

The Dying Experience at Home and the Hospice Care Organization: A Cast of Nurses, Family Members, and the Patient

**Maximiliano Mendieta
University of Michigan at Flint**

This study aims to understand how individuals cope with a family member entering hospice care, how role dynamics and the formation of meaning reveal insights about the process of death, and how dying relates to the hospice organization, hospice administrators, managers, and supervisors, the patient, and surviving family members. The axioms of symbolic interactionism provide both a useful framework and the theoretical insight for healthcare administrators and researchers to better understand the relationship between the organization, patient outcomes, and the death and dying experience of families while moving management theory towards a patient-centered perspective.

INTRODUCTION

Symbolic interactionism provides a methodology that connects language to action as individuals communicate verbally and then take action. Language and action in hospice care at home provide data that can be captured by field observations and recorded interviews. The roles and symbolic interactionism frameworks can inform end of life and hospice care research by shedding light on an area considered part of the black box that is the hospice care setting.

These frameworks can start moving hospice care research past the black box of the hospice setting by outlining the roles that emerge and the different interactions that occur during hospice care. Next is the theoretical framework, followed by the study section where the setting, method, analysis, and emerging themes are explained. The paper continues to the discussion section, where the role and symbolic interactionism theoretical frameworks are applied to the study, and ends with the conclusion section.

Theoretical Framework

This qualitative study is rooted in role theory's symbolic interactionism (Blumer, 1969). The three theoretical premises of Blumer's symbolic interactionism posit that 1) humans act toward things based on their assigned meanings 2) such meanings are acquired through social interactions between individuals and 3) meanings are altered through an interpretative process within the minds of the participants (p. 2).

For Blumer, meaning is derived through social interaction and is the result of an interpretative process. The interpretative process requires that the individual communicate with himself. It is during this communication that the individual "selects, checks, suspends, regroupes and transforms the meanings in the light of the situation in which he is placed and the direction of his action" (Blumer, 1969, p. 5). Interpretation is not the result of selecting predefined meanings, but the result of a formative process where meaning undergoes use and constant revision.

Analysis of the action taken by individuals after engaging in an interpretative process (Blumer, 1969) can shed light on the roles and subroles (Emanuel, Bennett, & Richardson, 2007) they occupy during the dying experience in hospice care. Also, this methodology allows for the opportunity to draw meaning from the verbal exchanges and actions taken as the actors occupy temporal roles. The analysis framework employed here is rooted in the premise that roles and subroles are the result of thought processes otherwise difficult, if not impossible, to derive under experimental conditions.

Symbolic Interaction in Healthcare

The symbolic interactionism literature includes a few empirical cases in health care. This gap represents an opportunity for the study presented in this paper. Following is an assessment of the literature in symbolic interactionism. In a study of geriatric patients in the nursing home setting, Gubrium (1980) focused on the strategic interaction between the clinical staff and the patients. The study applied interaction as a label and concluded that “strategic interaction”, as a concept of planned actions and scripts, benefitted the staff as well as the patient by promoting collaboration and inclusion

In emergency care, the survival of a patient depends largely on the communication between the paramedic and the emergency room nurse (Mellinger, 1994). The communication is characterized as a “give-and-take” process in which the nurse and paramedic exchange information, collaborate and agree on a course of action. This process can be equated to bargaining activities as meaning is derived before action can be taken (Mellinger, 1994, p. 179).

This pattern of communication establishes a “turn-by-turn” interaction and meaning formation, resulting in a sequential structure that guides the negotiation between two health care professionals. In this sense, Mellinger (1994) is similar to Blumer’s *meaning* and *interaction* principles. However, Mellinger (1994) pursues a negotiated order framework—a mechanistic view—rather than the principle of *interpretation* simplifying what in practice is a complex and dynamic process of meaning formation and action.

The interaction between individuals updates meaning according to a specific situation, and that meaning is interpreted within the mind of the participants (Blumer, 1969). The constant process of cognitive evolution reflected in meanings is what facilitates communication. In the past, the culture in the operating room was driven solely by the skill of the surgeon and the supreme role vested in their position. Nurses and other medical personnel followed short and specific instructions given by the surgeon, thus excluding *interaction* and *interpretation*. This model worked well during routine procedures, but failed when surgical complications emerged. During complications, two-way communication became the norm in an environment driven by the authoritative role of the surgeon (Bezemer, Murtagh, Cope, Kress, & Kneebone, 2011).

Contemporary medicine has started to move towards a model that values communication, a nontechnical skill, as much as it values the technical skills of the surgeon. The symbolic interactionist perspective applied in Bezemer et al. (2011) is a first step in recognizing that communication in medicine is likely to affect the safety of patients, the quality of care, and efficiency of the health care system. However, it does not explain how communication occurs within a group.

Hospice has a basic meaning that changes through interaction and a given situation. For example, in a study of two hospices with different philosophies regarding the role of the volunteer caregivers, Baugher (2008) found that the dying experience of the terminally ill patient was influenced by how the role of the caregiver was defined. In the first hospice, caregivers were trained to conform to a static-self role, modeled to promote life review and listening without judgment. In this case, the caregiver role did not include *interaction* and *interpretation*. The second hospice was centered on the Buddhist principle of mindfulness, which promotes living in the moment. Caregivers give their patients their total focus and are not distracted by unrelated thoughts of past or future events.

The caregivers in the first hospice reported having difficulties listening and talking with the dying patients about their feelings and fears. This is because isolating *meaning* from *interaction* and *interpretation* is counterintuitive to the goals of hospice care of compassion, dignity, inclusion, and self-determination. On the other hand, the second hospice Baugher (2008) parallels Blumer’s principles of

meaning, interaction, and interpretation. In the hospice organization, organizational factors and individual actions can be considered as interrelated, which within the evidence-based practice and health outcomes context is characterized as a relation that is not clear (Rivard & Katz-Navon, 2014).

When considering the organizational culture within Veterans Health Administration hospitals as control-oriented, Rivard & Katz-Navon (2014) further conceptualized the control-oriented culture as bureaucratic culture and production culture. The authors concluded that the bureaucratic culture was associated with lower mortality when compared to the increased mortality of the production culture. This new-found association not only supports the posits discussed in this paper, but establishes a theoretical foundation for pursuing research to better understand how organizations and the individuals within the organization affect the outcomes of the patients in their care.

METHODOLOGY

The Study

The Setting

The patient's home is the most common venue for hospice care in the United States, not only because patients prefer to die in their homes, but also because Medicare benefits are inclusive when hospice provides care in the patient's home (Pritchard et al., 1998). The hospice care experience is a very intimate one as nurses enter your home, become part of your daily life, and eventually may even be considered a family member.

Gathering Insight

The study follows a behavioral approach in order to capture the richness of roles that develop during this trying time for a family. This study, though a single case, provides insight and awareness of the language, behaviors, and actions that take place during hospice care at home. This insight can contribute to future research projects as it offers a glimpse to the backstage of hospice care.

Field Observations

I gained access to the family home setting of an actual hospice patient, as I was an extended family member of the patient. The potential bias of being an emotionally vested insider was outweighed by the tradeoff of gaining a first-hand account of a patient and family that was entering hospice care. I gained access to the admissions "process," the first "family meeting," daily interactions between family members and the staff, family members' interactions with one another, staff interaction with one another, and the resulting interaction of me being there.

The Interviews

Interviews were conducted with several informants including a hospice admission nurse (Nicole), a family caregiver (Amy) and a family member (Ann). Ad-hoc interviews were conducted with the case manager (Linda), nurse (Jessica) and home health aide (Ashley)¹. In total, three semi-structured and three ad-hoc interviews were conducted during a period of three months. Medical informants were asked to share their experiences as they interacted with family members and patients during hospice admissions, everyday hospice care, and hospice operations. The admission hospice nurse (Nicole) stated, "I've been told by my friends to write these down, but I haven't."

Nicole was interviewed in her office at Sunrise Hospice, where she seemed comfortable and at ease. Interview questions included, "Tell me if you can, memory wise, recall your first admission or the admission that you remember the most. I am thinking of a typical situation that you had that comes to mind in which the family dynamics of a hospice patient has become a vivid memory for you. What comes to mind right off?" And as immediate follow-up I stated, "Feel free to be as graphic as you need, that is exactly the kind of knowledge we want to get from you." Nicole's physical and verbal response was:

(Laughter, giggles) Children arguing over the deathbed, literally as the mother is dying. That is pretty vivid don't you think? (Laughter, giggles). It was a very tense household, there were multiple children, and clearly a history of issues, between the children, people can change the mood for these things, the way they've lived their lives and because a family member is sick and dying does not make everyone (laughter, giggle) behave.

Analysis

The interviews were recorded using a digital recorder and a digital transcription program was used to transcribe the wave file. Each interview and field observation was analyzed manually using the grounded analysis method of Strauss and Corbin (1998) and merged with Herbert Blumer's conceptualization of symbolic interactionism (1969).

DISCUSSION

Themes Emerging from the Data

According to the three axiomatic premises of symbolic interactionism, all objects have a given meaning which is an important component of human action, the meaning we assign to objects results from interacting with other individuals, and the meaning resulting from interaction is interpreted by each individual (Blumer, 1969).

Hospice care at home lends itself to be viewed from the sociological perspective of dramaturgy, which views everyday life as theater with actors, scripts, and interactions. The implied role of the physician affected the everyday lives of the patient, family caregivers, paid caregivers, home health aides, and case manager. This paper theorizes that similarly to physicians, the administrators, managers, and supervisors of hospice organizations impact (Rivard & Katz-Navon, 2014) the death and dying experience while pursuing the managerial and operational responsibilities outlined by government regulation, organizational directives, professional associations, facility culture, and career goals.

I posit that family relatives not only fragment along family lines (family and in-laws), but also take "camping out" positions throughout the hospice home based on their acceptance or disapproval of the prognosis of imminent death and their perceptions from interactions with clinical, administrative and volunteer hospice personnel. While the hospice organization providing hospice care at home may have an agreed upon synergistic message and culture, the message or dying experience provided breaks down as personnel interact one-on-one with the dying patient and the surviving family. Through its personnel, it is here where the organization impacts the dying experience, whether it be through the synergistic message or by the human dynamics of caring for end of life patients and their families.

Control

The day started early, with the patient being fed and medications administered by 7:00 a.m. This routine did not vary unless the patient was nauseated. The physician's office was called regularly to address "curative" measures for bedsores, "hallucinations" (dementia), and "emotional" outbursts. The hospice case manager had medications "to manage the pain," but the physician had to authorize and prescribe any medication that treated a condition.

The wife had a large role, as she was legally responsible for all the medical decisions about her husband, the dying patient. Metaphorically, a ballet of actors assembled around the wife when she arrived from work every day as each dancer (actor) took turn reporting their contact with the patient throughout the day and any significant events.

You Are Dismissed

Physicians in American society enjoy a position of prestige and separation above the rest. The relationship with physicians is formed through our childhood as vaccinations, yearly visits and physicals are the norm. Also, the expectation of "curative" infallibility attributed to physicians contributes to the role of hope vested in them. This is in line with role theory and the role expected of the physician as the

result of personal, societal, and cultural norms and expectations. This was best illustrated through the narrative of the admission nurse (Nicole):

I recall that the patient was a relatively young man who had young children, and had pancreatic cancer, which typically goes very quickly, often a far advanced diagnosis, there are not a lot of treatment options. They were interested at looking at treatment options, and the physician was essentially saying there is no treatment for you, nothing to be done. That kind of dismissive quality is what they really took offense to.

Patients expect the physician to always provide “treatment options” even when facing hospice care. This sense of entitlement for a cure is perpetuated by Medicare’s requirement for the physician (the gatekeeper) to issue the “certification” of hospice care, which also ushers the physician into the hospice setting. This implicit, yet active, role in absentia was best described by one of the family caregivers (Amy):

...if the hospice feels the patient needs medication for this or that, they will contact them if they need to, but it’s several days before the doctor even gets back to them. So luckily, according to the nurse, they have a number of drugs they can get filled, a standing order, for pain medication only. According to her, once the doctor refers the patient to hospice they are pretty much done.

The relationship with a physician is one that, in most cases, is characterized by loyalty, intimacy, and reverence. Do we really want an expert in life and “hope” in charge of our death? The whole mission of hospice is to ease the patient into the late stages of life, but in their mission for “a good death” and “comfort measures,” hospice made compromises that perpetuate the physician’s role of supremacy.

The physician’s role in absentia seems to interfere with the natural process of death as patients and their families use hospice for continued access to their physician. I conclude that the physician role overburdens the interaction (role) of the different actors, but also the “role-taking” dynamic of human interaction. I equate “role-taking” to an overload of static in the process of human communications that short-circuits other interactions that could be more productive for the patient and the families if the physician role was not present. The physician role eclipses not only the “palliative” roles of hospice, which are already subordinated by Medicare’s mandate, but supersedes the role of spouses, caregivers, and family members.

Ultimate Judgments and Decisions

By the time a family member enters hospice care, a hierarchy of authority has been established. I observed that the wife played several roles in the “dying experience” of her husband. She went to work every day as the sole provider, made sure all medications were sorted for dispensing, “called in” for refills of prescriptions, prepared evening meals and provided care throughout the night. The caregiver role during the night was one that required “turning” the patient to avoid bedsores, preparing a snack in the middle of the night so “meds” could be taken, “checking” her husband for urine, and staying up with her husband when he had “hallucinations.”

According to Turner (1962), this “superordinate” role is inadvertent to the patient, but was very evident to others in the household when hospice asked during the admissions process if a “living will” and “medical power of attorney” existed. These documents not only established that the wife was legally the person in charge of making all decisions of care, but was at the top of any other hierarchies in the house. This was best exemplified by the hospice admission nurse (Nicole):

A long stand-in caregiver like that...are more skeptical and also more controlling, they have been in control for so long and they don’t readily relinquish that role, ... there can be some tension.

The law empowered the wife and patient as the rulers of the hierarchy and established hospice's role as an advocate for the patient and advocacy within the family unit. But how can we set aside our responsibility to our siblings or parents? How can a spouse overwrite the authority of the bloodline? The language used by hospice--"have been in control," "always the decisionmaker," "usurp," "tension," and "being in that role"-- implies the existence of a hierarchy and the conflicts that arise from that system of organization when other family members enter the household.

Caring for the patient throughout the day by in-laws was welcomed as long as it did not challenge the control of the wife. One informant (Amy), a temporal family caregiver, participated in daily care activities that included preparing meals for the patient (her brother), administering "meds," "checking for fever," and "making sure" the patient was re-positioned often in the hospital bed. These activities were crucial for the care and comfort of the patient and Amy's contribution was appreciated, but her role was subordinated to the wife, her sister-in-law. Amy best responded to this issue when she said:

Since I am not the primary caregiver, I am a sister, the wife gets to make all the judgments regarding his care and I don't really want to step on her toes, it's hard enough for her as it is. ... but I have been suggesting, repeatedly, that I feel we need to address his agitation that he has been having recently, and I don't think she is acting on it fast enough. Not really telling her what to do, but just that we should consider this, or maybe we should consider that, but ultimately it is her decision.

So, temporal members of the immediate family are not exempt from the hierarchy that exists in the house, and that even though their familial relation prevents them from being linearly subordinated, the circumstances of hospice care mandates their role to be supportive of the surviving spouse. This subordination may as well undermine their ability to play the advocacy role that best serves the patient.

Family Members Take Sides

Though a sense of family unity existed, more than one set of hierarchies was usually in play, which was complicated by the different roles and "role-taking" that occurred during this stressful time. This is best described when Mary (the wife's sister) and Ruth (the patient's mother) first interacted:

Mary's raises her voice as she says, "I am here for my sister; she has no emotional strength left to give – she needs me!" Mary reached out and gently placed her hand on Ruth's shoulder while she greets her, "How are you holding up? How was your trip?" Ruth responds, "That's O.K., we are here for Jim, -- my trip was fine!"

In a short period of time emotions went from high, as territory and roles were staked, to lows, as "role-taking" occurred in the form of empathy and maybe some hypocrisy. The tension of roles and "role-taking" fragments the unity of the family, as communication shifts from the role of who we are to "role-taking," which is fluid, constant, and maybe not too honest in its content, as coping adaptations of the self occur.

The friction and fragmentation of the family, at different levels of familial relation and its intensity, varied with the age of the actors engaged in the temporal conflict. This fragmentation affects how the roles of the patient, hospice and family members play out in the overall quality of the "dying experience." Can we get along and still advocate for our loved ones? Do we really care to get along if the dying person is the only link between you and the opposing camp? In the case of Mary (the patient's sister-in-law), age 60, and Ruth (the patient's mother), age 70, the conflict--within minutes--was placed on the backstage of their relationship as they seemed to have a moment of grief together immediately following their terse exchange. This was not the case when the sister of the patient (Amy) and temporal caregiver differed in opinion with the wife during a "crisis episode:"

He was having an episode with nausea and vomiting. She (the wife) wanted to give him pain medication, orally. Luckily the hospice nurse was there and suggested that the medicine could be applied topically. I insisted it be given topically. I don't think it caused a major problem, just a little friction.

Amy also reported that the body language of her sister-in-law was subtle, but the disagreement was palpable. She stated that her sister-in-law “appeared a bit tense” and an effort to avoid a confrontation was evident as there were no signs of “outright anger.” Amy was asked how she felt about this encounter a few days later and she said, “I have to stick up for him,” and, “I was just not going to have it,” when referring to giving the patient medication orally instead of topically during an episode of dry heaves.

The Language of Dying

Hospice personnel are trained in using language, the message that is designed to be inclusive and soften the reality of entering hospice care. The language is especially necessary when the admissions nurse first encounters the dying patient. In some cases the patient may be “semi-comatose,” “non-responsive,” or “in crisis,” which dictates if the nurse speaks with the caregiver in charge off the patient. The hospice admissions informant (Nicole) shared some of the language used:

We use language like serious life threatening condition, exhausted all the curative treatments, the focus now is on comfort measures, life limiting, shift from curative to comfort measures, our program, give us a try.

This language may soften the communication that occurs at the veneer level, but may not change the reality, the “back stage,” that the actors inside the home face. This language is important not only to encourage communication with the actors, but also to ease hospice into the home environment and the role that it plays in the “dying experience.”

Body language, a non-verbal approach that hospice personnel use, exacerbates or heightens verbal language. Actors made a conscious effort to get along, be patient, be considerate, and attempt to appear unified for the patient’s sake, but this “role-taking” process made verbal queues more important in their everyday lives. The family caregiver informant (Amy) commented on her conversations with the home health aide (Ashley):

[Ashley] told me, “I don't think he is going to be leaving this house again.” I wish [Ashley] would pay more attention to my brother's needs... her patient that she is in-charge of, but I think she is dealing with this in her own way because once the passing comes she's got her own unemployment problem to deal with and I think she is anticipating that, and I guess that is a natural human response.

Amy’s comments were referring to the change in Ashley’s behavior. Within the first month of hospice care at home starting, Ashley’s behavior changed from being engaged with the patient to appearing relegated to the sidelines as family members and hospice nurses landed on the home. What happened to Ashley? Are her feelings hurt or is she just coping? Ashley now spends most of her days on her cell phone texting, or on personal calls, and the remainder of the time instant messaging on the Internet. Amy also commented that Ashley was probably responding to the many people (*role-taking*) that she was coming in contact with and to what she perceived to be her new place (role) in the home hospice setting.

Putting the Puzzle Together

Hospice care has changed healthcare with its tenets of family and patient-centered care, comfort and palliative measures, and its advocacy. For forty years hospice has empowered patients and families not only to be self-determinant during a terminal illness, but established the “dying experience” as a humane and gradual process of closure. Over the years, important contributions have been made in understanding

the role of the hospice nurse, first as the patient's advocate in charge of the interdisciplinary care team and most recently in Emanuel et al. (2007), where "the dying role" has re-gained some attention from medical professionals and academics. This theoretical and philosophical revival is an important element to be considered, as the U.S. healthcare field faces conflicting pressures from multiple outlets. The market sector urges for severance from its socialized roots, while the government approaches a political solution along the lines of a full-fledged program for universal care.

This study draws attention to the "front stage" and "back stage" aspects of hospice, and explains how hospice care can be informed by symbolic interactionism. First, on "the front stage," is critical to understand the physician role in absentia and the looming influence it imposes on role dynamics. Second, the authoritative role of the surviving spouse and advocacy for the patient's best interests may be mutually exclusive. Third, roles and "role-taking" create static and subsequent fragmentation in human interaction. Fourth, language used by hospice personnel softens the veneer, but in the backstage supplants verbal communication for the more subtle meanings of body language. In order to better understand "the back stage" and the "dying role," it is obligatory to understand the dominant roles in hospice care at home, which include the surviving spouse, the temporal family caregiver, hospice personnel, the home health aide, siblings and in-laws.

The themes that emerged from the data include *You are Dismissed, Ultimate Judgments and Decisions, Family Members Take Sides and The Language of Dying*. The application of the symbolic interactionism axioms to the emerging themes follows. For ease of analysis and comparison, the three axioms are conceptualized as *meaning, interaction, and interpretation*.

In *You are Dismissed*, the role of the physician emerges as a dominant figure embedded in Medicare policy and, subsequently, in the hospice setting. The *meaning* axiom highlights our social conditioning to treat physicians as superior to most of the roles individuals encounter in their daily lives. The superior role society assigned the physician is reinforced by the imagery of the white coat. The *meaning* of a physician is profoundly internalized in our psyche, as they are there when we are ushered into the world, when we face sickness or injury, as we grow old, and when our health starts to fail.

The *interaction* axiom defines the physician role according to the context in which the interacting individuals engage in meaning formation. The hospice setting makes for a context that reaffirms the superior role of the physician, the gatekeeper, at a time when the patient and family members are likely distraught by having to cope for their first time in their adult life with issues of mortality and the end of life.

The *interpretation* axiom requires that the meaning of the physician, as defined by the interaction situation, be reformulated once more as individuals fine-tune the meaning agreed upon from *interaction* with their own thoughts. This reassessment is likely driven by their own values, norms, biases, and experiences. In other words, what appears to be a common canvas where individuals follow absolute rules, norms and roles, is actually individual realities that formulate temporarily as we come in contact with others.

For example, in *You are Dismissed* we learn from Nicole, the hospice admission nurse, that patients are vulnerable to the physician's authority role when being labeled sick or terminally ill. Nicole's dialogue shows that she disagrees with how the physician in her experience handled the situation. Her narrative, in addition to her verbal and body language, show that her meaning for the event is one driven by compassion, empathy, and care. Her view is in stark contrast to the more direct, pragmatic, view of the physician in her example. For Nicole, the meaning of hospice traveled from its genesis in her nursing education, through the action situation of the physician and the patient, and interacted with her personal and professional values and norms as a hospice admission nurse.

In *Ultimate Judgments and Decisions*, the second theme emerging from the data, the *meaning* axiom helps us understand what it is to be a caregiver. The role is associated, according to Nicole's interview, with power over the patient and all patient-related matters. For Nicole, the role of the patient and the caregiver differ in authority, as the patient is the ultimate decider. While the caregiver's influence is acknowledged, it is not accepted as superior.

In terms of *interaction*, Nicole negotiates her role as a hospice nurse with that of the caregiver. Her meaning for the role of the caregiver emerges as she elucidates her concern over “usurping” the caregiver’s role. She explains that the action situation was loaded with power and control overtones, as the “long stand-in” caregiver did not want to “relinquish” her power. Nicole redefines her role from a strong hospice care and patient rights advocate to one subservient or nonthreatening to the caregiver.

The *interpretation* axiom helps explain how Nicole recognized the caregiver’s power role and adapted her own role from a strong patient advocate to that of a nurse whose sole purpose was to provide help to the patient and the caregiver. In a situation charged with dominant roles, power and hierarchy, Nicole’s choices were limited to being turned away or invited into the home and the dying experience. Ultimately, as a hospice nurse, Nicole wanted access to the patient.

In *Family Members Take Sides*, the *meaning* axiom helps decipher the different roles individuals occupy as they move across action situations. Mary (the wife’s sister) and Ruth (the patient’s mother) first interacted in a manner that revealed that both intended to protect their own blood relative and the turf that came along with it. Once the first *interaction* occurred, both retreated to their in-laws roles and exchanged socially dictated niceties. Having to interact under the premises of being in-laws, Mary (the wife’s sister) and Ruth (the patient’s mother) quickly redefined their battleground roles to ones of unity as a support group. Mary’s expression of concern and physical contact with Ruth, and Ruth’s response to Mary’s concern, “*We are here for Jim, -- my trip was fine!*” inject a degree of tolerance and focus on the patient. This exchange can be understood as a reflection of the *interpretation* axiom as Mary and Ruth took a step back from the ongoing family differences and agreed to be a group.

The Language of Dying is the last theme that emerged from the data. The *meaning*, *interaction*, and *interpretation* axioms are likely best suited to shed light on this theme because language can be considered a fair representation of our thoughts, values, and norms. In *meaning*, the hospice personnel use a softened approach to describe the harsh reality the patient faces entering hospice care. Our hospice nurse informant (Nicole) was blunt about how words as “serious life threatening condition,” “exhausted all the curative measures,” “our program,” and “give us a try” are used during the initial home visit. The *interaction* axiom shows how an otherwise morbid and maybe misleading choice of words can be reformulated through the hospice at home and end of life context to communicate choice, empathy, and self-determination. The *interaction* comes at a time when terminally ill patients may be tired of medical care, weakened by their illness, concerned for their families, and worried of becoming a burden. Their families are likely facing caregiver fatigue, economic hardship, and health issues of their own. The Medicare hospice program can be very enticing for patients and their families, as it eliminates the cost burden of copays and deductibles characteristic of traditional Medicare and other required healthcare insurance supplements. Simply put, hospice can provide relief for dying patients and their families.

Finally, the *interpretation* axiom highlights how language can have a different meaning once an individual has interpreted the meaning derived through interaction and applied their own context. For example, a caregiver facing caregiver fatigue can give hospice a try and conclude that hospice is a viable alternative for their loved one and them. They realize that granting their loved one’s wish of dying at home may be more difficult than anticipated. Our home health aide informant, Ashley, recognized how the role and demeanor of the patient’s wife had changed as weeks of caregiving came and went. She explained how the wife transitioned from devoted to withdrawn, as, what Ashley thought, was a realization of what is going to happen to me once Jim, her husband, passes away. This particular example embodies a transition in context as a meaning is reinterpreted and redirected from “I am the caregiver” to “What happens when I am no longer needed?”

This new holistic perspective of hospice care and role theory as one field of study fills in the gap of previous qualitative studies, which focused on a given role rather than the different actors and roles in hospice care in the home. A possible model should include the actions, reactions, communication, and consequential effects of these on the “back stage” of the “dying experience.” Theoretically, on “the back stage,” the dynamics of unchecked roles and “role-taking” in hospice care create a hyperactive circle—a barrier—around the patient, who ultimately ends up spending more time alone than realized by the actors in the home.

CONCLUSION

The evolution of hospice care can be energized and taken to the next stage by including the study of role dynamics and symbolic interaction among the patient, the family, clinical personnel, managers, and hospice administrators in order to better serve the dying patients and their families. The application of the roles and symbolic interactionism frameworks can start moving hospice research from reporting statistics and costs to gaining theoretical understanding and theory development.

The roles framework provides a methodology to discern the different actors and the multiple roles they play; the symbolic interactionism provides a methodology that connects meaning, interaction, and interpretation to the roles and actions individuals take while fulfilling the obligations of the temporal roles they occupy. The methodological and theoretical fusion applied in this study highlight the impact each individual (family, staff, clinical, and management) has on the dying experience of the patient, family, and hospice personnel.

ENDNOTES

1. Names and identities changed in order to honor confidentiality agreement.

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