Research Article

Soliciting Patients Goals for Care on Hospital Discharge: The Gateway to Shared Decision-Making

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ABSTRACT

Background: To determine the frequency and type of adult patients goals for care during and after hospitalization.

Methods: As part of a larger readmission reduction study, between 10/1/10 and 11/30/13, goals for care were solicited and recorded by nurses and social workers after Coleman model readmission reduction training which included soliciting patient's goals for care in hospital, and then again at a home visit. Patients consisted of a consenting convenience sample of Medicare, Medicare Advantage, commercial, Medicaid HMO and uninsured patients discharged from three Monroe County, NY hospitals with an NYU Preventable Admission Algorithm diagnosis. Patient age, gender, ethnicity, and elicited goals were recorded. Qualitative analysis was applied to determine the frequency and percent of medical versus non-medical goals. Further analysis determined if goals were specific or general.

Results: 1411 patients participated in the study: 39.3% were ages 46-65, 34.2% ages 66-80; 67.4% were Caucasian, 23.3% African-American, and 3.9% Hispanic. No goal was recorded

for 41% of inpatients 19% of home visits. Overall, 2127 goals were elicited, 469 in hospital, and 1658 at home. 54.95% of home elicited goals were medical and 45.05% non-medical. The most common in-hospital goal was "get out of the hospital".

Conclusion: Patient's goals for care are often non-medical, The goal solicitation process is most appropriately conducted after discharge. Identifying non-medical goals may be important in beginning the shared decision-making process. By using patient identified goals as a starting point of medical decision making, patients may more clearly identify with the medical objectives presented to them. Research is needed to determine optimal solicitation approaches to most effectively identify patients' and families' goals for care and then prospectively asses the effect of goal solicitation on health outcomes.

Keywords: Shared decision-making; Goal solicitation; Practitioner-patient communication; Qualitative research; Patient engagement.

How This Fits in with Quality in Primary Care

To successfully integrate shared decision making into discharge care plans with patients, clinicians should solicit goals for care after hospital discharge but early in the follow up process. Goal solicitation is currently overlooked and needs to be carefully integrated into the opening of the shared decision-making process. Because we are hindered by a lack of research on the effectiveness of differing solicitation methods on the quality and quantity of goal responses, if patients have difficulty articulating goals, alternate solicitations should be attempted.

Introduction

Risk of not soliciting patients goals

My first year of medical school, I (AB) spent Monday afternoons at a Bronx, NY nursing home practicing interviewing skills and getting an introduction to the clinical world. Most of the residents are permanent, but there are a number of patients in longer- and shorter-term rehab. One afternoon I interviewed a woman who, at 68, was relatively young for the facility. She had been there for two years, recovering from a stroke that left her partially

paralyzed on her left side. She got around in a wheelchair and was able to walk less than half the length of the hallway with a walker. In taking her history I learned that her primary goal was to restore her ability to walk independently because she didn't want to return home with her son until she was confident she wouldn't be a burden. However, because her clinical course had plateaued, Medicare had stopped reimbursing for physical therapy (PT) three weeks ago, and she hadn't been to PT since. Regardless, she felt optimistic that it was still a matter of effort, time, and patience until she'd be walking on her own and going home.

At the end of the interview my preceptor joined us to check in with the woman. When the woman asked about returning to PT, my preceptor explained that Medicare would no longer pay for it. Given that two years had passed since the stroke, and her progress had plateaued, any remaining paralysis was permanent and additional PT would not result in her being able to walk independently. Upon hearing his prognosis, the woman looked to be on the verge of tears. It seemed to me that this was the first time she heard this message. Because the preceptor did not know about her goal of going home, he didn't understand the devastating effect of what he had just told her. For the past two years she had been holding tightly to her plan of recovering the ability to walk so that she could go home "without being a burden," and she had just been casually told this was impossible.

Two or three weeks passed before my next visit to the nursing home. When I returned I planned to follow up with the woman and see how she would adjusted to the news. But she was no longer in the same room, and since I hadn't included her name in my notes, my preceptor couldn't find where she was. Over the next two visits I searched hallways, hoping I would run into her or walk past her room, but I never did. I wondered if she'd reevaluated her priorities after that conversation and had simply given up.

The value of knowing patients goals

Ms. R is 88 years old and said she felt every day of those eighty-eight years. She reported her biggest problem was left knee pain, which had been going on for years and regularly caused 9/10 pain intensity. She had tried conservative treatments which were unsuccessful. Her clinical team determined that any improvement would require knee replacement, but the decision was complicated by her obesity, hypertension, sedentary life style and chronic hallucinations felt secondary to early Lewy Body dementia. As part of her evaluation for surgery, I (HB) asked her what she wanted to be able to do if her knee replacement was successful. Without hesitation, she replied, "Go to Vegas for a vacation."

After surgery, I visited Ms. R in the hospital. When asked how she was doing, she responded. "I hate these physical therapists, they keep trying to get me up and it hurts. Why can't I just stay in bed?" My response was, "If you want to go to Vegas, you have got to get up and get that knee working." She thought for some seconds and responded, "Go get them then." For the next few hospitalized days continuing her rehab, she worked diligently at her PT regimen.

The United Stated continues to struggle to provide high value care to its population [1]. In response, both the private and public sectors have begun focusing on improving value through multiple mechanisms. One of the most prominent is Medicare's focus on reducing preventable hospital readmissions and emergency department visits [2]. At the same time, there is an emerging awareness that quality care requires a quadruple aim: focusing on improving quality of care, lowering the cost of care, while improving patients' and staff's experience [3]. An increasingly recognized approach to help achieving these goals is fully engaging patients and their families as active participants in the process [4]. A major component of engaging patients and families more effectively is recognizing the role patients and their families play in creating plans for evaluation and treatment. This partnering to develop successful therapeutic plans is housed within an approach termed shared decisionmaking and involves incorporating the patient/family needs, values and preferences into the medical decision making process [5,6]. One recent definition of shared decision-making is "decisions that are shared by doctors and patients, informed by the best evidence available and weighted according to the specific characteristics and values of the patient" [7]. Another suggests, "This process of sharing in the decision-making tasks involves developing a partnership based on empathy, exchanging information about the available options, deliberating while considering the potential consequences of each one, and making a decision by consensus" [8].

While defining the attributes of effective shared decision-making, previous work suggests that those proposing a partnership approach must help practitioners develop the communication skills needed to effectively and efficiently understand the patient/family needs, values and preferences [4,9,10]. Similar to what we learned in the vignettes above, it is important to first listen to what people-patients, and/or caregivers/ families-- hope to accomplish through a care plan. Once understood, health care providers and teams can begin honest, effective and efficient discussions to craft plans with the patient/ family more likely to be on board.

In our clinical work, we observed little attention paid to explicitly soliciting patients' goals for care in the shared decision-making literature. The study of goal setting began around 1970 [11] when Ryan introduced the notion that conscious goals affect action. At that time, the observation was used mostly in the business world and focused on achieving results consistent with the organization's interests. This approach eventually spread into health care when. Bodenheimer and Handley [12], in a review article, defined goal setting for health behavior change as, "a process by which a caregiver and patient agree on a health related goal." The focus on a health behavior rather than a life goal, be it medical or not, seems to require medicalization of the patient's focus. Like the 86 year old who wanted to go to Vegas in the second vignette, knowing what a person hopes to achieve, allows the medical goals to be directed towards achieving the patient's life goals—goals which are important and, more importantly, motivating to the patient. Not knowing those goals, as was the case with the 68 year-old stroke victim in the first

vignette, runs the risk of unknowingly dashing a patient's goal, and irreversibly damaging the provider-patient relationship.

We view effectively soliciting patient/family goals as the critical first step in understanding how a patient views his or her illness and what he or she hopes to accomplish in working with health professional teams. In addition, as evidenced in our opening vignettes, soliciting a patients goal(s) provides a critical point of context for discussing treatment options as diagnoses and management options are entertained. This understanding is particularly important in working with patients and their families at the time of a hospital discharge, a time of increased patient vulnerability. Knowing when and how to solicit a patients and/ or family's goal(s) for care provides professionals a gateway into the partnership process after which a mutually created care plan can be developed. The same shared decision-making process helps the patient and his or her loved ones explicitly state their respective roles to support the care plan. If plans need to be altered, or new goals arise, an efficient and effective communication process is in place to move the health care planning process forward.

Unfortunately, the literature is silent on when and how to solicit patients' goals for care. As part of a larger community wide quality improvement program, partly funded by CMS [13] and local insurers to determine the influence of health coaches on reducing preventable hospital readmissions and ED visits, health coaches were able to visit with patients in the hospital and at home soon after discharge, to, among other things, solicit patient goals as part of the intervention developed by Coleman and colleagues [14]. This study describes the influence of timing of the solicitation of goals on the goals provided and shares the spectrum of goals offered by this large diverse sample of patients.

Methods

In 2010, as part of an effort to reduce preventable hospital readmissions, the greater Rochester, NY, United States community, through the auspices of a regional health collaborative (Common Ground Health, formerly, Finger Lakes Health Systems Agency) embarked on a coaching program modeled after the Care Transitions Intervention (CTI©) developed by Eric Coleman, MD and colleagues [14]. Using this model, toward the community goal of reducing the frequency of readmissions to the hospital and emergency room, trained nurses and social workers engaged with consenting Medicare Advantage, Medicare Fee For Service, Medicaid HMO and commercial patients during and after an index hospitalization to offer support and skills over the four weeks post discharge. The program was initially funded by two local insurers for their Medicare Advantage, commercial and Medicaid HMO patients identified in the hospital to have a diagnosis from the NYU ED Algorithm [15]. In September 2010, 30 individuals from 2 home care agencies, area hospitals, health plans and community organizations were trained on-site by the Coleman team in their coaching methodology; each coach trainee received certification after that training. The goal of the program was to help patients, and when necessary, their families or caregivers, improve their ability to advocate for themselves, and learn and become more confident in their problem solving skills.

The trained coaches were employed by either of two home care agencies, Lifetime Care and UR Medicine Home Care (then known as the Visiting Nurse Service of Rochester), or Lifespan, a community organization focusing on improving elder care. Between October 2010 and January 2011, coaching programs were initiated for the insurers' commercial, Medicare Advantage and Medicaid Fee For Service patients. In 2011, Lifespan led the effort to secure funding from Medicare (CCTP grant CBO0017) [13] to include Medicare Fee For Service patients, and Common Ground Health (formerly Finger Lakes Health Systems Agency) secured a New York State HEAL 19 grant support to cover coaching services for uninsured patients. By 2012, the program had extended from Monroe to Livingston, Ontario and Wayne counties of New York. This research focuses on only those patients living in Monroe County and admitted to one of three area hospitals for one or more of the index conditions between October 1, 2010 and November 30, 2013.

Dr. Coleman's Care Transition Intervention (CTI©) involved identifying, contacting and initiating the care transition intervention with consenting patients in the hospital, following up with a home visit (preferably within a few days after hospital discharge) and then completing a series of three follow up phone calls over the next month. The initial home visit focused on four pillars of process, encouraging patients to acquire skills that increase their ability to participate more effectively in their care. Three follow up phone calls were scheduled and intended to reinforce patients' and their families' problem-solving capacity, and practice the skills encouraged during the home visit.

As part of the hospital and home visit protocol, coaches were instructed to solicit the patient's goals for care and record them electronically. In reviewing the CTI training, there was no specific direction about how to solicit patient goals, including what question(s) to ask, whether to ask if there were multiple goals, or what to do if the patient or family member could not articulate a goal. The solicitation of goals was expected at both hospital and home visits regardless of whether hospital goals were elicited. Goals were entered onto an electronic form that was completed by the coach at the time of the visit.

Visit forms were then uploaded into an Excel spreadsheet kept by the coaches' employer. For this study, the home care agencies created de-identified files which were shared with the authors. These de-identified data files included: age, sex, ethnicity, diagnosis, and home goals. One of the home care agencies' Excel file also included hospital goals. If goals were not solicited, the reason was requested and recorded in the goal column by the visiting nurse or social worker. When multiple goals were offered, each was recorded with no ranking of priority. Entries were excluded if the patient was <18 years of age, the goal was attributed to someone other than the patient (e.g. "to get her home and take better care of her"), or no goal was entered for both home and hospital.

The data was combined into one master Excel file, and unique identifiers applied using an Excel randomization formula.

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Entries with multiple goals were then separated out, thus one unique identifier could be listed multiple times. For example, one home goal recorded was to "be able to help her husband with more housework and continue to read books as she enjoys it" and was split into "be able to help her husband with more housework", and "continue to read books." Goals were also judged by the authors as being medical or non-medical and general or specific, Goals were then categorized using an iterative process. Initially, a pilot sample of 100 goals were categorized by one investigator (AB), and then brought to the team and

discussed until a consensus set of categories was created. Another 100 goals were then selected and reviewed to further define and identify categories. The process was continued until saturation was reached (no new goals were identified). After the final categories were selected, inter-rater reliability between two coders (AB and HB) was calculated using Cohen's kappa statistic. The classification system is provided as Table 1.

After this classification system was created, the two reviewers then developed a consensus classification that focused on the

		Table 1: Patient goals classification.
Major Goal	Sub-category	Description and/or some example/s
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Stay out of hospital/go home		Wanting to leave the hospital or stay out of hospital General goal of wanting to be better, get better, be healthier, get healthier. If a specific
Feel better/Get better		is given, then it will go under a different category.
Stay well/Stay healthy		Wanting to maintain health/wellness
Get better care		Any goal relating to improved service and/or provision of care
Improvement in disease or sy	mptoms	Any goal of improving a disease state in general, or specific symptoms of a disease
Improve disease indicators		Goals about specific disease indicators, e.g. HbA1c
	Adherence	Goals relating to improved adherence to a medication or medical treatment regimen (e.g. dialysis)
Medication	Side effect	Goals relating to improving/reducing burdensome side effects of medication or medical treatment
	Other	Goals specifically about medication or medical treatment, but don't fall into the adherence or side effects categories. Usually a desire to be less reliant on medication or medical therapies.
	Smoking	Goals about quitting smoking. Mention of alcohol and recreational drugs also coded here
Continue /Change behavior to improve health	Exercise Nutrition Weight loss	Goals about increasing amount of exercise or maintaining current level of exercise. Goals about improving nutrition, e.g. "I want to eat better". Goals about losing weight.
Social and contextual change	s	Goals about making social changes, or changes in one's life such as move to a safer neighborhood This goal also includes environmental improvements and staying in one's own home.
	Work	Goal of getting back to work or school.
Return to/Improve activities	Daily activities	Goal of being able to do any daily/common activities, e.g. chores, grocery shopping, cleaning, etc.
	Hobbies	Goal of being able to do hobbies/leisure activities, e.g. volunteering, religion, sports, and other.
Attend an event or milestone		Goal of attending a <u>specific</u> event or milestone, e.g. "I want to make it to the family reunion next year".
Independence/Not be a burde	en	Goals expressing a general desire to be independent and/or not be a burden to other's.
More control/better management of disease		Goal that <u>explicitly states</u> wanting more control of their condition or to better manage it.
Knowledge		Goals about increasing knowledge of conditions, warning signs, causes, etc.
Stay alive		General goal to live for longer or "keep going". If a specific event was stated, then it is coded under attend an event or milestone.
Quality of life		Non-specific goal regarding quality of life. If something specific given then categorized somewhere else. Example is, "I just want to be able to enjoy my life."
Improve self-care		General goal about improving one's care for self. Example is, "to take better care of himself" or "appreciate health more and treat body better".
Avoid relapse Miscellaneous		Goal about avoiding a medical event or the consequences of a medical event. Goals that do not fit into the categories above.

broad intent of the articulated goal. The simplified system was then shared with the other authors and revised until consensus was achieved. This simplified classification is provided as Table 2. We also used the same approach to evaluate the goals based on whether they were medical or non-medical and general or specific.

Statistics

The Kappa statistic was used to measure inter-rater reliability.

IRB Approval

The initial data was obtained as part of a larger quality improvement project. The use of the qualitative improvement data for this research was approved by the Einstein College of Medicine Institutional Review Board (IRB #2013-2296).

Results

A total of 1,411 patients participated in the study and had goals for care solicited. The socio-demographics of the patient population from whom goals were solicited is provided in Table 3. The majority of patients were between ages 45-65. Most identified as Caucasian or White Non-Hispanic (68%). The next largest group identified as African American or Black American (23%).

In total, the 1411 patients offered 2,127 goals. 469 were elicited in the hospital while 1658 goals were elicited during the home visit. In the hospital, the average number of goals per patients for whom a goal was recorded was 1.2, and in the home setting the average was 1.6. Of note, in the hospital setting no goal was recorded for 41.5 percent of patients (N=318). Of those, 175 (39%) were unable to articulate a goal, 89 (28%) were not solicited. For 104 (32%), the coach did not state why no goal was provided. In the home setting, in only 268 (19%) of the patients, was a goal not recorded. Table 4 provides the top 5 goals for both hospital and home settings.

In order to compare the goals offered in the hospital versus at home, we grouped goals according to medical versus non-

	General	Specific
Medical	0097 (05.85%)	0814 (49.1%)
Non-medical	0276 (16.65%)	0471 (28.4%)

Table 3: Patient socio-demographics	S.
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Table 3: Patient socio-demographics.			
SD	Sub-Group	N	%
Age			
	18-45	155`	10.99
	46-65	554	39.26
	66-80	486	34.16
	≥ 81	219	15.45
	Unknown	2	00.14
Gender			
	Male	611	44.30
	Female	800	56.70
Ethnicity			
	African American	329	23.32
	Hispanic	53	03.76
	Caucasion	951	67.40
	Other	5	00.35
	Unknown	73	05.17

Table 4: Top 5 Goals hospital and home.

Top 5	Hospital Cooks	% of	Home Goals	% of
Goals	Hospital Goals	Hosp./N	nome Goals	Home/N
1	Feel better/Get better	23	Continue/Change behavior to improve health	24
2	Stay out of hospital/Go home	21	Return to/Improve Activities	18
3	Return to/Improve Activities	19	Improvement in disease or symptoms	13
4	Improvement in disease or symptoms	11	Feel better/Get better	11
5	Continue/Change behavior to improve health	05	Social and contextual changes	04

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medical goals, and specific versus general goals. How the goal categories originally fell into these four groups is outlined in Table 5. Table 6 compares the percent of goals in the four groupings in the hospital versus home setting. It should be noted that a significant percentage of patients articulated non-medical goals. Fully 45% (N=747) of the 1659 solicited in home goals were non-medical.

Statistics

The Kappa statistic for inter-rater reliability for classification of goals was 0.812.

Discussion

A number of recommendations can be made from this largest study to date of patient goals for care. First, while the hospital is a reasonable place to begin the process, soliciting goals should primarily be conducted after the patient is discharged. Two observations contribute to this recommendation. In the hospital setting, 41% of patients were unable to provide a goal in response to the goal solicitation, whereas in the home setting only 19% could not articulate a goal. Next, 20% of the articulated in-hospital goals were to either stay out or get out of the hospital. Patients seen in the hospital are in a precarious position (Table 4) and may focus on immediate goals such as going home. These data indicate that while the hospital is a reasonable place to introduce the shared decision-making process and encourage the patient and family to begin

formulating goals going forward,, the hospital is a sub-optimal place to elicit a final set of goals of care.

The second observation is that many patients identify their goals for care as non-medical. Acknowledging these goals as an introduction to the shared decision-making process (see narrative 2) is currently underrepresented in the SDM conceptual model. This can result in the medical team promoting medical outcomes as goals while the patient may identify the medical interventions as objectives (an activity designed to reach a goal) [16,17]. This suggests the need for research on how one precisely and effectively solicits goals for care. That research would likely require future investigation into which goal solicitations are most likely to be effective based on such variables as gender, age, medical literacy, ethnicity and medical diagnoses.

The narratives at the beginning of this paper exemplify the risks (Narrative 1) and/or benefits (Narrative 2) of omitting or incorporating goal solicitation explicitly into the shared decision-making process. As a response to the absence of a solicitation gold standard, Coleman and Min have begun to improve their home visit process [18]. In our work,, we are left wondering whether the patient's initial answer was the recorded goal, or if goals were redefined as a result of additional questioning. Additionally, questions arise as to the responses by patients with different levels of health literacy, or as a result of sociodemographic variables. Further research is needed to compare

Table 5: Classification of goals as medical or non-medical.			
Category Grouping	Categories		
General Medical	Avoid relapse		
	Feel better/Get better		
	Stay well/Stay healthy		
	Continue/Change behavior (including all the subcategories)		
	Get better care		
	Improve disease indicators		
Specific Medical	Improve self care		
Specific Medical	Improvement in disease or symptoms		
	Knowledge		
	Medication (including all the subcategories)		
	More control/better management of disease		
	Quality of life		
General Non-medical	Stay alive		
	Stay out of hospital/Go home		
	Return to/Improve activities (including all the subcategories)		
C'C- M1'1	Social and contextual changes		
Specific Non-medical	Independence/Not be a burden		
	Attend an event or milestone		

Table 6: Distribution of home collected goals as medical, non-medical.				
Category Grouping	Hospital Goals Percent/N	Home Goals Percent/N		
General Medical	05.97/28	05.85/97		
Specific Medical	30.49/143	49.10/815		
General Non-Medical	42.86/201	16.65/276		
Specific Non-Medical	20.68/97	28.40/471		
Total	100/469	100/1659		

the results of differing solicitations and follow up protocols. Now that we have determined a significant percent of goals are non-medical, further research is warranted to better understand the role of multiple variables in creating the most successful solicitations and capturing the most accurate goals for care

Recently, the role of health literacy has been explored as an additional confounding variable. Muscat and colleagues [19] conducted interviews with 26 low literacy adults. They concluded that the interviewees desired an active role in decision-making, especially in knowing the benefits and harms of clinical approaches but felt limited by the way risks and benefits were communicated. For those unable to articulate a goal, specific attention should be paid to the possibility that the patient may have limited understanding of the goal solicitation process. Alternative solicitations should be developed based on testing of results in populations with differing degrees of literacy.

Additional research is also needed to understand the meaning of "goals" to different socio demographic and ethnic groups. It may be that some groups of patients struggle with the meaning of the word goal itself,. This is based on the observation that a significant percent of patients failed to provide a goal for care. That 19% of the home group was unable to articulate a goal suggests other synonyms might be more effective. For example, one might ask, "What would you like to be able to do in the next months that you are unable to do now? More demographic information regarding those who were unable to articulate a goal would be valuable in understanding the role socio-economics might play.

There are some significant limitations to this research. First, the data base dates from 2010-2013. However, there is no data demonstrating a significant change in admission diagnoses or influences on patients goals during the past 8 years. In addition, the patient data base consists of patients from one geographic community. To generalize the results, other geographic sites in the United States would be required. Third, the absence of standardization of the solicitation process may well have confounded our results. While we know that Coleman's program required goals be solicited, the absence of specific instruction, especially in the absence of recorded conversations, means the coach may have either accepted the patient's initial goal, or if uncomfortable with the generality of the goal or its non-medical nature, may have queried the patient further to provide more specific and/or more medical goals.

The observation about the wide variation in types of care goals requires additional research that leads either to standardizing the solicitation process or records the solicitation sequence. Such a study could also examine the variation in responses by patient ethnicity, age and gender, or active diagnoses. As more information becomes available, a spectrum of solicitations may be identified as most effective for particular diverse populations. Attention will need to focus on the degree to which patients' goals are related to life planning, rather than a more medical focus. In our study, 45% of patient's goals were non-medical. In determining how best to motivate and engage patients in their

care, we believe that knowing what a patient wants to achieve as a result of initiating treatment is critical to creating a realistic effective plan which fully engages patients and care-givers/families. We believe this lack of clarity may well have resulted in the underestimation of non-medical goals in our study. Because of these methodologic limitations, we believe that in-home or office goal solicitations should be standardized going forward.

Conclusion

Our data demonstrate the wide variation in patients goals for care and the difficulty predicting any one patient's goals based on current socio-demographic variables. Patients' goals can have a medical focus but often do not. Goals can be either general or specific, suggesting that the way goals are solicited may be important in influencing the goals patients offer. We argue for explicitly soliciting patients' goals for care as the initial step in meaningful shared decision making to ensure that both parties understand and agree on why treatment is being initiated. While understanding the patient's values, beliefs and context is critical, not knowing what a person hopes to achieve as they evaluate options seems a critical omission in the process. Further research is needed to 1) understand the effect of health literacy and other socio-demographics on the solicitation for goals, 2) clarify the difference between goals and objectives while understanding the importance of both, and 3) identify the spectrum of successful goal solicitations for patients and families of different ages, socioeconomic groups and ethnicities.

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Authors Contributions

Alice Beckman – Cleaning data, Analysis and interpretation of data, drafting portions of the article, revising it, final approval.

Melisa Wendland - Conception and design of study, Acquisition of data, revising article, final approval.

Eva Cohen – Conception and design of study, Acquisition of data, revising article, final approval.

Brenda Bartok - Conception and design of study, Acquisition of data, revising article, final approval.

Jeanne Chirico - Conception and design of study, Acquisition of data, revising article, final approval.

Howard Beckman - - Conception and design of study, Analysis and interpretation of data, drafting portions of the article, revising article, final approval.

Declaration

Anonymity – We confirm that all patient/personal identifiers have been removed or disguised so the patient/person's described are not identifiable through the details of the story. Alice Beckman (Narrative 1), Howard Beckman (Narrative 2)

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