

UCSF

UC San Francisco Previously Published Works

Title

Feasibility and acceptability of chaplain decision coaching on Periviable resuscitation decision quality: A pilot study.

Permalink

<https://escholarship.org/uc/item/3rh3z3t5>

Authors

Varner-Perez, Shelley

Hoffman, Shelley

Bhamidipalli, Sruthi

et al.

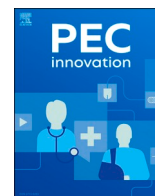
Publication Date

2024-12-01

DOI

10.1016/j.pecinn.2024.100266

Peer reviewed



Feasibility and acceptability of chaplain decision coaching on Periviable resuscitation decision quality: A pilot study[☆]

Shelley E. Varner-Perez^{a,*}, Shelley M. Hoffman^b, Kimberly Coleman-Phox^c,
Sruthi Bhamidipalli^d, Patrick O. Monahan^d, Miriam Kuppermann^c, Brownsyne Tucker
Edmonds^b

^a Department of Spiritual Care and Chaplaincy, Indiana University Health, Indianapolis, Indiana, USA

^b Department of Obstetrics and Gynecology, Indiana University School of Medicine, Indianapolis, Indiana, USA

^c Department of Obstetrics, Gynecology & Reproductive Sciences, University of California San Francisco, San Francisco, California, USA

^d Department of Biostatistics and Health Data Science, Indiana University School of Medicine, Indianapolis, Indiana, USA

ARTICLE INFO

Keywords:

Periviable delivery
Decision making
Patient centered
Decision support tool
Spirituality
Chaplain

ABSTRACT

Objective: To pilot test and assess the feasibility and acceptability of chaplain-led decision coaching alongside the GOALS (Getting Optimal Alignment around Life Support) decision support tool to enhance decision-making in threatened periviable delivery.

Methods: Pregnant people admitted for threatened periviable delivery and their ‘important other’ (IO) were enrolled. Decisional conflict, acceptability, and knowledge were measured before and after the intervention. Chaplains journaled their impressions of training and coaching encounters. Descriptive analysis and conventional content analysis were completed.

Results: Eight pregnant people and two IOs participated. Decisional conflict decreased by a mean of 6.7 (SD = 9.4) and knowledge increased by a mean of 1.4 (SD = 1.8). All rated their experience as “good” or “excellent,” and the amount of information was “just right.” Participants found it “helpful to have someone to talk to” and noted chaplains helped them reach a decision. Chaplains found the intervention a valuable use of their time and skillset.

Conclusion: This is the first small-scale pilot study to utilize chaplains as decision coaches. Our results suggest that chaplain coaching with a decision support tool is feasible and well-accepted by parents and chaplains.

Innovations: Our findings recognize chaplains as an underutilized, yet practical resource in value-laden clinical decision-making.

1. Introduction

Born between 22 and 25 weeks in pregnancy, periviable neonates have not developed enough gestationally to survive outside the womb without intensive care. Even if resuscitation is successful, survival beyond the NICU is not guaranteed. Furthermore, babies who survive periviable birth are at a higher risk of developing moderate to severe neurodevelopmental disabilities, ranging from deafness and blindness to severe cognitive delays and cerebral palsy [1-4]. Expectant parents

facing the possibility of delivery during the periviable period (referred to as “threatened periviable delivery”) are therefore confronted by the heavy burden of making “end-of-life decisions at the very beginning of life” [5] as they navigate the decision for resuscitation and the uncertainties surrounding delivery and their child’s quality of life. Making these high-stakes decisions can leave some parents with long-term mental health issues, including depression, anxiety, and post-traumatic stress disorder [6].

The American Academy of Pediatrics calls for shared decision-

[☆] Certain aspects of this study were presented in poster format at the 2022 North American Annual Meeting of the Society for Medical Decision Making (SMDM) in Seattle, Washington, October 2022.

* Corresponding author at: Department of Spiritual Care and Chaplaincy, Indiana University Health, 1812 N Capitol, Wile Hall W230, Indianapolis, IN 46202, USA.
E-mail addresses: svarnerpe@iuhealth.org (S.E. Varner-Perez), laymans@iu.edu (S.M. Hoffman), Kimberly.Coleman-Phox@ucsf.edu (K. Coleman-Phox), sbhamid@iu.edu (S. Bhamidipalli), pmonahan@iu.edu (P.O. Monahan), miriam.kuppermann@ucsf.edu (M. Kuppermann), btuckerredmon@iuhealth.org (B. Tucker Edmonds).

making (SDM) to support parents who are faced with making resuscitation decisions, including in the context of periviable delivery. This framework requires a bi-directional flow of information between providers and parents. The physician presents clinically relevant information (e.g., the options, alternatives, risks, and benefits) and elicits parents' values, preferences, and goals [7,8]. Despite the recommendations for SDM, the current practice of decision-making in the context of periviable delivery is not shared, well-informed, or patient-centered [5,9-12]. Our research suggests that institutional policies or norms and physicians' values and practice patterns, typically organized around gestational age 'cutoffs,' drive care for periviable delivery more than conversations regarding parents' hopes, fears, or concerns [13-15]. Parental values and goals are often not elicited during periviable counseling [8], missing a crucial opportunity to improve communication and values-aligned care delivery.

The most widely cited theoretical framework for providing decision support is the Ottawa Decision Support Framework, which suggests that decisional needs affect decision quality, with direct implications on actions, behavior, health outcomes, emotions, and use of health services [16-20]. Decision support tools (DSTs) can enhance SDM and decision support by providing information, realigning expectations of outcomes, clarifying values, and augmenting decision-making skills [17].

Prior research has found that DST users report being more knowledgeable, better informed, and more explicit about their values [21]. To optimize periviable counseling, we previously developed and published a report describing the development process for a personalized DST called "GOALS" (Getting Optimal Alignment around Life Support decisions) [22,23]. As part of that work, we utilized a novel, patient-engaged approach in partnership with over 100 patient advisors and healthcare colleagues to create a mobile application that integrated values clarification with personalized neonatal outcome estimates. The app was designed for parents to review independently and is intended to supplement, not replace physician counseling.

During the prior development of the GOALS DST, our healthcare colleagues and patient advisors felt strongly that spiritual care would benefit families making decisions for neonatal resuscitation or comfort care. Spiritual care is an essential component of high-quality health care for patients who are critically ill and their family members [24]. In particular, professional healthcare chaplains are skilled at building relationships, addressing goals of care, and helping patients navigate existential issues or spiritual distress [25]. Integrating chaplains within multi-professional teams (such as palliative care teams) increases patient satisfaction with communication in ethically critical situations [24].

In the maternity care setting, parents may receive a chaplain visit in the inpatient setting if a referral is placed to address spiritual, religious, or existential concerns. The literature primarily reports on the role of chaplains in supporting parents through stillbirth without describing chaplains' role in periviable decision-making [26-28]. However, care during threatened periviable delivery poses the unique challenge of attending to end-of-life decision-making in the antenatal care setting, suggesting the opportunity for a tailored approach. Decision coaching is individualized, non-directive facilitation of a patient's preparation for SDM [29]. Research has found that, across a range of clinical contexts, in isolation and combination with decision aids, decision coaching may improve patient satisfaction and knowledge in the decision-making process [29,30].

To fill the critical gap in shared decision-making in the context of threatened periviable delivery, we conducted a small-scale pilot study to assess the feasibility and acceptability of a chaplain-led decision-coaching model in conjunction with the GOALS DST. We aimed to describe knowledge and decisional conflict among parents who viewed the GOALS DST and received chaplain coaching. Because this model has not been utilized with chaplains previously, we also conducted an in-depth analysis of chaplains' experiences as decision coaches to better understand feasibility and acceptability from chaplains' perspectives.

2. Methods

This study was approved by the Indiana University (IU) and the University of California, San Francisco (UCSF) Institutional Review Boards (Protocols #2001702982 & 16-20,705). Informed consent was obtained from all study participants prior to their participation.

2.1. The decision coaching guide

Two of the authors (BTE and SVP) developed the decision coaching guide based on the Ottawa Personal Decision Guide [16,17]. The guide was organized around four coaching steps: (1) Clarify the decision; (2) Explore the decision; (3) Identify decision-making needs; and (4) Plan next steps based on identified needs. Each step is further delineated into elements such as Assessing Understanding; Clarifying Values; Building Skills in Deliberation; and Assessing Support. These elements were adapted to periviable resuscitation decision making. The process for each element is described along with the suggested language in Appendix A.

2.2. Staff training

Chaplain decision coaches were conveniently selected from both institutions with input from chaplaincy leaders based on the chaplain's experience with the study population, availability to complete decision coach training, certification status (board eligible or board-certified), and interest in research [31]. All research team members, including the study chaplains, underwent extensive communication and empathic skills training. They participated in at least two virtual mock encounters (4-6 h of training per individual) with a standardized patient (SP) actor experienced in improvisation, patterned from VitalTalk training [32]. Case materials were provided to the trained SP to prepare for the training session (Appendix B). Chaplains engaged in role-play encounters to rehearse and refine their delivery of the decision coaching guide to ensure model fidelity. The study team was also trained in N.U.R.S.E. statements for responding to emotions [33] and practiced navigating challenging encounters with participants (e.g., managing interruptions, short timelines, difficult family members, and bereavement).

2.3. Eligibility & Intervention

The design of the GOALS app, including alpha and beta testing, has been described previously [22,23]. Recruitment took place between November 2020 and December 2021 of English-speaking, adult (≥ 18 years) pregnant people (i.e., expectant parents) between 22 0/7 and 24 6/7 weeks' gestation who were admitted to labor & delivery (L&D) for a complication that threatened periviable delivery (e.g., preterm premature rupture of membranes, preterm labor, pre-eclampsia). Pregnant people were counseled regarding neonatal treatment options by a neonatologist or obstetrician prior to being approached by the study team and were excluded if they were actively in labor, medically unstable, or had an intrauterine fetal demise. Pregnant people were asked to identify an 'important other' (IO) upon whom they primarily relied for assistance in making decisions regarding their delivery plan (e.g., a family member, significant other, etc.). IO participation was not a requirement for pregnant people to participate. Using a HIPAA-compliant app, the Research Assistant (RA) notified the study chaplain team of the enrollment.

A trained RA conducted the interview in the patient's private room and, to mitigate literacy concerns, verbally administered survey instruments including the Decision Conflict Scale (DCS) and a knowledge questionnaire. The 16-item DCS consists of five response categories with scores ranging between zero (no decisional conflict) and 100 (extremely high decisional conflict) [34]. The true/false knowledge questionnaire asked about treatment options and possible outcomes, adapted from a previously published tool (possible range: 0-21) [35]. The expectant

parent (i.e., pregnant person) and IO (if enrolled) were interviewed at the same time, taking turns to answer each question. Parents viewed the GOALS app independently using a study iPad. After viewing the GOALS app in its entirety, the RA introduced the chaplain coach and left the room to allow privacy for the decision coaching session.

Following the decision coaching session, the RA returned to the room and completed the post-intervention interview, which consisted of the Preparation for Decision Making Scale [36,37] and Decision Aid Acceptability Questionnaire [38], followed by the DCS and knowledge scales again, and sociodemographic items. They were also asked an open-ended question to explain if and how they found the intervention to be helpful, harmful, or neither. Pregnant people and their IOs each received a \$40 gift card, and pregnant people also received a small gift bag.

2.4. Chaplain journaling

To assess the acceptability of the decision coaching model from the chaplains' perspective, a journaling component was incorporated at the study's midpoint using a journaling method modeled after Desjardins and Redl [39]. Chaplains were given open-ended prompts and asked to journal their experiences of coaching training and impressions of participant encounters. Example prompts included "Please write about your experience of chaplain coaching training, including working with a Standardized Patient and becoming familiar with the coaching guide;" "We invite you to reflect on coaching the pregnant person and important other;" and "How are you thinking about the chaplain's role in the study?"

2.5. Analysis

Data from the parent interviews were analyzed quantitatively. Descriptive analysis was conducted for demographics and scale scores. The Decision Conflict and Knowledge scales were reported as mean and standard deviation at pre- and post-intervention, and mean difference. Descriptive analysis of parents' (and IOs' if enrolled) responses to the Decision Aid Acceptability and Preparation for Decision Making questionnaires were reported using frequency and percentages.

Chaplain journal entries were de-identified for qualitative analysis. The goal of the qualitative analysis was to assess the intervention's feasibility and acceptability from the chaplains' perspective. Three members of the research team (BTE, SMH, SVP) developed a codebook to explore chaplains' perspectives of the guide and training, their contributions to the chaplain coaching role, and participant encounters. Journal entries were coded independently by SH and SVP and then double coded to reach consensus. Disagreements were discussed until the team reached agreement. Codes were evaluated using a conventional qualitative content analysis to create categories [40].

3. Results

Here, we present findings from both the parent interviews and the chaplain journal entries. First, we present the quantitative findings from the parent interviews, along with noteworthy quotes from open-ended prompts. In the second part of this section, we present critical categories that emerged from qualitative content analysis of the chaplains' journal entries regarding the acceptability and feasibility of their role in the study.

3.1. Parents' feedback: acceptability & feasibility

Eight hospitalized pregnant people and two IOs were enrolled in the study. Among participants, 60% were white and 90% were Non-Hispanic/Latinx (Table 1). All parent participants were married or partnered, and a majority reported being religiously affiliated (80%). None of the participants had prior experience making resuscitation

Table 1
Participant & Chaplain Demographics.

| Characteristics | Pregnant Persons N = 8 | Important Others N = 2 | Study Chaplains N = 8 |
|--|---------------------------|---------------------------|--------------------------|
| Mean Age (Range), yrs. | 30 (20–38) | 30.5 (25,36) | |
| Sex | | | |
| Male | 0 | 2 (100%) | 2 (25.0%) |
| Female | 8 (100%) | 0 | 6 (75.0%) |
| Race | | | |
| White | 4 (50.0%) | 2 (100.0%) | 2 (25.0%) |
| Black or African American | 1 (12.5%) | 0 | 5 (62.5%) |
| Asian | 0 | 0 | 1 (12.5%) |
| Other/Declined | 3 (37.5%) | 0 | 0 |
| Ethnicity | | | |
| Non-Hispanic/Latinx | 7 (87.5%) | 2 (100.0%) | 8 (100%) |
| Hispanic/Latinx | 1 (12.5%) | 0 | 0 |
| Marital Status | | | |
| Single/Never Married | 0 | 0 | |
| Married | 3 (37.5%) | 1 (50.0%) | |
| Significantly Involved with a Partner | 5 (62.5%) | 1 (50.0%) | |
| Education | | | |
| High school or less | 2 (25.0%) | 1 (50.0%) | |
| Some college | 5 (62.5%) | 1 (50.0%) | |
| College graduate | 0 | 0 | |
| Graduate school | 1 (12.5%) | 0 | |
| Household Income | | | |
| <\$25 K | 2 (25.0%) | 1 (50.0%) | |
| \$25 K-\$49,999 K | 2 (25.0%) | 1 (50.0%) | |
| \$50 K-\$74,999 K | 1 (12.5%) | 0 | |
| ≥\$75 K | 3 (37.5%) | 0 | |
| Health insurance | | | |
| Private | 4 (50.0%) | 0 | |
| Public | 4 (50.0%) | 2 (100.0%) | |
| Uninsured | 0 | 0 | |
| Religious Affiliation | | | |
| Protestant | 3 (37.5%) | 1 (50.0%) | 5 (62.5%) |
| Catholic | 1 (12.5%) | 0 | 0 |
| Other | 3 (37.5%) | 0 | 3 (37.5%) |
| None | 1 (12.5%) | 1 (50.0%) | 0 |
| Chaplaincy Certification Status | | | |
| Board-Eligible | | | 2 (25.0%) |
| Board Certified Chaplain | | | 6 (75.0%) |
| Years in Healthcare Chaplaincy | | | |
| <1–5 | | | 0 |
| 6–10 | | | 6 (75.0%) |
| 11–15 | | | 1 (12.5%) |
| ≥16 | | | 1 (12.5%) |
| Experience in making resuscitation decisions | | | |
| Yes | 0 | 0 | |
| No | 8 (100.0%) | 2 (100.0%) | |
| Experience with pregnancy loss | | | |
| Yes | 5 (62.5%) | 1 (50.0%) | |
| No | 3 (37.5%) | 1 (50.0%) | |
| Parent of a child with special needs | | | |
| Yes | 1 (12.5%) | 0 | |
| No | 7 (87.5%) | 2 (100.0%) | |

decisions. Five of 8 pregnant people, and 1 of 2 IOs had previously experienced pregnancy loss. Notably, one of 8 pregnant people was parenting a child with special needs.

At baseline, decisional conflict (DCS) scores for participants (pregnant people and IOs combined) averaged 16.9 (SD = 11.0) at baseline and 10.2 (SD = 8.9) post-intervention, demonstrating a mean decrease of 6.7 (SD = 9.4) (Table 2). Participants' knowledge of periviable delivery and resuscitation outcomes increased from a baseline score of 18.3 (SD = 3.7) to 19.7 (SD = 2.4) with a mean increase of 1.4 (SD = 1.8). Among the pregnant people, resuscitation was the predominant neonatal treatment preference at baseline (87.5%) and post-intervention (75.0%), with one participant feeling undecided post-intervention. Another participant was initially undecided but preferred resuscitation following the intervention.

Parents' feedback in the Decision Aid Acceptability Questionnaire was positive. When asked to rate their experience with the intervention, all said the amount of information was "good" or "excellent" and that they received enough information to make a treatment decision. Most participants (80%) found the duration of the intervention was "just right;" the information about both options (from the app and talking with the chaplain) was "balanced;" and 100% felt the intervention prepared them (with enough information and usefulness) to make a decision about treatment and resuscitation or comfort care (Table 3). Furthermore, 90% of participants selected "quite a bit" or "a great deal" when asked if the intervention prepared them to make a better decision, helped them recognize how involved they want to be in the decision-making, helped them identify questions to ask their provider, and prepared them to talk to their doctor about what matters most to them (Table 4). All participants said the intervention was "helpful," and none noted it was harmful. Participants noted that talking with the study chaplain helped clarify medical terminology and concepts presented by the physicians; navigate how the situation may impact other aspects of their lives (e.g., their children); and reach a decision.

"I think it's helpful just to have somebody to talk to...not only what's going on, but what else is going on in life...other children and other things." - Pregnant Person #21.

"[The chaplain] helped explain things in detail and like if we couldn't understand something, she told us, like with medical issues." - IO #36.

"...I have a hard time making a decision. [The chaplain] helped me get to my decision part." - Pregnant Person #23.

3.2. Chaplains' feedback: feasibility and acceptability

Study chaplains were Masters-level educated professionals with at least 4 units of chaplain residency (i.e., Clinical Pastoral Education certified by the U.S. Department of Education) in a healthcare setting providing care for patients from diverse religious backgrounds, spiritual identities, and races (Table 1). Notably, five of 8 study chaplains were Black or African American. All study chaplains had 6 or more years of healthcare chaplaincy experience. Two chaplains' full-time clinical assignments were in the L&D unit as part of the interdisciplinary care team, and all study chaplains worked in settings where they may be called to L&D for after-hours spiritual care coverage. Five of the nine study chaplains submitted journal entries describing their experiences of

Table 2
Decisional Conflict and Knowledge Pre- and Post-Intervention (N = 10).

| Scale | T0 Mean (SD) | T1 Mean (SD) | T1-T0 Mean (SD) |
|---------------------------------|-------------------------|------------------------|------------------------|
| Decisional Conflict Scale (DCS) | (n = 10) 16.9 (11.0) | (n = 10) 10.2 (8.9) | (n = 10) -6.7 (9.4) |
| Knowledge Questionnaire | (n = 10) 18.3 (3.7) | (n = 10) 19.7 (2.4) | (n = 10) 1.4 (1.8) |

Table 3
Decision Aid Acceptability Questionnaire Responses (N = 10).

| | n (%) |
|---|-----------|
| The length of the app and talking with a chaplain was | |
| Too long | 2 (20%) |
| Too short | 0 |
| Just right | 8 (80%) |
| The amount of information in the app and talking with a chaplain was: | |
| Too much information | 0 |
| Too little information | 0 |
| Just right | 10 (100%) |
| I found the app and talking with a chaplain to be: | |
| Slanted towards choosing resuscitation | 1 (10%) |
| Slanted towards choosing Comfort Care | 1 (10%) |
| Balanced | 8 (80%) |
| Do you think there was enough information in the app and talking with a chaplain to help you decide on a treatment for your baby? | |
| Yes | 10 (100%) |
| No | 0 |
| Did you find the app and talking with a chaplain useful to help you make a decision about resuscitation or comfort care? | |
| Yes | 10 (100%) |
| No | 0 |

Table 4
Preparation for Decision Making (PrepDM) Scale Responses (N = 10).

| To what extent do you agree with each of the following statements? Did the app and talking with a chaplain... | Not at all n (%) | A little n (%) | Somewhat n (%) | Quite a bit n (%) | A great deal n (%) |
|---|---------------------|-------------------|-------------------|----------------------|-----------------------|
| Help you recognize that a decision needs to be made? | 0 | 1 (10%) | 1 (10%) | 0 | 8 (80%) |
| Prepare you to make a better decision? | 0 | 0 | 1 (10%) | 2 (20%) | 7 (70%) |
| Help you think about the pros and cons of each option? | 0 | 0 | 2 (20%) | 1 (10%) | 7 (70%) |
| Help you think about which pros and cons are most important? | 0 | 0 | 2 (20%) | 1 (10%) | 7 (70%) |
| Help you know that the decision depends on what matters most to you? | 0 | 0 | 0 | 1 (10%) | 9 (90%) |
| Help you organize your own thoughts about the decision? | 0 | 0 | 2 (20%) | 1 (10%) | 7 (70%) |
| Help you think about how involved you want to be in this decision? | 0 | 0 | 1 (10%) | 2 (20%) | 7 (70%) |
| Help you identify questions you want to ask your doctor? | 0 | 0 | 1 (10%) | 2 (20%) | 7 (70%) |
| Prepare you to talk to your doctor about what matters most to you? | 0 | 0 | 1 (10%) | 2 (20%) | 7 (70%) |

the training; reflections on using the coaching guide; time investment; and applying their clinical chaplain skill set to the study role. The following categories emerged from a conventional content analysis: (1) Training with a Standardized Patient, (2) Reflections on Using the Guide, (3) Time Investment, and (4) Applying Chaplain Skillset to Study Role.

Training with a Standardized Patient (SP). Chaplains described the virtual training sessions with the SP felt "real," "refreshing," and "valuable." Chaplains noted it was beneficial to observe each other's encounters and that learning the N.U.R.S.E. acronym expanded their empathic listening skills.

"It felt like having a real conversation with a real mother who would have to make a real decision." - Chaplain #2

"While it is crucial to stick with the flow of the survey questions [guide], it is equally important to take the time to listen actively..." - Chaplain #11

Reflections on Using the Guide. Before the study started, chaplains expressed mixed emotions about using a guide for their decision-coaching encounters. One chaplain initially felt "uncomfortable" asking questions outside of their typical practice, and another worried that following a guide would come across as "disingenuous." Some chaplains struggled to initially adjust to a new role:

"It was challenging for me to switch from being a chaplain to being an interviewer [decision coach]." - Chaplain #2

However, practicing with a standardized patient and implementing the guide in real-life encounters helped them feel more "comfortable," "focused," and "free" to ask sensitive questions. The guide provided clear directions and prevented them from getting "lost in their emotions."

"To my surprise, my anxiety level decreased, having a [guide] provided. The [guide] allowed me to be present in the study and not get lost in my emotions." - Chaplain #4

"Having the survey questions guided me through the visit, and that I did not have to worry about what direction or end goal to take." - Chaplain #11.

One chaplain commented about how the guide helped maintain consistent communication with participants of varying health literacy.

"Because this [pregnant person] had higher medical literacy, the [pregnant person] felt more like a peer, and I struggled not to over-engage, i.e., to maintain consistency in how I was using the coaching tool and when I chose to probe or expand or improvise the wording a bit." - Chaplain #5.

Time Investment. Chaplains' comments about time varied from focusing on the time commitment required for study involvement (e.g., study training or being "on-call" for a study enrollment), amount of time spent delivering the intervention, and challenges accommodating the short notice of the study visit given other work obligations. Their encounters sometimes took longer than anticipated because of interruptions. As such, they "felt very conscious of the time" and were concerned about interrupting the workflow of patient care. One chaplain noted overall the on-call role worked well for balancing "personal...and professional obligations," even though it was sometimes challenging to respond so quickly in such a short timeframe. Despite these concerns, they reported their coaching encounters "went smoothly."

Applying Chaplain Skillset to the Study Role. Chaplains' combination of skills, such as compassion, patience, empathy, and the use of lay language, made them ideal candidates for the decision coaching role. By leveraging these skills, the chaplains helped participants navigate their options. One chaplain described a lengthy encounter because the pregnant person felt overwhelmed and mentally foggy, struggling to comprehend her options and the questions being asked.

"...She kept apologizing for "not understanding" some questions asked, and she told me "repeat the question" a few times... I recall she told me, "My mind is so foggy right now. I really appreciate your help with this." [When] the session ended she responded, "with your help, I do have a better understanding of my options." - Chaplain #3.

Another chaplain used observation skills to identify familiar objects in the room to increase rapport and engagement.

"I was still able to use my skills of observation to engage with pregnant person on an individual level... like noticing something in the room and using it as a basis to form connection." - Chaplain #5.

Participants valued the chaplains' role and openly engaged with

chaplains about their situation. One chaplain reflected in a journal entry:

"I was very inspired and deeply touched by [her] openness to talk about her thoughts and feelings as she responded and reflected on the survey questions. Amazingly, despite the feelings of anticipatory grief and loss, [she] expressed her gratitude for the GOALS study, which provided clear information about her pregnancy, which guided her and her husband to make decisions, which they believed are best for her baby and herself." - Chaplain #11.

4. Discussion & conclusion

4.1. Discussion

The objective of this study was to assess the feasibility and acceptability of chaplain-led decision coaching with the GOALS app in a small-scale pilot study from the perspective of both parents and chaplains. Overall, parents and chaplain coaches found the combined intervention of DST and chaplain coaching feasible and acceptable. Participants noted the chaplains helped them clarify their options and reach an informed decision. They also valued the chaplains' use of lay language, empathic communication, and assistance in clarifying values. Chaplains noted that training with a standardized patient was valuable and seemed to adapt well to the new use of their skill set.

To our knowledge, ours is the first study to utilize chaplains as decision coaches. Chaplains are a natural fit for this role because, as part of usual care delivery, chaplains build relationships, address goals of care, and help patients navigate existential issues of spiritual distress [25]. Furthermore, the role of chaplains in medical decision-making has gained additional visibility in recent years [41]. Most of these publications described chaplains' in-hospital role in family conferences or with palliative care teams but have not addressed periviable delivery contexts other than stillbirths [26,42-45]. Utilizing chaplain decision coaches with patients at risk of periviable delivery expands chaplains' skills to a population whose spiritual care needs were previously underserved by chaplains.

Furthermore, adding chaplains to team-based care in the maternity setting may have important implications for patient equity [46-48]. In a study of chaplains' roles in end-of-life decision-making, authors found that African American families experienced greater satisfaction in end-of-life care when chaplains have engaged [46]. This has particular relevance in maternity care, wherein Black families bear the disproportionate burden of extreme prematurity and resultant morbidity and mortality. Chaplains may serve to augment and support the care of Black families, who often experience and/or perceive discrimination, neglect, and mistreatment in maternity and end-of-life care settings [13,15,46,47]. Our study results must be interpreted with several limitations. First, our study sites were limited to two geographic locations and may not be generalizable to all regions of the country. This limitation is offset by racial, ethnic, and socioeconomic diversity, which are strengths of the study. Additionally, we were unable to deliver the chaplain decision coaching to non-English speakers. Though the GOALS app was developed in English and Spanish, funding limitations for this small pilot study precluded the use of translation services. Furthermore, our pilot included a small sample size limited by lower birth rates during the COVID-19 pandemic. Additionally, we have limited details about the spiritual/religious identities of those who participated in the study. Despite these limitations, participants reported high levels of satisfaction with the chaplain decision coaching intervention and valued the contributions of chaplain coaches.

4.2. Innovations

This pilot study lays the groundwork for exploring the utility and effectiveness of chaplain decision coaching. To our knowledge, our

study is the first to utilize chaplains as decision coaches. Our results suggest that chaplain coaching in conjunction with a decision aid is feasible and well-accepted by both parents and chaplains. Chaplains may represent an underutilized resource for offering decision support in the context of value-laden clinical decision-making. The use of such value-oriented support has the potential to reform the way that clinical decision-making is navigated in such sensitive settings, improving the overall experience for patients undergoing a healthcare crisis, especially in the realm of periviable delivery.

4.3. Conclusion

Future studies may explore using chaplain decision-coaching combined with DST in a clinical trial and delivering the intervention in Spanish. Since chaplains provided decision coaching in this pilot study, but not usual spiritual care, a future study might choose to supplement chaplain coaching with usual spiritual care, including spiritual history-taking, spiritual assessment, and spiritual coping resources when appropriate. Chaplain coaching shows promise to reduce decisional conflict and improve knowledge in the context of threatened periviable delivery. Participants valued chaplain involvement as decision coaches. Participants and chaplains reported decision coaching is feasible and acceptable. Decision coaching leverages chaplains' skills to address complex and challenging patient and family decisions in situations that could otherwise have high potential for poor outcomes.

Funding

This study was conducted with support from an internal grant from the Indiana University Health Values Fund and partly funded by the Precision Health Initiative of the IU Grand Challenges program.

CRediT authorship contribution statement

Shelley E. Varner-Perez: Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Shelley M. Hoffman:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Investigation, Data curation. **Kimberly Coleman-Phox:** Writing – review & editing, Supervision, Project administration, Investigation, Data curation. **Sruthi Bhamidipalli:** Writing – original draft, Formal analysis. **Patrick O. Monahan:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis. **Miriam Kuppermann:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Conceptualization. **Brownsyne Tucker Edmonds:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Methodology, Investigation, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We are grateful to the Spiritual Care Departments at Indiana University Health and the University of California, San Francisco, who contributed meaningfully to the successful completion of the study. We would also like to thank chaplaincy leaders, L. Vern Farnum, Director of Spiritual Care and Chaplaincy at IU Health, and Susan Conrad, Director of Spiritual Care and Chaplaincy Education at UCSF Health, for supporting this study's efforts and for identifying study chaplains.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2024.100266>.

References

- [1] Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. *Pediatrics*. 2009;123(6):1509–15.
- [2] Carlo WA, McDonald SA, Fanaroff AA, et al. Association of antenatal corticosteroids with mortality and neurodevelopmental outcomes among infants born at 22 to 25 weeks' gestation. *JAMA*. 2011;306(21):2348–58.
- [3] Tyson JE, Parikh NA, Langer J, Green C, Higgins RD. Intensive care for extreme prematurity—moving beyond gestational age. *N Engl J Med* 2008;358(16):1672–81.
- [4] Moore GP, Lemyre B, Barrowman N, Daboval T. Neurodevelopmental outcomes at 4 to 8 years of children born at 22 to 25 weeks' gestational age: a meta-analysis. *JAMA Pediatr* 2013;167(10):967–74.
- [5] Tucker Edmonds B, McKenzie F, Panoch JE, Wocial LD, Barnato AE, Frankel RM. "doctor, what would you do?": physicians' responses to patient inquiries about periviable delivery. *Patient Educ Couns* 2015;98(1):49–54.
- [6] Youngblut JM, Broton D, Cantwell GP, del Moral T, Totapally B. Parent health and functioning 13 months after infant or child NICU/PICU death. *Pediatrics*. 2013;132(5):e1295–301.
- [7] Batton DG. Clinical report—Antenatal counseling regarding resuscitation at an extremely low gestational age. *Pediatrics*. 2009;124(1):422–7.
- [8] Cummings J. Antenatal counseling regarding resuscitation and intensive care before 25 weeks of gestation. *Pediatrics*. 2015;136(3):588–95.
- [9] Tucker Edmonds B, McKenzie F, Panoch JE, White DB, Barnato AE. A pilot study of neonatologists' decision-making roles in delivery room resuscitation counseling for periviable births. *AJOB empirical*. Bioethics. 2015:1–8.
- [10] Roscigno CI, Savage TA, Kavanaugh K, et al. Divergent views of hope influencing communications between parents and hospital providers. *Qual Health Res* 2012;22(9):1232–46.
- [11] Tucker Edmonds B, McKenzie F, Panoch JE, Frankel RM. Comparing neonatal morbidity and mortality estimates across specialty in periviable counseling. *J Matern Fetal Neonatal Med* 2015;28(18):2145–9.
- [12] Tucker Edmonds B, McKenzie F, Panoch JE, Barnato AE, Frankel RM. Comparing obstetricians' and neonatologists' approaches to periviable counseling. *J Perinatol* 2015;35(5):344–8.
- [13] Tucker Edmonds B, McKenzie F, Robinson BK. Maternal-fetal medicine physicians' practice patterns for 22-week delivery management. *J Matern Fetal Neonatal Med* 2016;29(11):1829–33.
- [14] Edmonds BT, McKenzie F, Hendrix KS, Perkins SM, Zimet GD. The influence of resuscitation preferences on obstetrical management of periviable deliveries. *J Perinatol* 2015;35(3):161–6.
- [15] Tucker Edmonds B, McKenzie F, Farrow V, Raglan G, Schulkin J. A national survey of obstetricians' attitudes toward and practice of periviable intervention. *J Perinatol* 2015;35(5):338–43.
- [16] O'Connor AM. Ottawa decision support framework to address decisional conflict. <http://decisionaid.ohri.ca/docs/develop/ODSF.pdf>. [Accessed 16 December 2022].
- [17] O'Connor AM, Jacobsen MJ, Stacey D. An evidence-based approach to managing women's decisional conflict. *J Obstet Gynecol Neonatal Nurs* 2002;31(5):570–81.
- [18] O'Connor AM, Tugwell P, Wells GA, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns* 1998;33(3):267–79.
- [19] Llewellyn-Thomas HA, Crump RT. Decision support for patients: values clarification and preference elicitation. *Med Care Res Rev* 2013;70(1 Suppl):50S–79S.
- [20] O'Connor AM, Jacobsen MJ. Workbook on developing and evaluating patient decision aids. <https://www.ohri.ca/decisionaid/>. [Accessed 16 December 2022].
- [21] Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4(4):CD001431 [Published 2017 Apr 12].
- [22] Tucker Edmonds B, Hoffman SM, Lynch D, et al. Creation of a decision support tool for expectant parents facing threatened Periviable delivery: application of a user-centered design approach. *Patient*. 2019;12(3):327–37.
- [23] Tucker Edmonds B, Hoffman SM, Laitano T, Coleman-Phox K, Castillo E, Kuppermann M. User-testing of a decision-support tool for parents facing threatened periviable delivery: the Periviable GOALS decision aid. *Patient Educ Couns* 2021;104(6):1286–94.
- [24] Clemm S, Jox RJ, Borasio GD, Roser T. The role of chaplains in end-of-life decision making: results of a pilot survey. *Palliat Support Care* 2015;13(1):45–51.
- [25] Jeuland J, Fitchett G, Schulman-Green D, Kapo J. Chaplains working in palliative care: who they are and what they do. *J Palliat Med* 2017;20(5):502–8.
- [26] Nuzum D, Meaney S, O'Donoghue K. The provision of spiritual and pastoral care following stillbirth in Ireland: a mixed methods study. *BMJ Support Palliat Care* 2016;6(2):194–200.
- [27] Nuzum D, Meaney S, O'Donoghue K, Morris H. The spiritual and theological issues raised by stillbirth for healthcare chaplains. *J Pastoral Care Counsel* 2015;69(3):163–70.

- [28] Cullen S, Power S, Coughlan B, Chaney J, Butler M, Brosnan M. An exploration of the prevalence and patterns of care for women presenting with mid-trimester loss. *Ir J Med Sci* 2017;186(2):381–6.
- [29] Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Légaré F. Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision AIDS. *Med Decis Making* 2012;32(3):E22–33.
- [30] Stacey D, Kryworuchko J, Belkora J, et al. Coaching and guidance with patient decision aids: a review of theoretical and empirical evidence. *BMC Med Inform Decis Mak* 2013;13(Suppl 2(Suppl 2)):S11.
- [31] Association of Professional Chaplains. 2017 Common Qualifications and Competencies for Professional Chaplains. <https://www.professionalchaplains.org/files/2017%20Common%20Qualifications%20and%20Competencies%20for%20Professional%20Chaplains.pdf>. Accessed July 27, 2022.
- [32] Back AL, Fromme EK, Meier DE. Training clinicians with communication skills needed to match medical treatments to patient values. *J Am Geriatr Soc* 2019;67(S2):S435–s441.
- [33] Pollak KI, Arnold RM, Jeffreys AS, et al. Oncologist communication about emotion during visits with patients with advanced cancer. *J Clin Oncol* 2007;25(36):5748–52.
- [34] AM.. Validation of a decisional conflict scale. *Med Decis Making* 1995;15(1):25–30.
- [35] O'Connor AM. User Manual-Knowledge [updated 2004], https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Knowledge.pdf. [Accessed 16 December 2022].
- [36] Bennett C, Graham ID, Kristjansson E, Kearing SA, Clay KF, O'Connor AM. Validation of a preparation for decision making scale. *Patient Educ Couns* 2010;78(1):130–3.
- [37] Graham ID, O'Connor AM. User Manual-Preparation for Decision Making [updated 2010], www.ohri.ca/decisionaid. [Accessed 16 December 2022].
- [38] O'Connor AM, Cranney A. User Manual-Acceptability [updated 2002], https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Acceptability.pdf. [Accessed 16 December 2022].
- [39] Desjardins CM, Redl N. In Their Own Words: Stories Of Chaplains' Courage, Creativity, and Compassion During the Early Pandemic. *Transforming Chaplaincy* Published February 27, <https://www.transformchaplaincy.org/wp-content/uploads/2022/02/eBook-final-22.2.27.pdf>. [Accessed 30 November 2022].
- [40] Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277–88.
- [41] Wirpsa MJ, Pugliese K. Chaplains as Partners in Medical Decision-Making: Case Studies in Healthcare Chaplaincy. Jessica Kingsley Publishers; 2020 Apr 21.
- [42] Jeanne Wirpsa M, Emily Johnson R, Bieler J, et al. Interprofessional models for shared decision making: the role of the health care chaplain. *J Health Care Chaplain* 2019;25(1):20–44.
- [43] Muehlhausen BL, Foster T, Smith AH, Fitchett G. Patients' and loved Ones' expectations of chaplain services. *J Health Care Chaplain* 2022;28(3):350–64.
- [44] Torke A, Burke E, Slaven J, Taylor T, Varner-Perez S, Maiko S, et al. A randomized controlled trial of a chaplain-led spiritual care intervention for the surrogate decision makers of ICU patients (SAPLEN 102). *J Pain Symptom Manage* 2022;63(6):1059–60. Jun 1.
- [45] Shields M, Kestenbaum A, Dunn LB. Spiritual AIM and the work of the chaplain: a model for assessing spiritual needs and outcomes in relationship. *Palliat Support Care* 2015;13(1):75–89.
- [46] Grant G, Perkins M, Binney Z, Idler E, Quest T. Chaplains' role in end-of-life decision-making: perspectives of African American patients and their family members (S711). *J Pain Symptom Manage* 2015;49(2):412–3.
- [47] Tucker Edmonds B, Hoffman SM, Laitano T, Jeffries E, Kavanaugh K. Diverse Perspectives on Death, Disability, and Quality of Life: An Exploratory Study of Racial Differences in Perivable Decision Making *Journal Of Perinatology*. Accepted for Publication; March 2020.
- [48] Tucker Edmonds B. Moving beyond the impasse: discussing death and dying with African American patients. *Obstet Gynecol* 2011;117(2 Pt 1):383–7. <https://doi.org/10.1097/AOG.0b013e31820773e9>.