ARTICLE

# A synthesis of theoretical models to guide decision support interventions for surrogate decision-making at adult end-of-life

James N. Dionne-Odom MSN RN and Marie Bakitas DNSc APRN FAAN

a Doctoral Candidate, William F. Connell School of Nursing, Boston College, MA, USA
b Associate Professor, Departments of Medicine and Anesthesiology, Geisel School of Medicine at Dartmouth, Lebanon, NH, USA

## Abstract

**Background:** Surrogate decision-makers (SDMs) take part in 1.5 million end-of-life (EOL) decisions per year. Most surrogates find the role burdensome, often do not make decisions concordant with patients' wishes and suffer negative psychological after-effects months to years subsequently.
**Objective:** To review the literature and synthesize theoretical models of surrogate decision-making at adult EOL to identify an explanatory foundation for decision support interventions.
**Design:** Literature published up to December 2011 was reviewed using PubMed, MEDLINE, CINAHL and EMBASE using the search terms "surrogate," "proxy," "end-of-life," "life support withdrawal/withholding" and "decision-making".
**Study selection:** Selection criteria included: (a) studies or integrative reports of the empirical and theoretical research relevant to EOL surrogate decision-making; (b) description of a model of how SDMs make decisions for decisionally-incapacitated adults at EOL and (c) diagrammatic depictions of SDM models specifying key concepts and theoretical relationships.
**Results:** Eight theoretical models met the selection criteria.
**Data synthesis:** Five key insights were that: 1) more consistency is needed between diagrammatic maps of surrogate decision-making and model descriptions; 2) models focused on description of concepts with a lesser focus on relational linkages and propositions; 3) there is a need for greater integration of ethical concepts and their relationships in conceptual maps; 4) there has been little emphasis on how theoretical frameworks might guide intervention development and 5) minimal attempts have been made to situate surrogate decision-making within a grander conceptual framework of decision-making.
**Conclusions**: Several theories of surrogate decision-making at adult EOL have been proposed, but further theory development is needed for these models to serve as the foundation for designing decision support interventions.

## Keywords

Decision-making, decision support interventions, decisional incapacity, end of life care, literature synthesis, patient-centered care, person-centered medicine, proxy, surrogate, theoretical models

## Correspondence address

Mr. James N. Dionne-Odom, William F. Connell School of Nursing, Boston College, 140 Commonwealth Avenue, Chestnut Hill, MA 02467, USA. E-mail: dionneod@bc.edu

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## Introduction

It has been estimated that surrogate decision-makers (SDMs) influence 1.5 million end-of-life (EOL) treatment decisions per year [1]. SDMs are expected to make these decisions for a decisionally-incapacitated loved one according to one of 3 ethical standards including stated wishes, best interest and reasonable person standards [2]. The underlying impetus of this autonomy-centric, 3-standard hierarchy is that medical treatments ought to approximate as closely as possible to the decisions a person would have made if they had the capacity to do so [3]. For the past 3 decades, this 3-standard model has served implicitly as the theoretical basis upon which SDM research and interventions have been based [4-6]. Yet growing empirical evidence indicates that this goal of concordant decision-making between SDMs and patients may not be realistic [7]. Researchers have found that SDMs poorly predict patient preferences [8-10], use different criteria than patients for identifying treatment preferences [8], have different perceptions of illness states than patients [9,11] and allow their own preferences for treatment to bias their decisions for the patient's care [12-14]. Despite the overwhelming evidence of the inadequacy of this 3-standard model, the research and intervention

development *agendum* continues to be based on this framework [5,15].

Because the 3-standard model of surrogate decision-making has performed sub-optimally, it is imperative to develop and identify alternative theoretical frameworks upon which interventions can be based. A key element of moving this agenda forward is the notion that scientifically rigorous testing of theoretically-based interventions should explicitly specify the underlying concepts and the mechanisms of their relationships [16,17]. Hence, the purpose of this article is to synthesize existing theoretical models of surrogate decision-making applicable to adult EOL in order to assess their progress and usefulness and to identify areas of improvement in order to begin the crafting of interventions that assist the SDM population.

## Methods

### Literature review definitions and search strategies

For the purposes of identifying and analyzing articles in this review, the following assumptions were used: A *theory* or *theoretical model* is regarded as a network of relatively concrete *concepts* linked together by specific relationships and set within a particular socio-cultural context [18]. Theoretical models are depicted diagrammatically in a conceptual map, which are also sometimes called nomological nets or path diagrams [19]. Relationships that link concepts are made explicit by *relational propositions*, which can describe the direction, shape, strength, symmetry, sequencing, probability of occurrence, necessity and sufficiency of a relationship between concepts in a nomological net [20]. Relational propositions should be sufficiently reflected in a theory's conceptual map. *Concepts* or constructs are words that represent key phenomena or essential characteristics of a phenomenon [21]. In contrast to a theoretical model, a *conceptual model* is a set of 2 or more relatively abstract concepts that have very loosely specified relationships. Fawcett [18] notes how conceptual models are often the precursors to theoretical models. In this same vein, theories can be identified along a spectrum ranging from abstract to concrete. Theoretical models are more concrete than conceptual models. *Grand theories* are more abstract than *middle range theories*, but less abstract than conceptual models [21]. In general, theoretical models serve to enhance the intelligibility of events and phenomena, to predict phenomena to a degree greater than chance and to serve as the basis for interventions [20-23].

We used Elwyn *et al.*'s [17] review of theoretical models of decision-making used in the development of decision aid supports to guide the current review. The first author (JND) searched PubMed, MEDLINE, CINAHL and EMBASE databases using various combinations of the search terms "surrogate", "proxy", "end-of-life", "life support withdrawal/withholding" and "decision-making" for all years up to 2011. Article reference lists were reviewed for additional reports. Selection criteria included: (a) studies or integrative reports of the empirical and theoretical research relevant to EOL surrogate decision-making; (b) description of a model of how SDMs make decisions for decisionally-incapacitated adults at EOL and (c) diagrammatic depictions of SDM models specifying key concepts and theoretical relationships. Articles focusing upon decision-making for decisionally-incapacitated children were excluded.

### Data extraction and data analysis

Relevant manuscripts that included theoretical models of surrogate decision-making were compiled into a data matrix (Table 1), which included authorship, methodology of theory construction, sample if applicable, theory focus and delineation of major and minor concepts of the model. The models were appraised for their suitability in the design of theory-based interventions. Theories were evaluated regarding their selection and ample description of concepts, their description of relational statements linking concepts, the degree to which conceptual maps were reflective of the literal articulation of concepts and conceptual relations and the degree to which authors of these theoretical models specified use of the model for possible measurement and intervention development.

## Results and Analysis

Eight manuscripts proposing 8 different theoretical frameworks met the selection criteria. Five theoretical models were developed using grounded theory approaches [15,24-27]. Of these, one cited using a ground theory approach in order to analyze a meta-synthesis of 14 qualitative studies [27]. The other 4 theories were developed using primary data collection by conducting face-to-face interviews and used grounded theory approaches (e.g., constant comparative analysis to analyze transcribed interviews). Two of the theoretical models were developed from other grander theories and had concepts further specified using support from the empirical and conceptual literature [1,28]. The model proposed by Wiegand, Deatrick and Knafl [29] was generated using a hermeneutic phenomenological approach.

Each theoretical model evidenced a distinctive scope and focus with which they attempted to capture the experience of surrogate decision-making. Two were framed at the level of the individual surrogate decision-maker [24,26]. Four of the models were conceived around the dynamics of interpersonal relations, locating the SDM within a network of family relations and family-healthcare team relations [15,25,27,29]. Two models used a systems perspective that included the surrogate, family, clinicians and environment [1,28].

In the following, a brief summary description of each of the 8 theoretical models of surrogate decision-making is given in alphabetical order of the lead author's last name. The reader is referred to Table 1 for the summary focus and key major and minor concepts of each theory.

Table 1 Published reports outlining theoretical models of the decision-making process of surrogates applicable to adult end-of-life

| Author(s) and citation | Method of theory development and sample (if applicable) | Summary focus | Key major and minor concepts of model | |
|---|---|---|---|---|
| Buckey and Abell, [1] | Developed from the Health Belief Model along with integration of empirical literature | Demographic characteristics, sociopsychological attributes and beliefs and physician-patient communication impact degree to which SDM perceives treatment as advantageous or disadvantageous. | • Physician and patient communication<br>• Age<br>• Education<br>• Gender<br>• Race-Ethnicity | • Religiosity-Spirituality<br>• Social Support<br>• Self-Efficacy<br>• SDM perception of Treatments as Benefits/Advantageous *vs.* Barriers/Disadvantageous |
| Caron, Griffith, and Arcand, [24] | Grounded theory, N=24 SDMs of dementia patients | Decision-making role is impacted by 1) the context of the interactions with the medical team, 2) the character of the treatment, 3) the family context and personal factors related to, 4) the dementia patient and 5) the caregiver (SDM) | • Decision-making<br>o Collaborative<br>o Unilateral<br>o Delegated<br>• Person with Dementia Dimensions<br>o General health<br>o Expressed wishes<br>o Stage of disease<br>o Quality of Life<br>• Caregiver (SDM) Dimensions<br>o Schema(s) of references<br>o Values<br>o Nature of relationship with patient<br>o Interpretation of experience | • Context of Interactions with Medical Team<br>o Quality of relationship<br>o Frequency of contact<br>o Level of trust<br>o Values and beliefs<br>• Family Context<br>o Absence of family ties<br>o Facilitating - supportive<br>o Conflictual – problematic<br>• Treatment<br>o Invasiveness<br>o Side effects<br>o Contribution or not to quality of life |
| Colclough and Young, [25] | Grounded theory, N=22 Japanese American family members | Age similarities and differences and the involvement of healthcare providers affect 4 dimensions of family understanding | • Age cohorts of SDMs (less than 70 years old and greater than 70 years old)<br>• Healthcare providers | • 4 Dimensions of Family Understanding<br>o Awareness of Seriousness of Condition<br>o Decision-making process<br>o Readiness for impending death<br>o Experience of dying process |
| Limerick, [26] | Grounded theory, N=17 SDMs | Decisions to withhold/withdraw LST are a result of actions undertaken by SDMs within a personal domain and an ICU environment | • Event triggering surrogate decision-making status<br>• SDM Personal Domain<br>o Rallying of family support, information sharing<br>o SDM Evaluation of patient condition | • ICU Environment Domain<br>o SDM seeks information from the healthcare team<br>o SDM develops relationship with the healthcare team<br>o Discusses the patient's potential outcome |

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| | | domain | o Realization of past and future patient quality of life | from healthcare team's perspective<br>• Coming to the Final Decision<br>o SDM arrives at belief about futility<br>o Inward reflection<br>o Makes and communicates decision |
| Meeker and Jezewski, [27] | Meta-synthesis of 14 qualitative studies using grounded theory | Family decision-making to withhold/withdraw LST involves 3 core processes including reframing reality, integrating and relating | • Reframing reality<br>o Cues<br>o Information<br>• Relating<br>o Family<br>o Providers | • Integrating<br>o Reconciling<br>o Going On |
| Radwany *et al*., [15] | Grounded theory, N=23 family members | How family meetings and emotional burden impact the decision-making process over time | • Illness Experience<br>o Understanding of the medical condition<br>o Occurrence of critical incident<br>• Family Meeting<br>o Preparation<br>o Support for decision-making<br>• Dying Process<br>o Information about the dying process<br>o Degree of consistency between decisions and care | • Emotional Burden<br>o Lingering issues or questions<br>o Resentment toward providers<br>o Decision guilt<br>• Time |
| White, [28] | Developed from the Donabedian structure-process-outcome theory and further specified by the conceptual and empirical literature | How barriers stemming from the family, the clinical team and the structure/process of care impact the optimal functioning of each in affecting good and bad outcomes of decision-making | • Family Barriers<br>o Emotional distress<br>o Uncertainty about patient's preferences<br>o Personal desires about goals for patients<br>o Intrafamily conflict<br>o Spiritual/moral concerns about stopping life support<br>o Distrust of clinicians<br>• Clinical Team Barriers<br>o Inadequate communication skills<br>o Lack of interest<br>o Cultural orientation toward "life extension/rescue"<br>o Personal moral beliefs about appropriate end-of-life care<br>o Inadequate attention to emotional and moral considerations<br>• Structural/Process of Care Barriers | • Ideal Surrogates<br>o Manages strong emotions<br>o Accurately understands and conveys patient's values<br>o Comprehends key medical information<br>o Authorizes decisions that promote patient's interests<br>• Ideal Clinical Team<br>o Accept diverse goals of care<br>o Effectively communicate prognostic information<br>o Present treatment options without undo bias<br>o Deliberate with surrogates<br>o Provide emotional and moral support<br>• Ideal Structure/Process of Care<br>o Early and timely communication<br>o Clinician continuity<br>o Convenient space for meetings<br>• Multidisciplinary involvement Mutual trust and |

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|---|---|---|---|---|
| | | | ○ Clinical turnover<br>○ Time constraints<br>○ Lack of convenient space for family meetings<br>○ Lack of timely/regular communication<br>○ Failure to include key members of family/team | respect<br>• Decision-making<br>• Good outcomes<br>○ Patient-centered decisions about life support<br>○ Health grieving<br>○ Appropriate resource use<br>• Bad outcomes<br>○ Nonpatient-centered decisions about life support<br>○ Adverse psychiatric sequelae for surrogates<br>○ Inappropriate resource use |
| Wiegand, Deatrick, & Knafl, [29] | Hermeneutic phenomenology, N=56 family members representing 19 families | How family management styles both affect and are affected by how family members define the situation, the management behaviors of families and the various consequences of the decision-making experience | • Definition of the Situation<br>○ View of the person<br>○ Illness/injury view<br>○ Management mindset/family readiness<br>○ Family mutuality<br>• Management behaviors<br>○ Family philosophy<br>○ Family interaction<br>○ Family presence<br>○ Preparing for death | • Consequences<br>○ Physiological effects<br>○ Emotive responses<br>○ LST withheld<br>○ LST withdrawn<br>• Family Members<br>• Family management style<br>○ Progressing<br>○ Accommodating<br>○ Maintaining<br>○ Struggling<br>○ Floundering |

### Buckey and Abell (2010): Surrogate decision-making framework based upon the health belief model

The theoretical model of surrogate decision-making proposed by Buckey and Abell (2010) is based upon the Health Belief Model (HBM) and is further specified by a review of the empirical literature. The HBM model was chosen by the authors due to one of its core tenets that individuals partake in actions that are believed to achieve an expected goal. Buckey and Abell's theoretical model was a prediction model that the authors developed primarily for use in a descriptive, cross-sectional survey in order to address the research question of whether surrogates' personal attributes, perceptions of communication, social support and self-efficacy influenced their life-sustaining treatment decisions. A variety of concepts were operationalized into measured variables that were used to predict the degree to which a surrogate perceived a treatment to be advantageous or disadvantageous to the decisionally-incapacitated patient. These variables fell into categories of demographic characteristics, socio-psychological attributes and beliefs and structural influences.

### Caron, Griffith and Arcand (2005): Dimensions associated with decision-making at the end-of-life of a relative with dementia

A grounded theory approach using a sample of 24 caregivers of dementia patients was used to generate 2 theoretical models: 1) the key factors caregivers of dementia patients took into account in their EOL decision-making and 2) the different phases of EOL decision-making. Regarding the former, key factors were grouped under 5 main dimensions that included factors associated with the person with dementia, factors associated with the caregiver, treatment considerations, family context and interactions with healthcare providers. This first model depicts how the combination of these factors under these dimensions impacts whether the surrogate's decision-making was "collaborative", "unilateral" or "delegated". The second model depicted 4 phases of the decision-making process including a transitory phase, curative phase, phase of uncertainty and palliative phase, which are defined by the family caregiver's perceived degree of quality of life of the patient. The model highlights how the type of care a patient receives is mostly dependent upon how high or low his or her quality of life is deemed to be by the SDM.

### Colclough and Young (2007): The four dimensions of family understanding in end-of-life decision-making among Japanese American families

Colclough and Young (2007) also used a grounded theory approach to interview 22 Japanese American family members in order to generate a theoretical model that focused on the impact that 1) age similarities and differences of individuals either less or greater than 70 years of age and 2) the involvement of healthcare providers had upon 4 dimensions of family understanding, which could range from high to low. These dimensions included awareness of the seriousness of the condition, the decision-making process, the readiness for impending death and the experience of the dying process. Within each dimension, the authors comprehensively described the components of each dimension which included further sub-components although these were not included in their conceptual map.

### Limerick (2007): The process used by surrogate decision-makers to withhold and withdraw life-sustaining measures in an intensive care unit environment

Interviews with 17 surrogates who decided to withhold or withdraw life-sustaining measures in the intensive care unit were analyzed using a grounded theory approach and used to generate a model that depicts the process individuals go through to make a decision to withhold or withdraw life-sustaining treatment. The process oriented model begins with an event that initiates surrogate decision-making status. From here the individual interacts within and between 2 main domains, the personal and the ICU environment. Within each of these domains are actions (see Table 1) undertaken by the surrogate that impact the final stage of the process, the decision domain, which includes 3 components: believing that LST is futile, inward reflection and making and communicating a decision.

### Meeker and Jezewski (2009): Meta-synthesis of family participation in decision-making to withhold or withdraw life-sustaining treatment

Meeker and Jezewski conducted a meta-synthesis of 14 qualitative studies using a grounded theory approach in order to generate a theoretical model consisting of 3 major, mutually interacting process categories including "reframing reality", "relating" and "integrating". Each of these categories had 2 sub-themes: "reframing reality" included "cues" and "information"; "integrating" included "reconciling" and "going on" and "relating" included "family" and "providers". Meeker and Jezewski's (2009) abstract and parsimonious conceptual map was complimented by an extensive description of each concept.

### Radwany *et al.* (2009): Theoretical model of end-of-life decision-making and emotional burden

Using grounded theory methods, Radwany *et al.* (2009) interviewed 23 family members who had acted as SDMs for a relative at EOL and who had also participated in a structured family meeting with palliative care clinicians in order to talk about those decisions. The theoretical model is oriented temporally having 3 distinct stages including "the illness experience", "decision-making in the family meeting" and "the dying process". Each of these stages includes 2 main themes which could be described as key tasks. The model emphasizes the role of emotional burden endured by surrogates and its impact on the transition from one phase to the next and upon the decision-making outcome.

### White (2011): Multi-dimensional framework of the barriers to high quality surrogate decision-making in the ICU

This theoretical model of surrogate decision-making is based upon the Donabedian structure-process-outcome theory and further specified by a review of the conceptual and empirical literature. The model depicts how dimensions of ideal surrogates, ideal clinical teams and ideal structure/processes of care are reciprocally supported by mutual trust and respect. These ideal dimensions are, however, negatively impacted by dimensions of family, clinical team and structure/process barriers. Both the ideal and barrier sets of dimensions are further characterized by multiple concepts (see Table 1). In addition, the model specifies good and bad outcomes resulting from the decision-making of surrogates.

### Wiegand, Deatrick and Knafl (2008): Family management styles of withdrawing life-sustaining therapy

A hermeneutic phenomenological research design using a sample of 56 family members representing 19 families was used to develop a model of different family management styles related to how surrogates decided to withhold or withdraw life-sustaining therapy. A typology of 5 family management styles is described including progressing, accommodating, maintaining, struggling and floundering. The major components that characterize the particular family management style include how the family defines the situation, the management behaviors and the perceived consequences of the actual or expected outcomes.

## Discussion

The purpose of this synthesis was to identify and evaluate theoretical models of surrogate decision-making to determine their usefulness in serving as frameworks from which to craft decision support interventions to improve the experience and performance of SDMs. Intervention developers use theoretical models as road maps for conceptualizing the design of an intervention and as guides in the identification of both modifiable mechanisms and appropriate outcome and process indicators [19,22]. In our analysis, we found a disconnect between theories of surrogate decision-making and development of theory-based interventions to improve outcomes related to EOL surrogate decision-making.

To our knowledge, none of the theories we examined has been used explicitly to test interventions, although Radwany *et al.*'s incorporated an intervention within their theory and only one has formally attempted to test and develop clinical measures of the relevant concepts and conceptual relations [1]. Most of the theoretical models with the exception of White were not explicitly intended by authors for the purpose of developing interventions. That others have not yet applied these theories in this way is not surprising given that most were developed recently. Therefore, this discussion highlights 5 key insights and reflects upon the traits of these models in terms of guiding intervention development.

### More Consistency is needed between Diagrammatic Maps of Surrogate Decision-Making and Model Descriptions

The mechanics of how the SDM decision-making process operates was only minimally illustrated in the conceptual maps of their theoretical models. Most authors provided detailed descriptions of concepts and conceptual relationships that were not included in their conceptual maps. White's model depicted an exhaustive list of concepts relevant to the surrogate experience which might seemingly be an exception in this regard; however, there is minimal representation in the model and little discussion specifying the particular relationships between these concepts. The dynamics of decision-making was often completely absent in conceptual maps. For example, the mechanics of a deliberation process where information, values and choice options were weighed and processed were mostly absent in over half of the identified models.

### Models Focused on Description of Concepts with a Lesser Focus on Relational Linkages and Propositions

Theoretical model descriptions were centrally focused on a systematic detailing of concepts in their model and not on the complexity and character of relationships existing between and among concepts in their conceptual maps. In general, there was little to no methodical listing of relational propositions that described the direction, shape, strength, symmetry, sequencing, probability of occurrence, necessity and sufficiency of relationships among concepts. Without such precise specification of relational linkages, it was difficult to discern whether a *process* was being

represented in most of the authors' conceptual maps. One exception was Limerick's [26] process oriented theoretical model. It was also notable that Bucky and Abell [1] did statistically test the hypothesized relationships between their predictor concepts and the degree to which SDMs perceived a treatment as advantageous or burdensome. However, Colclough and Young [25] devote an entire section to the systematic discussion of the relationships among concepts in their model and yet their discussion was not inclusive of all the concepts in their conceptual map. Given that most of the identified theoretical models were descriptive in nature, Burns and Grove [20] note that such early stage models are typically evidence sparse in their discussion of relational propositions between concepts. However, interventions need to be based upon fully characterized conceptual relationships, because it is essentially these relationships that get tested through interventional research [19,20].

### There is a Need for Greater Integration of Ethical Concepts and their Relationships in Conceptual Maps

As mentioned in the introduction, the 3-standard model is an inadequate ethical foundation upon which to base expectations about how surrogate decision-making should be performed. SDMs often suffer negative after-effects related to guilt, shame and rumination upon whether they had done the "right" thing for this patient. Thus, it is imperative that theoretical models of surrogate decision-making attempt to incorporate how concepts related to ethics and values operate in this process. However, though often literally discussed, over half of the authors' conceptual maps completely lacked concepts related to values and ethical concerns. Although White's model had concepts related to ethics and values such as "Spiritual/moral concerns about stopping life support" and "Accurately understands and conveys patient's values", it remained unclear from the model how these ethical and moral concepts operated cognitively and psychosocially and in relationship to other concepts in their map. In their conceptual map, Caron, Griffith and Arcand similarly depicted a concept called "values and beliefs", but again there was no indication of how this concept interacted with other phenomena.

### There has been Little Emphasis on how Theoretical Frameworks Might Aid Intervention Development

Consistent with Elwyn *et al*.'s [17] findings from their review of decision-making theories, the primary aims of authors developing surrogate decision-making theories have focussed on depicting how decision-making occurs, rather than describing how key concepts and their relationships could be developed into measures and interventions. It behooves the researchers working with these kinds of theoretical frameworks to specify in their discussions how they think interventions and confirmatory type research might be developed based upon their theories. In this regard, only White [28] focused extensively on how interventions could be developed from his theoretical model. Buckey and Abell's [1] theoretical model was tested using survey instruments and thus was able to test several measures important to surrogate decision-making. Otherwise, discussions of how interventions and measures could be based upon theoretical models were brief or absent.

### Minimal attempts have been made to situate Surrogate Decision-Making within a Grander Conceptual Framework of Decision-Making

Buckey and Abell's (2010) and White's (2011) theoretical models were the only 2 models that were conceptualized in part based upon grander conceptual models. The process of formulating a middle range theory from a grand theory or conceptual framework has been noted in the literature to have the advantages of comprehensively accounting for the major concepts and relationships of a topical area instead of naively or prematurely claiming that "not much is known" [30,31]. As noted by Elwyn *et al*. [17], it may be the case that theory developers are simply unaware of the plethora of decision-making conceptual frameworks in existence.

## Conclusion

There is a critical need for theory-based interventions targeting the optimization of the decision-making role and processes of SDMs in light of the mounting criticisms and research indicating the inability of many SDMs to serve their expected purpose. This is pressing in the context of a healthcare system that will have to accommodate a projected doubling of the population of older adults by 2030 [32], many of who will inevitably become decisionally incapacitated. Given the significant impact of the SDM role on caregiver and patient outcomes, a review and analysis of 8 theoretical models of surrogate decision-making was undertaken in order to offer possible reasons why theoretical models of surrogate decision-making have yet to spawn theory-based interventions that do not implicitly rely exclusively on the 3-standard model. We found that although several theories of surrogate decision-making at adult EOL have been proposed, further theory development and refinement is needed for design of decision support interventions.

Hence, the following concluding recommendations are given to advance the state of the science. First, theoretical maps need to reflect the complexity of surrogates' decision-making processes as described in researchers' studies and the greater empirical literature. Comprehensive theoretical frameworks are needed in order to address all of the design requirements of decision support interventions. Second, the various concepts in a theoretical framework

upon which decision support interventions might be based need to have relational propositions specified and a time-process orientation in order to allow interventionists to target people and variables at particular critical points in time that would most enhance outcomes [33]. Third, ethical and normative concepts and their mechanics need to be integrated into theoretical frameworks. Fourthly, researchers should emphasize how their theoretical framework could advance intervention development. Finally, researchers and theory developers should consider currently available conceptual and grand theory frameworks of decision-making (e.g., prospect theory, fuzzy-trace theory, affective forecasting theory, *etc*.) as they formulate middle range theories of surrogate decision-making.

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## References

[1] Buckey, J. & Abell, N. (2010). Life-Sustaining Treatment Decisions: A Social Work Response to Meet Needs of Health Care Surrogates. *Journal of Social Work in End-of-life and Palliative Care* 6 (1-2) 27-50.
[2] Beauchamp, T. & Childress, J. (2009). Principles of Biomedical Ethics. Sixth ed. New York: Oxford University Press.
[3] Buchanan, A. & Brock, D. (1990). Deciding for Others: The Ethics of Surrogate Decision Making. New York: Cambridge University Press.
[4] Jonsen, A. (1998). The Birth of Bioethics. New York: Oxford University Press.
[5] Berger, J., DeRenzo, E. & Schwartz, J. (2008). Surrogate Decision Making: Reconciling Ethical Theory and Clinical Practice. *Annals of Internal Medicine* 149 (1) 48-53.
[6] Shapiro, S. (2007). When Life Imitates Art: Surrogate Decision Making at the End of Life. *Topics in Stroke Rehabilitation* 14 (4) 80-92.
[7] Dionne-Odom, J. & Bakitas, M. (2012). Why Surrogates Don't Make Decisions the Way We Think They Ought To: Insights from Moral Psychology. *Journal of Hospice and Palliative Care Nursing* 14 (2) 99-106.
[8] Pruchno, R.A. (2006). Predictors of Patient Treatment Preferences and Spouse Substituted Judgments: The Case of Dialysis Continuation. *Medical Decision Making* 26 (2) 112-121.
[9] Fried, T.R., Bradley, E. & Towle, V.R. (2003). Valuing the Outcomes of Treatment: Do Patients and Their Caregivers Agree? *Archives of Internal Medicine* 163 (17) 2073-2078.
[10] Shalowitz, D.I., Garrett-Mayer, E. & Wendler, D. (2006). The Accuracy of Surrogate Decision Makers: a systematic review. *Archives of Internal Medicine* 166 (5) 493-497.
[11] Phillips, W.T., Alexander, J.L., Pepin, V. & Riley, C. (2003). Cardiac Rehabilitation Patient Versus Proxy Quality-of-Life Perceptions. *Clinical Nursing Research* 12 (3) 282-293.
[12] Marks, M.A.Z. & Arkes, H.R. (2008). Patient and Surrogate Disagreement in End-of-Life Decisions: Can Surrogates Accurately Predict Patients' Preferences? *Medical Decision Making* 28 (4) 524-531.
[13] Ditto, P.H., Danks, J.H., Smucker, W.D., Bookwala, J., Coppola, K.M., Dresser, R., Fagerlin, A., Gready, R.M., Houts, R.M., Lockhart, L.K. & Zyzanski, S. (2001). Advance Directives as Acts of Communication: A Randomized Controlled Trial. *Archives of Internal Medicine* 161 (3) 421-430.
[14] Fagerlin, A., Ditto, P.H., Danks, J.H. & Renate, M.H. (2001). Projection in Surrogate Decisions About Life-Sustaining Medical Treatments. *Health Psychology* 20 (3) 166-175.
[15] Radwany, S., Albanese, T., Clough, L., Sims, L., Mason, H. & Jahangiri, S. (2009). End-of-life Decision Making and Emotional Burden: Placing Family Meetings in Context. *American Journal of Hospice and Palliative Care* 26 (5) 376-383.
[16] Charles, C., Gafni, A., Whelan, T. & O'Brien, M.A. (2005). Treatment decision aids: conceptual issues and future directions. *Health Expectations* 8 (2) 114-125.
[17] Elwyn, G., Stiel, M., Durand, M-A. & Boivin, J. (2011). The design of patient decision support interventions: addressing the theory-practice gap. *Journal of Evaluation in Clinical Practice*. 17 (4) 565-574.
[18] Fawcett, J. (1999). The Relationship of Theory and Research. Third ed. Philadelphia: F. A. Davis.
[19] Shadish, W., Cook, T. & Campbell, D. (2002). Experimental and Quasi-Experimental Designs for Generalized Causal Inference. Belmont: Wadsworth.
[20] Burns, N. & Grove, S. (2009). The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence. Sixth ed. St. Louis: Saunders Elsevier.
[21] Fawcett, J. (2005). Criteria for Evaluation of Theory. *Nursing Science Quarterly* 18 (2) 131-135.
[22] Conn, V., Rantz, M., Wipke-Tevis, D. & Maas, M. (2001). Designing Effective Nursing Interventions. *Research in Nursing and Health* 24 (5) 433-442.
[23] Wu, H-L. & Volker, D. (2009). The use of theory in qualitative approaches to research: application in end-of-life studies. *Journal of Advanced Nursing* 65 (12) 2719-2732.
[24] Caron, C., Griffith, J. & Arcand, M. (2005). End-of-life decision making in dementia: The perspective of family caregivers. *Dementia* 4 (1) 113-136.
[25] Colclough, Y. & Young, H. (2007). Decision Making at End of Life Among Japanese American Families. *Journal of Family Nursing* 13 (2) 201-225.
[26] Limerick, M. (2007). The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Environment. *Oncology Nursing Forum* 34 (2) 331-339.
[27] Meeker, M.A. & Jezewski, M.A. (2009). Metasynthesis: withdrawing life-sustaining treatments: the

experience of family decision-makers. *Journal of Clinical Nursing* 18 (2) 163-173.
[28] White, D. (2011). Rethinking Interventions to Improve Surrogate Decision Making in Intensive Care Units. *American Journal of Critical Care* 20 (3) 252-257.
[29] Wiegand, D., Deatrick, J. & Knafl, K. (2008). Family Management Styles Related to Withdrawal of Life-Sustaining Therapy From Adults Who Are Acutely Ill or Injured. *Journal of Family Nursing* 14 (1) 16-32.
[30] Siggelkow, N. (2007). Persuasion with Case Studies. *Academy of Management Journal* 50 (1) 20-24.
[31] Corbin, J. & Strauss, A. (2008). Basics of Qualitative Research. Third ed. Los Angeles: Sage Publications, Inc.
[32] Angus, D., Barnato, A., Linde-Zwirble, W., Weissfeld, L., Watson, S., Rickert, T., Rubenfeld, G.D. & Robert Wood Johnson Foundation ICI End-of-Life Peer Group. (2004). Use of intensive care at the end of life in the United States: An epidemiologic study. *Critical Care Medicine* 32 (3) 638-643.
[33] Henly, S., Wyman, J. & Findorff, M. (2011). Health and Illness Over Time: The Trajectory Perspective in Nursing Science. *Nursing Research* 60 (Supplement 3) S5-14.