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The Cultural Context of Ethicists' Case Examples and Consumer Narratives of Decisions About Life Supporting Technology

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Abstract

Ethicists and clinical decision-makers, in order to illustrate moral, legal, and cultural issues, commonly use constructed case studies. They convey a sense of immediacy, practicality, and concrete experience required for teaching ethical and clinical decision-making. Unfortunately, their relation to the events reported is also often problematic in the sense that they decontextualize and reconstruct accounts to sustain biomedical and ethical frameworks.

This paper illustrates the contribution of anthropology to understanding case studies and narrative approaches to decision-making about life support technology. It contrasts clinical ethicists' case studies illustrating decisions to initiate or discontinue life support with ventilator users' accounts of their own use of mechanical ventilators. It explores the cultural, structural and methodological context of constructed case studies developed by ethicists to illustrate decision principals. Life narratives reconstructed by ventilator users are explored to examine the contribution made by cases based on thick description and reconstructed life narratives emphasized by the social sciences.

This paper describes one case study developed by clinical ethicists documenting a person living with progressive disability and his decision to discontinue life support. It contrasts this approach with narratives collected by an anthropologist describing decision making by long-term ventilator user who relied on life support for 30-40 years.

The analysis suggests that formal case histories used by clinical ethicists often emphasize exposition of principles. The anthropological life narratives describing decisions taken by ventilator users are characterized by a sense of biographical integration and temporality, an awareness of the complex patterns of social interaction in treatment/non-treatment decisions, and an awareness of the impact of structural barriers to ethical choice.

This paper advances discussion of "end of life" decision making while offering a critique of formal case histories which do not engage the perceptions, experiences, and active participation of people who use life supporting technologies.

INTRODUCTION

This paper applies the perspective of anthropology to interpretation of constructed case studies and narrative approaches to decision-making involving mechanical ventilation. It contrasts clinical ethicists' case studies, illustrating the application of principles in initiating or discontinuing life support, with ventilator users' accounts of their own decisions about mechanical ventilation. It explores the cultural, structural and methodological context of case examples constructed by ethicists and life narratives of ventilator users describing the complexity of their own decisions. One case example of end of life decision-making constructed by ethicists is contrasted with a consumer's complex and contextualized life narrative using the approaches of "thick description" and narrative reconstruction.

I will focus on cultural construction of case examples describing decisions involving mechanical ventilation technology in clinical ethics and use of consumer narratives in the emerging literature in disability studies. I will draw on more culturally contextualized narratives of people living with disability which are utilized extensively within the field of disability studies. Anthropological approaches emphasize need for development of case studies based on life narratives emphasizing cultural context and rich descriptive narratives of the decision-makers. I will examine anthropological approaches to developing more culturally contextualized case studies in the field of ethics through the use of "thick" description and narrative reconstruction.

Ethicists and clinical decision-makers commonly use constructed case studies to illustrate moral, legal, and cultural dimensions of end of life decision-making. Authoritative interpretation is often sustained by reference to precedent cases and principles of moral philosophy. Ethicists, for example, have documented and then constructed case studies centered on discontinuation of life support by persons living with disabilities. Widely disseminated case studies, including popular films such as "Whose Life is It Anyway," depict situations involving acceptance, rejection or discontinuation of life supporting technologies.

Implicit in ethicists' perspective in building case studies is a series of medico-legal narratives that support their assumptions about the quality of life of persons living with disability who need mechanical ventilation. This perspective is reflected in constructed examples where descriptions sustain values about life quality prevalent among physicians, ethicists and members of the general public. Ethicists deal with the whole medical legal spectrum of clinical practice and often are asked to advise on both clinical and resource allocation decisions. The clinical ethicist is rewarded for giving pragmatic advice based on principals and widely held values. They may also be called upon to communicate approaches to decision making through case examples.

Because ethicists and clinicians frequently interpret and construct cases from a professional perspective emphasizing medical data and an ethical aesthetic, their case studies may represent the "quality of life" and prospects for independent living in ways that contrast dramatically with personal narratives of persons living with disabilities. In an attempt to reconstruct the broad sequence of medical decision making, many ethicists' case examples typically omit biographical and contextual information to present a clearer moral analysis of the decision. Decisions described in such constructions thus are seldom anchored in the decision-makers' life history. In addition, formal case studies rarely acknowledge the past experience of the technology user, the care-provider, or the relationship they share. Nor is recognition typically given to the institutional context in which such decisions are made or to structural barriers, which from the person with a disability's perspective may critically influence decisions. The importance of these factors in understanding the principles and issues which constructed studies profess to illustrate is the central focus of this paper.

BIOGRAPHICAL CONTEXT

As a medical anthropologist my awareness of the contrasting approaches to case studies of ethical decision evolved as I became more committed to research and advocacy activities within the independent living movement. My involvement shifted from more epidemiological studies of disability prevalence to doing qualitative research on consumer narratives describing their experiences in accessing and using enabling technologies and the independent living movement. I worked with members of post-polio support groups to record life narratives describing technology access experience and involvement with the independent living movement. Their life narratives provided critical and policy relevant insights about the ethics of access to life supporting technology and consumer perspectives on autonomy in end of life decision-making. My identification with the disability movement has been reinforced by personal experience with the consumer movement, cardiovascular disability, bypass surgery and encounters with the rehabilitation system.

Case Examples

In this paper I contrast a single reconstructed, decontextualized case presented by ethicists at a disability studies conference with a long term ventilator user's account of decisions to use mechanical ventilation.[1] The conference was convened by The World Institute on Disability, Rehabilitation International and the World Rehabilitation Fund. It was held simultaneously with the Society for Disability Studies. The conference was attended by disability studies researchers, ethicists and representatives of consumer organizations. The ethicists' case study describes one person's decision to discontinue life support designed to illustrate moral, legal, and cultural dimensions of end of life decision-making. The consumer narrative is one of ten life histories I collected among people who used mechanical ventilation after sustaining respiratory impairment in the 1952-53 polio epidemics. They described their experiences with successive generations of mechanical ventilation technology.[2] Participants had been using mechanical ventilators for more than 35 years. In the context of an integrated biographical narrative, they described repeated experiences of respiratory insufficiency, equipment failure, and anxieties related to future crises. In this paper I will compare consumer narratives describing crisis events involving respiratory failure with more recent experience in deciding whether to use more effective, but more invasive life support technology. More particularly, several informants expressed concerns over how their voice - documented in advance directives - would be represented in end of life decisions.

The Ethicists' Case Example

The distance between the formal case studies and the histories of consumers with personal experience was highlighted at this national conference on ethical decision making and disability. Meeting participants included social scientists, ethicists, and clinicians. In addition, more than half the participating membership was composed of persons with disabilities. At the final session of the two-day meeting, a case involving end of life decision making was presented by two physician ethicists from a rehabilitation hospital. Neither had attended the rest of the conference.

The speakers opened with a 40 minute long videotaped reconstruction of the case-history of a 50 year old man with progressive impairment resulting from Amyotrophic Lateral Sclerosis (A.L.S.). Its focus was his decision to discontinue his life support. Made six months after the man's death, the tape showed the clinical ethicist and another attending physician discussing the sequence of events leading up to the final decision to disconnect the patient's respirator. One speaker described the course of the person's illness, the progressive impairment of his respiratory system, and the initial decision to perform a tracheotomy and support breathing using a portable ventilator.

The ethicist then described other events occurring in the man's life, particularly his profound depression following the sudden death of his wife. The speakers emphasized that the death of his primary family caregiver made it extremely unlikely that the man would be able to return home. The two clinicians then described their efforts to help him explore alternative ways of enhancing his life quality. Rather than pursuing other options, the man requested that his ventilator be turned off, saying that he found the current quality of life and his prospects for future suffering unbearable.

The videotape then described a sequence of repeated consultations with the patient, psychiatrists and representatives of the hospital's Institutional Review Committee. These culminated in an agreement that the man was fully informed, understood the limited prospects for the future quality of his life, and was making a valid and consistent request for discontinuation of life support. The presentation concluded with a description by physicians of their role in disconnecting the ventilator and providing him with palliative care.

Reaction

The two speakers then turned to the audience. Expecting to lead the usual academic discussion, they faced instead a series of critical, often angry, comments and questions. While none of the commentators questioned the man's right to decide that life support should be discontinued or the validity of this experience of suffering, the constructed case study was criticized for what it did not discuss or portray. Further, as one discussant noted, the tape revealed an attitude prevalent within the medical rehabilitation community and shared by many members of general public. This perspective was characterized by devaluation and emphasis on quality and resource implications of technology use.[3] Several discussants with personal experience using life support focused on the man's isolation and dependence on the two clinicians for information about the options available to him. He had not been encouraged to meet with people living at home with life supportive technology or to speak with other users of mechanical ventilators, for example. Others criticized the clinician's decision not to involve people with high-level quadriplegia as consultants. Other discussants decried the lack of effort made to help the man to fully explore the various alternative services that might have enabled the man to live at home.

Criticism was not limited to audience members with long term ventilator experience. One ethicist commented on the compressed time frame of the case study's reportage, noting that no account seemed to have been taken of the length of the usual period of depression following the death of a spouse. Another stated that, from her perspective as an ethicist and as a woman with a disability, the presentation reflected both the hazards of oversimplification and the lack of consumer input she had experienced during her participation in a state ethics commission. Her primary criticism was that the "rehabilitation personal in charge had not offered the man a vision of a good life in spite of his disability."[4]

A spokesperson for consumer perspectives commented on the way in which the clinician's account served to decontextualize the man's decision.[5] Structural barriers, such as the limitations of state and federal benefits, the shortage of community living options, the lack of respiratory home care, while perhaps critical to decision making were ignored in their case presentation. The final discussant noted that the tape revealed an attitude, prevalent within the medical rehabilitation community (and among the general public), that life with a disability was a devalued life and one perhaps not worth living.[6]

The outraged reaction surprised the presenters who clearly thought they had presented a sympathetic account of their role in helping a patient accomplish his own decision. For its part, the audience saw the video as a demonstration of the powerlessness of an individual totally dependent on health care providers for information, and without full knowledge of potential living options.

The audience's reaction to the case example presented at the disability studies conference may reflect criticism of ethicist's construction of key medical legal cases involving discontinuation of life support or active euthanasia. The audience emphasized that the case presented by the ethicist did not acknowledge the full impact of resource constraints or decision maker's isolation from peer advice from other ventilator users.

We need to recognize that these conflicting approaches to case study development reflects not just a conflict between interpretations emphasized by ethicists and accounts of consumers. The consumer reaction may also reflect a more global critique of ethicists' and physicians' approaches to defining quality of life. It may reflect more general concerns about the power of professionals in proxy decision-making where the person's "best interest" is externally defined.

The ethicists' lack of awareness of culture and ethical context of the field of disability studies meant that they did not expect to have their case analysis contested. Their inability to anticipate the consumer response reflected their own cultural orientation as benevolent and pragmatic clinical and ethical decision-makers.

Anthropological interpretations may contribute to understanding of both consumer's perspective on end of life decision-making and the cultural context of clinical ethics. Professional and clinical cultures inculcate and reinforce the importance of physicians and clinical ethicists roles in helping to interpret the availability and quality of life achievable using alternative life supporting technologies.[7]

Description and Authenticity in Case Studies

The clinicians' account of the decision to discontinue life support differed in many critical respects from the narratives that my colleagues and I documented in interviews with long term ventilator users. Their account was reconstructed after the man's death from the perspective of the attending physician and the consulting clinical ethicist. It did not use thick description to convey either a sense of the patient's own voice or a detailed description of the context of his decision. Their case was strategically constructed to sustain an analysis emphasizing autonomy and beneficence.

Part of the technology users' criticism of the case was that, although it was based on a real experience, it did not contain the detailed descriptions or narrative quotes which adequately conveyed his perspective on his own decision. Several members of the audience emphasized that the clinicians account of actual decision-making failed to convey a sense of authenticity and voice.

Thick Description and the Perspective of the Narrator

Chambers has described the limitations of teaching cases like this one which are constructed to illustrate a particular principle or theory.[8] As an alternative to constructed case studies to illustrate principles, Davis draws on the perspectives of anthropologists like Clifford Gertz in emphasizing that detailed descriptions of "real" experiences keep the ethicist "honest" and invite varying interpretations.[9] Davis has proposed the use of "thick description" to develop "rich cases" describing in detail the context of ethical decision-making and sense of meaning as an alternative approach.

In the ethnographic tradition rich case descriptions can either be drawn from actual incidents, from cases that are documented in the media or from fictional accounts. Davis asserts the benefits of using rich cases to develop a more detailed moral response. At the same time she has also recognized the dilemmas of using "thick descriptions" of actual cases because of the need to protect the confidentiality of the decision-makers in the actual case while at the same time conveying detail. Despite these constraints, Davis asserts that thick descriptions of real experiences allow ethicists to draw conclusions while also allowing readers to make their own independent moral and social analysis. Davis concludes: "We need thick descriptions to allow cases to remain open to different interpretations over time and also to enable cases to ground an ethics of care."[10]

The other dimension of the consumer critique of the ethicists' representation of the man's decision to discontinue mechanical ventilation centered on the question: whose point of view was represented in the case narrative? Chambers analysis of the literary dimension of ethicists' cases concluded that they can be constructed from multiple perspectives and that the ethicists relationship to the participants is often unclear.[11] In many case studies the narrator will adopt the position of an unseen or non-participant observer. They also frequently adopt the perspective and voice of the clinician.

In recent case studies in narrative ethics, the perspective of the person with a disability has been featured. Despite this growing recognition that the cases can be constructed from multiple perspectives, Chambers concludes: "narrative continues to be used by most ethicists in a somewhat naive way, as if it simply reproduced reality without also interpreting the world in a manner that colors the readers perspective."[12]

The remainder of this paper will examine the impact of reconstructing descriptions of decisions about mechanical ventilation from the perspective of the technology user, recognizing that this narrative may not fully represent the perspective of either the clinician or ethicist.

Chambers asserts that "all representations must adopt a particular point of view and that point of view will always carry with it a partial and limited understanding of the world."[13] I examine the process of narrative construction to understand consumers' accounts of life threatening events and decisions about treatment and non-treatment.

Narrative Reconstruction of Threatening Events

In contrast to ethicists' formal case examples, the life historical accounts of key decisions made by long term ventilator users include both thick description, a sense of personal voice and detailed information about the context in which the decision was made. The process of integrating consumer accounts of illness and treatment/non-treatment decisions into life narrative is explained by Williams' sociological approach to the concept of narrative reconstruction.[14] In William's approach, narratives explain: "How and why people see their illness originating in a certain way, and how people account for the disruption that disablement has wrought in their lives."[15] His approach to reconstruction emphasizes that individual narratives reconstruct causal connections between disease and antecedent factors. They also explain the context of illness by providing "narrative reference points between the individual and society in an unfolding process which has become profoundly disrupted."[16] Williams' initial research involved life narratives of persons with disabilities associated with rheumatoid arthritis. He conducted life historical interviews with thirty individuals who had been diagnosed with rheumatoid arthritis for at least five years. His qualitative interviews focused on the experience of living with arthritis including explanations of the origins and genesis. Examples of reconstructed narratives among Williams' informants explained causation in terms of political or environmental determinants, social or psychological explanations, such as stress and narratives describing overcoming the impact of disability through personal faith.

Williams' interpretation of the process of narrative reconstruction to understanding the persons' perspective on the genesis of chronic illness is also applicable to interpreting the technology user's accounts of key decisions. We will apply it in key treatment/non-treatment decisions within the context of long term ventilator users' life narratives. These life narratives provide reconstructed accounts that contain thick description and a sense of the person's voice.

Life Narratives of Ventilator Users

In my life historical interviews discussion of treatment and discontinuation occurred within the context of an integrated biographical narrative. Living for from 30 to 40 years "on and with" life support technology had given them many opportunities to define life priorities in terms of both personal values and their rights as consumers. Their descriptions of these decisions were characterized by: a sense of biographical integration and temporality; an awareness of the complex patterns of social interaction between the machine (e.g. the technology itself), the user, (professional) care givers and the members of family; a recognition of the impact of structural barriers limiting options for independent living and empowerment.

This is precisely the type of data omitted in the case study of the ALS patient. The biographical connections and critical awareness which characterize long term ventilator users narratives of past crisis events also appear to have influenced the technology user's approach to negotiating advance directives and do-not-resuscitate orders. Clearly, the approach of ventilator users to defining the criteria for discontinuing treatment or giving consent to alternative forms of life support was very different to the reasoning process emphasized in ethicists' case examples.

Several informants' life narratives described near death situations in which treatment/non-treatment decisions were interpreted in the context of past biographical and social experience. These narratives were used, in William's words, to "reaffirm the impression that the self has a purpose or telos."[17] Ventilator users also applied their long term biographical experience in defining the terms of advance directives. In these statements they frequently referenced crisis situations associated with respiratory insufficiency which had resulted in the adoption of more efficient, but more invasive and less easily controlled technology.

A Narrative Example

It is useful to focus on a single ventilator user's interpretation of decisions about adoption or discontinuation of life support technology. One of the persons from our interview series, a 45 year old man, had used a range of different mechanical ventilation systems over a thirty five year period following the onset of respiratory paralysis associated with poliomyelitis. His approach to decision-making is characterized by biographical integration, engagement of the complexity of technology choices, an understanding of the dynamics of social interaction in decision-making, and an awareness of structural barriers to consumer choice. In his narrative he described his experience as an adult, living independently in the community and working as a senior hospital administrator and civil servant. Despite use of a rocking bed and a single cycle respirator at night, when in his mid 40s the narrator started to experience increasing respiratory difficulty. He then asked his physician if he could explore more efficient forms of mechanical ventilation using a mask or mouth tube. The initial response of the physician was to limit discussion of treatment options to continuous positive ventilation requiring a tracheotomy and permanent rather than periodic respirator dependence. In his narrative, the man described his interaction with his physician's argument for a more invasive, but more effective mechanical ventilation than the patient wanted.

> It's not bad enough yet, you are still functioning, carry on with your rocking bed but you are probably going to have to have a tracheotomy or tracheostomy. (I never could understand which is which, but anyway it is a hole in the neck).
>
> At the same time Dr. ___ was having discreet chats with me saying, "Have you thought about the tracheotomy sort of thing?" So that is how things were left at that time. I continued on the rocking bed and things were getting worse and worse and I was trying to struggle to keep working. I remember at the end of those days just crawling home and getting into bed. I was absolutely, totally exhausted, completely drained. So that I was sort of beginning to realize I was coming to the end of the line. I should be checking out what my pension was going to be and if there was something that I could do to continue.

As his breathing problems increased, his medical caregivers remained committed to the single invasive treatment the narrator hoped to avoid. His physician advised him that less efficient technology would result in respiratory failure. In describing these events, and his efforts to negotiate an alternative form of life support, the man discussed what he thought was his physician's interpretation of the biographical experience of people with polio related respiratory impairment.

> I believe Dr. ___ has a theory that all us post-polios have this recollection of the acute stages of people having trachs, you know - they come in the middle of the night and rush you down the hall and they stick this tube in your neck - that this is supposed to be a kind of subconscious phobia or fear of tracheotomies - it seems to be a pretty strong tendency to go ahead and give a tracheotomy and if you don't want it, well maybe there is some mental block there that is preventing you from seeing the light and getting this done.

In describing his rejection of his physician's advice, he asserted the validity of his resistance to being tracheostomized.

> I don't really feel I have to defend or explain why I don't want somebody to punch a hole in my neck. It seems to me that if I can find some way of shoving air through some orifice that is already there, that to me has a certain ring

> of logic to it. I really don't think I have to be psychoanalyzed for making that decision.

Complexity and Social Interaction in Consumer Narratives

The complexity of the narrator's interpretation - including his understanding of the physician's perceptions - provides a more grounded and personally owned account of the choices available to him, one which may be difficult for clinicians and others to perceive. As Linn et al. put it in terms of cancer decision making:

> The person without cancer can afford to be more dogmatic about cancers and likely to think in stereotypes. The closer he comes to dealing with the disease, the less clear cut and more complex the explanation becomes.[18]

Discussing the negotiation of options, this man described his search for alternatives. He compared his preference for adopting some form of nasal ventilation over his physician's decision to "push" for a tracheotomy as a more familiar and less ambiguous treatment option:

> I think that with nasal ventilation, it seems to me that there is a lot more patience required, a lot more innovation in playing around with it. It is not something which is a black and white sort of thing, there are a lot of grays and you have got to gradually play around and get the hue up to the right level. It is much more of a personal thing. I think that is probably the hardest part for the professionals to deal with... and I guess that is my concern; getting the professional help you need to get it working.

The complexity of treatment options and the need for innovative, long term co-participation is not usually captured in ethical case studies which tend to focus on acute situations and decisions involving tracheotomy and short term ventilation of patients in emergency room settings.

In his search for an alternative, the narrator discussed his situation and concerns with other ventilator users, care givers, and leaders of the consumer movement he met at an international post-polio meeting. There he also learned about an alternative means of connecting his ventilator.

> And then I was able to make the trip to St. Louis and that gave me - if I was thinking of giving up on this type of ventilation - the trip to St. Louis convinced me that I wasn't playing with something that was sort of pie in the sky; which I think it was viewed as by some of the doctors. You could see the vision from the outside that there were more alternatives.

Following the conference, he then found a respiratory therapist with recent experience using nasal masks, one willing to work with him to develop efficient, alternative means of life support that would be less invasive than that recommended by the physician:

> I kind of lucked into [name of Respiratory Therapy Technician] who helped me set up alternative therapy... that she was trying to make a point and wasn't about to let me slip out, to let the thing fail.

The man recognized the active role that he played in the decision process and in researching his own treatment options:

> Obviously not everybody is going to have the luck or the resources to follow the kind of approach that I took (e.g. going to consumer conferences and finding alternative care providers and technology options). The person on the street is not going to be able to go somewhere else and have this kind of access. They don't have the capability to do the research and keep looking for other solutions.

Structural Barriers and Empowerment Strategies in Consumer Narratives

Case examples used in teaching ethics typically adopt a microanalytic perspective, one de-emphasizing the impact of structural barriers and the limited access to alternative modalities of life support or options for independent living. These include barriers to assessing information about treatment and technology options, economic constraints and inadequate or inaccessible services. Structural barriers practically diminish the option of living independently with disabilities.

In the first case, for example, the ethicists presumption that the person with ALS had the information and resources to make an informed choice was criticized by long term users of ventilation for ignoring the myriad ways of using technology and services to live with autonomy and dignity. As Koch et al. have noted, the failure to assure logistical, informational and peer support resources present structural barriers that impede access to interesting and active continuance.[19] In cases where persons who depend on technology do not have access to resources to sustain quality of life the only option presented may be "death with dignity."[20]

The effect of structural barriers is also considered in medical and ethical summaries of two well-known Canadian Supreme Court decisions. Nancy B. requested discontinuation of mechanical ventilation.[21] Susan Rodriguez's requested euthanasia.[22] Consumer reaction to both decisions emphasized that Nancy B. had very limited information about the availability of independent living options, such as home respiratory care programs in Quebec. Disability organizations also emphasized that Sue Rodriguez may not have been informed about home hospice care options in British

Columbia.

In contrast to the reconstructed case of the ALS patient, the narratives of long time users of life support technology often incorporated structural critiques emphasizing their experience in overcoming barriers to accessing alternative treatment or their strategies for empowerment and advocacy. Their experience was consistent with that of arthritis patients interviewed by Williams whose narratives explained the impact of disability in terms of structural or political determinants such as occupational risks, barriers to service access, and the impact of social inequality on prospects for independent living.[23]

Thus for this narrator, and for other narrators in our group, issues of treatment choice may be dependent on barriers to information, travel, and knowledge access. More generally long term technology users may both more accurately identify structural barriers to alternative treatment and living options, describing experiences of empowerment and advocacy in which they were able to overcome systemic barriers.

Proxy Decision-Making

A final theme in consumer narratives describing decision to accept or discontinue the use of life support technology centers on the need for the person to maintain control of the definition of the quality of their own life. Some of the initial reaction to the clinical ethicist's case presentation of a man's decision to discontinue mechanical ventilation centered on the perception that the physicians acted inappropriately as proxy decision-makers. Among the ten long term ventilator users, half commented on the hazards of allowing clinicians to interpret present or prospects for future quality of their lives related to their present or future respiratory function. A psychologist and ventilator user, Audrey King, at another conference, captured their perceptions.

She stated: "No one can prejudge or project `quality of life' issues for those who are ventilator dependent. Neither can an individual facing ventilator dependency express a valid opinion until he/she is well into the experience."[24] King then described consumer concerns about professionals' control within institutional settings:

> Support structures [that] enable him/her to live within their communities have provided greater opportunities to become empowered, regain autonomy and consequently enjoy a better quality of life. However, this autonomy is increasingly threatened as well meaning health care providers impose institutional models within the community and encroach on individual rights and freedoms in doing so."[25]

Her statement emphasizes the importance of the consumer's long term experience with technology. It also clearly focuses on the questions of whether the autonomy of the technology dependent person may be restricted by resource constraints and the range of treatment and living options made available. King's analysis recognizes the interaction of resource availability, self-advocacy, social network and quality of life.[26]

The majority of the ventilator users I interviewed described the problems of proxy decision-making when they were asked to develop advance directives and do not resuscitate orders. Several voiced their reservations about orders which would place the power of final decision-making in the hands of a clinician who was not aware of their long term life experience and previous decisions about continuation or discontinuation of life support. They also voiced concerns over the dual roles of clinicians' proxy decision-makers and as gatekeepers with control over allocation of resources for community living.

Conclusion

In the context of interviews with an anthropologist, long term ventilator users contextualized their current and future decisions about continuing mechanical ventilator accepting alternative form of technology or negotiating advance directives within the structure of their life historical narratives. In contrast, ethicists' clinical case description of ventilator users' life historical narratives are intended to enable their caregivers and family to understand contemporary decisions and future choices within the context of multiple crisis situations, evolving definitions of quality of life, and the consumer's long term experience with uncertain technology.

Long term users of life support technology describe a life time experience characterized by crisis events and continuing vulnerability that they draw on when making choices about their future. From their perspective, a series of issues bear upon their decisions regarding continuation or removal of life support. These are relational involving familial and professional caregivers and structural barriers to service access, knowledge and prospects for empowerment. This multi-layered, grounded portrait is in sharp contrast with the decontextualized and principle centered account dominating the ethicist's case study. Consumer narratives also reveal the importance of knowing the nature of the structural barriers that must be overcome in achieving control over their lives. The biographical connections and critical awareness which characterize narratives describing past crisis events also influence the technology user's approach to negotiating advance directives and do-not-resuscitate orders.

An anthropological presentation of the thick description emphasizing the richness of consumer narratives provides a balance to the assumptions of ethicists and clinicians who, with the best intentions, may counsel patients without understanding the complex personal or social realities of the person. It is one thing to promise patient autonomy, another to assure that the support systems are available to make the appearance of individual choice a reality. As a result, anthropological approaches to narratives reconstructing personal experience teach the medical decision-maker about the socially constructed options they often do not perceive. They also provide a sense of the life context of the decision-maker and an indication of the structural constraints which influence choice. Like all case-based presentations, neither clinical cases constructed by ethicists nor life narratives reconstructed at the request of an anthropologist by people who depend on technology, can fully represent either an individual nor represent the perspective of all decision-makers or claim general applicability. As complimentary modalities, together they can inform us about both general theory in ethical decisions and its relationship to the lived reality of complex decisions that draw on individuals' experience over the life course.

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