

# THE ECOLOGY OF DYING: COMMODITY CHAINS, GOVERNANCE, AND THE MEDICALIZATION OF END-OF-LIFE CARE

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## ABSTRACT

*Purpose – Millions of people die of chronic diseases within inpatient settings annually in the United States, despite patient preferences for dying at home. This medicalization of dying has received social and economic critiques for decades. This chapter offers a further analysis to these critiques by examining the ecological impacts of inpatient end-of-life care on the natural environment and occupational and public health.*

*Methodology – We compare the ecological health outcomes of medical care in three inpatient units (conventional cancer unit, palliative care ward, and hospice facility) using ethnographic observations, semi-structured interviews, and institutional records on medical supply use, waste generation, and pharmaceutical administration and disposal.*

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*Findings – Care provided on all three medical units had significant socioecological impacts. Cumulative impacts were greatest on the conventional unit, followed by palliative care, and lowest on the hospice unit. Variations in impacts mirrored differences in dependence on material interventions, which arose from variations in patient needs, institutional policies, and nursing cultures between the three units.*

*Practical implications – Social and economic concerns have been major drivers in reforming end-of-life medical care, and our analysis shows that ecological concerns must also be considered. Transitioning terminal patients to less materially intensive modes of care when appropriate could mitigate ecological health impacts while honoring patient preferences.*

*Originality – This chapter describes how the medicalization of dying has converged with institutional policies, practices, and actors to increase the negative consequences of medical care, and recognizes that the far-reaching impacts of clinical decisions make the provision of medical care a socioecological act.*

**Keywords:** Cumulative life-cycle analysis; environmental justice; ethnography; occupational health exposures; qualitative methods

## INTRODUCTION

A century ago, death and dying mainly occurred at home under the care and observation of family, friends, and neighbors (Aries, 1974). Rapid advances in the science and standardization of medicine, combined with the social changes of industrialization that brought laborers from rural to urban areas, have led hospitals to become a primary site for end-of-life care (Starr, 1982). Post-World War II scientific and technological advancements further medicalized the dying process by improving chances to fight disease and prolong death (Connelly, 1997). This displacement of the dying to hospitals first met with criticism in the late 1960s with landmark studies that exposed the social isolation, anxiety, mistrust of staff, and withholding of terminal diagnoses that dying patients often experienced in hospitals (Glaser & Strauss, 1965; Sudnow, 1967). More recently, end-of-life care has undergone criticism that the high cost of care does not change the outcome of disease: patients undergoing intensive medical interventions still die in the same amount of time and with lower quality of life than those who forgo such

treatments (Institute of Medicine, 1997). Furthermore, research suggests that up to 81% of all patients and up to 90% of cancer patients would prefer to die at home (Higginson & Sen-Gupta, 2000), but only 24–30% actually do (National Center for Health Statistics, 2011). These social and economic concerns regarding the medicalization of dying have been major drivers in proposals to reform end-of-life medical care (*ibid.*). Our analysis shows that ecological concerns also warrant discussion.

The aim of this paper is to argue for the inclusion of ecological concerns into health care practices, policies, and decision-making by (1) providing a comparative analysis of the socioecological consequences of care provided in three end-of-life inpatient settings in the United States (conventional cancer care, palliative care, and hospice), and (2) examining the social factors that govern differential impacts in order to reveal points of intervention.

## **ECOLOGICAL IMPACTS OF MEDICINE**

A recent health care “greening” movement has focused on reducing the impacts on humans, wildlife, and ecosystems that result from medical facilities and operations (see Jameton & Pierce, 2001). Organizations such as Health Care Without Harm have developed tools and best practices for addressing the environmental consequences of health care through environmentally preferred purchasing, energy efficiency, waste management, and similar programs (Health Care Without Harm, 2013). While these efforts have done much to mitigate the consequences of health care facilities and operations, the driving forces behind the provision of medical care – clinical practices, policies, and decision-making at the patient bedside – have not been analyzed for their socioecological impacts.

At the patient bedside, medical care practices impact local and global workers, communities, and ecosystems through life-cycle processes of commodity chains. In other words, the medical supplies and pharmaceuticals that support patient care each have an environmental legacy resulting from their extraction as natural resources through to their manufacture, distribution, consumption, and disposal as medical products (Jameton & Pierce, 2001). For example, the life cycles of petroleum-based plastics that are commonly used in medical supplies and packaging have a number of socioecological consequences. Oil extraction pollutes and degrades natural ecosystems throughout exploration, drilling, and transport, and refining phases, and causes long-term harm to wildlife including marine mammals,

migratory birds, and fish populations (O'Rourke & Connolly, 2003). During manufacturing, workers who are exposed to vinyl chloride monomer (the building block of polyvinyl chloride used in intravenous (IV) bags and tubing) have an increased incidence of angiosarcoma of the liver (Creech & Johnson, 1974; Lee & Harry, 1974), while communities living near PVC manufacturing plants face health risks from chemical emissions (Markowitz & Rosner, 2002). Further downstream, both workers and communities face health risks from medical waste incineration which releases heavy metals, dioxins and furans, and persistent organic pollutants (Rowat, 1999; Sedman & Esparza, 1991). The persistent, bio-accumulative effects of dioxins released via PVC incineration have long-term impacts on both human and wildlife health (Thornton, McCally, Orris, & Weinberg, 1996). Plastic manufacturing and medical waste incineration also pose environmental justice concerns since these facilities are disproportionately sited in minority communities (Brown, 1995; Bryant & Mohai, 1992). Together, these life-cycle impacts of plastics commodity chains highlight how medical resource use at the patient bedside ties the delivery of health care to the global environment. A key factor in this study is the fact that the provision of medical care requires the simultaneous use of multiple medical supplies and pharmaceuticals, each of which has their own life-cycle impacts. Therefore, our approach examines the cumulative socioecological impacts that result from patient care.

## **FOCUS ON THE ECOLOGICAL IMPACTS OF END-OF-LIFE MEDICINE**

Current medicalized approaches to end-of-life cancer care offer a unique setting for studying the socioecological impacts of medical care for three reasons. First, end-of-life care is an extreme example of expensive, materially intensive care: between a quarter and a third of all Medicare expenditures are spent on the 5% of patients who die each year (Barnato, McClellan, Kagay, & Garber, 2004). Second, these settings serve a large number of patients (1,500 cancer deaths each day in the United States; American Cancer Society, 2010), which suggests potentially high and far-reaching cumulative ecological impacts. Third, three existing medical models for end-of-life cancer care (conventional curative care, palliative care, and hospice) differ in their approach, thereby providing an opportunity for comparative analysis. Conventional curative care offers materially

intensive treatments of surgery, radiation, and chemotherapy; the increasing effectiveness of these treatments has resulted in more patients seeking aggressive care right up to the point of death (Earle et al., 2004). Hospital-based palliative care services offer less materially intensive pain and symptom management for patients with life-limiting illness, as reflected by a 38% lower average daily cost per patient compared to conventional services (Elsayem et al., 2004). Likewise, hospice care is characterized by a comparatively low level of material interventions as evidenced by a 27% lower cost than conventional care (Emanuel & Emanuel, 1994), but typically provides end-of-life care external to the hospital. Since the three end-of-life care models differ in their reliance on material interventions, a comparative analysis of these three medical models offers an opportunity to examine the socioecological impacts resulting from common medical practices.

## METHODOLOGY

We employed a multisited ethnography (Marcus, 1995) that draws on (1) institutional records from our sites to quantitatively measure impacts of resource use and waste generation, and (2) observations and in-depth interviews to qualitatively measure the factors that govern these impacts. Our approach parallels the “ethical life-cycle analysis” of Pierce and Kirby (1999) by taking into account the cradle-to-grave socioecological consequences of supply chains, and is complimented by the application of a “social metabolic” lens which recognizes that resource use is a function of social organization (Fischer-Kowalski & Hüttler, 1998).

## RESEARCH SITES

This study compares common medical practices on three inpatient units: a conventional cancer ward (~30 private patient rooms), a palliative care unit (~10 private rooms), and a hospice center (~30 private rooms). The units were selected because each provided care to terminal cancer patients. The conventional and palliative care units were both located within a teaching hospital in a Midwestern city; the hospice inpatient unit was within a stand-alone facility run by a nonprofit organization in the same city. Each of these settings was situated within an ecological context (historically prairie, in this case) which provided the backdrop for the buildings, roadways, landfill,

water treatment plant, and other infrastructure that supported health care delivery.

This study was reviewed and approved by the Institutional Review Board of the University of Wisconsin, and administrators at both the hospital and hospice organization granted written permission to conduct the study. Participants (physicians, nurses, housekeepers, administrative staff, and waste handlers; 73 total) provided written informed consent before entering the study. Patients provided verbal consent to allow the researcher to shadow participating staff members within their rooms. Data were collected while observing the care of 56 conventional cancer patients, 21 palliative care patients, and 56 hospice patients.

## DATA COLLECTION

We used two common ethnographic methods to collect qualitative data: participant observation and semi-structured interviews. A single field researcher gathered over 255 hours of observational data from May 2008 to June 2009. Observations were made at each site in two rounds of approximately two months each; the first two months were spent on the conventional unit, the next on the palliative care unit, and the next at hospice. This approach allowed us to gather extensive information at each site, then revisit each site for further observation. We shadowed participants (i.e., physicians, nurses, housekeepers, etc.) for up to eight hours a day, and made observations on all days of the week and all shifts (day, evening, and night). The majority of observations occurred during weekday day-shifts because this is when the most physicians round and patient–physician consultations occur, and consequently when most resource-use decisions are made.

Thirty-three hours of semi-structured interviews with 36 participants (30–90 minutes long) were audio-recorded, transcribed, and coded for analysis. Interviewees were purposefully selected after at least one round at a unit to shed light on observations and to provide insight into clinical resource use decision-making. Interview questions were designed to inquire about common material resources used in each site, ecological health concerns regarding resource use, differences and similarities in end-of-life care models, and factors that govern resource use decision-making (i.e., political economy, cultural norms). A single researcher coded and analyzed all data using inductive, directed content analysis (Hsieh & Shannon, 2005; Miles & Huberman, 1994); data were entered into a digital matrix to

facilitate data organization and retrieval for thematic and pattern identification. Unreferenced quotations are drawn directly from interview transcripts.

We obtained institutional records on medical supply use, waste generation, pharmaceutical administration, total patient days, and average length-of-stay from the research sites for the annual period that corresponded with observational data. This quantitative data provided insight into the scope of resource use on a per patient basis, but had a number of limitations for comparing material intensity between the sites. The hospital's conventional and palliative care units were considered a single cost unit, so medical supply data were available only for the two sites combined. Likewise, medical supply data for the hospice unit includes annual usage for both the inpatient hospice facility and hospice services provided to patients within their own homes. Similarly, waste generation data was only available for the entire hospital and hospice facilities (including inpatient units, administrative offices, laboratories, cafeterias, etc.), rather than for our specific research sites. To address this shortcoming, we have augmented our quantitative data with observational data to tease apart variations in medical supply use, waste generation, and disposal practices at each site.

## **FINDINGS**

In this section, we first provide a quantitative comparison of the consumption and disposal of medical supplies and pharmaceuticals at each site, then describe our qualitative findings that explain the policies, practices, and decision-making which govern observed differences in the socioecological impacts of each site.

### **COMPARISON OF IMPACTS**

#### *Medical Supply Consumption and Waste Generation*

According to institutional records, the hospice site used the lowest volume of supplies per patient and generated the least waste (Table 1) as compared to the conventional and palliative care sites. Since the hospital where the conventional and palliative care units were located considered the two wards a single cost unit, it was not possible to get separate institutional data

**Table 1.** Comparison of the (1) Volume of the Three Most Commonly Used Medical Supplies,<sup>a</sup> (2) Volume of Waste Generation,<sup>b</sup> and (3) Number of Doses of the Three Most Commonly Dispensed Pharmaceuticals per Patient Day<sup>c</sup> on the Conventional Cancer, Palliative Care, and Hospice Inpatient Units (2009).

Medical supply use	Conventional		Palliative Care		Hospice	
	Rank	Volume per patient day	Rank	Volume per patient day	Rank	Volume per patient day
Medical gloves	1	67	1	67	1	2
Wound dressings	2	5.5	2	5.5	4	0.4
Intravenous tubing	3	2.5	3	2.5	n/a	n/a
Oral swabs	35	0.01	35	0.01	2	0.8
Incontinence briefs	28	0.04	28	0.04	3	0.4
Waste generation	Rank	Average pounds of waste per patient day (percentage of total)	Rank	Average pounds of waste per patient day (percentage of total)	Rank	Average pounds of waste per patient day (percentage of total)
Total	–	30	–	30	–	14
Municipal waste	1	20 (67%)	1	20 (67%)	1	10 (71.2%)
Recycling	2	6 (20%)	2	6 (20%)	2	4 (28.5%)
Infectious	3	4 (13%)	3	4 (13%)	3	0.04 (0.3%)
Drug (purpose)	Average doses/patient day (rank)	Average dose	Average doses/patient day (rank)	Average dose	Average doses/patient day (rank)	Average dose
Total	20.57	–	10.66	–	16.28	–
Acyclovir (antiviral)	1.23 (1)	519.7 mg	0.03 (63)	11.8 mg	0.01 (127)	6.8 mg
Pantoprazole (stomach acid reduction)	0.78 (2)	31.1 mg	0.32 (8)	12.7 mg	0.34 (12)	13.8 mg
Oxycodone (pain)	0.67 (3)	8.48 mg	0.41 (5)	7.69 mg	0.33 (13)	7.19 mg
Acetaminophen (pain/fever reduction)	0.64 (4)	425.6 mg	0.50 (3)	385.4 mg	0.58 (5)	364.7 mg
Morphine (pain)	0.59 (7)	16.3 mg	1.61 (1)	71.2 mg	2.33 (1)	125.3 mg
Lorazepam (sedative/muscle relaxant)	0.56 (8)	0.35 mg	0.66 (2)	0.51 mg	1.06 (2)	1.02 mg
Docusate-senna (laxative)	0.48 (12)	0.74 Tablet	0.46 (4)	0.92 Tablet	0.74 (3)	1.40 Tablet

<sup>a</sup>Institutional supply data were not available separately for the conventional and palliative care units because these wards operated as a single cost unit at the hospital where they were located. Likewise, data for the inpatient hospice unit were only available combined with in-home supply use.

<sup>b</sup>Waste generation data specific to our research sites were not available; data reflect cumulative waste generated by each facility including patient care areas, cafeterias, administrative offices, etc.

<sup>c</sup>“Patient day” represents the total number of days that all patients were in a medical facility (i.e., 100 patients in hospital for 1 day equals 100 patient days).

detailing the differences in supply use and waste generation for these two sites. However, our observations revealed that patient care on the conventional unit utilized larger volumes of medical supplies, and in turn generated larger volumes of waste, than the palliative care unit. For example, IV bag use per patient was highest on the conventional unit (average of 2.4 IV bags per patient per day), followed by the palliative care ward (0.7), and lowest on the hospice unit (0.07). IV bag use is indicative of supply use intensity and waste generation because each bag represents the use and disposal of a number of other materials including tubing, wound dressings, dressing change kits, medical exam gloves, and sterile packaging. IV bag use is also indicative of socioecological impacts of medical care since these PVC-containing materials are associated with the environmental, human, and wildlife health consequences described previously.

#### *Drug Use and Administration*

Pharmaceutical use is difficult to compare across the research settings for a number of reasons. The drugs that work best for managing pain and other symptoms change as diseases progress; the amount of drugs needed for symptom control increases as patients develop tolerance to them, particularly in the case of narcotics (Way, Leong, Loh, & Shen, 1969); and as patients transition from aggressive disease treatment toward symptom management, certain medications are stopped because they no longer make sense to administer (e.g., cholesterol-lowering drugs may no longer be beneficial at end-of-life). In addition, each drug has its own history and life cycle of development, manufacture, and disposal, and each patient has their own requirements for different drugs during the course of their treatment. Given these difficulties, we examine the socioecological impacts of pharmaceuticals across the three research units in general terms, by focusing on the total number of drugs administered on each unit, the average number of drugs administered per patient day (indications of occupational nursing exposures and volume of potential upstream and downstream impacts), and known concerns regarding occupational exposures to specific pharmaceuticals.

According to both institutional records and observations, the conventional unit dispensed more drugs than the other two units in terms of the largest number of drugs dispensed in total, largest average number of doses and largest volume of drugs administered per patient day. In 2009, 577 different drugs were dispensed to patients on the conventional unit, 428 on the hospice unit, and 270 on the palliative care unit. Likewise, the largest

average number of medication doses per patient day was administered on the conventional unit (20.57 doses; Table 1), followed by the hospice unit (16.28 doses), and the palliative care unit (10.66 doses). In addition, observational data indicated that patients on the conventional unit received between five and six drugs on average each day in addition to chemotherapy, most of which were intended to alleviate chemotherapy side effects. Palliative care and hospice patients received an average of about two medications per patient per day. Based upon the sheer number and volume of pharmaceuticals administered, it appears that the conventional unit had the largest cumulative socioecological impacts, followed by the hospice unit and finally the palliative care setting.

Of all the drugs administered on our sites, chemotherapy agents appear to have the greatest known occupational health concerns at the point of administration. Many chemotherapy drugs are classified as hazardous substances and exposure to them has negative health impacts including increased incidence of adverse reproductive health outcomes such as miscarriage and stillbirth (Valanis, Vollmer, & Steele, 1999), as well as infertility, premature delivery, and low birth weight (Fransman et al., 2007). Nurses who are exposed to these anticancer agents may also have an increased risk of developing leukemia (Skov et al., 1992). Health concerns are greatest among pharmacists and nurses who handle chemotherapy regularly or their coworkers who come into contact with contaminated surfaces (Sessink, Boer, Scheefhals, Anzion, & Bos, 1992). Our observations confirmed that while occupational exposure to chemotherapy varied across settings, nurses on the conventional unit had the greatest occupational exposure risks to chemotherapy based on volume of drugs administered and delivery mechanism (IV administration in the conventional setting versus oral delivery in hospice). Institutional data showed that nurses on the conventional unit dispensed a total of 1,990 doses of fifteen different cancer chemotherapy drugs to their patients in 2009, or about one dose per nurse per day. No chemotherapy drugs were dispensed on the palliative care unit. Nurses on the hospice unit administered a total of 12 doses of 5 different oral chemotherapy drugs (or about one dose per nurse every three months) as palliative treatment.

### *Pharmaceutical Waste and Disposal*

The conventional and palliative care units disposed of pharmaceutical waste via incineration, while the hospice facility relied on a combination of incineration and flushing drugs down the drain. Both methods pose

ecological health risks. Pharmaceutical waste generated on the conventional and palliative care units was mingled with various other forms of hazardous waste produced at the hospital and sent to a regulated incinerator in Port Arthur, Texas – a community that has historically been about 80% African American and Latino (Cole, 1994). Toxic ash that resulted from the incineration process was then transported to the largest hazardous waste dump in the United States, located in Emelle, Alabama, a poor, rural community. This landfill was sited in 1978 when there were no minority representatives on the county industrial development board, county commission, or in the state legislature (Bullard, 2000). Though hazardous waste facilities are highly regulated by the Resource Recovery and Reclamation Act and incinerators are equipped with devices to minimize emissions (EPA, 2011), these facilities are associated with a number of public health concerns due to the release of heavy metals and persistent organic pollutants (Rowat, 1999; Sedman & Esparza, 1991). Poor and minority communities living near hazardous waste facilities bear the greatest public health burden of emissions, making medical waste disposal an issue of environmental justice, especially since the minority populations most burdened by pollution are typically underserved by the health care community (Shavers, Klein, & Fagan, 2012).

On the hospice unit, the majority of pharmaceutical waste was also disposed of via incineration using the same hauler contracted by the hospital where our other two sites were located. However, nurses on the hospice unit commonly flushed unused portions of narcotics down the drain. Little is known about the human health effects of exposure to drugs that enter the water system, but there are some concerns regarding long-term human health exposure to the cocktail of pharmaceutical residues in drinking water that treatment plants are unable to filter out (Daughton, 2003). The environmental impacts of certain types of drug waste in aquatic ecosystems have received greater attention, including reproductive problems in fish exposed to medications, particularly from birth control pills (Corcoran, Winter, & Tyler, 2010).

Surprisingly, we learned that hospice nurses who provided care to patients in their own homes flushed all pharmaceutical waste down the drain. Although this was not the standard practice on our hospice inpatient unit, it is particularly important to note since about 40% of hospice patients received in-home care (the remaining 60% received hospice care in nursing homes or other medical facilities). Only 6% of all hospice patients were ever admitted for short-term acute care to the hospice inpatient unit where unused drugs were disposed of by incineration. As a result, we presume that

a large volume of unused pharmaceutical products entered the local water system, particularly since nurses reported flushing large quantities of medications that had accumulated over years of conventional care, but no one can quantify the amount of drugs that were flushed. This suggests that the cumulative impacts of down-the-drain pharmaceutical disposal from in-home hospice care are relatively large.

### *Cumulative Impacts of Medical Supply and Pharmaceutical Use and Disposal*

The cumulative socioecological impacts that resulted from medical supply and pharmaceutical use and disposal across our three sites depend upon the number of days that patients remain within each setting. The target length-of-stay for patients on each unit was as follows: conventional care, 11 days (ranging from 3 days for oncology patients to 20 days for bone marrow transplant patients); palliative care, 3 days; hospice, 3 days. As a result, conventional care had the largest cumulative impacts of medical supply use, waste generation, and pharmaceutical use, while the differences between palliative care and hospice are less clear since resource use and waste generation were similar on these sites.

## **SOCIAL GOVERNANCE OF IMPACTS**

### *Medical Supply Consumption and Waste Generation*

Observed differences in supply use intensity and waste generation across our sites are not surprising since conventional patients typically undergo more medical interventions than palliative care or hospice patients. A physician on the conventional ward contrasted the settings by saying, “Conventional care means more imaging, more blood tests, chemotherapy oftentimes. And anytime you have an intervention that you do, it means everything else that’s associated with it – bloods, and scans, and x-rays, and catheters, and IV’s, and you know, everything else. And there are just more interventions with conventional care. So more interventions means more of everything else.”

However, we identified nursing practices and infection control policies that combined to exacerbate the volume of medical supply use and waste generation on the conventional and palliative care units. Nursing practices

on the conventional and palliative care units focused on emergent response to patient needs: when a patient called for help, nurses quickly selected a range of medical supplies to bring into the room in response to the situation, though typically only a small portion of the supplies were required. Infection control policies required any material that entered a patient's room to be disposed of because after crossing the threshold into the room it was considered "contaminated." Infection control was considered of utmost importance at each of our research sites, and such policies are mandated and enforced by national accreditation organizations (e.g., Joint Commission) to help reduce the transmission of hospital-acquired infections which result in medical costs ranging from \$3.2 to \$7.3 billion annually (Roberts et al., 2010), and nearly 100,000 deaths (Klebens et al., 2007).

Interestingly, nurses who divided their time between the palliative care and conventional units continued the more intensive habit of resource use despite palliative care's purportedly less aggressive interventional stance. Despite there being fewer "emergencies" on the palliative care unit, nurses found it hard to break the habit of bringing extra supplies with them when responding to patient calls. As a result, a large volume of unused medical supplies were disposed of on both the conventional and palliative care units. For example, following a patient's death on the palliative care unit, the room-cleaning process generated three 30-gallon bags of garbage. Two bags were filled with the waste of supplies used to treat the patient. The third bag was full of unopened supplies that had been brought into the room during an emergent situation, were not used, but were discarded because they were considered "contaminated."

In contrast, practices and policies converged to minimize supply use and waste generation at the hospice site. A nurse on the hospice unit said, "in hospice, we say there's no such thing as an emergency. Even though our patients are very ill and need very intense care, it's different from the care you would give in a hospital." As a result, hospice nurses were more likely to first assess a patient's situation and then retrieve supplies. For example, after the death of a hospice patient, a much smaller volume of waste (less than one 30-gallon garbage bag) was generated when the room was cleaned. Additionally, infection control policies on the hospice unit had evolved to designate a "clean" area in each patient room where any supply could be placed and, if unused, returned to the supply closet (a policy that was, in part, possible at the hospice facility because patient rooms were more spacious than in our other two sites).

We did, however, observe instances on the hospice unit when supplies met criteria for being "contaminated" by entering patient rooms without being

placed in the “clean” area, but rather than being disposed of, they were donated to a local nonprofit agency for distribution to medical centers in developing countries. Nurses often opened bags of adult diapers in patient rooms, and stored the unused portion of diapers in the room (not in the “clean” area) for later use. Any unused diapers that remained after the patient died or was discharged were picked up by the donation organization. This supply donation program diverted nearly one ton of medical supplies from the hospice’s waste stream each year, but raises an ethical dilemma concerning the trade-off between ecological impacts of waste disposal and potential health impacts of sending potentially contaminated materials to developing countries where health care systems are poorly resourced.

### *Drug Use and Administration*

Occupational exposures to chemotherapy on the conventional unit were exacerbated by two factors: institutional policies that endorsed chemotherapy preparation at the bedside, and nurses’ concerns that protective gear decreased patient satisfaction. A conventional unit pharmacist told us that, regarding IV chemotherapy delivery, “one of the most hazardous steps is actually the nurses attaching the tubing to the chemotherapy bag because you’re essentially poking a sharp object into the bag. So we’ve pushed for having that done in the hood in the central pharmacy where it’s a controlled setting and any spill would be contained and the technician always has protective gear on.” Instead, the institutional policy and practice was for nurses to prepare IV bags on the inpatient unit, which had resulted in a few spills that exposed nurses, patients, and housekeepers to the toxic agents. We learned from a unit pharmacist that the push for safer chemotherapy preparation had met with resistance because of the increased technical labor required for such a protocol.

Institutional policies were in place to protect nurses when handling IV chemotherapy by requiring them to wear certain protective equipment (e.g., chemotherapy-rated gowns and exam gloves), and recommending the use of other equipment (e.g., face masks). However, some nurses reported to us that they did not wear all of the recommended personal protective equipment out of concern for patient satisfaction. One nurse stated, “... the way the drug is administered can affect the way the patient feels about what you’re putting into their body... If you walk into the room with goggles and gown and mask, and they’re like okay this is what you’re putting in me and you can’t even come into contact with it?” Nurses’ concerns over patients’ psychological impacts from protective equipment have been reported

previously as a barrier to preventing occupational exposure to antineoplastic agents (Eisenberg, 2009), but ways to mitigate this barrier have received little attention in the literature.

### *Pharmaceutical Waste and Disposal*

In both the inpatient and in-home hospice settings, down-the-drain pharmaceutical disposal emerged as a way for the hospice institution to remain in compliance with Drug Enforcement Agency (DEA) regulations to prevent narcotic diversion (see [Office of National Drug Control Policy, 2009](#)). When asked about the potential impacts of flushing narcotics down the drain, a hospice pharmacist said, “The DEA scares us more than the EPA. They have guns and can put you in jail. The EPA might fine you.”

### *Cumulative Impacts and Decision-Making*

This section reports the social factors that prevent patients from transitioning to palliative care and hospice when medically appropriate and patient preferred. As stated above, previous studies have illustrated that the majority of patients (cancer patients, in particular) would prefer to die at home (Higginson & Sen-Gupta, 2000), but only a small portion actually do (National Center for Health Statistics, 2011). Our ethnographic data indicates five barriers that prevent patients from shifting from conventional care to less materially intensive modes of care.

First, clinicians reported that making a terminal diagnosis is difficult because prognostication is difficult. In reference to the Medicare hospice rule that requires physicians to certify that a patient may likely die within six months, one palliative care nurse practitioner stated, “When is end-of-life? When is six months?” Second, the goals of care within the conventional model make it difficult for physicians to see the value of transitioning to palliative options unless the patient is actively dying. A conventional physician who had recently received palliative care training illustrated this point by saying, “I think most health care providers don’t think of palliative care as a legitimate option for patients. It’s okay if you’re dying, but if you’re not dying the default pathway should always be toward life prolonging treatment.” As a result, participants reported that conventional physicians do not have conversations to determine patients’ goals of care and whether palliative care might be a good option.

Third, conventional physicians are not trained to discuss end-of-life goals with patients, so even though a patient may be appropriate for palliative care or qualify for hospice they may not realize they are terminally ill. According to a palliative care physician, conventional doctors, “won’t bother having this conversation with the patient. They’ll just refer [terminally ill patients] to me and let me have the conversation ... I worry that we’re not training [physicians] to have these conversations.” In addition, a hospice physician stated, “if you look at referrals to hospice I would guess there are pretty strong patterns of certain docs who do refer because they have more skill at having those conversations, they’re more comfortable saying this [curative] treatment is really not likely to help you and it may cause your quality of life to be worse as you go through the last few months of your life.” Fourth, even if a conventional physician is trained in end-of-life conversations there is a systemic lack of time for holding such discussions. An oncologist who had palliative care training stated, “If you have a patient who is actively getting chemotherapy for lung cancer, and it may be someone who is dying from their disease, there’s a lot you have to do to make sure it’s safe to give chemotherapy, to assess their ability to tolerate it, to dose it, to do all of that stuff. And if you have 20, 30 minutes with the patient, that’s going to take up the bulk of that time. And so you don’t have a lot of time to explore [their preferences].”

Finally, there is a general lack of understanding about palliative care and hospice which prevents patients from enrolling in these modes of care early enough in their disease progression to benefit from these options. According to a palliative care physician, “Patients almost universally don’t know what palliative care is ... I think practitioners have the same confusion – ‘you’re going to get my patient to forgo treatment?’ ... As opposed to really just having us try to provide options.” Another palliative care physician said that this model of care will, “always be considered part of the death squad but the reality is that we deal with anyone who has life limiting illness...where the goal is comfort and quality of life. I have patients who probably have years to live who are getting palliative care. So they’re not eligible for hospice, but they [are no longer interested in curative treatments].”

## CONCLUSION

Each of the three end-of-life medical models examined here had significant socioecological consequences resulting from medical supply and

pharmaceutical use that impacted local, regional, and global ecosystems through pollution and degradation from commodity chain life-cycle processes, and occupational and public health exposures to hazardous materials, many of which disproportionately affect disadvantaged social groups. However, the volume of material interventions used in each setting led to differences in cumulative socioecological impacts between the three sites. As expected, the conventional cancer care inpatient unit exhibited greater intensity of medical supply use, waste generation, and pharmaceutical administration than the palliative care and hospice units. The impacts of waste generation were higher than expected on the palliative care unit due to a combination of nursing culture and institutional infection control policies. Also surprisingly, pharmaceutical disposal practices surfaced as a problem in the in-home hospice setting where standard practice for in-home patients called for flushing all medications down-the-drain where they enter surface waters.

More importantly, our findings trace these differential impacts to the governance of institutional policies and practices that produce complex, and often contradictory, pressures to prioritize concerns about some types of adverse impacts over others. For example, institutional policies that required the disposal of unused medical supplies may have prevented the spread of infectious agents, but may also have disproportionately impacted communities located near manufacturing plants and hazardous waste facilities. Likewise, the donation program at the hospice facility decreased waste generation, but raises ethical concerns by sending potentially contaminated medical supplies to developing countries because they are unfit for use in the United States, but better than nothing for other communities. Similarly, down-the-drain pharmaceutical waste disposal allows health care facilities to comply with DEA drug diversion mandates but ignores the ecological impacts associated with such practices. Overall, our findings demonstrate the kinds of impacts resulting from complex institutional pressures, while also making institutional relationships and the assumptions behind them visible.

### *Policy Implications*

Many of the impacts identified here are the product of institutional policies and practices and are therefore amenable to change. At the broadest level, this chapter shows how the complex and often contradictory policies and regulations that health care settings are subject to lead to negative socioecological consequences because those actors that hold the most power

do not currently account for the ecological impacts of their mandates. In order to ensure more ecologically minded and broadly ethical quality clinical care, these regulatory and professional agencies need to begin accounting for the socioecological harms that result from clinical practices and decision-making, and coordinate the directives they issue to health care institutions.

In addition, our findings show that practices involved in the sourcing, use, and disposal of medical supplies and pharmaceuticals require particular concern for mitigating the socioecological impacts resulting from health care. The current invisibility of natural and human resources within the commodity chains that support health care raises the need for policies to develop appropriate measures to account for socioecological impacts.

Implications for end-of-life decision-making, in particular, revolve around developing standards and policies for transitioning patients out of materially intensive and ecologically damaging conventional medical settings, and into palliative care and hospice settings when medically and socially appropriate. The median length-of-stay that patients spend in hospice has consistently remained under one month, despite the fact that the Medicare hospice benefit is available for at least six months prior to death (National Hospice and Palliative Care Organization, 2005). Since the majority of patients would prefer to die at home, transitioning patients to less materially intensive settings when medically appropriate has the potential to honor patient preferences, decrease the economic costs of care, and decrease the cumulative ecological health impacts of care. One successful model that has the potential to support this transitioning is the concurrent provisioning of conventional curative care and palliative care, which helps identify patient preferences and gets patients into preferred settings earlier (Byock, Sheils Twohig, Merriman, & Collins, 2007). Policies that support such practices could serve to improve the patient experience of end-of-life care, lower the cumulative costs of care, and act as preventive measures for decreasing the ecological health impacts resulting from the material supply chains that support clinical care.

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