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Internists' Tales from High-technology Work Places**

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Abstract

Public and professional discourses in American society about what constitutes a “good death” have flourished in recent decades, as illustrated by the pivotal SUPPORT study and the growing palliative care movement. This paper examines a distinctive medical discourse from high-technology academic medical centers through an analysis of how physicians who are specialists in internal medicine tell stories about the deaths of patients in their care. 163 physicians from two major academic medical centers in the United States completed both qualitative open interviews and quantitative attitudinal measures on a recent death and on the most emotionally powerful death they experienced in the course of their careers. A subsample of 75 physicians is the primary source for the qualitative analysis, utilizing Atlas-ti.

“Good death” and “bad death” are common in popular discourse on death and dying. However, these terms are rarely used by physicians in this study when discussing specific patients and individual deaths. Rather, physicians’ narratives are nuanced with professional judgments about what constitutes quality end-of-life care. Three major themes emerge from these narratives and frame the positive and negative characteristics of patient death. ***Time and Process***: whether death was expected or unexpected, peaceful, chaotic, or prolonged. ***Medical Care and Treatment Decisions***: whether end-of-life care was rational and appropriate, facilitating a “peaceful” or “gentle” death, or futile and overly aggressive, fraught with irrational decisions or adverse events. ***Communication and Negotiation***: whether communication with patients, family and medical teams was effective, leading to satisfying management of end-of-life care, or characterized by misunderstandings and conflict. When these physicians’ narratives about patient deaths are compared with the classic sociological observations made by Glaser and Strauss in their study *Time for Dying* (1968), historical continuities are evident as are striking differences associated with rapid innovation in medical technologies and a new language of medical futility. This project is part of a broader effort in American medicine to understand and improve end-of-life care.

Key Words: Good Death/ Bad Death/ End-of-life Care/ Palliative Care/ High-technology Medicine/ Narrative Analysis/ Culture of Medicine

“ So in the end it was a good death but it took a very long time, and it took a long time to get to the point where we realized and she realized that there wasn’t any other medical treatment.”

--- female intern

“What makes a bad death is when the family has unrealistic expectations and the health care professionals feel that what they are doing is medically futile.” --- female resident

“There’s no good death, really.” --- male attending

Biomedicine as Cultural Context

Public and professional discourses in American society about what constitutes a “good death” have flourished, especially since the 1960s. Biomedicine as a cultural system is global and cosmopolitan yet practiced locally.¹ Academic internal medicine as taught and practiced in the United States reproduces a culture of its own, including clinician experiences, local knowledge, affective expressions and characteristic narratives about patient deaths. In this special issue, Seale and van der Geest have provided a venue for cross-cultural comparisons of the social and technological ways of death and explorations of similarities and differences in the semantics of “good death/ bad death.” Our contribution analyzes the nuances behind the broader popular categories of “good” and “bad” deaths that American internists bring to their narratives about dying patients and the culture and practices of end-of-life care in major academic medical centers. “Good death” and “bad death” are terms rarely used by these physicians in discussing specific patients and individual deaths.

In this paper, we focus on a distinctive medical discourse from high-technology academic medical centers through an analysis of how physicians who are specialists in internal medicine tell stories about the deaths of patients in their care. The study, *Physicians’ Emotional Reactions to Their Patients’ Deaths*, was carried out in 1999-2001 at two major academic medical centers in the United States. One hundred and sixty-three physicians from internal medicine services were interviewed about patients who had recently died; in addition, they were asked to tell the story of the most emotionally powerful death they had experienced over the course of their professional careers. This study is part of a wider effort within American postgraduate medical education to understand and improve clinician training in palliative care.²

¹ Writings on cosmopolitan and local medicine are vast. Our historical lineage includes Seale, 1991, 1998; Leslie, 1976; Leslie & Young, 1992; Dunn, 1976. Also Seake 1991, 1998, and Good, 1995, 1998.

² Among the many articles and presentations in this field are Billings & Block, 1997; Field & Cassel, 1997; Christakis, 1999; Gadmer, Ruopp, Arnold, Redinbaugh, McDonald, Seltzer, Good, & Block, 2000; MacLeod, 2001; Solomon, 2000; Solomon, O'Donnell, Jennings, Guilfooy, Wolf, Nolan, et al., 1993; Weissman & Block, 2002; Ruopp, 2002; Meier, Back, & Morrison., 2001; Johnson, Cook, Giacomini, & Willms., 2000; Sullivan, Lakoma, & Block.,ms. 2002; Chappel, 2001).

Classic sociological analyses of medical work, such as Glaser and Strauss's *Time for Dying* (1968) and *Awareness of Dying* (1965), launched a concerted theoretical effort within the medical social sciences not only to analyze but to improve the way clinicians cared for dying patients in contemporary America. Glaser and Strauss's studies were based on interviews and observations of physicians and nurses caring for patients in San Francisco area hospitals and on comparative observations in similar settings in Italy, Greece and Asian countries in the mid and early 1960's. Despite extraordinary developments since that time in the robustness of medical technologies to intervene in what Glaser and Strauss termed "dying trajectories," their insights have more than historical relevance. In their introduction to "Dying Trajectories and the Organization of Work" (1968:chapter 1) they urge researchers to attend to clinicians' narratives about *the work* of caring for dying patients, a goal of contemporary worth as well.

When not entirely medical or technical, most writings about terminal care focus on the psychological or ethical aspects of behavior toward dying persons. Those emphases flow from the psychological, and often ethical, difficulties that accompany death and dying. However much of the behavior of people toward the dying may be just as legitimately viewed as work....Work has important temporal features....The temporal ordering of work on each service is ...related to the predominant types of death. (1968:1-3)

Glaser and Strauss identified types of temporal narratives about care for the dying and about the process of dying. Among these dying trajectories are tales about "unexpected deaths," about deaths regarded as "certain" that the patient will "die on time." Other dying trajectories include "lingering" and "prolonged" deaths and deaths in which clinicians are certain the patient will die but "when is quite unknown" (1968:12). Glaser and Strauss observed that "miscalculations in forecasting or perceiving trajectories can play havoc with the organization of work – as when one or more patients unexpectedly and swiftly begins to die" (1968:13). Telling stories about expected and unexpected deaths and well-managed or disrupted dying trajectories was fundamental to professional work in care for the dying in the 1960s (1968: 230). Physicians and nurses sought resolution in their care for a patient who died by telling stories of the death to each other; when kin were not present at a death they also told stories to family members, often conveying a "perfect image of death" in peace and comfort with which to leave the bereaved (1968:236). The sociological interest in various dimensions of temporality in medical work continues, as exemplified by *Death Foretold* (1999), an analysis of prognostication by Nicholas Christakis, a physician-sociologist.

Almost half a century after Glaser and Strauss's breakthrough study, we find striking cultural continuities in our study. Discussions of temporality, dying trajectories and processes of medical work in care of the dying are fundamental to physicians' narratives about patients' deaths. Yet, in spite of continuities with medical culture of the 1960s,

much has changed in the technological nature of end-of-life care. These changes also influence the way clinicians formulate narratives of patient deaths.

Public Concern and Professional Responses

As biomedicine's technological advances have expanded options for sustaining life in terminally ill patients, public and professional criticism of highly interventionist and apparently futile end-of-life care has become ever more vocal. The grassroots American hospice movement launched in the 1970s and the academic palliative care movement which gained prominence through the 1990s sought to change the way Americans die and the way clinicians think about and care for the dying. Public actions, from governmental support for hospice care through the Medicare Hospice Benefit established in 1983, to decisions in a series of classic legal cases affirming patients' rights (and those of their proxies) to refuse or discontinue life sustaining treatment, have influenced medicine's debates about appropriate end-of-life care (Jonsen, Veatch, & Walters, 1998: 111-237). The Federal Patient Self-Determination Act of 1991 and state-sponsored regulations have sought to encourage patients to identify health care proxies or to formulate living wills in order to redress public distress about medical dominance over decisions at life's end.³ These issues remain salient in American society today and are expressed through popular politics, such as Oregon's referendums to legalize physician assisted suicide (*New York Times*, 1996, 1999a, 1999b; Center for Ethics in Health Care, 1999), and judicial decisions, such as the Supreme Court's 1997 affirmation of what Burt (1997) interprets as a patient's constitutional right to palliative care even as the court denied the right to die. Patients and families also act; many have chosen alternatives to hospital dying and one quarter of Americans who died in 2000 received some form of hospice care.⁴

Despite considerable public attention to patient dignity and self-determination, the culture of practice in many American hospitals as well as patients' and families' investments in prolonging life perpetuates high-technology end-of-life care that often leads to prolonged and/or painful deaths. Many physicians find standard clinical practices that compromise death with dignity disturbing; in addition, there is considerable professional concern about how to work with patients and families who request highly aggressive and extreme measures that are regarded by physicians as medically futile. Thus, both medical professionals and the public frequently revisit the pathways to and meanings of "good death" and "bad death," of positive and negative ways of dying and caring for those at the end of life.

Academic Medicine and End-of-Life Care

The 28 million dollar SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) "to improve end-of-life decision

³ Wolf, Boyle, Callahan, Fins, Jennings, Nelson, et al., 1991; Orentlicher, 1992; Menikoff, Sachs, & Siegler, 1992; Asch, Hansen-Flaschen, & Lancken, 1995; AMA, 1992; American Board of Internal Medicine, 1996).

⁴ (www.hospiceinfo.org, 2000, www.nhpco.org, 2001:3; see also Seale, 1998).

making and reduce the frequency of a mechanically supported, painful and prolonged process of dying” proved to be a highly influential and pivotal project that sharpened critiques of the culture of end-of-life clinical care in academic medical settings (SUPPORT Principal Investigators, 1995:1591). SUPPORT was “a two year prospective observational study (phase I) with 4301 patients selected from five teaching hospitals in the United States. It was followed by a two year clinical trial (phase II) with 4804 patients and their physicians randomized by specialty group to the intervention group (n=2652) or control group (n=2152).” The intervention sought to improve end-of-life care and to correct “shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital death” that had been documented in phase I. Specially trained nurses were assigned to patients and their families with goals “to elicit preferences, improve understanding of outcomes, encourage attention to pain control, and facilitate advance care planning and patient-physician communication.” The SUPPORT findings were disturbing. Phase I findings documented “substantial shortcomings in care for seriously ill hospitalized adults” in pain control, communication about CPR/ DNR, and excessive time spent in intensive care units. Phase II findings were disheartening and unsettling as well. The “intervention failed to improve care or patient outcomes” in pain control, use of hospital resources, and patient-physician communication about CPR and DNR. Despite efforts to change clinical practice, no changes were documented in level of patient and family comfort and support.⁵ Despite the disappointment over the effectiveness of the intervention, the SUPPORT study provided a scientifically and medically reputable critique of how patients died in American hospitals. SUPPORT legitimized new societal and educational investments within academic medicine designed to transform standard practices of end-of-life care.

Concomitantly, the palliative care movement within academic medicine began to attract considerable financial support from private philanthropies, such as the Robert Wood Johnson Foundation and The Open Society Institute’s Project on Death in America, for training and demonstration projects. For example, OSI sponsored a Faculty Scholars program devoted to developing medical leadership and educators in the palliative care movement. Palliative care clinical services began to grow in many academic medical centers across the country and integrated elements of hospice culture into these settings.

The Study

These recent efforts to change medical practice at the end of life provide the context for the project described here. Our research sought to answer the following questions. Given the popular and professional American cultural contexts of death and dying, how do American physicians who work at medicine’s cultural core speak about how their patients die? What types of narratives do they tell about dying? How do they discuss their own professional agency in caring for patients at the end of life? How do they experience the dying of patients in their care? How do they link clinical practice in

⁵ SUPPORT Principal Investigators , 1995:1591; Teno, Lynn, Wenger, Phillips, Murphy, Connors, et al., 1997; Lynn, 1997; Lynn, Harrell, Cohn, Wagner, & Connors, 1997).

care for the dying with reflections on patient death? The academic physicians in this study belong to an institutional culture in which care is frequently questioned, and simple distinctions of “good death” and “bad death” are uncommon. Rather, tales about management and “work” are foremost. These clinicians reflect on how well they manage the dying process, what clinical actions and interpersonal skills lead to “smooth deaths.” They speak about difficult or rewarding relationships with patients, families, or medical teams; about recalcitrant or unexpected disease processes and adverse medical events; about miscommunications and errors; they speak about moving and satisfying deaths and about disturbing deaths; and on rare occasions they use the terms “good death” or “bad death”⁶

Goals, Sample and Methods

The original goal of the study was to examine how internists practicing on the medical services and in the medical intensive care units of two major academic medical centers experience patient deaths. The project’s primary investigators were particularly interested in factors influencing physicians’ emotional reactions to patients’ deaths, including position in the training hierarchy, relationship to patient, emotional and collegial support, and past personal experiences with death. Three categories of physicians were recruited: interns (first year post graduate clinical trainees), residents (2nd to 4th year trainees), and attendings (clinical faculty responsible for teaching students, interns, and residents).

A sample of internal medicine physicians who recently had cared for dying patients was identified through weekly chart reviews of patient deaths from the medical and intensive care services of two academic medical centers. Two deaths per week were randomly selected at each site for a total of 66 patient cases for the qualitative and quantitative study. Patient age ranged from 28 years to 94 years, with a mean age of 66, and 51% were male. Primary diagnostic categories included oncological disorders (17%), cardiac diseases (24%), respiratory disorders (24%), and 35% other disorders, with frequent comorbidity with oncological disease. Members of the medical team who cared for the patient at the time of death were contacted within two weeks of the death and invited to participate in the study. 163 physicians participated in the interviews about the recent patient death and their most emotionally powerful patient death, with a response rate of 81.5%. Respondents were nearly equally divided by training level: interns constituted 33% of the sample, residents 31%, and attendings 36%. Two-thirds of participants were male. In addition to the 163 physicians described here, another 33 physicians were asked to complete only the closed-ended items relating to the recent patient death to maximize power for statistical analyses. For this report, we include only those 163 physicians who were asked to describe both recent and most powerful deaths. We tested differences between the sample of 163 and the additional 33 physicians, and found no statistically

⁶ Abstracts and scientific presentations that preceded the publication of this essay include the following: Gadmer, Ruopp, Arnold, Redinbaugh, McDonald, Seltzer, Good, & Block, 2000; Ruopp, 2002; Jackson, Sullivan, Gadmer, Seltzer, Mitchell, Lakoma, Arnold, & Block, ms. 2002, submitted to *Annals of Internal Medicine*.

significant differences between patient diagnoses, physician demographics, and the majority of quantitative measures.

Narratives and Numbers

The interview included qualitative open-ended questions designed to elicit physicians' stories about both the recent and the most emotionally powerful deaths, and quantitative attitudinal measures including ratings and adjective check lists characterizing the process of dying, scales on the physician-patient relationship, pain management, burnout, social support, and general attitudes towards death and palliative care for both the most recent and the most emotionally powerful death. The interview lasted 80 minutes on average, including both qualitative and quantitative questions.

The qualitative interview sought to elicit physicians' subjective experience. Physicians were first asked about the recent death. Questions included: "please start by telling me the story of [patient's name] illness and death"; "what was the cause of death?"; "I'd like to hear about how patient A's death affected you. Please take me through the sequence of your own reactions to patient A's death." "Looking back on your care of patient A, is there anything that you would have done differently?" Probes included questions about medical circumstances, relationships with patient and kin and the medical team, treatment goals and changes over time; emotions generated, coping responses, and characterizations of the nature of clinical work and quality of end-of-life care. Physicians were asked to describe what aspects of the experience were most disturbing, what was most satisfying, and in what ways, if any, it was an emotionally powerful experience. They were not explicitly asked about whether they considered the patient's death to be "good" or "bad." Physicians were then asked parallel questions about a patient death they experienced in the course of their professional career that they regarded as "most emotionally powerful." Although the qualitative interview was semi-structured in order to insure comparability in topics covered across both deaths, the highly experienced interviewers encouraged physicians to tell the stories of patient deaths as fully as they wished.

The quantitative measures included items specifically developed for this study as well as existing measures. Items developed for this study included interviewer-administered questions about ratings of how emotionally powerful the death was for the physician, how disturbing it was, how satisfying it was to participate in care for the patient, how much conflict there was regarding the patient's care, how close they felt to the patient, and how much the patient suffered. Existing measures included adaptations of the following self-administered scales: Relative Grief Measurement Scale (Jacobs, Kasl, Ostfeld, Berkman, Kosten, & Charpentier, 1986), Brief Situational COPE Scale (Carver, 1997), Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979), Maslach Burnout Inventory Human Services Survey (Maslach, Jackson, & Leiter, 1996), and the Collet-Lester Death Anxiety Scale (Lester, 1994).

We selected narratives of the 75 physicians at one site to build the qualitative thematic analyses. Types of narratives and detailed characteristics about patient deaths and about physicians' work in caring for patients at the end of life were coded and interpreted.

Stories of most recent deaths and most emotionally powerful deaths were used in building the thematic analysis. Qualitative analyses were carried out utilizing ATLAS/ti[®] (Release 4.2. Muhr, 1997-2000), a data management program that assists in creating interpretive codes. Purposive coding, an ATLAS/ti technical process, included selection of phrases, sentences, and paragraphs of common as well as unique themes. In addition, we utilized ATLAS/ti's automatic coding function to identify words and phrases and to confirm and tabulate these throughout all interviews. We examined variations within and across groups, comparing themes and responses by position in the medical hierarchy and by gender. Selected findings derived from the auto and purposive coding of the qualitative data for these cases are reported below in narrative and numerical formats. To assess representativeness of this subsample, we compared the qualitative subsample (n=75) with the rest of the sample of 163 physicians (n=88), and found no statistically significant differences on quantitative or demographic measures.¹

Quantitative analyses were carried out using SAS[®] statistical software (Version 8.2, Cary, 2002). We carried out *t*-tests and chi-square tests for independence to compare physician groups on continuous and categorical measures, respectively. To compare within-person responses related to the most recent death with those describing most emotionally powerful death, we employed dependent-groups *t*-tests to compare continuous measures and McNemar's test for paired data to compare categorical measures. Descriptive data from the study's quantitative measures for the total sample of 163 physicians are included to situate the discussion of case material within the broader group of respondents.

Relationships with Dying Patients

What are physicians' relationships with patients about whom they speak? The majority of relationships between physicians and dying patients in academic medical centers are characteristically brief. In our analyses of most recent deaths, 34% of all physicians (n=163) interviewed cared for their patients for three days or less; 69% for a week or less. Only 7% of physicians were with the patient at the time of death, although 84% had seen the patient within hours of death. Patients were frequently in and out of consciousness, and physicians often commented that they identified more with family members than with patients. They did not feel particularly close to patients, rating "closeness" on a scale of 0-10 at 2.9 ± 2.3 on average (\pm standard deviation). These measures of relationship contrast with the way physicians assessed the most emotionally powerful death of a patient in their care, with 35% of residents and 19% of attendings recalling that they were with the patient at time of death; ratings of closeness were almost twice as strong (5.5 ± 3.1) ($t=8.2$, $p<.0001$).

Physicians were also most likely to characterize the way they personally felt about the death of patients as "sad" (70% for recent deaths; 89% for most emotionally powerful deaths). "Frustrated" was also a frequently chosen adjective, with one-third of all physicians indicating they felt frustrated about the recent death and almost half (49%) about the most emotionally powerful death.

Are there “good” and “bad” deaths?

“So I’ve seen – quote – “good deaths” out there, I’ve seen some here, but you remember the ones that occur in the intensive care units.”

-- male attending

“It was a mirror of a bad death, not a good death, --- here’s a gentleman who had been alone in an outside hospital and now he’s alone here.”

-- male intern

Physicians tell complex tales, using multiple narrative plots to typify deaths and to speak about the quality of the process of dying. Terms such as “good death” or “bad death” are used only on occasion and are not part of most physicians’ common parlance when they tell a story of a particular patient death. Public discourse on “good” and “bad” death has not significantly influenced the metaphors of physicians caring for dying patients. Only 17% of physicians in the qualitative subsample (n=75) used “good death” and/or “bad death” in their accounts of recent deaths. Only five physicians spoke about the most emotionally powerful deaths in a language of “good” and “bad” death. However, since our earliest analysis of the qualitative interviews and through subsequent interpretations, we find that these physicians do not shy from telling richly evocative, compelling, poignant, compassionate, and at times frightening and judgmental tales, about the quality of end-of-life care and of the dying process.

Images of Patient Death, Medical Work, Quality of Care and Communication

Physicians’ stories of patients’ deaths are entwined with reflections upon and assessments of their own medical work and the effectiveness of their interactions and communication with patients and families. This mode of narrating patient deaths through reflections on one’s medical work in caring for patients at the end of life is similar to the earlier observations by Glaser and Strauss about narratives of death, dying trajectories and reflections on the organization and nature of the work of terminal care (1968). Figure 1 illustrates the major themes and specific characteristics derived from physicians’ stories of both recent and most emotionally powerful deaths that typify and categorize patient deaths and processes of dying. These include positive and negative aspects about time and process, medical care and medical communication. Specific deaths in contrast to ideal-typical deaths are often mixtures of positive and negative characteristics that may vary at different points in the process of dying, just as care may be more positive or negative, varying as well over the course of medical treatment. Illustrative cases follow.

**Figure 1. Physicians' Perceptions of Patient Deaths
Positive and Negative Characteristics**

<i>Positive</i>	<i>Negative</i>
TIME AND PROCESS	
Expected Peaceful Timely	Unexpected Chaotic Prolonged
MEDICAL CARE AND TREATMENT DECISIONS	
Rational/coherent "Appropriate" care Facilitating smooth, peaceful or comfortable death	Irrational/ lacking coherence Futile or overly aggressive care Adverse events, leading to painful dying and or hastening death
COMMUNICATION AND NEGOTIATIONS	
Effective communication with patient, family, team	Ineffective or absent communication, conflict or misunderstandings with patient, family, medical team

Characteristics of Dying

Death and dying is typified in terms of whether and when a patient was expected to die, measured by severity of disease, by age, by life chances. Timeliness of the death and quality of the dying experience are important. Is this the appropriate moment for this person to die, even if ill and elderly, given the confluence of the patient's personal goals and wishes, medical status, possibilities for future life? Is the quality of dying peaceful, without pain? Were family present and able to cope with the death? Were the patient's wishes honored? Deaths that were unexpected, or prolonged and "torturous" (not a salient term in the 1968 discourse related by Glaser and Strauss), were particularly disturbing to physicians, in contrast to deaths described as peaceful, expected, and timely.

"Good" or positive deaths were described as "smooth and easy." A female resident describing a recent death of an elderly cancer patient commented: "I felt good that he died in a comfortable way and that it wasn't prolonged for him. I guess I just knew it would happen in 24 hours, so it just doesn't become a shock at all, you know." "Bad" or negative deaths were not described in the popular language of "bad death" but rather in

terms of the clinicians' own feelings, of "shock" and "guilt" and "not doing right." Physicians not only related their own feelings but interpreted those of kin and conveyed the sense of rupture an untimely death brings to both clinician and family.

"It's so shocking and people just can't believe it. They're in denial and all this guilt and all these awful feelings come up...you feel like ...nothing has been resolved."

-- male intern

Quality of Caring and Questioning High-technology Interventions

Futile care is associated with deaths clinicians regard as unnecessarily prolonged. Medical interventions that appear to disrupt a patient's dying trajectory and the process of dying "on time" (as used by Glaser and Strauss) often lead clinicians to experience frustration.

"It made me feel frustrated...we were working on the wrong goals...we did not do right by her, by keeping her going so long."

--female resident

The work of end-of-life care is categorized by whether it facilitates "smooth" deaths or precipitates disruption, chaos or "havoc" (Glaser and Strauss, 1968; SUPPORT Principal Investigators, 1995), leading to disturbing deaths. Adverse events due to medicine's inherent riskiness, futile and overly aggressive care, errors or iatrogenic hastening of death, or care driven by a culture of high-technology medicine rather than patient comfort, were critically discussed by many physicians in our study. Physicians' stories of death also address the limits of the high-technology fix that can no longer ward off death. Residents and interns in particular fault oncology and its experimental and at times toxic interventions at the end of life. Routine dismay is captured by matter-of-fact comments such as that of a female intern:

"She came in for a bone marrow transplant to cure her [cancer] and as a complication of BMT got pulmonary toxicity and died."

Other disturbing accounts of end-of-life care identify adverse events that lead to emotionally distressing deaths. Physicians engage in typical narratives about iatrogenic precipitants to unexpected or untimely deaths, even of patients who are elderly. Because of the fragility of the elderly, as well as the propensity for bad things to happen in the hospital, physicians often are uncertain why the patient died.

A male attending commenting on an elderly patient who appeared well when she came to the hospital remarked:

“As is often the case with people that age, the wheels are only lightly screwed on and then you know bad stuff happens and more bad stuff happens.”

An oncology attending spoke about the negative aspects of modern technology when he recounted taking responsibility for directing the end-of-life care for a 40-year-old man suffering from an unexpected lung cancer. The attending told his tale haltingly, clearly affected and distracted by the “hectic” work situation which characterized the final days of this patient’s dying. The patient had suffered a stroke, likely related to blood thinning medications taken as part of his anti-cancer therapy. He had numerous procedures, CT scans, intubation, additional tests and interventional technology. In concluding his tale, the attending remarked:

“And that... is the sort of situation we basically find ourselves in and you can say we can torture you with modern technology and the outcome is gonna be the same, whereas you can have a peaceful pass out. ...we were realizing that we were going to hurt him if we, for example, kept him on ventilators and kept trying to keep a body alive that was just not wanting to be alive. And everybody figured: ‘what the heck, give it a shot, see what happens.’ And that was very aggressive management certainly. We gave him that shot. And the house staff, who tend to have more common sense, say, ‘why are we doing all this?’ You know, they are smart enough to say don't just sort of take this problem and see that people are getting tortured by toxic drugs and toxic treatments and then ultimately they get burned out.”

Quality of Communication

Quality of communication with patients, kin and team members is fundamental to physicians’ assessments of the quality of the process of dying. Physicians express far greater satisfaction with the care they are giving when communication with patient, family, other clinicians and health care units is smooth, positive, functional, and of high standard. Physicians associate “good communication” with “good medical care” and appropriate management of dying. For example, when family anger generates physician anger, clinicians question themselves and the quality of their work.

A female resident commented on the way angry families make caring for dying patients exceedingly difficult:

“There was a lot of anger in the meetings and a lot of thinly veiled frustration by the family with us. I left feeling angry because the whole thing [the care of the dying patient] ended up being about [them] and not about the patient.”

Caring for dying patients who have appreciative families can be highly satisfying to physicians and deaths are spoken about in a more positive way, even if “sad.” Two comments by attendings illustrate:

“Ultimately we ended up being as much a caretaker of the family as of the patient, we were there for them.”

--male attending

“This family was very appreciative. They kept saying ‘we appreciate everything that’s been done’ and it was actually a very warm feeling to have the appreciation.”

--female attending

Positive and negative stories about dying are thus closely associated with the quality of clinicians’ relationships with family members. Positive relationships with family members and alliances between kin and clinicians are built on growing trust and produce concordant goals in patient care. Decision-making is spoken about as thoughtful, engaged, and in the clinicians’ view, “reasonable.” Physicians often identify with families who show gratitude and collaborate in care of their dying kin. Negative stories are associated with distrust, confrontation, conflict, and power struggles over treatment goals and medical details. “Irrational” decision-making by families affects medical work, often generating conflicts of conscience and frustration about being responsible for the provision of futile care. In these cases, physicians often regard the dying process as chaotic, triggered not by medicine’s technical irrationalities but by familial irrationalities. Family anger and hostility can generate strong emotions in clinicians, as identified not only in the quantitative adjective check list but in the language used by clinicians themselves in telling the stories of patients’ deaths. Although anger words are infrequently used by the physicians in our study (16% used them in stories of recent death), negative emotions appear muted and professionalized and are expressed as frustration. These negative feelings color how clinicians tell stories about their management of the care of dying patients and how they characterize a patient’s death. Expressions of sadness are frequently associated with routine deaths, although intense feelings of sadness also arise when the social context of a patient’s death is disturbing, such as when patients die alone, are very young, or leave young families behind.

The quality of communication with referring physicians and medical institutions and with “in-house” colleagues is also associated with positive and negative stories of patient deaths. For example, one clinician in telling the story of a most emotional death experienced during early years in training, repeatedly returned to an error made in the referral process regarding the patient’s allergies to certain medications.

“We did not know him [the patient] and the referring physician did not tell us anything about this [medication allergy]....If I had known this one single piece of information....I would have been able to save his life...and I always questioned the fact that I could have known more. ...It was a painful experience.”

--- male attending

Figure 1 typifies positive and negative dimensions about death and caring for the dying that emerged from our structural analysis of physicians’ stories. However, as noted

above, physicians' stories of patients' deaths are not simply characteristic tales of opposition, of "good" or "bad" deaths. They are nuanced, filled with narrative twists and turns, often with some ambiguity and uncertainty, and often with a mixture of positive and negative characteristics. The following two cases illustrate how physicians weave images of time and process, evaluate quality and appropriateness of medical management and end-of-life care, and discuss variations in effectiveness of communication with other clinicians and health care teams and with patients and families. Relationships with dying patients and their kin, as well as physician agency and feelings, are integral to these often dynamic tales of managing and at times mismanaging end-of-life care.

Time and Process

"Mr. F. had been a long-term patient of our group... in contradistinction to the usual demeanor when he was in previous hospitalizations, it was clear when Mr. F. came to the hospital he was desperately ill... disoriented, comatose. And the feeling of his caretakers was that this was now a situation where he was in a near death situation, and that we should focus on comfort care."

-- male attending

I actually came into this one where the pulmonary consultant had already come by and said 'this is terminal.' So when I got to know [Mrs. E.], it was in the context of somebody who was already felt to be terminal. I never spoke with the woman. I really viewed my role on the team as yes, taking care of her, but really taking care of her family."

-- female resident

Although most relationships with dying patients are recent and brief, primary care givers become familiar with patients through their bodily responses and tests, as well as through more personal interactions. Patients' medical history becomes their personal history, known through chart notes and unwritten professional memories clinicians hold. Patients are also known as persons, even when often less than lucid, through their families and through interactions with other members of the medical profession, both those on the caregiving team and those who have referred the patient. When gaps in medical knowledge about a patient occur, as noted in the above comments about the patient with allergies to medication, failures in professional communication make clinicians uneasy about the quality of their own medical management as well as that of other professionals. Families are also key players – and as noted by many physicians interviewed and mentioned above, much end-of-life care is family care, and family responses and cooperation make medical work and care for dying patients gratifying or frustrating.

The following case vignettes introduced with the above quotations are drawn from accounts of two recent deaths. They illustrate in greater detail some of the many nuances of characteristics of dying noted in Figure 1.

An Elderly Vigorous Man: Mr. F.

“I have always had strong feelings that we have underestimated the concept of comfort care, and underestimated how we convey to families that concept; that we communicate with the family that the patient is not being deserted, that the family isn’t being deserted....

“Here was an individual who up until his last ... admission, was being cared for in the most aggressive way, and [we were] doing everything possible for him. At this point in time...it was clear he had multiple problems ...he was not going to survive, and that our responsibility as physicians was to support him and care for him, and communicate to the family that now there was a fundamental shift in management, -- but not one that was detrimental to him or uncaring to him, but was predicated on ...**do no harm**. And making him comfortable, doing much **for** him but little **to** him....

“He was at a point in his life, in his nineties, that the fabric of his life was incredibly vigorous and involved, far longer than most of us will have the opportunity. He wasn’t someone who spent the last five or ten years ...progressively demented. He was always...very sharp. But it was clear when he came in this time, there was just too much going on for him to survive...there were a couple of days where he was oriented and had a sense of what was going on.”

--- male attending

A Young Cancer Patient: Mrs. E.

“She was a young woman in ...her late 30’s who had been diagnosed some years ago with Hodgkin’s Disease. She’d undergone chemotherapy and had a relapse...and she came in for a bone marrow transplant for her recurrence. It was known up front that it was a fairly risky transplant, probably higher than average risk because she had had so much prior chemotherapy that ...her organs were vulnerable including her lungs. The oncologists designed a regimen of chemotherapy ...to protect her ...from the extra toxicity. She just didn’t do well with the transplant at all...

“The time that she was intubated for about a week or so, it became pretty clear everything we tried to do to fix it wasn’t working.... We didn’t have anything else real or experimental to offer to try and make it better. So I came on the service about this time and she had been sedated, fairly comfortable on the breathing machine.... Her family was involved in decision-making...we sat down and said: ‘you know, it really doesn’t look like she’s gonna get better. This is probably a terminal event for her.’ And they really struggled with that and wanted some outside consultants to come in at that point. We had one of the pulmonary

attendings offer another opinion. ...He came to the same conclusion that there really wasn't any hope...and he wrote that in an official letter to them and they had an hour- long meeting with him. And at some point the ethics committee also became involved because they wanted further information and evaluation of the situation. At that point it really was clear to us that we couldn't fix it, and that all we were doing was supporting her but not to any, you know, end. ...

“There was some difficulty, some conflict [with her health care proxy] who was ... was very jealous of the decision making. ...Nobody was gonna make any decisions, nobody else was gonna have any influence, nobody was gonna tell... what to do. Her husband, and to some extent [other family members]...were ready. The husband knew it was her time and wanted to just let her go gently. But he had no input into the process, no official power. I became involved more and more as this went on day after day...and intermittently suggested we could back off and they just really didn't want any part of it. ...

“We were concerned about her comfort and felt like that was our primary intervention with her, I mean we had to try and take care of her, not just her health care proxy.”

---female resident

Physicians begin each of these stories of most recent deaths with characterizations of the individual patient -- “a vigorous elderly man who was in final stages of heart failure,” “a young married woman who was suffering terminal cancer.” Temporality and timeliness of dying are central to the unfolding plot. And yet, timeliness is not simply determined by patient age, nor even in terms of patient disease state and whether clinicians expected these patients to die during this specific hospitalization. In these two cases, death was expected because of the severity of disease. Timeliness is also linked to clinical actions, work, and communication processes. The limitations of medicine's interventions for seriously ill patients were noted in both accounts, setting the background for each story as it unfolded. The quality of clinical actions and judgment were not questioned in the first case; in the second case, the physician spoke about the family's hostile questioning of aggressive cancer treatments, including the most recent treatment, bone marrow transplant with chemotherapy, that failed to reverse a serious terminal illness and hastened the time of death. Unlike cases in which there are adverse events, in this particular situation, family anger at the limits of medicine's technologies to defeat disease resistant to treatment becomes transformed into an accusation of medical mismanagement. Time dragged for the resident. In both cases, the physicians found that explaining to patients' families the transition from aggressive care to end-of- life comfort care is often the most difficult challenge in end-of-life clinical tasks.

In the first case, the transition to comfort care and managing family response were time-consuming and detailed but the family and physicians worked collaboratively, and the professional power of the physicians allowed them to make the medical decisions without contest. The attending noted, when he spoke in general about the difficulties of conveying the transition to comfort care:

“the other piece of that is meeting with the family and integrating the house staff in those meetings, and not relying on the house staff alone to be making decisions or putting the responsibility of the care-taking on the house officers... an intern or a resident who has had minimal or limited experience, ... it’s not fair to put them in a position where they feel uncomfortable because we haven’t defined how we want care to be given.”

In discussing the case of Mr. F., the attending described how the family was integrated into the end-of-life discussions. Many family members were engaged and present but others lived at a distance, including abroad. The physicians involved were not only highly prestigious clinicians and thus had cultural power in this case, and controlled decision-making, they were also skilled at prognosis, reading the body and the disease process, and thereby narratively emplotting a successful story of a good ending to life’s journey.⁷ In the process, as recounted by the attending, the physicians sought to create a sense of the timeliness of dying, even as they were conveying to family and staff that appropriate clinical actions were being taken for the patient, with a goal of comfort care. The attending concluded the story of his patient as follows:

“Well the family...it was orchestrated through Dr. X (another attending), there were a lot of phone calls that were coming in to him, [he] essentially explained and facilitated the management at that point in time. So in a way, there was a certain atypicality to Mr. F.’s dying because there was the family who understood, and it wasn’t as if we had any discussions about death and dying.”

The attending rated his patient’s death as extremely satisfying (7), neither emotionally powerful (3) nor disturbing (3), as did the intern on the case (extremely satisfying, 10; not emotional, 2; not disturbing, 2). Both described their patient’s death as timely, dignified, and peaceful on the self-rating adjective list. The patient was a ninety-year-old gentleman who had lived a full life.

The difficulties in the case of the young cancer patient, Mrs. E., arose from conflicts among family members and the silencing of some in the face of the fury of others. The resident’s story is filled with her interpretation of this family’s intense anger over the failure of the advanced chemotherapy in combination with a bone marrow transplant – a treatment they were convinced was “a safe regimen.” Anger and frustration colored all interactions between the team -- including nurses and physicians -- and one relative in particular. Faced with intense and highly expressive family anger and aggressive decisions to control all medical decision-making, the resident was stymied and unable to engage the family in formulating a narrative of a peaceful death. However, with time, the resident and nurses were able to achieve clinical care at life’s end that fitted with their goals of allowing the patient a peaceful and gentle death, recalling Glaser and

⁷ For method and theory on narrative analysis in medical anthropology see B. Good, 1994; M. Good, 1995; Mattingly, 1998; Mattingly and Garro, 2000.

Strauss's "image of a perfect death." In recounting the last days of caring for Mrs. E., the resident reflected on the family crises and how these led to a prolongation of dying.

"I felt [the relative] was cheating her of a peaceful way to go, and certainly cheating the rest of [the] family of the opportunity to have any input. And I felt that the situation was set up so that would be potentially explosive. ... The nurses were really upset because they felt that they were not doing right by their patient just to keep her going this way, that their commitment was to her, not to her [kin]."

In discussing meetings between the medical team and family members, she described daily encounters :

"Yes, [we met them] on a daily basis, and [we] certainly dealt with the family extensively at the bedside. But it was hard because it is not really our role to say to them, ... directly, 'you gotta pull the plug.' But it was as clear a case as any in terms of our ability to gently recommend something and it was just terrible, not because they disagreed with us, but because their way of dealing with it ... was so difficult."

And at the end, as oxygen support was slowly withdrawn, the resident stayed after her shift to assist a new intern who had just come on and was unfamiliar with the case and with procedures.

"So I stayed, so I stayed. ... She was worsening ... we turned her to room air ... And the family was in the room and it was just this long terrible thing where her heart was slowing a little at a time, and I remember everybody was watching it on the monitor ... it just kept gradually slowing, it was just kind of awful when you've got that technical stuff involved in death and you just see it on the screen. It was really painful. ... She went very peacefully. There was no obvious thing other than that her heart stopped. ..."

"And then her family came out and [a relative] said 'I have some demands... I want a full post-mortem exam because this was not supposed to happen... we were told this was a safe regimen.'"

The resident experienced this death as emotionally powerful (8), disturbing (7) and the care was not very satisfying (3). On the adjective check list she described her patient's death as chaotic, degrading, overtreated; she characterized her patient as isolated and full of suffering. For the resident, the process of dying was very time consuming and frustrating, and she was relieved when death was finally allowed. Although she felt moderately satisfied (5) in how she managed the family's distress, she felt no satisfaction in how she managed internal family conflict and their conflicts with the health care team, nor in the degree to which she was able to control the use of life-prolonging interventions. The new intern on the case while aware of the intensity of the conflict was

minimally involved in patient and family care and simply expressed relief at Mrs. E.'s death.

The resident's narrative of Mrs. E.'s end of life was fraught with her own frustration at her inability to wield enough professional power and influence to facilitate her patient's transition to comfort care, not to irrationally prolong death but rather to effect a peaceful, gentle and "timely" death, even of such a young person. Her identification with the young woman's husband and his desire for his wife to have a gentle end added intense emotionality to caring for this patient at the end of her life.

The contrast between these two cases highlights nuances in the positive and negative categories noted in Figure 1. These are stories of contrasts in professional power and authority as well. In the first case, the senior cardiologists were highly esteemed men, powerful clinicians in the medical community. In the second case, the physician telling the story was not only a young woman resident, she was not the primary specialist for the patient, as were the oncologists.

Although "good death" and "bad death" are not characteristics common to the explicit language of these physicians' narratives, clearly the positive and negative descriptions of aspects of the death shape distinctive and contrasting plots. The first case is clearly a story of a death that is smooth, peaceful and timely, in which the quality of medical judgment and procedures is not questioned and communication among professionals and with the family is effective and integrative. The transition to comfort care is an issue, but it is made without conflict. When end-of-life narratives are formulated effectively by physicians and decision-making is a professionally led effort with family members positively engaged and respectful of professional choices, then physicians experience satisfaction with their work.

The second story illustrates physician distress over what is regarded by both the resident and the nursing team as medically futile and irrational treatment. It also exemplifies how family conflicts may lead to treatment actions by health care teams, where they feel compelled to act against their professional judgment because of family wishes. In the case of Mrs. E., death was medically untimely in that it was prolonged, as well as untimely because of the patient's youth. Dying was chaotic from a medical management perspective, as interventions to sustain the patient's life that were requested by the family disrupted the dying trajectory felt to be appropriate by the nurses and physicians. In this particular case, the difficulties in communication according to the resident's story were not due to lack of effort by the nurses and physicians on the medical service responsible for caring for the patient at the end of life. Rather, the resident felt that denial and intense grief prevented some family members from accepting the inevitability of the patient's death. In addition, deep family distress over the outcome of aggressive BMT and salvage chemotherapies suggests that the patient's relatives misperceived the gravity of her illness and misunderstood the vulnerability of her body to BMT procedures with inherent high risk. This misperception and the subsequent anger at a bad outcome may have arisen from slippages in communication between the family and the oncology service, as noted by the resident, although the source of misunderstanding and lack of clarity is

uncertain. Nevertheless, family emotionality and conflict over choices regarding medical interventions to prolong life seriously affected the medicine team in the unit where Mrs. E. spent her last days under the care of the resident who told the story of her dying.

Even in this resident's story, fraught as it was with negative characteristics of the process of dying, the disposition of the patient at life's end (Glaser and Strauss) is conveyed through the telling of a final moment of "a perfect death."

"She went very peacefully. There was no obvious thing
other than that her heart stopped."

Concluding Reflections

We began this essay noting that although our societal discourse on death and dying has formulated broad cultural categories of "good death" and "bad death," physicians in our study do not commonly use these terms in telling stories about specific patients' deaths (13 for recent deaths; 5 for most emotionally powerful deaths). Even the three quotations we chose as a segue for the topic of this special issue conjure images that are more complex than simply "good" or "bad" deaths. The first alludes to a lengthy, unsuccessful search for efficacious treatment and technological interventions, and tells how physicians and their patient were slow to realize that there were no other pathways to maintain an on-going life. The second quotation alludes to complexities of relationships with families and tensions within the staff over technological actions and futile treatment, not simply to a "bad" death. The third very brief quotation implies that for this physician hospital deaths simply cannot be "good." When physicians speak about actual cases of patients who have died rather than about ideal types of deaths, they discuss characteristics that make a death better or worse, more positive or more negative, more satisfying or less so. The broad themes outlined in Figure 1 – time and process, quality of medical care and of communication with patient, family and medical team – are one way to categorize physicians' experiences in caring for dying patients, as well as relational and medical details and judgments.

The physicians' narratives in this study also include a strikingly large degree of biomedical description, about technologies chosen, interventions used, and successes and limits of medical decision-making.⁸ Physicians speak very much in the critical cultural discourse of internal medicine; they puzzle over choices gone awry and question the latest inherently risky treatments that may be utilized at the end of patients' lives. Through the interviews, physicians revisit clinical decisions and actions that they and their colleagues performed. These are distinctive high-technology and academic medical discourses, and they contrast with those clinical conversations observed by Glaser and

⁸ These are discussed in a complementary manuscript (Good, Ruopp, Gadmer, Lakoma, Sullivan, Arnold, & Block, ms. 2002).

Strauss in an earlier era.² Although cultural similarities about temporality, dying trajectories, and management of patient and kin persist, the practice of biotechnological actions and the organization of clinical care – of who does what – have fundamentally changed, with increasing medical and nursing specialization and an increasing pace of in-hospital actions. (Reading Glaser and Strauss, 1968, one has an impression of a slower paced medical world, -- Dr. Welby rather than ER in popular television imagery.)

There is also a good deal of commentary on what is medically and technologically possible but perhaps not desirable, such as extending bodily time without life time. As one of our interviewees remarked “we can keep a body alive that no longer wants to be.”⁹ Thus in response to the possibilities of new biotechnologies, discourses on “medical futility” and “medical torture” have become increasingly salient in American academic medicine and in community hospitals as well. These discourses are underpinnings of the central concerns of the SUPPORT study: overly aggressive treatment leading to prolonged and painful hospital deaths, lack of attention to patients’ wishes and comfort, and misuse and overuse of hospital resources. Some leaders in the palliative care movement, concerned about the extent of this cultural shift, ask, “are we allowing some patients to die prematurely whom we might be able to save?” (Block, 2001).

Thus, innovations in contemporary medical technology have expanded not only possibilities for intervention but also the difficulty in ascertaining when a patient is dying. This, in turn, has produced an ever-wider array of material medica that influences the time and pacing of medical work and of dying trajectories. New technologies can prolong life, prolong death, or precipitate an unexpected death. They have created more choices and thus have forced more medical decisions about what to do in end-of-life care. They have also highlighted the degree to which “the right time to die” must be negotiated with patients and/or families. Again, this change reflects an evolution from the model presented by Glaser and Strauss where physicians had much more social power and ability to unilaterally make medical decisions for patients.

Recent technological innovations have also influenced the organization of contemporary clinical work and the division of labor within teaching hospitals with respect to who cares for the dying. Recall that in our study, patients are most often hospitalized for brief periods prior to death, and they are cared for in their dying days by physicians who for the most part are “strangers” to them, making Charles Rosenberg’s characterization of hospital care in the early 20th century, *The Care of Strangers* (1995), truly poignant for the 21st century as well. Continuity of care and long term physician-patient-family relationships are rare in academic internal medicine services, especially at the end of life when continuity and long-term relationships may be the most important. Thus, it is not surprising that the SUPPORT study identified communication between physicians, nursing staff, and dying patients and their families as problematic, requiring improvement via intervention and reform of standards of practice. Perhaps the SUPPORT study and other educational efforts in palliative care have had some degree of influence. It is remarkable how many physicians in our study were able to tell stories about how they

⁹ See also Truog, 1997, for a discussion of new biomedical support systems that can prolong a body’s existence beyond the ambiguous category of brain death.

successfully managed communication with families and patients and came to establish concordant treatment goals with the families of their patients, and to make the transition to comfort care at the end of life.

Over and over, physicians' narratives in this study reveal that dying is not easy and straightforward for patients; nor is it for physicians. Ambiguities abound. Is the patient dying or can she be saved? Is this a time for aggressive care or a focus on comfort (why can't these be done simultaneously)? Is this family unwilling to do what the physicians believe is right because they "can't let go" or because they recognize an important need to have the dying process unfold over time, for their own, very appropriate and understandable reasons? How do the physician's values and uncertainty about what should happen influence, subtly or overtly, the decisions made by families?

These subtleties remind us that dying is difficult, particularly in the modern hospital where there are so many treatment options and where relationships are short, discontinuous, without a perspective on the patient as a person, and with little time to acquire it. "Good deaths," if they exist, take place in the context of relationships in which the patient's personhood is known and valued. Often, as seen in our study, family members can bring this perspective to the medical context. Nonetheless, the ambiguities uncovered in this study are an essential element of the dying process as it unfolds in our troubled health care system.

This study illustrates that there is much to learn from physicians' nuanced narratives about patients' deaths, from both positive and negative dimensions in these stories. Physicians in this study were at times both troubled and gratified by their roles in caring for dying patients. Although they do not commonly use the terms "good" and "bad" to describe their patients' deaths, they clearly have reflected on their experiences and thought hard about what makes for positive, gentle, peaceful dying versus prolonged, torturous, painful dying. **Figure One** summarizes major themes that emerged from physicians' stories of their patients who died. *Time and Process, Medical Care and Treatment Decisions*, and *Communication and Negotiation* are the broad categories that have historical and cultural resonance, as noted above, with observations by Glaser and Strauss on narratives about dying trajectories and the work of caring for terminally ill patients. These cultural and discursive continuities are intermixed with changes reflected in the extraordinary innovations in biomedical technologies that influence dying trajectories of patients and the nature of ambiguity in clinical work in end-of-life care.

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¹ The subsample of 75 physicians was chosen for the interpretive analysis in this essay as several of the authors personally interviewed these participants. In addition, the authors built the qualitative coding schemas out of multiple close reading of all 75 interviews, following a traditional grounded theory and anthropological mode of interpretive analysis. A comparison reading of fifteen selected cases from the second site indicated that the broad narrative themes were similar for both groups.

² Glaser and Strauss's research for *A Time for Dying* (1968) included interviews and observations with physicians and nurses at San Francisco General and included critical reflection on their work.