Published in final edited form as:

Appl Nurs Res. 2012 November ; 25(4): 271–275. doi:10.1016/j.apnr.2011.03.003.

Decisional conflict and regret: Consequences of surrogate decision-making for the chronically critically ill

Ronald L. Hickman Jr., PhD, RN, ACNP-BC [Lecturer and Clinical Research Scholar],
Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH

Barbara J. Daly, PhD, RN, FAAN [Professor], and
Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH

Eunsuk Lee, PhDc, RN [Doctoral Student]
Frances Payne Bolton School of Nursing, Case Western Reserve University, Cleveland, OH

1. Introduction

Chronic critical illness amplifies the complexity of shared decision-making. Spanning a range of clinical characteristics, chronic critical illness affects 297,000 patients each year and will impact more than 600,000 patients by year 2020 (Zilberberg, De Wit, Pirone, & Shorr, 2008; Zilberberg, Luippold, & Sulsky, 2008). The incidence of impaired cognitive status in chronically critically ill (CCI) patients adds to the complexity of the shared decision-making process by preventing the CCI patient from making collaborative healthcare decisions with critical care clinicians (Camhi et al., 2009; Daly et al., 2010; J. Nelson et al., 2004).

For those CCI patients with impaired cognitive status, a surrogate decision maker (SDM), a family member or legal representative, will often interact with critical care clinicians to make healthcare decisions on behalf of the patient. There is more than three decades of research on the needs of family members and SDMs exist. Most of this research underscore the need for psychological and decisional support to facilitate shared decision-making in the intensive care unit (Leske, 1986; Molter, 1979; J Nelson, Kinjo, Meier, Ahmad, & Morrison, 2005; Shelton, Dea Moore, Socaris, Gao, & Dowling, 2010). However, there is insufficient evidence on how to the best provide decisional support to SDMs of the CCI.

Ineffective or non-existent support from critical care clinicians may predisposes patients to decisional conflict. O'Connor and Jacobsen (2007) comment that decisional conflict, a state of uncertainty about a course of action or decision, may arise from several conditions: inadequate informational and psychological support, social pressures or norms that favor certain choices, limited time for careful deliberation, and unclear explanations from healthcare professionals about possible alternatives and their consequences(O'Connor, 2002;

© 2011 Elsevier Inc. All rights reserved.

Corresponding Author: Ronald L. Hickman, Jr., PhD, RN, ACNP-BC, Address: 10900 Euclid Avenue, Cleveland, OH 44106-4904, Ronald.Hickman@case.edu, Telephone: 216 368-2147, Fax: 216 368-5989.

Funding Disclosure: This publication was made possible by grant KL2RR024990 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research. Its contents are solely the responsibility of the author and do not necessarily represent the official view of the NCRR or the NIH.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

O'Connor & Jacobsen, 2007)(Guerriere & Llewellyn-Thomas, 2001; O'Connor, 1995). When these conditions are not addressed, patients and potentially SDMs are more likely to experience decisional conflict.

The appraisal of decisional conflict may position SDMs for an increased risk of making healthcare decisions that are not aligned with the patient's healthcare preferences and enhance the SDM's likelihood of experiencing negative postdecision consequences. The impact of decisional conflict on decisional outcomes, such as decisional regret, delayed decision-making, and postdecision quality of life, has been established in patients faced with making healthcare decisions for themselves (O'Connor, 2010). However, there is limited evidence concerning the influence of decisional conflict on decision regret among SDMs involved in making critical choices for CCI patients.

According to Brehaut et al (2003), decision regret is a decisional consequence characterized by a feeling of self-blame or disappointment regarding a choice that failed to produce a desired outcome. The association between decisional conflict and decision regret has been examined among patients, yet it is unclear if this association between decisional conflict and decision regret exists among SDMs. It is known that that surrogate decision-making for a CCI patient differs from making a decision for one's own self (Wendler & Rid, 2011). However, we postulate three conditions that may enhance decisional conflict and decision regret in SDMs of cognitively impaired CCI: first, insufficient foreknowledge regarding the patient's healthcare preferences; second, low decision-making self-efficacy associated with the probability of making a decision error, and third, a heightened sense of self-blame and disappointment related to the responsibility of being the patient's SDM. Although these differences in the surrogate decision-making have not yet been studied in detail, descriptive exploration into the perceptions of the decision-making experience and its consequences is fully warranted among SDMs of CCI patients.

1.1 Study purpose

This preliminary study focuses on the understudied area of decision science and is as a first step in understanding the association between decision conflict and decision regret. Therefore, the purposes of the preliminary investigation were to: describe the incidence of decisional conflict and decision regret; examine the predictive associations between subscale scores of the decisional conflict scale and decision regret scores; and report the decisional support preferences of SDMs of CCI patients.

2. Methods

2.1. Design

This is an exploratory, cross-sectional, survey study. A convenience sample of SDMs was recruited from a neuroscience, surgical, and medical intensive care unit at an academic medical center in Northeast, Ohio. Recruitment of participants was conducted from July, 2009 to May, 2010.

2.2. Sample

Participants were 18 years of age and older; able to speak and understand English; and recognized by the healthcare team as the primary SDM responsible for making a healthcare decision (in this study, placement of a tracheostomy or feeding tube) for a decisionally impaired CCI patient. Critically ill patients were classified as CCI based on the following criteria: at least 18 years of age; requiring an ICU stay of at least 72 hours; lacking the ability to participate in decision-making as evaluated by an ICU attending physician, and requiring a decision with regard to the placement of tracheostomy and/or feeding tube.

2. 3. Measures

Decisional Conflict Scale (DCS)—This 16-item scale captures factors associated with decisional conflict or uncertainty. The DCS has three subscales: decisional uncertainty, factors that contribute to uncertainty, and perceived effective decision. Each of these items are scored on a five-point Likert Scale scored from 1 (strongly agree) to 5 (strongly disagree). Subscales scores were calculated in these steps: reverse scoring the five negatively phrased items (1, 3, 7, 10, and 11); estimating the mean scores for each subscale; subtracting 1 from each mean subscale score and then multiplying the subscale scores by 25 (Koedoot et al., 2001; O'Connor, 2010). Total subscale scores range from 0 to 100, and higher subscales indicate greater severity of decisional uncertainty, greater contributors to uncertainty, and greater perceived ineffectiveness of the decision-making process (O'Connor, 1995, 2010). The DCS has established reliability and construct validity in several samples of patients; however, reliability and validity have not been evaluated among SDMs (O'Connor, 1995, 2010; O'Connor & Jacobsen, 2007).

Decision Regret Scale (DRS)—A reliable and valid measure of decision regret in patients, the DRS, assesses the decision maker's remorse or regret associated with a healthcare decision (Brehaut et al., 2003; Davison, Parker, & Goldenberg, 2004; Sheehan, Sherman, Lam, & Boyages, 2007). The DRS is a 5-item scale that asks subjects to reflect on a particular decision and then rate each item on a 5 point scale from 1 (strongly agree) to 5 (strongly disagree). A total DRS score is derived from reverse scoring items 2 and 4, calculating a mean score, and transforming the mean scores by subtracting 1 and then multiplying by 25. The total DRS scores range from 0 to 100 and higher scores indicate a greater appraisal of decision regret.

Assessment of Decision Support Preferences—A single item, "What is your preference for receiving information or decision support?" was utilized to capture the preferences for the delivery of decision support interventions in this clinical sample. Participants were instructed to choose only one preferred method of receiving informational and decisional support.

2. 4. Procedures

Subject Screening and Recruitment—Prior to the conduct of this clinical research, the procedures for this study were reviewed and approved by the institutional review board (IRB) at the recruitment site. Screening of critically ill patients was conducted each weekday by research assistants (RAs) to identify eligible criteria for SDMs. When the RA identified a patient who met all of the screening criteria, the patient's cognitive status and the need for a tracheostomy or feeding tube were discussed with the attending critical care physician. The ICU attending physician then confirmed the decision about a trach or feeding tube was made by the patient's SDM and then RA approached the eligible SDM to participate in this study. Once informed consent was obtained, the participant completed the study questionnaires.

Data Collection—A structured interview format was used to administer the study questionnaires to participants at enrollment. Participants were administered a demographic form, DCS, and DRS, in this order, within five days after making a healthcare decision for a CCI patient.

2.5. Data Analysis

Data were analyzed using the Statistical Package for Social Sciences (SPSS; version 19, Somers, NY). Descriptive statistics, bivariate correlations, and a multiple regression analysis were used to address the study aims. Consistent with correlation coefficients reported by

Brehaut et al (2003), only study variables that had statistically significant correlation coefficients ($|r| \geq .30$) with the dependent variable, decision regret, were entered into the regression model. The criterion for statistical significance for each analysis was $p \leq .05$.

3. Results

3.1. Sample Characteristics

Table 1 shows the sample characteristics of the participants ($N=16$). This sample of SDMs were mostly middle-aged ($M = 57.8$ years, $SD = 15.6$), white (75%), females (75%), who were either the spouse (56%) or adult child (19%) of a CCI patient. Half of the sample did not have prior experience with surrogate decision-making, yet they were in circumstances which required them to make a healthcare decision that included a tracheostomy and feeding tube decision for a CCI patient.

3.2. Incidence of Decisional Conflict and Decision Regret

The means and standard deviations for the DCS subscales scores and DRS scores are shown in Table 2. In this sample of SDMs, the highest subscale score on the DCS was decisional uncertainty ($M = 69.79$, $SD = 12.50$), which indicates that participants perceived a lack of certainty about which option to choose for their CCI patient. Within the first week of making a decision, this sample of SDMs reported moderate levels of decision regret ($M = 16.25$, $SD = 11.61$, range = 0–100). However, a majority (63%) of our participants had mild decision regret (scores from 1 to 25), 6% of the sample actually had strong decision regret (scores ≥ 26), and less than one-third (31%) reported no decision regret (scores equal to zero) after making a tracheostomy or feeding tube decision.

3.3. Predictors of Decision Regret

Based on the bivariate correlations presented in Table 2, decision regret was regressed on two dimensions of decisional conflict (contributors to uncertainty and perceived effectiveness of the decision). This two predictor model accounted for 56% of the explained variance in decision regret. The appraisal of a perceived effective decision ($\beta = .49$, $p < .01$) was the only influential predictor of decision regret, while adjusting for the contributors to uncertainty (see Table 3). A post hoc power of .66 was calculated for this regression model (Faul, Erdfelder, Buchner, & Land, 2009).

3.4. Assessment of Decisional Support Preferences

Participants were asked to report their preference for receiving informational and decisional support. Of the 15 participants who responded to this question, more than one-third (36.4%) of participants preferred to either receive decisional support through electronic media, and roughly another third (36.4%) desired face-to-face interactions with healthcare professionals. The remaining proportion (27%) of participants preferred to receive brochures, videos or books.

4. Discussion

Decisional conflict and regret exist among SDMs of CCI patients. Of the three dimensions of decisional conflict, decisional uncertainty ($M = 69.79$, $SD = 12.50$) and contributors to uncertainty ($M = 28.64$, $SD = 13.10$) had the highest magnitude of scores. Among SDMs, decision regret affected more than two-thirds (69%) of participants, while a minority (31%) of participants did not experience decision regret. However, the only influential predictor of decision regret was found to be the SDM's perception of the effectiveness of the decision. Although decision uncertainty had the highest magnitude of three dimensions of decisional conflict, it was not correlated with decision regret. Decisional uncertainty is a ubiquitous and

time-sensitive state of not knowing that seems to enhance the complexity of surrogate decision-making, but does not directly influence the SDM's expression of decision regret (Neville, 2003). The results of this study provide preliminary evidence that support further assessment of the decision-making experience in SDMs of the CCI.

In the present study, electronic and face-to-face counseling interventions were the preferred methods of receiving decision support among SDMs. Based on these preliminary findings, a "one size fits all" approach for decision support is not likely to effectively meet the individualized needs of the SDMs. Therefore, the use of adaptive technology or decision counseling may promote the SDM's engagement in the decision-making process and provide effective method of delivering health information needed to facilitate (de Vries, Kremers, Smeets, Brug, & Eijmael, 2008; Hyman, Pavlik, Taylor, Goodrich, & Moye, 2007).

4.1 Study limitations

The limitations of this study primarily focus on generalizability. First, the small sample size restricts the study's internal and external validity. Second, the DRS had a low internal reliability coefficient ($\alpha = .44$), and construct validity has not been confirmed in SDMs. Third, the sample population was composed mostly of white female spouses of CCI patients, thus limiting the generalizability of the study results to other subgroups of SDMs. Lastly, covariates, such as the SDM's and patient's characteristics, were not evaluated for their potential influence on decision regret.

5. Conclusion

SDMs of the CCI patients experience decisional conflict and regret as a consequence of ineffective decision support. Critical care clinicians may apply these findings by evaluating the SDM's preferences for decision support that will enhance shared decision-making. In future studies, scientists may consider evaluating the psychometrics of DCS and DRS in larger, more diverse samples of SDMs. High impact intervention research that incorporates adaptive decision support interventions may significantly reduce negative SDM outcomes, such as decisional conflict and decision regret, and prevent the over utilization of health care resources by the CCI (Collins, Murphy, & Bierman, 2004; Collins, Murphy, & Strecher, 2007).

References

- Brehaut JC, O'Connor AM, Wood TJ, Hack TF, Siminoff L, Gordon E, Feldman-Stewart D. Validation of a decision regret scale. *Medical Decision Making*. 2003; 23(4):281–292. [PubMed: 12926578]
- Camhi S, Mercado A, Morrison S, Du Q, Platt D, August G, Nelson J. Deciding in the dark: Advance directives and continuation of treatment in chronic critical illness. *Critical Care Medicine*. 2009; 37(3):919–925. [PubMed: 19237897]
- Collins L, Murphy S, Bierman K. A conceptual framework for adaptive preventative interventions. *Prevention Science*. 2004; 5(3):185–196. doi: 1389-4986/04/0900-0185/1. [PubMed: 15470938]
- Collins L, Murphy S, Strecher V. The multiphase optimization strategy (MOST) and the sequential multiple assignment randomized trial (SMART): new methods for more potent eHealth interventions. *American Journal of Prevention Medicine*. 2007; 32(5 Suppl):S112–S118.
- Daly B, Douglas S, O'Toole E, Gordon N, Hejal R, Peerless J, ... Hickman R. Effectiveness trial of an intensive communication structure for families of long-stay ICU patients. *Chest*. 2010 [Epub ahead of print].

- Davison BJ, Parker PA, Goldenberg SL. Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision making. *BJU International*. 2004; 93(1):47–51. [PubMed: 14678366]
- de Vries H, Kremers S, Smeets T, Brug J, Eijmael K. The effectiveness of tailored feedback and action plans in an intervention addressing multiple behavior change. *American Journal of Health Promotion*. 2008; 22(6):417–425. [PubMed: 18677882]
- Faul F, Erdfelder E, Buchner A, Land AG. Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*. 2009; 41:1149–1160. [PubMed: 19897823]
- Hyman D, Pavlik V, Taylor W, Goodrich G, Moye L. Simultaneous vs. sequential counseling for multiple behavior change. *Archives of Internal Medicine*. 2007; 167:1152–1158.
- Koedoot N, Molenaar S, Oosterveld P, Bakker P, de Graeff A, Nooy M, ... de Haes H. Decisional conflict scale: further validation in two samples of Dutch oncology patients. *Patient Education and Counseling*. 2001; 45:187–193.
- Leske J. Needs of relatives of critically ill patients: a follow-up. *Heart & Lung*. 1986; 15(2):189–193. [PubMed: 3633247]
- Molter N. Needs of the relatives of critically ill patients: a descriptive study. *Heart Lung*. 1979; 8:332–339. [PubMed: 253712]
- Nelson J, Kinjo K, Meier D, Ahmad K, Morrison R. When critical illness becomes chronic: informational needs of patients and families. *Journal of Critical Care*. 2005; 20:79–89. [PubMed: 16015521]
- Nelson J, Meier D, Litke A, Natale D, Siegal R, Morrison S. The symptom burden of chronic critical illness. *Critical Care Medicine*. 2004; 32(7):1527–1534. [PubMed: 15241097]
- Neville K. Uncertainty in illness: an integrative review. *Orthopaedic Nursing*. 2003; 22(3):206–214. [PubMed: 12803150]
- O'Connor A. Validation of a decisional conflict scale. *Medical Decision Making*. 1995; 15(1):25–30. [PubMed: 7898294]
- O'Connor A. An Evidence based approach to managing women's decisional conflict. *JOGNN*. 2002; 31(5):570–581. [PubMed: 12353737]
- O'Connor, A. User Manual - Decisional Conflict Scale [document on the Internet]. 2010. Retrieved from http://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf
- O'Connor, A.; Jacobsen, M. Decisional conflict: supporting people experiencing uncertainty about options affecting their health. 2007. monograph. Retrieved from https://decisionaid.ohri.ca/ODST/pdfs/DC_Reading.pdf
- Sheehan J, Sherman KA, Lam T, Boyages J. Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction. *Psycho-Oncology*. 2007; 16(4):342–351.
- Shelton W, Dea Moore C, Socaris S, Gao J, Dowling J. The effect of a family support intervention on family satisfaction, length-of-stay, and cost of care in the intensive care unit. *Critical Care Medicine*. 2010; 38(5):1315–1320. [PubMed: 20228678]
- Wendler D, Rid A. Systematic Review: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine*. 2011; 154(5):336–346. [PubMed: 21357911]
- Zilberberg M, De Wit M, Pirone J, Shorr A. Growth in adult prolonged acute mechanical ventilation: Implication for healthcare delivery. *Critical Care Medicine*. 2008; 36(5):1451–1455. [PubMed: 18434911]
- Zilberberg M, Luippold R, Sulsky S. Prolonged acute ventilation, hospital resource utilization, and mortality in the United States. *Critical Care Medicine*. 2008; 36(3):724–730. [PubMed: 18209667]

Table 1

Sample Characteristics of Surrogate Decision Makers

Variable	<i>n</i>	%
Race: white	12	75
Gender: female	12	75
Marital Status: Married	12	75
Employment Status: Employed	9	56
Prior SDM Experience: Yes	8	50
Relationship to Patient:		
Spouse	9	56
Adult Child	3	19
Other Relative	3	19
Guardian/DPOA	1	6
Education:		
Less than high school	2	12.5
High school	7	44
1–4 years of college	5	31
Graduate studies (>5 years of college)	2	12.5
Type of Decision		
Tracheostomy	6	37.5
Feeding tube	2	12.5
Both	8	50

Note. *N* = 16. Race = white vs. nonwhite, Marital Status = married versus not married, SDM = surrogate decision maker, DPOA = durable power of attorney.

Table 2

Summary of Bivariate Correlations, Means, Standard Deviations, Actual Ranges and Internal Reliability Coefficients and for Scores on the DRS, DCS subscales, and POMS-SF subscales

Measure (Subscale)	1	2	3	4
1. DRS	-	-.28	.61 [*]	.69 ^{**}
2. DCS (decision uncertainty)		-	-.28	-.10
3. DCS (contributors to uncertainty)			-	.52 [*]
4. DCS (perceived effectiveness)				-
<i>M</i>	16.25	69.79	28.64	14.06
<i>SD</i>	11.61	12.50	13.10	12.18
Actual Range	0–30	42–92	0–50	0–31
α	.44	.84	.68	.88

Note. *N* = 16. For all scales, higher scores are indicative of more extreme responding in the direction of the corresponding construct. DRS = Decision Regret Scale, DCS = Decisional Conflict Scale, POMS-SF = Profile of Mood States, Short Form. *M* = mean, *SD* = standard deviation, and α = alpha coefficient.

^{*}
p < .05.

^{**}
p < .01.

Table 3

Predictors of Decision Regret

Variable	Decision Regret		
	B	β	95% CI
Constant	.73		[-10.29, 11.75]
Contributors to uncertainty	.30	.34	[-.11, .71]
Effective decision	.49	.52 *	[.05, .93]

Note. $N=16$. Model statistics: $R^2 = .56$, $R^2_{adj} = .50$, $F(2, 13) = 8.34^*$. Based on the following parameters: $\alpha = .05$, effect size (f^2) = .56, critical $F = 3.81$ and $\lambda = 8.99$, the post hoc power ($1-\beta$) for this regression model is .66 (Faul, et al., 2009). B = unstandardized coefficients, β = standardized coefficients, CI = confidence interval.

* $p < .01$.