth: “And seventy-two condemned to hang by that signature?” (Miller 1981, 80)
the small community of Salem itself is implicitly at risk.

In the case of the young woman with AN who does not want treatment, her parents who want involuntary treatment, and a healthcare team willing to provide such treatment, the community’s involvement exists as per two substantive concepts. The first concept is *parens patriae*, a Latin term which means someone’s native country or homeland has parental responsibilities for that person. In other words, the “ruler” or “rulers” have obligations to protect those who cannot care for themselves. Relative to healthcare situations, this obligation exists in Canada and the United States as confirmed by civil trials and health legislation that permit

clinicians, with the assistance of the community’s “guardians” (i.e., the police), to involuntarily hold and/or treat people seen as a serious risk to themselves or others.

The second ethical concept comes from Cartesian dualism (Lester 1997). In the *Meditations* (1993), Descartes searches for irrefutable truth. One thing that he finds impossible to doubt is his ability to think, as per the historic phrase “Cogito ergo sum; I think therefore I am.” This epistemological conclusion prompts an ontological conclusion: human reason is separate and superior to human physicality. Privileging reason has continued to today and is in evidence in contemporary healthcare: when a patient disagrees with a clinician’s treatment recommendation, a common response by clinicians—and even ethics consultants—is to immediately wonder, “Does the patient have the capacity to decide?”

Many feminist writers reject favouring reason over other human attributes as well as dividing human nature into the physical and the mental. Embodiment, a substantive concept, is offered as a corrective to Descartes. Every person is an embodied self, which means that the self is inextricably linked with and influenced by the body. Moreover our bodies are not just instruments we use. Instead, if you had a markedly different body—perhaps you were 15 centimetres taller, had a very efficient cardio-respiratory system, or only one fully-formed hand—your identity and your life would likely be different, too. In political debates about and legislative initiatives for people living with a disability, the concept of embodiment is clearly involved. Embodiment is a useful concept for exploring the meaning of some women’s AN behaviours. For instance, Lintott (2003) and Lester (1997) suggest that an anorexic person may not want her self to be completely defined by her body and so she tries to control its demands. With this said, though, the influence of communal norms is inescapable: “Women cannot simply make thinness mean whatever they want it to mean” (Lester 487).

As an example of ethics-as-process, the Salem witch trials are meant to help protect the community from Satan and those in his employ. Yet the process is logically flawed (i.e., if someone is accused of engaging in devilish behaviour, has actually behaved in this way, and voluntarily confesses, he or she will not be punished. But if he is falsely accused and thus does not confess, he will be punished). In the case of AN, our community extols thin female bodies. Accordingly this value is used to fuel our consumer-based economy. Ethics-as-process would demand public debate to challenge the ubiquitous thin paradigm in our community. While some people have taken up this challenge (e.g., fashion houses not hiring too thin models, retailers offering “plus size” lines), I think it is very uncertain how much this will increase and be sustained in our highly competitive marketplace.

At first blush, the community is among the participants in the crucible of AN because of its *parens patriae* responsibilities and its emphasis on human reason. However, focusing just on reason is ethically problematic because it erroneously trivializes human bodies. Including the concept of embodiment in public and institutional deliberations should help increase our understanding and, as appropriate, support of people who have AN. And ethics-as-process is important for our community because open debate and dialogue are necessary if we are to relinquish unhealthy, fatal and singular ideals for female beauty.

Conclusion

It's possible the young woman will not live to celebrate her 23rd birthday. It's possible her parents will have to contact several treatment programs to find the long-term, involuntary hospitalization they believe their daughter needs. It's also possible her hospital care team will be deeply divided over the repeated use of restraints when she is artificially fed. The stakes are high for everyone involved with AN. In this paper, I have explained how published articles about severe, treatment resistant AN commonly use substantive ethical concepts to support a woman's refusal of treatment, families' insistence on mandatory care, and clinicians' strong reluctance to honour the patient's wishes. Furthermore, I have argued that some of these concepts warrant modification, namely autonomy with relational autonomy, independence with interdependence and human rationality with embodiment.

Frank's distinctions between ethics-as-substance and ethics-as-process have been used to demonstrate additional types of ethical engagement needed in situations of AN. Frank identifies four shortcomings with ethics-as-substance analysis: (1) it usually focuses on having a decision made, such as whether to accept the young woman's treatment refusal or whether to forcibly bring her to hospital. But decisions are only part of what is happening. Ethics-as-process focuses more on how people work through their troubles, (2) the focus on decision making can mean the focus is on the here and now. This can ignore the woman and family's lived experience of the past four years. Disregarding the past has two negative implications: epidemiological information is overlooked and their struggles and successes are disrespected. Ethics-as-process demands that events leading to today must be understood if effective and defensible decisions are to be made, (3) in healthcare, ethics-as-substance has tended to focus solely on the client and her illness or injury. Ethics-as-process broadens the focus to include other key participants and their inclusion means that there will be conflicting interests to address, and (4) even if our concern was supposed to be directed only at patients, the substantive concept of patient autonomy is now trumping other values patients might hold.

The metaphor of a crucible confirms that powerful forces are involved in AN. They include suffering in the presence of others, preventable death, familial-professional-communal duties to act, uncertainty of clinical knowledge, incommensurable values, and individual integrity. This paper has explained how ethics-as-process can deepen our engagement and understanding of these forces in hopes that no one is sacrificed as the situation moves inevitably towards some type of conclusion.

Endnote:

1. In 1993, the Supreme Court of Canada dismissed Ms. Rodriguez's claim that British Columbia's legal ban on physician-assisted suicide was discriminatory. Ms. Rodriguez suffered from amyotrophic lateral sclerosis (i.e., Lou Gehrig's Disease) and in 1994 she died, either by her own hand or with others' assistance.

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