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The Role of Proxies in Treatment Decisions: Evaluating Functional Capacity to Consent To End-of-Life Treatments within a Family Context

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Abstract

Psychology as a profession has entered the arena of palliative and hospice care later in the process than other health care professions. Through the use of Familial Advance Planning Evaluations (FAPEs), however, psychologists can assist individuals and families in facing end-of-life transitions in important ways. Hospice and palliative care philosophy treats the patient and family as the unit of care. End-of-life decision-making is therefore a family matter as well as a normative developmental transition. Yet, little is known about the decision-making process. This paper reviews the literature regarding informed consent, advance care planning, and proxy decision-making and outlines a theoretical model for familial decision-making. Previous models of end-of-life capacity evaluations and family assessments are presented and serve as the basis for a comprehensive assessment of familial decision-making at the end of life. Functional capacity evaluations of individuals at the end of life regarding decisions about life-sustaining medical treatments enable both the individual patient and one identified proxy from his or her family to discuss important issues families may face during medical crises at the end of life. The information gleaned from such evaluations has the potential to assist psychologists and other professionals in designing family-specific interventions to reduce caregiving distress, improve quality of life for dying patients, and ease the transition to bereavement for caregivers.

Until recently, psychology as a profession had virtually ignored its potential role in assisting older adults and their families in decision-making at the end of life. This omission is surprising given the roles of psychologists in medical, long term care, and legal settings (Haley, in press; Haley et al., 1998b; Smyer & Allen-Burge, 1999). The American Psychological Association (APA) has identified the need to define and expand the role of psychologists in end-of-life care as a priority issue (APA, 2000). Several authors have called for more research in this area (Baron, 2000; Benjamin, 2000; Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Jamison, 2000; King, Kim, & Conwell, 2000; Terry et al., 1999; Werth, Benjamin, & Farrenkopf, 2000; Zuckerman & Wollner, 1999). With extensive training in assessment, intervention and research skills, psychologists are in a unique position to assist in the process of end-of-life treatment decisions within various health care settings. One purpose of this paper is to serve as a selective review of areas in which psychologists can improve the process of end-of-life decision-making.

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Complexities involved in end-of-life decision-making include communication barriers regarding what treatments to initiate. Advance care planning has been proposed as one means of improving communication between patients, families, and health care professionals (Ditto et al., 2001; Lynn et al., 1999). Typically, advance care planning emphasizes what treatments an individual does not want rather than active interventions one desires (Cicirelli, 1997; Zuckerman & Wollner, 1999). Even when advance directives are available or individual treatment decisions are obtained, these treatment preferences often are not linked to effective plans for instituting the desired care, particularly when this care is palliative (Holtzman, Pheley, & Lurie, 1994; Mor et al., 1997). Palliative, or comfort, in contrast with 'curative' care, is one treatment option at the end of life typically provided by hospice services (see Lynn et al., 1999, for a discussion of end-of-life care ethics and advance care planning in the context of dementia). Hospice referrals, however, are often made very late in the disease process, such that the median length of stay in hospice programs nationally is only 19 days (U.S. General Accounting Office, 2000). Such short lengths of stay require resource intensive interventions that do not provide individuals and families with the full range of treatment options that may be available earlier in the disease process (Christakis & Escarce, 1996). Although much research has focused on barriers to communication between health care professionals and patients (Molloy et al., 1996; Palker & Nettles-Carlson, 1995; Teno et al., 1997), the potential role of psychologists in end-of-life treatment planning may best be couched in improving communication, knowledge, and acceptance of the need for such decisions within the family system. Psychologists may then assist in communicating the outcome of family-based assessment, intervention, and research to other health care professionals for clinical and scientific benefits.

Many of us will be personally involved in the decision-making process for end-of-life medical treatments within our extended families, either for ourselves or in the role of caregiver for someone near death. These are normative, developmental processes in which psychologists may assist via assessment, intervention, and research. Specifically, patients and their families may need information and support in advance care planning for decisions regarding (i) anticipated changes in the patient's functional capacity, pain, or distress, (ii) foreseeable cognitive changes, (iii) possible changes in care setting, (iv) legal or financial concerns, (v) changes in familial/caregiving responsibilities (particularly when the family's matriarch or patriarch is ill), (vi) spiritual considerations, and (vii) anticipatory grief (Zuckerman & Wollner, 1999). In this paper, we focus on medico-legal concerns in treatment decision-making necessitated by changes in the patient's functional capacity that may drive changes in caregiving responsibilities.

Primary considerations in advance care planning include the extent to which a patient retains decisional capacity to participate in treatment planning and the extent to which family caregivers are stressed by the potential role of decisional proxy. In this paper, we integrate research regarding consent capacity and caregiving stress and offer an experimental, theoretical model for conducting Familial Advance Planning Evaluations (FAPEs). Authors have previously discussed the potential impact of family members on autonomous decision-making regarding physician assisted suicide (King et al., 2000) but no specific model exists for the integration of family members' input into the assessment of medical decision-making. In fact, it is the capacity of the family *unit* for end-of-life decision-making that needs to be evaluated, because family decisions are frequently the procedures implemented in clinical settings. The patient and family are concurrent foci of care in the palliative care philosophy. This idea will be elucidated in the section describing and evaluating the FAPE model.

We propose an investigational model for the evaluation of capacity to make end-of-life treatment decisions within a family context. In so doing, we restrict our focus in several ways. First, our model focuses on decisions made by *older* adults and their families. This scenario

is, and will continue to be, the most common faced by families making end-of-life treatment decisions. The fastest growing age cohort in most developed countries is persons 80 years and over (WHO, 1998). These are precisely the individuals at risk for medical crises due to increased incidence of frailty and impaired cognitive functioning that may require long periods of family caregiving (Lynn, 1997; Zuckerman & Wollner, 1999). Thus, some authors have argued that end-of-life decision-making is particularly poignant among older adults and their families (Beder, 1998). The stress engendered by lengthy caregiving careers has been the focus of much previous research (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Haley et al., 1995).

Second, our model focuses on dyadic familial decision-making rather than full family systems assessment. Most states, in accordance with the Patient Self Determination Act (PSDA; Omnibus Budget Reconciliation Act, 1990), provide for the identification of one health care proxy to make substituted judgments for incapacitated adults. Additionally, information provided by nursing homes in compliance with the PSDA is most frequently given to one family member or other potential proxy decision-maker (Bradley, Walker, Blechner, & Wetle, 1997). Our model focuses on the functional assessment of decisional capacity within the older patient/proxy dyad because it is this system that is most likely to be directly involved in advance care planning.

Third, we restrict our focus to situations in which the patient is capable of spontaneous verbal interaction, with a minimum response criterion of multi-word phrases (Allen-Burge, Burgio, Bourgeois, Sims, & Nunnikhoven, 2001; Bourgeois, 1993; Burgio et al., 2001). This procedure has been used extensively in communication interventions with demented older adults (Bourgeois, 1990, 1992a, 1992b; Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Bourgeois & Mason, 1996), and as an inclusion criterion for an investigation of end-of-life decision-making capacity among nursing home residents (Allen et al., manuscript submitted for publication). Using this inclusion criterion, we have successfully conducted functional capacity assessments with over 80% of nursing home residents varying in cognitive status.

Finally, we restrict our focus to 'familial' proxy decision-makers rather than health care professionals. Respect for diversity requires that our definition of 'familial' be inclusive of fictive kin and others with close personal ties with the older adult patient. We focus on familial proxies because older adults generally prefer these individuals to collaborate in health care decisions. European-American families have been shown to prefer, in descending order, involvement of spouses, adult children, siblings, or other family members in the decision-making process (Gamble, McDonald, & Lichstein, 1991; High, 1988, 1993; King et al., 2000; Lurie, Pheley, Miles, & Bannick-Mohrland, 1992; Sehgal et al., 1992). African-American families, in contrast, may consist of diverse relatives and fictive kin and may encourage the participation of multiple family members in treatment decision-making (Caralis, Davis, Wright, & Marcial, 1993; Gardiner, Mutter, & Kosmitzki, 1998; Janevic & Connell, 2001).

Another reason for relying on familial proxies is that physician's judgment for determination of demented older adults' capacity to consent to treatment is unreliable (Marson, McInturff, Hawkins, Bartolucci, & Harrell, 1997). Inter-rater agreement between five experienced physicians (two neurologists, one geriatric psychiatrist, two geriatricians) who were asked to make judgments regarding the consent capacity of mild Alzheimer's disease patients was no better than chance (Cohen's kappa = 0.14). Symptoms of psychiatric distress may also influence capacity assessments, and physicians are notoriously poor at detecting symptoms of clinical depression among their patients (Benjamin, 2000; Martyn & Bourguignon, 2000). The presence of a mental illness is not sufficient to determine that a person is incapable of making informed decisions (Grisso & Appelbaum, 1998). A diagnosis of Alzheimer's disease,

however, may directly affect legal determination of competence as well as clinical decision-making capacity in some jurisdictions (Goodwin, Smyer, & Lair, 1995; Smyer & Allen-Burge, 1999). Notably, individuals with decisional capacity as defined by mental status testing or physician's ratings are more likely to choose to forego life-prolonging medical treatments, whereas those of questionable capacity are more likely to request aggressive treatment (Diamond, Jernigan, Moseley, Messina, & McKeown, 1989).

The purpose of this article is threefold. First, we review the literature regarding the assessment of consent capacity within the context of end-of-life medical decisions. Second, we review the literature regarding discrepancies between older adults and their identified familial proxy regarding life-sustaining treatment decisions and consider reasons why such discrepancies exist. Finally, we propose a theoretical model for the evaluation of capacity within the context of family decision-making, incorporating potential cultural influences and expanding the model proposed by Werth and colleagues (2000).

Functional Assessment of Consent Capacity for End-of-Life Medical Decisions

The bioethical principles relevant to functional consent capacity assessments include beneficence and nonmaleficence on the part of health care professionals and autonomy on the part of the competent patient (Brock, 1994; Drought & Koenig, manuscript submitted for publication, cited with permission). The ethical principle of autonomy rests on the assumption that individuals will be motivated to document or communicate to others their wishes regarding medical care. However, older adults' belief that family members, physicians, or others (e.g. God) will take care of their future health care needs may be a primary barrier to the completion of advance directives (Parker & Nettles-Carson, 1995). Compared with other adults, individuals who possess advance directives are older, white, more highly educated, middle class, in poor health, and may have had informal discussions with spouses regarding end-of-life care (Fried, Rosenberg, & Lipsitz, 1995; Schonwetter, Walker, Solomon, Indurkha, & Robinson, 1996). End-of-life treatment decision-making can be clarified but not completely resolved with written advance directives. Some authors have suggested that determinations of decisional capacity should vary depending on the severity of the consequences involved in the decision (Drane, 1984). Regarding end-of-life medical treatments, the consequences of choice are by definition life or death issues. Thus, it is incumbent on clinicians to fully understand the model of informed consent, and the oft-competing values of autonomy and family involvement in the decisional process.

The Model of Informed Consent

In order for an individual's informed consent to be valid, it must be given voluntarily, knowingly, and competently (Appelbaum & Grisso, 1995; Grisso & Appelbaum, 1998). It is important to note here that, although older adults may prefer the involvement of family members in treatment decision-making, a familial proxy holds no *legal status* under current laws of informed consent unless the patient has been determined to be incompetent. Therefore, clinicians conducting FAPE may question each component of informed consent. For example, the requirement that consent be given *voluntarily* means that the individual must not be coerced into making the decision. Given concerns older adults may have about being a burden and protecting their family members from unwanted financial or emotional hardship (High, 1988; King et al., 2000; Terry et al., 1999), this determination may not be easy to make. Family proxies, meanwhile, may be so overwhelmed with anguish during medical crisis that, in seeking to do what is 'best' for their family member, they may use undue influence to impose their wishes on the older patient's decision. The frequency with which this actually occurs has yet to be determined.

Second, the requirement that consent be given *knowingly* means that individuals must have all the information that is necessary to be able to make the decision. This notion that individuals will be fully informed regarding diagnosis, prognosis, and disease course, and be in a position to *choose* among treatment alternatives, may be more fiction than fact (Drought & Koenig, manuscript submitted for publication, cited with permission). The requirement that patients give consent knowingly implies that the physician has fully disclosed relevant treatment information. Families may wish to protect their older patient from the knowledge that they are dying and bargain with health care professionals to withhold information. Alternatively, physicians may not fully disclose information regarding terminal conditions because prognostications of imminent death are rarely used in clinical practice (Christakis & Iwashyna, 1998). Physicians simply may not be good at making determinations of terminal illness for all types of illness category, and may in fact be overly optimistic in their expectations for a patient's survival (Christakis & Lamont, 2000; Zuckerman & Wollner, 1999). Some physicians who fully disclose information regarding their expectations for a patient's survival may be reluctant to share treatment decision-making with the patient and family (Drought & Koenig, manuscript submitted for publication, cited with permission).

Finally, even cognitively intact patients may lack understanding and knowledge of their treatment options at the end of life (Mitchell, Berkowitz, Lawson, & Lipsitz, 2000; Park, Morrell, & Shifren, 1999; Silveira, DiPiero, Gerrity, & Feudtner, 2000). Even with adequate understanding, patients will likely maintain overly optimistic expectations for their chances of survival (Coppola, Danks, Ditto, & Smucker, 1998). Thus, clinicians conducting functional, family capacity evaluations must be prepared to face situations in which the older patient and his or her family member may not share *or even be willing to share* all the relevant information with which to make treatment decisions.

The last component of informed consent, *competency* or *capacity*, is considered to be the most ambiguous. Legal scholars have identified at least four legal standards of consent capacity: (i) the ability to communicate a treatment choice, (ii) the ability to appreciate the consequences of the choice made, (iii) the ability to understand relevant information, and (iv) the ability to rationally manipulate the information provided and to give reasons for one's treatment decision (Appelbaum & Grisso, 1988, 1995; Appelbaum, Lidz, & Meisel, 1987; Appelbaum & Roth, 1982; Marson, Chatterjee, Ingram, & Harrell, 1996; Marson, Cody, Ingram, & Harrell, 1995; Marson, Ingram, Cody, & Harrell, 1995; Roth, Meisel, & Lidz, 1977). Marson and colleagues have included a fifth standard, that individuals make the most reasonable choice, but we choose not to use this standard in the cultural context of end-of-life treatment decision-making due to the difficulty in determining what the 'reasonable' choice may be in all cases.

It has been generally agreed upon that the simple ability to state a treatment preference is too lenient for the determination of competence to give informed consent (Stanley, 1987). The requirement that an individual be able to understand all the information that is presumed by law to be part of treatment decision-making is the most commonly used standard of decisional capacity (Appelbaum & Grisso, 1995; Stanley, 1987). It is also the most consistent with the law of informed consent (Meisel, Roth, & Lidz, 1977).

One of the primary contributions of Appelbaum and Grisso is the notion that it is the process by which an individual arrives at a decision that is important, not the final decision made (Grisso & Appelbaum, 1998). In contrast, one contribution of Marson and colleagues has focused on linking various legal standards of consent capacity to underlying neuropsychological processes. Whereas simple cognitive abilities such as auditory comprehension or verbal skills may underlie the capacity to state a treatment preference (Frank, Smyer, Grisso, & Appelbaum, 1999; Marson et al., 1996), higher order cognitive abilities appear to be needed to rationally manipulate treatment information, appreciate the

consequences of one's decision, and give reasons for one's treatment choice (Frank et al., 1999; Marson et al., 1995a).

Patient-Proxy Discrepancies Regarding End-of-Life Treatment Decisions

When the ethical principle of autonomy cannot be followed due to incapacity or when the older adult patient competently abdicates the right to make autonomous treatment decisions, identified proxy decision-makers are called upon to use available knowledge about the patient's wishes and values to decide as the patient would have decided (Brock, 1994). Such *substituted judgment*, however, may not accurately reflect the autonomous wishes of the patient (Allen-Burge & Haley, 1997; Ditto et al., 2001; Eleazer et al., 1996; Karel & Gatz, 1996; McNabney, Beers, & Siebens, 1994; Uhlmann & Pearlman, 1991; Uhlmann, Pearlman, & Cain, 1988; Zweibel & Cassel, 1989). Rather, familial proxies tend to overestimate the frequency with which patients would like to receive treatment (Uhlmann et al., 1988).

Ditto and colleagues recently published initial results of the Advance Directives, Values Assessment, and Communication Enhancement (ADVANCE) project, showing that even with structured interventions to encourage (i) use of instructional or values-based advance directives and (ii) discussion with target family members/patients about their treatment wishes, proxy decision-makers are inaccurate in providing substituted judgment (Ditto et al., 2001). The best predictor of the treatment choice a proxy will make for a patient is the proxy's own treatment preference for themselves (Allen et al., manuscript submitted for publication; Fagerlin, Ditto, Danks, Houts, & Smucker, 2001; Karel & Gatz, 1996). For a full discussion of this projection bias, readers are referred to Fagerlin and colleagues (2001).

Although few investigators have attempted to identify factors involved in treatment preference disparities, caregiving stress is clearly a potential mediator of the relation between familial factors and treatment preference discrepancies between patients and proxies. The omission of caregiving stress as a potential mediator of treatment preference discrepancies may be partially attributed to most published work omitting seriously ill patients and their active caregivers as decision-making dyads. It is precisely within the context of serious illness that families are most likely to be in distress and in need of assistance with end-of-life decision-making.

Caregiving stress may be exacerbated because the treatment preferences of health care proxies are poorly related to an individual's autonomous treatment preferences. In a study of nursing homes in Canada and the U.S., only 47.9% of proxies who made the decision to place their resident on a feeding tube felt confident that their resident would have wanted the procedure (Mitchell et al., 2000). These proxies reported understanding the benefits (83%) but not the risks (48.9%) of tube feeding. Perhaps as a consequence of stressful medical decision-making, surviving family members of recently deceased residents reported greater dissatisfaction with nursing home care than with any other aspect of treatment for their relative at the end of life (Hanson, Danis, & Garrett, 1997).

There is great diversity in an individual's response to caregiving stress. Haley's stress process model (Haley, Han, & Henderson, 1998; Haley, Levine, Brown, & Bartolucci, 1987; Haley et al., 1995) suggests that African-American caregivers possess certain stress-buffering mechanisms enabling them to experience less negative caregiving outcomes (i.e. depression, burden) than white caregivers. African-American caregivers may be more acquainted with trouble throughout their lives. King and colleagues propose use of the Strength-Vulnerability (S-V) Model of Family Functioning, or S-V Model of Health and Illness (Shields & Wynne, 1997), for familial assessment of decisions regarding physician-assisted suicide. This model describes the family as a system moving through time with predictable, normative transitions and unique, family-specific and cultural challenges. Older adults who remain disengaged from familial proxy decision-makers during times of transition are at increased risk for potential

conflict in treatment decisions, including requests for physician-assisted suicide (King et al., 2000). Understanding cultural and ethnic differences in the adjustment to normative developmental life cycle transitions such as the death of a family member will help psychologists design specific interventions to improve familial decision-making.

The S–V Model of Health and Illness states that characteristics of both the patient and the proxy will impact decision-making. Allen-Burge and Haley (1997) found support for this hypothesis. In responding to a vignette about an older male relative who had suffered cardiac arrest, proxies were much less likely to desire the initiation of any life-prolonging treatment when the patient was described as moderately demented rather than cognitively intact. The most compelling finding, however, was that white caregivers were much less likely than African–American caregivers or noncaregivers, or white noncaregivers, to desire the initiation of CPR and ventilation or CPR and tube feeding. Both ethnic background and prior caregiving experience appeared to play a role in decisions regarding CPR and ventilation. Proxies with prior experience regarding end-of-life treatment issues were less likely to opt for any life-prolonging medical treatment and were more likely to want information regarding the patient's prognosis. Additionally, proxies who mentioned consideration of the patient's previous quality of life were more likely to mention their own spiritual values.

Replicating and extending these findings, Allen and colleagues (manuscript submitted for publication) investigated aspects of advance care planning among nursing home residents and their identified proxy decision makers, including (i) consent capacity and (ii) predictors of residents' possession of formal advance directives. Allen and colleagues found evidence for retention of the most lenient standard of decisional capacity (e.g. ability to state a treatment preference), but variability in the retention of the capacity to appreciate the consequences of one's decision and the capacity to understand the treatment situation. Predictors of residents' possession of formal advance directives included proxy spiritual beliefs and behavioral characteristics of the resident (e.g. social engagement).

Investigation of the correlates of proxy treatment preferences is important and the discrepancy between proxy and patient reports is potentially alarming if the goal of substituted judgment is to preserve patient autonomy. However, the discrepancy between individual and proxy treatment preference may have little practical importance. For example, competent patients may choose to abdicate decision-making responsibility to physicians or familial proxies. Using qualitative data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT; SUPPORT Principal Investigators, 1995), Hiltunen and colleagues (1999) found that families were extensively involved in the decision-making process along with the patient, particularly when decisions involved the withdrawal of medical treatment. These authors noted that vacillation in decision-making was common, with patients and proxies stating unstable treatment preferences across time. Such vacillation in treatment preference during end-of-life health transitions may be dependent on fluctuations in symptom management, available information for informed consent, and levels of distress.

In one of few studies directly targeting terminally ill adults, Terry and colleagues (1999) identified which treatment option a patient would want to have implemented if their advance directive differed from the legal proxy's treatment preference for the patient. These authors found that a slight majority of patients selected their proxy's decisions for implementation (54%). Preference for their own decision was less likely when their legal proxy was the person they preferred to make decisions for them (Terry et al., 1999). Patients who preferred to have their proxy's decision implemented were more often spouses or parents of the proxy. This finding supports the notion that patients may competently choose to abdicate decision-making responsibility. Reasons stated for choosing to have proxy's treatment preference implemented

included trust in the proxy's judgment (63%), having a trusting relationship with the proxy (22%), and concern for the proxy's best interests (21%).

In contrast, patients' preference for advance directives was greater when no informal discussion of treatment wishes had ever occurred with the proxy (Terry et al., 1999). Of patients who wanted their own decisions followed, reasons reflected a desire for self-determination (57%), concern about being a burden (18%), belief that the proxy would be too emotional to make decisions at the critical time (15%), and perceived value/belief conflict with the proxy (11%). Unfortunately, Terry and colleagues did not assess the inter-rater agreement obtained in the assignment of open-ended responses to categories, making it difficult for readers to assess the stability of categorizing reasons behind prox-advance directive treatment decisions.

Although improving the agreement between autonomous treatment preferences and proxy treatment preferences may be an unrealistic goal, advance care planning interventions have shown that older adults benefit from discussing their preference for life-prolonging medical treatments. Kellogg, Crain, Corwin, and Brickner (1992) found that depression scores among older adults improved after physician-initiated advance care planning discussions. Ditto and colleagues (2001) also found that identified patients and their proxies reported perceived benefit from the advance directive and discussion intervention. Thus, other outcomes such as improved satisfaction with decision-making and reduced stress may ensue from familial advance care planning.

The state-of-the-art guidelines proposed by Werth and colleagues (2000) for assessing the mental capacity of patients who request physician-assisted death provide a solid foundation for the development of FAPE in the general end-of-life decision-making context. Werth's guidelines take a broad perspective and recommend ancillary cognitive and emotional assessment. The guidelines represent a significant advance and serve as the building blocks for our proposed model of FAPE.

Werth's Guidelines for the Assessment of Individual Capacity

Werth et al. (2000) advocated use of the MacArthur Competence Assessment Tool-Treatment (MacCAT-T; Grisso & Appelbaum, 1998) and other instruments for conducting legal capacity evaluations in the specific case of individuals considering physician-assisted suicide. Their model, like other models of informed consent, assumes that the patient be considered capable unless shown to be incapable of forming reasoned decisions. Information is gleaned over a period of time from the individual patient, collateral sources including treating professionals and family, and medical records documenting the physical limitations of the person and the complicating effects of medications (see also Fisher et al., 2002; Horgas & Tsai, 1998, for methods to quantify the impact of analgesic drugs on behavior). If the evaluation results in a patient being found to suffer from impaired judgment, the guidelines recommend that treatment be provided and a second evaluation be conducted post-treatment, with separate clinicians conducting the evaluation and providing treatment. Although these guidelines touch on the issue of familial involvement in end-of-life treatment decision-making, they do not offer recommendations for the integration of family members' input in the context of functional capacity determinations.

Several authors have advocated a revised conceptualization of consent capacity assessments based on a socially embedded, joint decision-making model (Balint, 2000; Hiltunen et al., 1999; King et al., 2000; President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983; Terry et al., 1999; Werth et al., 2000; Zuckerman & Wollner, 1999). Multiple reasons for proposing such a model exist, including the need to reduce the stress of treatment decision-making among patients and proxies, the need to provide structure and emotional support for patients and proxies to discuss treatment

preferences, and the need to improve communication between patients and proxies regarding treatment wishes and decisional capacity. Recommendations for a joint decision-making model, however, *currently hold no legal status* in the United States' judicial system.

In our FAPE, a family system facing the death of one of its members, and in which the patient and at least one proxy retain close personal ties *requires* that the proxy be involved in treatment decision-making. Due to the reciprocal emotional and instrumental support between the patient and proxy, the reactions of the proxy to fluctuations in medical status will influence treatment outcomes for the patient. Thus, the *functional capacity* of the patient and proxy to make medical treatment decisions must be understood, and FAPE provide a semi-structured interview format in which to engage patients and proxies in the decision-making process. Of note, decisional proxies that live at some geographic distance from the patient could be included in FAPE by means of teleconferencing or use of other technologies.

The Familial Advance Planning Evaluation

The Familial Advance Planning Evaluation (FAPE) is an investigational model designed (i) to improve satisfaction with decision-making and reduce distress among older patients and their designated proxy, (ii) to provide a standardized method of communication for older adults and one proxy to assess each other's understanding of end-of-life medical treatments, (iii) to provide information to the patient and proxy about the other's treatment preferences, (iv) to provide information to the proxy about the patient's functional capacity for informed consent regarding end-of-life medical treatments, and (v) to provide the clinician with information regarding the *functional capacity* of the decision-making dyad. For these purposes, the FAPE model uses a semi-structured family interview including the clinician, the identified patient, and the identified proxy decision-maker. In our ongoing project, Care Integration Team Intervention During Hospice Care (CIT Project; K01AG00943, R. Allen, PI), we are assessing the reliability, validity, and utility of the MacCAT-T for functional assessment of civil decisions regarding end-of-life care, contrasting understanding of palliative treatment to life-sustaining treatment options.

It is critical to realize that the purpose of FAPE is not to conduct a *legal* capacity evaluation acceptable in a court of law, because dyadic capacity is not currently a legal model of informed consent. Rather, the purpose of FAPE is to provide a structure in which the clinician, patient, and proxy can discuss plans for end-of-life medical crises and wishes for treatment. In the context of this interview, the clinician simultaneously gains information regarding the capacity of the patient and the proxy to participate in the decision-making process. While improved effectiveness of substituted judgment and reduced levels of treatment preference discrepancy could be important target outcomes of more advanced FAPE models (and may be a happy consequence of our current model for some patient/proxy dyads), the goals of our current FAPE model are more modest. Successful FAPE interviews result in improved communication between the patient and proxy, greater understanding on the part of the patient and proxy about current and alternative treatments, greater understanding on the part of the proxy regarding the patient's abilities, and information for the clinician regarding the *functional* decision-making capacity of the patient/proxy dyad. Given the specialized skills psychologists possess regarding assessment, clinical interviewing, and single-subject research design, we recommend that psychologists or other mental health professionals conduct evaluations. We shall now describe FAPE evaluations as they are being conducted within the CIT Project.

The CIT Project, including the FAPE interview model, has been reviewed and approved by the University of Alabama and the University of Alabama at Birmingham institutional review boards. Patients older than age 55 who are enrolled in participating hospice or palliative care programs are eligible to participate in the CIT Project. After the study is introduced to the

patient and proxy by hospice staff, potential participants are contacted by telephone to ascertain their interest in participation. At the first visit with CIT Project staff, and prior to initiation of the FAPE interview, written informed consent for study participation is obtained. If there is any question regarding the capacity of the patient, proxy consent is obtained for the patient along with the patient's assent.

The cornerstones of FAPE interviews are the Alabama Natural Death Act ('Alabama Act 97', 1997) advance directive form and an augmented MacCAT-T. The Alabama Natural Death Act form is administered to the patient/proxy dyad first in interview format to familiarize the dyad with advance care planning topic areas for potential discussion. In the FAPE model, the MacCAT-T is still individualized to the particular circumstances of the patient and family. However, the FAPE model as used in the CIT Project uses five modifications to the standardized usage of the MacCAT-T as presented in the manual (Grisso & Appelbaum, 1998): (i) both the patient and proxy are present with the clinician during the interview; (ii) interviews are audiotaped for later transcription and analysis; (iii) external visual stimuli are available to the patient and proxy during the interview (e.g. prompt cards individualized to assist disclosure); (iv) individual interviews are conducted with the parameters that one treatment option is always palliative, or comfort, care; and (v) a menu of alternative treatments targeted to the specific concerns of the dyad are considered, perhaps including resuscitation, tube feeding, or hospitalization. In our ongoing study, we augment the MacCAT-T interview with laminated prompts and response cards for use with the patient and proxy describing palliative care and a limited menu of treatment alternatives (e.g. hospitalization, feeding tubes, emergency room visits with resuscitation).

Thoroughness is a necessity and facilitates understanding; this is why we advocate the use of prompts as environmental supports for patients and families. Our use of transcriptions of audiotape recordings of dyadic interviews builds on the case method used in civil and criminal law. Thus, *if* dyadic capacity for consent were to become an accepted legal model, true capacity evaluations could be facilitated by allowing the courts to more easily decide whether the FAPE interview meets the standard of care (Baron, 2000). Building on the S-V model (King et al., 2000), consideration is given to familial and cultural context at each step in the assessment. As such, disclosure may be couched in hypothetical terms or even limited based on the assessment of the treatment team and FAPE clinician regarding the dyad's level of comfort in directly discussing the inevitability of death.

Similar to Werth's model (Werth et al., 2000), the patient's ability to understand is assessed in relation to three areas: the actual disorder limiting life expectancy, alternative treatments, and the benefits and risks of alternative treatments. Because this is a functional capacity assessment within the family context of end-of-life decision-making, FAPE interviews within the CIT project compare and contrast palliative treatment options to one or two alternatives requiring life-sustaining medical interventions. The availability and likelihood of receiving life-sustaining treatment options is not the focus of FAPE, as these treatments may not be recommended by the patient's physician or available within the context of palliative care. Rather, the patient and proxy's capacity to understand the treatment situation and make plans is of interest.

In the FAPE model as used in the context of CIT, the clinician may opt not to fully probe the patient to determine the patient's understanding of imminent death under the following conditions: (i) the cognitive understanding of the patient as documented in the patient's medical chart regarding imminent death is limited; (ii) the proxy has been documented in the medical chart as stating that direct conversations of imminent death are unwelcome; or (iii) it becomes clear to the clinician during the FAPE interview that the patient is becoming distressed with the discussion to the point that it no longer serves a therapeutic purpose to continue. Thus, in

the FAPE model as used in CIT, if the proxy does not want the patient fully informed of his or her condition, the family's wishes are respected and disclosure is limited to the effects of illness rather than imminent death. The clinician then inquires about the patient's understanding of the disclosed information *in the presence of the proxy*. Finally, for any of the important elements regarding palliative and life-sustaining care that the patient has omitted or has described incorrectly after being probed, the clinician re-discloses that information *within the limits of the proxy's wishes due to the patient's vulnerabilities* and re-inquires about the patient's understanding.

The patient's ability to reason is also assessed in three ways. First, the patient is asked to indicate a choice between palliative care and life-sustaining treatments and to explain that choice. The clinician probes the patient's explanation in order to develop an understanding of the reasoning that was used. The proxy is present in order to gain understanding of the patient's cognitive reasoning skills. Two types of reasoning are assessed: consequential and comparative. The patient is then asked to generate consequences for both palliative care and the life-sustaining treatment option. The purpose of this is to determine whether he or she is able to translate the medical circumstances of the life-limiting illness into practical, everyday consequences. Finally, the patient is asked to make a final choice about palliative versus life-sustaining treatment and to explain the choice. The clinician probes this explanation to assess the logical consistency of the choice. Again, the proxy is present throughout this evaluation. When the patient has finished, the clinician works through the MacCAT-T interview again with the proxy while the patient is occupied with an assistant on other tasks. The focus of the MacCAT-T interview with the proxy remains on the treatment of the patient and the proxy's understanding of the patient's decisional capacity.

Ancillary Assessments

We also recommend use of additional standardized measures and clinical interviews with patients and proxies facing end-of-life treatment decisions (King et al., 2000; Werth et al., 2000). In our ongoing palliative care and hospice project, we have found that interviews up to 40 minutes in length are well tolerated by patients. Interviews up to 75 minutes in length are well tolerated by proxy caregivers. Our general assessment battery includes a visual analog pain assessment reported by the patient and the proxy, hospice quality of life assessments for both the patient and the proxy (McMillan, 1996; McMillan & Weitzner, 1998), measures of cognitive status in the patient (Folstein, Folstein, & McHugh, 1975), measures of caregiving and psychological distress in the proxy (Derogatis & Spencer, 1982; Zarit, Stephens, Townsend, & Greene, 1998), and an assessment of analgesic medication dosages (Fisher et al., 2002; Horgas & Tsai, 1998). It is our standard practice always to send two interviewers into the field. Thus, one individual can interview and then sit with the patient while the proxy completes additional interview assessments. If either party requests, the evaluation can be discontinued for 24 hours.

Benefits and Drawbacks of FAPE

There are limitations to the FAPE model. First is the fact that such interviews do not provide legal capacity evaluations for the determination of the decisional capacity of a patient at the end of his or her life. Given the emphasis in the FAPE model on familial and cultural context of decision-making at the end of life, the model does not fit readily into current legal conceptualizations of consent. A second drawback is that the evaluations can be time consuming, lasting between 30 minutes for the patient and 90 minutes for the proxy. The semi-structured method also loses some of the flexibility of the MacCAT-T in terms of its specificity to issues faced by a given dyad. Finally, FAPE evaluations conducted in the context of palliative care (i.e. as in the CIT Project) may be limited by their analog nature—discussion of treatment alternatives may improve communication within the patient/proxy dyad but have no influence

on actual treatment provision. In the context of terminal illness, physicians may not be willing to recommend life-sustaining treatments, and such treatments are not typically reimbursable palliative treatment options.

The very nature of the FAPE model and its emphasis on familial and cultural context and improving communication, however, has multiple advantages. In our clinical experience, FAPE assessments may be the only type of functional capacity evaluation possible within the end-of-life treatment context. Fully informed consent to the autonomous patient may not be possible in current medical systems (Drought & Koenig, manuscript submitted for publication, cited with permission). Indeed, our current legal model of informed consent would necessitate that, during a legal capacity evaluation, the patient (and, in the FAPE model, the proxy) must fully confront, process, and engage their mortality in a rational, primarily cognitive manner (Drought & Koenig, manuscript submitted for publication, cited with permission). Such intense explicit processing of imminent death may not be necessary to improve emotional, psychological, and spiritual outcomes for patients and proxies at the end of life. Improved communication and satisfaction with 'decision-making' may be the most useful and feasible goal of advance decision-making in end-of-life care.

Conclusion

Individuals and families facing end-of-life decision-making are in need of information and assistance. Although this developmental transition is normative, the process of discussing end of life issues often engenders high levels of distress among patients and families. Psychologists are well equipped to assist individuals and families with issues of understanding, assessment, communication, fear, anxiety, grief, and loss. Comprehensive familial advance planning evaluations and functional capacity assessments may assist families in facing these transitions. It is time that psychologists embraced their potential to utilize assessment, intervention, and research skills in the service of patients, families, and the health care system during end-of-life care.

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