Ethical Considerations for Elderly Patients with Cutaneous Malignancy

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KEYWORDS

• Cutaneous malignancy • Care of elderly • Medical decision-making capacity
• Shared decision making • Palliative care • Narrative • Ethics

KEY POINTS

- In elders, changes in ability and function affect the entire circle of caregiving—within the family and the social support system of nursing facilities and community-based services. Medical decision making needs to consider these repercussions.
- The traditional principles of medical ethics (beneficence, nonmaleficence, autonomy, and justice) may not be sufficient to account for the issues facing the elderly patient with advanced skin cancers and their care givers. The ethical framework of narrative ethics can offer additional understanding and guidance.

INTRODUCTION

Cutaneous malignancy, particularly in elderly patients, poses unique challenges to explanation, understanding, and decision making. Skin cancers, for many patients, elderly or not, have become a regular part of life with preventive skin screening examinations, proactive ablation of small lesions, and biopsy-proven cancers that are easily treated. Lay understanding of most nonmelanoma skin cancers is that they are a minor nuisance that can be easily dealt with, sometimes with just an ointment.

When faced with a skin cancer that has become life threatening, patients are challenged to recalibrate their thinking and expectations. This is particularly true if the

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disease presents in an untreated nodal basin or recurs after well-tolerated treatment. Patients may have to come to terms with the fact that what has been previously treated in the office may now require general anesthesia, a hospital stay, or even life-changing surgery. For some, the introduction of a neck dissection or a parotidectomy seems like too much for a skin cancer. For patients facing more radical extirpations, such as a temporal bone resection or an orbital exenteration, it can be hard to make the mental transition that this is all necessary for a skin cancer. They may respond with denial or disproportionate fear, or they may be dealing with anger or decisional regret about prior treatments and decisions. Often the surgeon treating this patient and his or her care circle is coming into his or her skin cancer story, midway or more through, sometimes for the final and unwelcome chapters.[1,2]

Cutaneous malignancies of the head and neck, such as melanoma, Merkel cell carcinoma (MCC), and nonmelanoma skin cancer (NMSC) including basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), have long plagued the aging population. Indeed, the incidence of invasive melanoma and MCC increases with age.[3–8] In addition to NMSC, more aggressive disease likely portends more intensive treatment, and discussions about the risks and benefits of management options become even more important.[6] In addition to an increased risk of skin cancer, elderly patients may have different goals and expectations for their remaining life, treatment, and symptom burden. Their medical decision-making capacity and autonomy may also be more limited in some cases.[6,9] Management of elderly patients requires frequent and in-depth discussions of options and goals, shared decision making, and thoughtful application of clinical ethics.

BACKGROUND

The most traditional and commonly taught ethical framework in medicine is principlism, which states that medical decisions should be made according to 4 core principles:[10]

- Beneficence: provide or maximize benefit to the patient
- Nonmaleficence: avoid or minimize harm to the patient
- Autonomy: respect the patient's right to make decisions
- Justice: promote fairness in distribution of scarce resources and acknowledge competing needs, rights, and obligations

Many individual and cultural factors challenge the application of these principles in situations with unclear solutions or competing principles.[11]

Elderly patients with cutaneous malignancies and those who care for them can find themselves in such situations. Although independence and medical decision-making capacity can be preserved into extreme old age, there is a greater incidence of dependent living and diminished capacity as people age.[12,13] Elderly patients may already be reliant on the care of loved ones or custodial care providers, or they may be only 1 episode away from becoming so. Thus, any decision that has the potential to affect their level of function or dependence necessarily affects their circle of care. This term, "circle of care," acknowledges the reality that some patients rely primarily on loved ones who may not be legally related family or may be family of choice. Other patients rely on paid provision of medical/custodial care, and medical decisions require recognition of their resources and how changes in their clinical and cognitive condition may affect their eligibility for services that they find acceptable.[14–17] The special characteristics of elderly patients with cutaneous malignancy offer an opportunity to explore shared decision making using the framework of narrative ethics.

Narrative ethics focus on the role that stories play in creating identity and ordering one's moral universe. Both the act of telling a story, and hearing a story, create a context for making sense of a situation. For narrative ethicists, such as Rita Charon and Arthur Frank, this applies to an individual and his or her particular circumstances, but it is also influential on a broader scale, guiding and shaping the decisions of others who use stories as generalizable moral guides—stories with morals. The use of literature to study narrative ethics in medicine has largely focused on the illness narratives that patients and their loved ones tell to make sense of their experience of pathology.[18]

Arthur Frank famously characterized 3 illness narratives: restitution (being restored to normal); quest (a journey to a new normal); and chaos (life interrupted, without trajectory.)[19] Qualitative researchers have identified similar narratives in cancer survivors and have correlated the choice of narrative to quality-of-life outcomes.[20] Beyond the patient's experience of telling a story, there is the practitioner's experience of hearing or witnessing the story.[18,21,22] Howard Brody in his book, The Healer's Power, illustrated the role of the physician in helping to repair a patient's "broken story." Physicians and patients thus benefit from training in empathic listening.[23]

Going a step further, physicians themselves are responsible for generating stories in how they explain diagnoses, treatment options, and possible outcomes to patients.[24,25] Every surgeon has had the experience of presenting information to a patient and having the patient lean toward a decision the physician does not think is in the patient's best interest, and feeling the need to explain it better, or differently. Whether physicians are aware of it or not, they have a long experience of developing narrative competence, or presenting information in a way that achieves a desired outcome. That outcome can be as generous as helping a patient achieve his or her own stated goals or as paternalistic as imposing what the physician thinks is the right decision.[26,27]

Describing options and their ramifications is an essential part of the decision-making and informed consent processes. These descriptions, however, are not value free, particularly when attempting to portray the natural progression of cancer. Palliative interventions are sometimes proposed to relieve a current symptom but can also be advocated to prevent predictable future suffering. Describing the possibility of imagined but not yet experienced suffering can be emotionally fraught for both patient and surgeon.[28,29]

The following cases will address some issues unique to elderly patients with cutaneous malignancy and the ethical resources that can be used to face them, focusing on eliciting goals and values and helping patients and their care circle make goal-concordant decisions.

CASE STUDIES

Case 1

An 87-year-old man underwent conservative excision of a 2 cm full-thickness cSCC of the scalp with rotational flap reconstruction 5 years ago, followed by radiation. Three years later, he returned with 2 full-thickness, ulcerative scalp defects with exposed calvarium (**Fig. 1**A, B) and biopsies returned with recurrent cSCC. He was denied treatment by his previous surgeon given his age and frailty. Since that time, he has experienced significant increases in pain with frequent bleeding from these sites, prompting him to stop his antiplatelet therapy that he takes for his mechanical valve replacement. He now presents to the clinic.

After much discussion, the patient elects to undergo excision of the scalp cSCC with free flap reconstruction. He has an uneventful postoperative hospitalization and

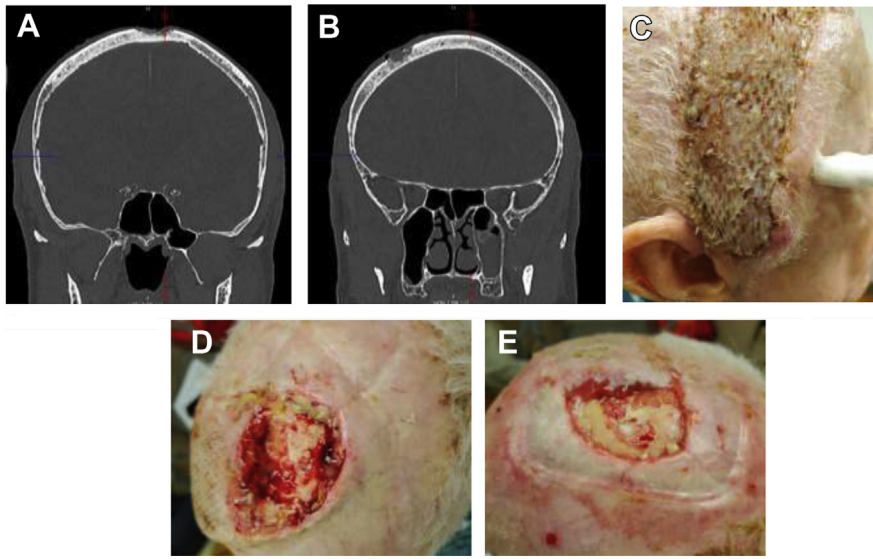

Fig. 1. (*A–E*): Case 1. (*A*): Coronal computed tomography (CT) scan showing midline soft tissue and bone defect resulting from chronic wound. (*B*): Coronal CT scan showing right lateral erosive soft tissue and bone lesion resulting from cutaneous squamous cell carcinoma. (*C*): 2-week postoperative photograph of well-healed right lateral scalp reconstruction with a latissimus dorsi free flap. (*D*): 2-week postoperative photograph of distal flap necrosis at scalp vertex. (*E*): 2-month postoperative photo of full-thickness distal tip flap necrosis with exposed calvarial bone.

is discharged to a skilled nursing facility to assist with wound care. At his 2-week postoperative visit, partial flap loss is noticed at the distal tip (Fig. 1C). He and his family are shown more complex wound management techniques that require dressing changes multiple times per day. After 2 months, he has full-thickness loss of the distal flap with exposed bone (Fig. 1D–E). Additional reconstructive surgery is offered, but the patient declines, stating that he prefers to "not go through that whole ordeal again" given his improved pain control and bleeding (see Fig. 1A–E).

Discussion

Elderly patients are often not treated aggressively for advanced cutaneous malignancies.[30] One can wonder if this patient was initially not offered guideline-based curative surgical treatment in an attempt to uphold the principle of nonmaleficence, despite it being well established that age alone is not a contraindication for curative treatment for cutaneous malignancies.[31] Because few elderly patients are included in studies and clinical trials because of age limitations within inclusion criteria, even fewer data exist to guide management algorithms in this age group.[32] In this instance, classic ethical thinking of nonmaleficence alone may not be sufficient.

After he did receive definitive treatment, the patient has what most physicians would consider a successful surgery, in that he developed no major or minor complications, and clear tumor margins were obtained. Additionally, he experienced relief of symptoms and had a relatively short convalescence for a major surgical procedure. He does, however, have a wound with exposed calvarium requiring chronic attention and long-term care. Although more reconstructive surgery has been offered, the

patient refused; from his perspective, the original goals of stopping chronic bleeding and relieving pain have been met, and he wishes to avoid further surgery.

In such a case, the surgeon may be tempted to persuade the patient to complete the second reconstructive surgery. With such a recent, extensive surgery, it perhaps seems counterintuitive to leave such a chronic wound untreated, but this is where narrative ethics may be used as a guide. Listening to this patient's story is key to understanding and guiding medical decision making, perhaps at times against the physician's own goals or wishes. On further discussion with this patient, for example, he divulges that his wife of 65 years has an end-stage cancer diagnosis of her own, and he feels he cannot risk another hospitalization and stay at a nursing facility under these circumstances. In meeting patients within their narrative story and engaging in authentic discussion, one may allow both parties to understand more clearly what is at stake and reach decisions together.

Case 2

A 72-year-old woman presents to the clinic with a chief complaint of double vision for 2 months. She has a large, 12 × 15 cm fungating lesion of the forehead; biopsy confirms BCC. On further questioning, she states that the spot has been on her forehead for a few years and got a little bigger recently. She lives in a rural area and takes care of her 94-year-old father, who has Alzheimer disease; she has 1 estranged sister who lives across the country. The surgeon advises the patient that surgery would require removing her eye and a part of her face and replacing it with tissue from her leg. Even though it would be a big operation, it could potentially provide a durable cure. In counseling, she is shown photographs of an identical operation to help in understanding the process, and outcomes (Fig. 2A–E).

When asked to restate the goals for surgery in her own words, she states that, "I would like the bump removed so I can see better to take care of my father." She also insists that the surgery be performed as an outpatient with no general anesthesia because, "my dad had general anesthesia years ago for heart surgery and that's what gave him Alzheimer's." Given concerns about the patient's medical decision-making capacity, you call the patient's sister to discuss the next steps in management of both the patient, and her father.

Discussion

As discussed previously, a head and neck surgeon is often entering a pre-existing narrative for an elderly patient with an advanced cutaneous malignancy. The ability to hear and empathically respond to the patient's prior history and beliefs about current condition is important and helps frame the next steps in the discussion. In addition to eliciting the goals and values of the patient and his or her care circle, the physician then must consider how to craft his or her own story about what the immediate future may hold. For elderly patients, this story will need to include multiple possible outcomes and may utilize a scenario-planning decision tool such as the "Best Case-Worst Case" tool developed by vascular surgeon and bioethicist, Margaret Schwarze.[33,34]

In this case, multiple factors must be considered during care discussions, including the establishment of decision-making capacity and a surrogate decision maker (the sister), coordination of care for both the patient and her father, and management of disease at an advanced stage. For this patient, the best case scenario would be an uncomplicated surgery with a well healed flap. Although hedgehog inhibitors should be discussed as an option for eye preservation, this patient's desire for quick recovery and return to her father, as well as her prior delay in seeking care with concerns for

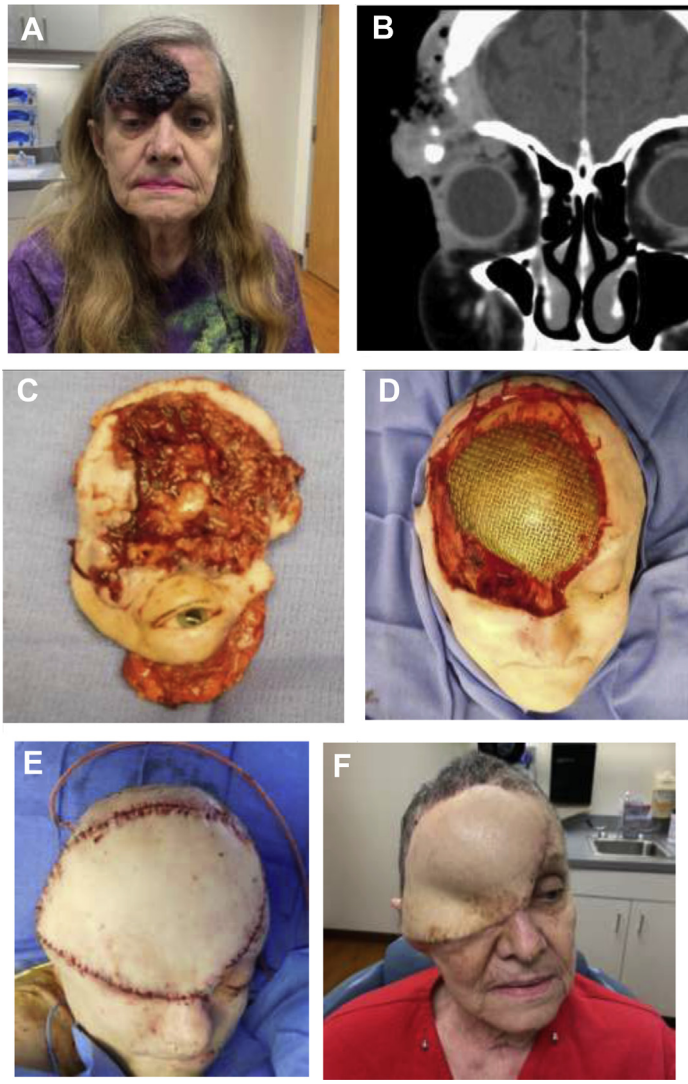

Fig. 2. (*A–F*): Case 2. (*A*): Image of a large, locally invasive basal cell carcinoma of the right forehead and brow. (*B*): Coronal image depicting the aggressive nature of the tumor. Bone destruction is noted, as well as intracranial and intraorbital invasion of tumor. (*C*): Surgical specimen clearly showing orbital exenteration as a component of the removed tumor. (*D*): Surgical reconstruction showing titanium mesh over the resected calvarial bone. (*E*): Soft tissue reconstruction with a large anterolateral thigh free flap. (*F*): 2-month postoperative photograph of the patient. (*Courtesy of* Peter Dziegielewski, MD, Gainesville, FL.)

medical decision-making capacity, may make definitive surgical management the better choice in this complicated case. Her father will likely require placement in a nursing facility during her hospitalization, and it is possible that both she and her father will require custodial care. Additionally, the failure of her sister to help with their father in the past may make the patient wary of relying on her for her own care or decision making, even if it is appropriate. By reframing the story of her acute problem to a

more holistic view of the care needs of both her father and herself, she may be able to pursue what Arthur Frank would call a quest narrative to a new normal, where she and her father may be able to reside in the same facility with mutual assistance.

SUMMARY

Ethical considerations in a certain disease in the aging population begs the questions: How is this different from general medical ethics for all patients, with all diseases? And Is there something unique about elderly patients with cutaneous malignancy that requires specific ethical considerations? This article has argued that yes, this disease in these patients poses ethical challenges that are better met by a relational ethical framework such as narrative ethics, which can enrich traditional ethical principlism.

There are, of course, more universal, general ethical considerations that also apply. These are perhaps best summed up by the questions: What is too much?, What is too little?, and Who decides? Specifically, this article has looked at a case of a patient who made age-based decisions for conservative care and had to pay the price of progressive disease at a later more fragile state and have grappled with the social and cultural challenges surrounding the care of a partially capacitated patient.

Some cutaneous malignancies threaten to be life limiting even at the time of diagnosis, such as MCC, melanoma, and cancers in immunosuppressed patients. For many patients, however, skin cancer is not understood to be potentially fatal. When it is, or when it threatens to be so, it can shake one's understanding of life and health. An analogy may be a refractory decubitus ulcer at the end of life; physicians push nutrition and wound care, but, in truth, this is an organ failure as much as heart or kidney or lung failure. It is an unfixable problem that portends approaching death.[35] When skin cancers break their polite social boundaries and become invasive, disfiguring, or regionally or distantly metastatic, they too are announcing the failure of the body's largest organ. These 2 cases have illustrated the use of narrative to help guide the process of shared decision making.

CLINICS CARE POINTS

- Patients and their families make decisions based on the information physicians give them, and they understand that information in the context of their existing identity and narrative. Considerable care must be taken to be comprehensible, compassionate, and fair in descriptions of the outcomes of treatments ranging from extensive surgery to supportive care.
- A palliative approach to patient care attends to the whole caregiving circle that encompasses the patient. Decisions that will result in dependence or change in caregiving needs affect more than just an autonomous individual, and those considerations are ethically valid and morally essential.

DISCLOSURE

The authors have nothing to disclose.

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