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Empower Seriously Ill Older Adults to Formulate Their Goals for Medical Care in the Emergency Department

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Abstract

Background: Most seriously ill older adults visit the emergency department (ED) near the end of life, yet no feasible method exists to empower them to formulate their care goals in this setting.

Objective: To develop an intervention to empower seriously ill older adults to formulate their future care goals in the ED.

Design: Prospective intervention development study.

Setting: In a single, urban, academic ED, we refined the prototype intervention with ED clinicians and patient advisors. We tested the intervention for its acceptability in English-speaking patients ≥ 65 years old with serious illness or patients whose treating ED clinician answered “No” to the “surprise question” (“would not be surprised if died in the next 12 months”). We excluded patients with advance directives or whose treating ED clinician determined the patient to be inappropriate.

Measurements: Our primary outcome was perceived acceptability of our intervention. Secondary outcomes included perceived main intent and stated attitude toward future care planning.

Results: We refined the intervention with 16 mock clinical encounters of ED clinicians and patient advisors. Then, we administered the refined intervention to 23 patients and conducted semistructured interviews afterward. Mean age of patients was 76 years, 65% were women, and 43% of patients had metastatic cancer. Most participants ($n = 17$) positively assessed our intervention, identified questions for their doctors, and reflected on how they feel about their future care.

Conclusion: An intervention to empower seriously ill older adults to understand the importance of future care planning in the ED was developed, and they found it acceptable.

Keywords: advance care planning; behavioral intervention; emergency department

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Introduction

IN THEIR LAST six months of life, 75% of older adults with serious illnesses visit the emergency department (ED).¹ ED visits often mark an inflection point in these patients' illness trajectories, signaling a more rapid rate of decline.^{2,3} Many of these patients have not formulated and communicated their goals for end-of-life care,⁴ and a systematic review revealed that the majority (56%–99%) of older adults do not have advance directives available at the time of ED presentation.⁵ Most patients have multiple goals and priorities, and without an understanding of what they are, and a plan to try to address them, they are at risk of receiving care that does not align with their goals.⁶ Therefore, the ED provides an opportunity and a setting in which clinicians can educate and empower patients who would benefit from formulating and communicating their goals for future medical care.

Emergency physicians recognize this opportunity and have expressed interest in engaging seriously ill older adults in a discussion of their end-of-life care⁷; however, the time-pressured ED environment, the acuity of many patients' medical needs, and lack of serious illness communication training make it very difficult to conduct effective, in-depth conversations with these patients in the ED.⁴ Interventions that fit the constraints of the ED and empower seriously ill older adults to formulate and communicate their goals for future care are needed to bridge this gap.

To address this need, we developed, refined, and tested a brief negotiated interview (BNI) ED intervention as a way to empower such patients to formulate and communicate their goals for medical care. Based on the Social Cognitive Theory⁸ and the Transtheoretical Model⁹ (the most well-established theories for how people change behavior in a series of stages including precontemplation, contemplation, and preparation before behavior change), a BNI intervention is a seven-minute, scripted, motivational interview by a clinician that explores health behavior change with patients in a respectful, nonjudgmental way. The BNI creates patient engagement and trust in targeted behavior change (e.g., alcohol abstinence) when clinicians show respect for patient autonomy and compassionate curiosity.¹⁰ The BNI interventions are tailored to allow busy emergency physicians to engage patients in addressing an important chronic care issue without conducting a time-consuming, sensitive conversation in the time-pressured ED environment. The BNI interventions have demonstrated to significantly improve outcomes for ED patients with substance abuse disorders by helping patients understand the obstacles to and reasons for their medical care.^{11–14} In this study, we sought to determine whether this process could be adapted to encourage serious illness conversations. We developed a prototype script for serious illness conversations based on the established BNI interventions. We refined the prototype script iteratively incorporating the inputs from ED clinicians and patients. Finally, we tested the acceptability of the refined intervention using semistructured qualitative interviews.

Methods

We conducted a systematic development process to design our BNI intervention. Through reviewing the literature and engaging an expert panel consisting of highly experienced

palliative care physicians/researchers (S.D.B. and J.A.T.) and an emergency physician/BNI researcher (E.B.), we created a BNI intervention prototype by adapting the established intervention for alcohol dependence to fit the needs of seriously ill patients. Subsequently, we used rapid qualitative inquiry to refine the intervention iteratively. Rapid qualitative inquiry is a team-based, applied research method designed to quickly develop an insider's perspective on and a preliminary understanding of a situation. Specifically, it combines data from multiple sources to conduct cycles of data collection and analysis using ethnographic approach.¹⁵ Our institutional review board approved this study.

1. Prototype BNI intervention refinement using rapid qualitative inquiry

Step 1: Mock clinical encounters. We conducted a series of mock clinical encounters using the prototype BNI intervention. We recruited attending emergency physicians and physician assistants to administer the BNI intervention. We asked our Patient Family Advisory Council (PFAC) members to play the role of the patients. The PFAC consisted of patients and family members who collaborate to improve the overall quality of care at our institution. They were experienced in working with clinicians to improve clinical care, design research studies, and execute patient engagement projects to incorporate patients' perspectives into care. A written clinical vignette ("a 75-year-old woman with stage 4 lung cancer is diagnosed with new deep vein thrombosis in the ED and was started on oral anticoagulation therapy prior to being discharged.") was provided to orient both the clinician and the patient.

Step 2: Cognitive interviews of clinicians and patients. We interviewed the clinicians and patients after the mock clinical encounters using a semistructured, cognitive interview guide developed by the research team to refine the BNI intervention. We prespecified four areas of focus: overall impression, respectfulness of the language used, the perceived intent of each question, and appropriateness in the ED setting. Immediately after the mock clinical encounters, interviews were performed with each participant (clinician and patient) independently by the trained interviewers. Interviewers (K.O. and a research assistant, RA) were trained on qualitative research methods, went through video-recorded practice interviews using the interview guides, and received feedback about their techniques. Within 24 hours of the interviews, both interviewers reviewed the video recordings to assess the overall intervention, respectfulness of the language used, the perceived intent of each question, and appropriateness in the ED setting. The interviewers identified common themes and concerns, and any differences were resolved by consensus.

Step 3: Iterative intervention refinements. Based on the consensus findings from the cognitive interview analysis, we modified the prototype intervention. An independent, attending emergency physician (N.G.) reviewed and verified the modifications to ensure objectivity. Once the modified intervention was approved by N.G., the refined intervention was used in the next mock clinical encounter with new sets of a clinician and a PFAC member. These steps were iteratively

repeated until thematic saturation was reached when the research team could no longer identify modifications to be made to the refined intervention. Refined intervention script is available online as supplementary material (www.liebertpub.com/jpm).

Acceptability study

We conducted a pilot study in the ED with seriously ill older adults. Convenience sampling was used to recruit patients from September to December 2017 in the ED. We included English-speaking patients ≥65 years old with serious illness (metastatic cancer, oxygen-dependent chronic obstructive lung disease, chronic kidney disease on dialysis, New York Heart Association stage 3 or 4 heart failure), or patients whose treating ED clinician answered “No” to the “surprise question” (“would not be surprised if died in the next 12 months”), and who had the capacity to consent. RAs asked the treating ED clinicians regarding the answer to the “surprise question.” We excluded patients who had a medical order for life-sustaining treatment, or whose treating ED clinician determined the patient to be inappropriate for this study (e.g., in acute physical or emotional stress). Our BNI intervention was administered by a trained physician or physician assistant (K.O., L.F., or A.R.). The training of these clinicians consisted of didactics on principles of BNI, communication skills training with trained actors to practice responding to extreme emotions, and bedside coaching by an experienced BNI-administering clinician. All encounters were video recorded for intervention fidelity.

After the participants had gone through the BNI intervention, we (K.O., A.R., and M.A.H. with masters or doctorate level training in qualitative methods) conducted one-on-one, semistructured, qualitative interviews to assess acceptability of our refined intervention. We focused on characterizing participants’ overall impression and clarity in main intent. The interviews incorporated cognitive interview probes that examined comprehension, interpretation, and relevance of the intervention,^{16,17} and also the open-ended questions¹⁸ that provided a broader context for exploring participants’ future care goals. The iteratively refined interview guide also sought to understand a detailed impression of

the individual steps within the BNI (terminology, order, and specificity) and participants’ perspectives on future care planning after the intervention.

Interviews were recorded and professionally transcribed. Transcripts were analyzed and summarized by two trained researchers (a male emergency physician, K.O., and a female PhD-level sociologist, A.C.R., to insert diversity into the analysis and reduce the risk of individual bias) according to standard comprehensive qualitative analysis methods. The analytic approach used framework analysis¹⁹ that allowed the flexibility of incorporating *a priori* considerations and emergent themes from the data. The coding structure was collaboratively and iteratively developed by K.O. and A.C.R. and included both prefigured and emergent codes.²⁰ Through comprehensive indexing and charting, we explored and compared patient experiences within and across interviews. These methods were conducted using NVivo 10 (QSR International) qualitative analysis software. We followed the consolidated criteria for reporting qualitative research.²¹

Results

Prototype BNI intervention refinement using rapid qualitative inquiry

We conducted 16 mock clinical encounters with 11 attending emergency physicians, 3 physician assistants, and 7 patients. Clinicians had a broad range of clinical experience (57% with <5 years, 7% with 5–10 years, and 36% with >10 years of experience after training) and 71% were men. Patients were 43% men with median age of 68 years. The mean acceptability using a Likert scale (0 not acceptable, 1–4 somewhat unacceptable, 6–9 somewhat acceptable, and 10 completely acceptable) was 7. Clinicians spent 6.8 minutes (±3 minutes) on average administering the BNI intervention. Areas identified for refinement are given in Table 1.

Acceptability study

We conducted semistructured interviews with 23 patients after their BNIs with ED clinicians. Mean age of patients was 76 years, 65% were women, and the most common serious

TABLE 1. MAJOR REFINEMENTS SUGGESTED BY THE PARTICIPANTS IN THE REFINEMENT STUDY

<i>Participant inputs</i>	<i>Prerefinement</i>	<i>Postrefinement</i>
Respectfully and specifically focusing on goals of care in the context of worsening serious illness	“Have you thought about what type of care you want in the future?”	“Because you have ____ (serious illness) and you are in the ED, I am worried that your disease may progress further. This is a really good time to think together about what kind of care is right for you if you get sicker. Can I help you talk to your doctor about what is important in your care when you get sicker?”
Focus on ED visit to the follow-up appointment	“I’d like to talk about what’s ahead with your illness”	“... what’s ahead after leaving the ED and seeing your outpatient doctor.”
Use Patient-Centered Language	“Prepare for what’s ahead”	“Share what is important in your care if you get sicker”
Avoiding numerical “Readiness” Scale	Numerical scale from not ready (1) to completely ready (10) to talk to your doctor about your preferences	Changed to categorical scale (not ready, somewhat ready, completely ready)

ED, emergency department.

TABLE 2. CHARACTERISTICS OF ACCEPTABILITY STUDY PARTICIPANTS

Sample size (<i>N</i>)	23
Age (years), mean (SD)	76 (9)
Female, <i>n</i> (%)	15 (65)
Non-Caucasian, <i>n</i> (%)	5 (22)
Serious life-limiting illness, <i>n</i> (%)	
Metastatic cancer	10 (43)
Oxygen-dependent COPD	1 (4)
NYHA stage III or IV HF	2 (9)
CKD on dialysis	2 (9)
ED clinician “would not be surprised if died in next 12 months,” <i>n</i> (%)	7 (30)
Hospital admission, <i>n</i> (%)	12 (52)

CKD, chronic kidney disease; COPD, chronic obstructive lung disease; HF, heart failure; NYHA, New York Heart Association; SD, standard deviation.

illness (43%) was metastatic cancer (Table 2). Major themes were identified in all four areas (Table 3).

Overall impression: How did participants feel? Most participants (*n* = 17) positively assessed the BNI intervention. Participants provided a wide range of reasons for their approval of the intervention, but the positive evaluations were

largely focused on the administering ED clinicians' gentle and comforting approach (*n* = 8), the participant's general comfort level (*n* = 6), the appropriateness of the discussion (*n* = 6), and the informative nature of the discussion (*n* = 4). The intervention was characterized as appropriate, reasonable, and understandable, and participants appreciated that the intervention identified questions for them to ask their doctors, and made them reflect on how they think and feel about their future care, with some characterizing as “enlightening and eye-opening (#10).”

Only two participants expressed a somewhat negative/critical sentiment regarding the intervention, focusing on their desire for a more direct and less vague discussion, respectively. Four additional participants had other responses that were not explicitly positive or negative. Participants repeatedly attributed most of their positive experience to the ED clinicians' approach.

Main intent: Did participants understand the purpose of our intervention? Most participants understood the main intent of the intervention. When asked to describe the intent of the intervention, participants described three main themes: communication (*n* = 13), assessment of current care (*n* = 7), and relationship with their clinician (*n* = 4). Participants understood one of the main goals as assessing if they had discussed future care planning with their outpatient

TABLE 3. MAIN THEMES IDENTIFIED IN QUALITATIVE INTERVIEWS

<i>Theme</i>	<i>Representative quotes with participant #</i>
Overall impression	
Positive (<i>n</i> = 17)	#6: “It was a pointed discussion with specific questions. I thought it went very well.” #14: “... jumpstarted my brain to think about questions I want to ask ...” #17: “I think that it's very helpful, and I think it would be beneficial to the doctor and the patient ... what you're doing is excellent.”
Negative (<i>n</i> = 2) or neutral (<i>n</i> = 4)	#9: “Hard to put because I thought it was so general.” #2: “She's very friendly... I'm probably not going to remember every detail because I have a memory problem.”
Main intent	
Current communication status (<i>n</i> = 13)	#18: “he was truly trying to find out if I had ever had a conversation with my personal care doctor about how I would be cared for. I am assuming he meant end-of-life issues or becoming much more ill.”
Current assessment of care (<i>n</i> = 7)	#13: “when I become most seriously incapacitated ... some people want to be kept alive at all costs for as long as possible, and other people would like to consider the quality of life.”
Relationship with providers (<i>n</i> = 4)	#5: “she actually wanted to find out if there was concerns that I may have that perhaps my doctor's not talking to me about or not—or I'm not comfortable enough asking him.”
Comprehension and relevance	
Future communication with provider (<i>n</i> = 13)	#13: “the best thing that came out (from the intervention) was that he convinced me that I should overtly talk with her (doctor) ... because I have hinted what my aims are regarding end-of-life care ... but we never had a frank discussion about it.” #14: “It was easy ... like talking to a friend ... wasn't embarrassing or private.”
Experienced positive emotions (<i>n</i> = 14)	
Attitudes toward future care planning	
Positive (<i>n</i> = 14)	#12: “(discussion) addressed what hadn't been addressed all that much before” #18: “like. ... a wakeup call ... to sit down with my doctor to discuss these (care planning) issues” #11: “already done that (discussion with the outpatient provider)” #16: “just tired. ... because I'll be 94-year-old soon ... any day God calls me home and I'm ready”
Negative or neutral (<i>n</i> = 7)	

clinician and encouraging them to have a conversation about such issues. Two of these 13 participants also focused on involving caregivers in future care planning. The goal of asking patients to assess current care was to understand whether and how the intervention encouraged patients to think specifically about different aspects of their care, including the future course of their illness, preparation, and their treatment possibilities. Although four participants described the intent as knowing/asking about their relationship with outpatient clinicians, only one participant expanded on this to explain that this means how you get along with your doctor. A minority of participants expressed ambiguity in the intent of the intervention ($n=3$, misunderstood it to be about current personal health issues; $n=3$, “unsure” of the main intent).

Comprehension and relevance: How would participants describe what happened? Overall, most participants felt that their perspectives were heard/understood while describing the importance of communication with their clinicians for their future illness. Most participants (10 of 13 who responded) described the intervention as concentrating on plans for their future care including the patient’s preferences ($n=8$) and end-of-life care ($n=2$). Five of the 13 described the intervention as focusing on communication with their doctor, including encouraging them to ask about their future care planning. The minority of participants expressed uncertainty ($n=2$, “vague/too broad”) and/or possibly misinterpreted the discussion ($n=2$, focused on immediate health concerns; $n=2$, general patient–doctor relationship unrelated to the participants).

Attitudes toward future care planning: How did participants feel about future care planning after the BNI intervention? Most participants expressed positive sentiments about future care planning. Among the 20 participants who responded to this question, 7 stated that the discussion positively influenced the way they think about future care planning. Although not explicitly stating that the discussion changed the way they think about future care planning, seven participants expressed qualifying ideas such as: “I would talk to Dr [Last Name] with the questions you asked me” despite stating that the discussion “didn’t really impact me (#10)”; the discussion “convinced me that I should overtly talk to her (outpatient clinician),” but was “very much expected

(#13)”; “it jumpstarted my brain to thinking about questions I want to ask,” but it did not change the way he thinks about future care planning (“not really,” #14). These participants denied that the intervention changed their attitudes, yet reported specific ways in which it changed the way they think about future care planning. However, six participants stated that the discussion did not change the way they think about future care planning and also felt that they already knew all the questions to discuss with their outpatient clinicians about future care planning (#8).

Most participants (17 of 23) found the questions to be acceptable, with only one participant describing the questions as too vague. In addition, participants experienced positive emotions during the intervention ($n=8$, positive feeling; $n=6$ feeling comfortable). Even when participants experienced somewhat mixed emotions during the discussion ($n=7$), they emphasized the helpful or nonproblematic nature of the intervention despite the upsetting topic. Only one had an explicitly negative reaction to the discussion, describing it as “frustrating (#11).”

Discussion

A BNI intervention to empower older adults to understand the importance of future care planning in the ED was developed and refined systematically. Most seriously ill older adults understood that this intervention is intended to empower them to seek out serious illness conversations with their trusted outpatient clinicians. Seriously ill older adults found this intervention acceptable and felt more activated to consider future serious illness conversations.

Clinicians in the ED urgently need a practical intervention to engage older adults in serious illness conversations. Our carefully developed, structured intervention represents a promising tool that respects the time demands of the setting, the acuity of patients’ medical needs, and the imperative to activate patients to seek conversations with their primary outpatient clinician.¹¹ The BNI intervention uses clinicians’ empathetic, reflective listening to elicit behavior change by helping patients appreciate the discrepancy between their goals and current behavior (e.g., having no advance directive) and ultimately resolve this ambivalence.²² Such interventions broaden patient skills and increase their confidence in assuming more control of their health care decisions that promotes better health outcomes and care experiences.²³ BNI

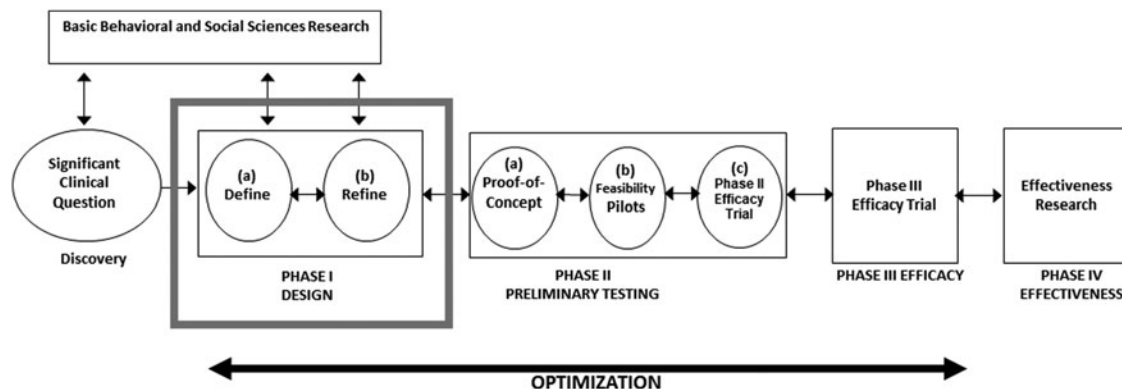


FIG. 1. The ORBIT model for behavioral intervention development. ORBIT, Obesity-Related Behavioral Intervention Trials.

interventions in the ED have been shown to be effective in facilitating health-related behavior changes in many other contexts.^{24–28} These studies demonstrate that emergency physicians can engage patients in BNI interventions not directly related to acute care. Our study is the first to adapt the BNI concept in the context of serious illness conversations.

Our BNI intervention is a behavioral intervention targeted to promote a specific behavior change (i.e., increased engagement in serious illness conversations). To better understand the process of developing a behavioral intervention, the Obesity-Related Behavioral Intervention Trials (ORBIT) Model can be used as a theoretical construct. Particularly for behavioral interventions, the key features are a flexible and iterative progressive process, prespecified clinically significant milestones for forward development, and return to an earlier phase for refinement in the event of suboptimal results. Within the ORBIT Model, our behavioral intervention is currently at an early phase in its development into what we hope will be an effective intervention (Fig. 1).²⁹ The feasibility and primary efficacy of this intervention are yet to be tested. Potential modifications of the intervention must be considered when patients have cognitive impairment or when caregivers wish to participate in this intervention. We also need to determine the easiest way for outpatient clinicians to reinstate the serious illness conversation after the patients are empowered. Furthermore, after the empowerment process for patients, measurement of key outcomes—increased serious illness conversation and communication about serious illness care goals—will be necessary to evaluate the impact of the intervention.

Limitations

Our intervention was developed using the inputs from clinicians and patients at a single, academic, tertiary medical center. We intended to capture inputs from patients with a variety of serious illness, yet most of our study participants had cancer. Given the pilot nature of the study, we only tested the BNI intervention on a small number of patients. As the intent of this study was to establish acceptability of the newly developed intervention, the follow-up outcomes data (e.g., documented serious illness conversation with primary care physicians) will be presented in future studies. Furthermore, implementation strategies, including the use of nonphysician clinicians (social workers, nurses, etc.) and financial compensations using the advance care planning CPT codes, will likely be necessary to scale this intervention in EDs across the United States.

Conclusion

We have developed and refined a BNI intervention to be delivered in the ED, to empower older adults to formulate their goals for future care. Older adults with serious illness found the intervention acceptable, understood its intent, and described ways to continue the serious illness conversation with their outpatient clinicians after leaving the ED. The key component of what made this intervention successful seems to be the gentle and comforting approach of the intervention questions to initiate/reintroduce what could be a sensitive conversation. The effect of this BNI intervention to facilitate the serious illness conversation after leaving the ED remains to be studied.

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Author Disclosure Statement

All authors report no conflict of interest.

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