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Acute Care of the Elderly Column




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Intervening in uncertainty

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As acute and critical care nurses caring for older people, we hear expressions of uncertainty many times each day. “Will I die?” is a common concern from patients, phrased as “Will they die?” by family and friends, is far different from the declaration of certainty “I am going to die.” For some of us, responding to the ‘will I die?’ question feels scary and burdensome, especially early in our careers. We wonder if the question requires us to disclose diagnosis, discuss prognosis, and more as we respond.

Other expressions of uncertainty may elicit less anxiety for us as nurses but are equally consequential for our patients. In fact, pressures of hospitalization today – high acuity, short length of stay, and system complexity – make uncertainty an almost constant element in caring for older patients. The less dramatic statements of uncertainty are nonetheless challenging to field. These questions often begin with ‘will’ or ‘how’ and entail worries about recovery, function, and returning home as well as balancing needed support with a sense of independence.

Informal caregivers – family, friends, and others – commonly struggle with uncertainty too. Their concerns may represent what they believe the older person for whom they care fears. Alternatively, they may express fears of their own including escalating demands for their caregiving, their own health worries, or a generally rising sense of burden. Older patients and their caregivers sometimes share concerns. Importantly, perceptions of symptoms, treatment, and prognosis among these patients and their family caregivers may differ significantly.

Expressions of uncertainty typically elicit reflexive efforts to reassure and comfort. Empathizing with such concerns about life after hospitalization is easy; our own perspectives on loss and change come quickly to mind and we seek to reassure and comfort. Critically, an impulse to ease uncertainty and create greater comfort may be ineffective. Shifting our perspective toward understanding what the expression of uncertainty entails offers greater benefit to patients and their caregivers. We may or may not be able to diminish the uncertainty but we are able to educate, counsel, coach, and refer once we understand the source of what our patients express as uncertainty.

Older people and their family caregivers interact directly with nurse practitioners and physicians on matters of uncertainty. Ambiguity in medical decision-making, generated by inadequate evidence or disproportionate complexity, is commonly called out by providers.[1] Yet patients are often unaware of what exactly is ambiguous in decisions about their care unless their provider discusses it with them. Far more often uncertainty arises for patients in relation to prognosis. Here again, lay people are generally unaware of actual prognostic accuracy, imagining providers able to predict life span within days to weeks. In truth, the frame is far larger with some studies examining precision within time frames as broad as months or one year.[2] Debates over disclosing diagnoses to older people, often substantiated with claims about protecting frail elders and preserving hope, add even more uncertainty to interactions among older people, their family caregivers, and their providers.

Today, more than ever before, hospitalization represents a crucible for uncertainty. Even well planned elective admissions are frequently challenging to navigate. Acuity escalates as treatment options multiply, often without clear evidence for risk and benefit, making choices complicated at best for older people and their families. Acuity encompasses severity of illness along with frailty and multimorbidity. The intersection of acuity, diagnostic and treatment options, and resultant demands for patient and family decisions generates situations where nurses must act ethically to educate, counsel, coach, and refer. The pace of acute care alone may limit our efforts and alter perceptions of success in approaching the topic of

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uncertainty with patients and caregivers. Thus, just how to intervene compassionately and effectively presents a significant challenge.

Caring for older people during general or intensive care hospital admissions typically places nurses in the midst of conversations about uncertainty. We field questions from patients and their families, facilitate conversations between them and their nurse practitioner and physician providers, and respond to the varied manifestations of distress, such as anxiety, frustration, and anger, that uncertainty begets. Typically, we respond but often find that the many different dimensions and contexts in which uncertainty occurs may quickly block or obscure our efforts. In the end, we may stand by, observing as uncertainty persists while our patients and their families find little information and limited support.

Uncertainty is a complex human phenomenon, common during experiences of serious illness and injury as well as frailty and multimorbidity in later life. The sense of uncertainty holds a clear place in nursing theory though perhaps less so in practice. We lack a robust repertoire of approaches informed by theory and interventions guided by evidence. The absence of consensus around meaning and experience along with application of relevant theory contributes to the vagueness uncertainty holds in clinical practice. Nursing's pursuit of understanding uncertainty is longstanding, spanning at least four decades of theorizing and investigation.

In the 1980′s, Mishel introduced her theory of uncertainty in illness, explicating concepts of stimuli, cognition, danger, opportunity, and appraisal as necessary to coping for adaptation.[3] Instrument development in the theory of uncertainty in illness identified the dimensions of ambiguity, complexity, deficient information, and unpredictability.[4] These dimensions resonate with nursing practice, identifying areas in which we aim for alleviation (e.g. ambiguity and information) or validation (e.g. complexity and unpredictability). Clinical value also exists in reflecting the juxtaposition of danger and opportunity under circumstances where perception of illness and events like hospitalization shift circumstances. Shifting circumstances demand new coping in order to adapt to change, minimizing danger and optimizing opportunity.

More recently, Han and colleagues synthesized a conceptual taxonomy useful for expanding clinical understanding and intervening in uncertainty.[1] This taxonomy of uncertainty first exposes the sources of this human experience. The three main sources are probability, ambiguity, and complexity. Each clearly manifests differently in illness, injury, and healthcare. Probability largely entails issues of outcome. Ambiguity is far more pervasive and involves extent of information, issues of opinion and conflict, as well as potential benefit. Finally, complexity, a source of uncertainty important for most frail elders, reflects the multiplicity of factors radiating influence over an elder's health situation.

Han and colleagues link these sources of uncertainty to a categorization of this ubiquitous human experience. The three categories – scientific involving data, practical entailing issues of systems, and personal regarding psychosocial and existential matters – may reflect any or all of the sources. Han and colleagues further argue that these categories exist on a continuum spanning considerations from focused on disease management to those centered on the patient, or more inclusively, person.[1] Critically, nurses hold an important place in healthcare from which to address the categories of the practical and the person in uncertainty. Personal and systems issues lie at the core of nursing expertise, suggesting opportunity to refine assessment and improve interventions to acknowledge, clarify, and limit uncertainty where the elder's health status and personal situation allow.

Communication lies at the heart of intervening in uncertainty. Han and colleagues[1] focused on medical decision making and care in their conceptual taxonomy, drawing on theoretical work done by Mishel in nursing as well as that completed by scholars from other disciplines. Their work corresponds to Mishel's classic work, highlighting ambiguity and complexity, and calling out the role information plays in generating or in diminishing uncertainty. Communication clarifies the source of uncertainty and leverages available information to resolve, validate, or redirect. Speaking about their findings into the specific context of disclosing advanced cancer diagnosis for Taiwanese elders, Tang and colleagues[5] eloquently highlight the power of communication in addressing uncertainty with elders. They say, "…patients need honesty and support while trying to make important (final) life choices, a conspiracy of silence may envelop them and hinder adjustments."[5](p. 365) (parentheses added).

Communication and exchange of information, where the health of an older person is concerned, is very often an emotionally and culturally charged matter. Social status, such as that held by physicians; cultural precepts, including filial piety or respect for elders; relational power, including that between provider and patient as well as between older patient and caregiver; and organizational norms, like those guiding disclosure of information interweave to create a complicated landscape. Within that landscape, older patient, family, and clinicians hold different information and perceive its exchange differently. In a phenomenology of elders' experiences of hospitalization, van der Meide and colleagues[6] found that these patients may feel left behind, restricted by systems and people in the hospital, and cut off from their daily life. The extent to which practical issues like hospital processes as well as personal factors such as information sharing between caregiver and patient shape uncertainty is often substantial. We, as nurses, hold positive power and professional accountability to recognize, classify, and then assess and intervene in these circumstances.

Moving forward with communication in uncertainty, both Mishel[3,4,7] and Han and colleagues[1] offer foundations and direction. Foremost, determining where uncertainty exists is key. Behavioral responses to uncertainty, including anxiety, frustration, and anger, are commonly diffuse and not specifically tied by patients to a single cause. Moreover, fending off seemingly personal assaults that result from these emotions – like expressions of anger directed at us – are tough to endure. Some patients and caregivers may share insight and say, "I am anxious because I do not know my chances of returning home", for example, but most others are able only to say or show how they feel. To say 'everything feels scary/constraining/threatening and this is why' is far more difficult given the existential and personal distress that hospitalization likely elicits. Detecting the origin of specific behaviors is an important first step in intervening in uncertainty.

Recognizing the source of uncertainty, having determined that uncertainty is generating an emotional or spiritual response helps outline options for our actions. Uncertainty related to probability – 'what are my chances, doc?' – when compared with that stemming from ambiguity and complexity – 'what does discharge to a skilled nursing facility mean?' – feels more straightforward, at least in the biomedical paradigm. Helping older people and their families to understand the limits of prognosis often echoes to the clarity actually receiving a diagnosis often brings. The clarity of hearing a diagnosis or prognosis may evaporate in the face of more 'what now?' questions. Coaching to understand diagnosis, as the beginning of a new journey in healthcare, and prognosis, as an estimate and not a guarantee, is a good starting point for many.

Intervening in ambiguity is often a matter of determining who holds what information. Careful assessment may reveal more of what information the patient and family possess, whether they received it in an understandable way, and if discord about the information, who should have it, and why it exists. A number of studies point to the erroneous assumption that families are successful in choosing to withhold diagnostic and health information from their elders.[5,8] Moreover, the belief that withholding information preserves hope and avoids existential or spiritual distress lacks convincing evidence

to support acting on these beliefs, without further exploration, in today's healthcare systems.[9] Sensitively negotiated facilitation of family conversations, often in collaboration with providers along with social work and chaplain colleagues, may help resolve some uncertainty arising from this source of ambiguity.

Addressing complexity frequently proves more challenging and commonly frustrating than tackling ambiguity. System barriers and inadequate processes may exacerbate the primary source of uncertainty, escalating a sense that even less control than medical probability suggests exists. Sifting through where complexity begins, which systems issues are at play, and where potential support lies takes time and many conversations. Here, perhaps more than in other sorts of uncertainty, teamwork, collaboration, and coordination become essential. Social work colleagues become primary allies. They understand existential dimensions of complexity in uncertainty while bringing an approach focused on elder and family strengths, in lieu of problem-focused biomedical approaches.

Take a moment to reflect on the sources and categories of uncertainty when next you hear or see it expressed by a patient and their family. Sorting through what their uncertainty is about is likely to help limit their distress by giving you options to intervene. Communication and information are frequently essential components of mitigating uncertainty that involves personal and systems issues. Focusing your communication to determine what information they require grounds plans for emotional support, tools for coping and adaptation, targeted interdisciplinary referrals, individualized education, and community resource connections. Magically resolving uncertainty about health, function, and independence is never possible. However, applying relevant theory and evidence to better assess and intervene in uncertainty helps everyone involved feel a greater sense of choice, engagement, and possibility.

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