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Video tools in pediatric goals of care communication: A systematic review



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1. Introduction

Medical advances mean a growing array of interventions, therapies, and technologies are available to support care for children with chronic and serious conditions. Some of these approaches are supported by robust data drawn from populations that perfectly reflect an individual patient's physiologic, psychologic, and social situation. But much more often, clinicians and families face decisions in the context of some—or much—uncertainty about whether the intervention will do a child more harm than good. This is particularly true for seriously ill children with a limited lifespan—whether the child is a neonate born with a life-threatening brain anomaly or an adolescent with cancer. Because there is no clear "right" decision in these circumstances, clinical teams review potential benefits and burdens and prioritize the care goals and expectations held by the child's family [1].

Communication about these aspects of care are often referred to as "Goals of Care". This patient- and family-centered approach identifies valued care, avoids unwanted interventions, and fosters holistic family support [2]. In their 2019 paper, Secunda, et al. offer an operational definition of Goals of Care: "...the overarching aims of medical care for a patient that are informed by patients' underlying values and priorities, established within the existing clinical context, and used to guide decisions about the use of or limitation on specific medical interventions" [2]. It is fundamental to shared decision-making and relies on bidirectional communication, particularly since care goals are usually discussed in the setting of clinical conflict, poor prognosis, or treatment limitations [3]. Yet while the "Goals of Care" terminology is often a vernacular phrase for clinical teams, it is, in fact, jargon that can be ambiguous in conversations with families [4]. A clinician's request to discuss "Goals of Care" may signal unfamiliar, confusing, intimidating, or emotionally laden conversational domains to families. Additional ambiguity arises from the fact that Goals of Care conversations often occur in the context of a changing prognosis and a background of baseline uncertainty. This gap in understanding and communication undermines family support.

Families processing their own hopes and goals for a child find a sense of solidarity and support from hearing about the experiences of other families facing similar situations [5-7]. Several studies have identified the value of video modality as a source for Goals of Care education, including readying viewers for discussion, enhancing emotional awareness, and processing information in a safe space [8-11]. Given the emotion-laden nature of Goals of Care conversations, videos have been recognized as helpful preparation for families [12]. Thoughtfully produced video content offers viewers access to insight, emotion, and knowledge in an almost experiential way. This may be particularly important to families of children with serious illness who often feel isolated from other families experiencing similar challenges [13].

With current confidentiality and privacy rules, health care teams cannot readily share the stories of other families in a personal way [5]. Tools to help families process and practice verbalizing their Goals of Care exist primarily in written format. Existing Goals of Care guides and tools are directed at adult patients and few employ audiovisual modalities [14]. Videos are a particularly promising tool for sharing information to increase patient knowledge, opening dialogue between clinicians and families, fostering engagement, improving shared decision-making processes, normalizing feelings, helping families realize they are not alone in their experiences, and providing information and guidance [15-23]. Audiovisual approaches support families with low literacy and enhance recall [24]. Young families are particularly receptive to video modalities, with at least one study showing that young parents prefer this format for information sharing [25]. Hence, videos may be a beneficial modality to help families understand, process, and articulate their Goals of Care and hopes for their child with serious illness.

Our objective was to apply systematic review methods to synthesize and describe pediatric-populated targeted Goals of Care video tools. Through thematic analysis of the available tools, we were able to assess the understandability and actionability of available videos by applying standardized video assessment tools and a novel tool developed specifically for Goals of Care content.

2. Methods

We conducted a review following an a priori protocol and reported the review following the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines. The PRISMA checklist and deviations from the protocol with justification are available in Appendix B.

2.1. Search strategy

An exhaustive search of literature was performed in partnership with a research librarian (CS). The electronic databases MEDLINE, CINAHL, and PsycINFO all via the EBSCOhost interface, EMBASE via EMBASE.com, the Cochrane Library via the Wiley interface, and Scopus were searched from May 17-19, 2021. Keywords and subject headings (when available) were used for each of the four search concepts: 1) infant - adolescent age group, 2) video, 3) life-threatening illness or end-of-life status, and 4) advance directive or goal of care decisions, family/patient decision making, or hospice care. Date limits were not applied to the search. Conference databases and grey literature were not searched. The complete search strategies are included in Appendix A.

2.2. Inclusion and exclusion criteria

Because video communication tools are likely culture- and language-specific, searches were limited to English-language papers. Either family caregivers or clinical care teams were included as the study subject and/or target audience. Papers were included if they described development of a Goals of Care or decision making video modality or used such a video intervention in their study. Clinical studies, reviews, and conference abstracts were included while editorials/opinion pieces were excluded. Papers were excluded if they were not pediatric-focused (defined as birth to young adulthood), did not include a video-like modality, or did not relate to Goals of Care or family decision making.

2.3. Search selection

Covidence systematic review software, Veritas Health Innovation (available at www.covidence.org), was used to organize the project. Covidence automatically identifies duplicates among imported references for ease of deletion. Two authors (MM and CN) performed screening at title and abstract level. Eligibility assessment was performed in a blinded standardized manner by these two screeners. Disagreement between reviewers were resolved through a discussion with a third author (MW) and consensus reached. Papers meeting abstract-level screening according to inclusion/exclusion criteria proceeded to full text review. A full text reading of the resulting papers was then conducted.

2.4. Data extraction

Data extraction was conducted by two members of the research team (MM and CN) using a data extraction form which was first piloted on three papers. Data extraction included information about the intended audience, method, patient population, funding source, outcomes, geography, and extent of participatory (family caregiver/clinical team) inclusion in the video-making process. The video content data extraction tool included video length, intended audience, description of visuals, types of characters, clinical context, language, and focused features. Study team members (MM, CN, MW, MN, RB) verified data extraction. If there were differences in perspective related to the extracted outcomes, a third study group member (MW) joined the conversation to reach team consensus through discussion to reach final agreement on data extraction items.

2.5. Video access

Videos were accessed through contact with paper authors to request a film copy (1 received via CD Rom, 3 via website, 2 unavailable due to

lack of video copies). One paper referred to a collection of videos on a website, so an exemplar video was selected for representative Goals of Care content. Four videos were procured and evaluated by five members of the research team (RB, MM, CN, MN, and MW).

2.6. Video assessment instrument selection

Using an initial video, the study team piloted the use of the five existing instruments developed for evaluating patient-facing educational materials (DISCERN Scale, JAMA Benchmark Material, Global Quality Score (GQS) Criteria for Quality Grade, Video Engagement Scale, and the Patient Education Materials Assessment) to select the instrument [12,26-29]. The existing tools most frequently used to assess audiovisual content were developed for written consumer health materials (DISCERN Scale and JAMA Benchmark Material) [30]. The GQS Criteria metric limits focus to subjective measure of overall information quality and flow [31]. The Video Engagement Scale measures the extent to which viewers identify with the characters (often patients) portrayed and to imagine themselves in that patient role [12]. After piloting the available instruments, the Patient Education Materials Assessment Tool for Audiovisual Materials (PEMAT-A/V) was selected by the study team via consensus discussions.

2.7. Patient education materials assessment tool for audiovisual materials (PEMAT-A/V)

PEMAT-A/V provides a systematic method to evaluate and compare the content, layout and design, understandability (13-items) and actionability (4-items) of patient education materials. All seventeen items contain the response options "disagree" (0) or "agree" (1) with some items additionally including a "not applicable" answer option. The higher the final PEMAT score, the more understandable or actionable the material. The PEMAT has demonstrated strong internal consistency ($\alpha = 0.71$), strong agreement per Gwet's AC1 (average = 0.74), and significant positive correlations between PEMAT scores and viewer-feedback results [29]. Additional research into PEMAT has shown median inter-rater reliability at 0.92 for understandability and 0.93 for actionability [32].

2.8. Goals of care content analysis tool

The study team developed a Goals of Care content analysis tool to evaluate video details (duration, intended audience, visuals, character descriptions, language) and to describe the extent to which each video addressed content domains relevant to Goals of Care communication. The content domains were based on the 2019 systematic review by Secunda, et al., which analyzed 214 healthcare papers ($n = 6$ pediatric papers) to generate an operational definition and conceptual model of "Goals of Care" [2]. The Goals of Care analysis tool content domains included: 1) overarching aims for medical care, 2) values and priorities, 3) clinical context, 4) medical decision, 5) dichotomous vs. inclusive treatment choices, 6) evolving goals over time, and 7) clinical team role in formulating care goals. In addition, the study team extracted video content related to the four quality of life domains as described by the World Health Organization: 1) physical health/independence, 2) psycho-spiritual, 3) social, and 4) environmental [33].

2.9. Video quality assessment

Each team member individually evaluated the videos using the PEMAT and Goals of Care content analysis tool. To enhance inter-rater consistency, each rater (MM, MN, MW, RB, CN) independently rated the videos. The team then identified items for which discrepancies in scoring were common on both tools and discussed rationale. Since the Goals of Care assessment consisted of a qualitative summary of each domain rather than a scoring system, descriptive domain content was finalized through two full team meetings to review line-by-line description for each domain in a collaborative fashion. Overall PEMAT scores for each video were determined based

on how the majority of scorers rated each video, and when scores were tied, an adjudicator (CN) resolved discrepancies.

3. Results

The final search yielded 793 results. As depicted in the PRISMA Diagram (Figure 1), 541 records for unique papers were screened at title and abstract level. Twenty-five papers were then screened at the full-text level, nineteen of which were excluded at this stage. Twelve of these papers were excluded because they were not associated with a produced video. Six of the excluded papers did not directly address Goals of Care or decision-making, and one did not address a pediatric cohort.

Six papers- three of them conference abstracts- met inclusion criteria: Hirsch, et al. (2013), Hulac (2001), Little, et al. (1999), Lord, et al., Spicer, et al. (2007) and Tucker-Edmonds, et al (2019) [34-39]. Hirsch, et al. created a documentary to humanize care of seriously ill and dying children and change the culture of healthcare for children with life-threatening conditions; the video was designed for provider education and the public. Hulac created a video for parents with infants that have uncertain prognoses. The video contains excerpts from parent interviews about how difficult it is to be a decision maker and to live with the decisions. Little, et al. created a film depicting parent involvement in decision making in the neonatal intensive care unit to spark discussion. Lord, et al. created an online interactive tool with video clips that provided perspectives and tips on palliative care and family experiences. Spicer, et al. created a documentary highlighting the care for and needs of a specific subset of children who receive palliative care, those with multiple special needs. The video was created for clinician education. Tucker-Edmonds, et al. created a decision support tool for parents. The final prototype was a tablet tool supplemented with family story videos.

The small number of applicable papers consisted primarily of descriptive papers without detailed summary of the video content. The study team could not view the video content associated with the papers by Hulac (2001) and Tucker-Edmonds et al. (2019). Four video tools were included in this review, and details for each study included in the review are provided in Table 1.

3.1. Intended video audience

The intended audience of the videos in the included papers include clinicians, educators, legislators, healthcare students, families, and parents. Only two papers (Hulac et al. and Lord, et al.) stated that the video was primarily intended for parents. None of the papers utilized numeric outcome measures to describe video impact; rather, the papers contained narrative descriptions of video development or video content.

3.2. Video content [Table 1]

Table 1 describes the author, the name and summary of evaluated video tools, the methods used for each paper, the geographic location of video production, and the pediatric context of the video. Hirsch et al. produced "Portraits of Life, Love and Legacy in Pediatric Palliative care" (referred to as *Portraits*). Little, et al. produced "Dreams and Dilemmas". The Lord, et al. paper refers to the videos on the *Courageous Parents Network* website, with the video titled "Follow the Child" selected for viewing. Spicer, et al. produced "Precious Lives, Meaningful Choices" (referred to as *Precious Lives*).

The total viewing time of the four videos analyzed was approximately two and a half hours, with cumulative time depicting Goals of Care conversations or content of <15 minutes. All four videos included parent interviews or forms of family stories; clinician interviews were included in three (Hirsch, et al. Little, et al. and Lord, et al.). The videos lacked representation of sociodemographic diversity: three videos featured only white parents, intergenerational family structures were not represented, and all parent couples were heterosexual. Conversational English was used in all videos, although medical jargon was noted in two videos. Examples of

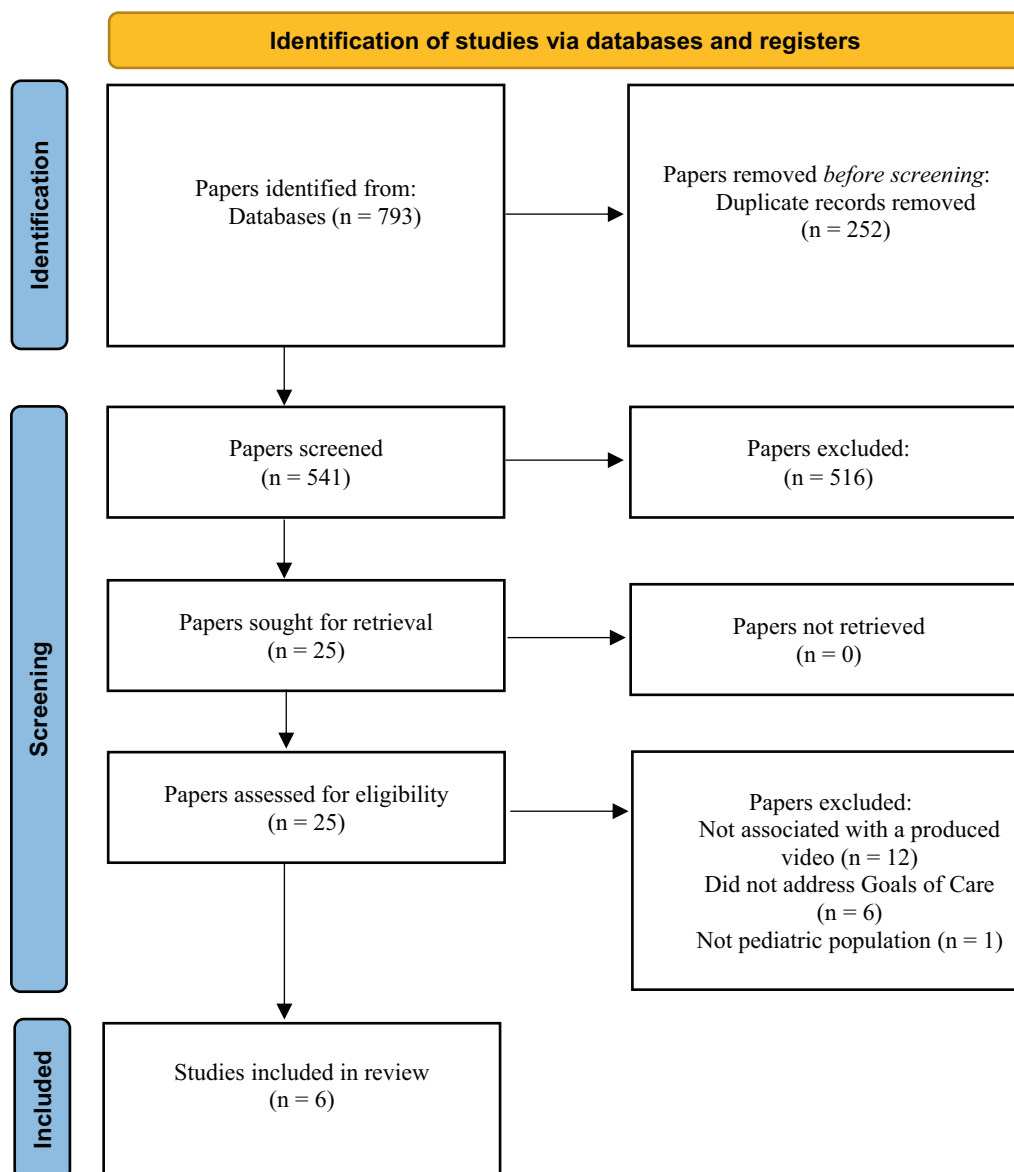


Fig. 1. PRISMA diagram. From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71 For more information, visit: <http://www.prisma-statement.org/>.

Table 1
Summary of the evaluated videos.

| Author (Year) | Name of video | Summary of video | Methods | Geographic location | Pediatric context |
|----------------|---|--|---|---------------------------------------|---|
| Hirsch, et al. | Portraits of Life, Love and Legacy in Pediatric Palliative Care | Interviews and video clips of parents and families and clinicians involved in a pediatric palliative care program describing their experiences in the program. | Conference abstract, no methods described. Parents and families shared their stories in a film for clinician, legislative and public education. | Akron, Ohio, United States | Pediatric Palliative Care |
| Little, et al. | Dreams and Dilemmas | Unscripted-documentary film depicting decision making with one family and the clinical team in the NICU. | Full text article includes a discussion about the decision to produce the film, the production of the film itself and its impact, no methods described. | Lebanon, New Hampshire, United States | Prenatal and Neonatal Intensive Care |
| Lord, et al. | Follow the Child | White-board style drawings with narration and parent and clinician interviews about factoring input from the child into decision making. | Conference abstract, no methods described. Abstract discussed the Courageous Parents Network website. Follow the Child was evaluated due to its Goals of Care content. | Boston, Massachusetts, United States | Chronic and Complex Pediatric Illnesses |
| Spicer, et al. | Precious Lives, Meaningful Choices | Interviews of parents of children with multiple special needs discussing family needs in the children's care. | Conference abstract, no methods described. Publication discusses that the film was produced to serve as a teaching tool for healthcare professionals to help them understand the experiences of families. | Calgary, Alberta, Canada | Pediatric Palliative Care |

medical jargon included diagnostic phrases such as “neonatal hypoxic ischemic encephalopathy” and “pulmonary atresia” or symptom terms such as “agonal” and “apneic” without clarifying descriptions. Videos portrayed a wide variety of pediatric clinical prognoses and diagnoses: *Dreams and Dilemmas* portrayed prognostic uncertainty in the Neonatal Intensive Care Unit (NICU), while the rest of the videos portrayed complex or chronic pediatric conditions.

3.2.1. Goals of care content [Table 2]

Table 2 describes the duration, intended audience, visuals, character descriptions, and language of the evaluated videos, as well as various Goals of Care content domains. Only *Portraits* and *Precious Lives* explicitly included the phrase 'Goals of Care'. *Follow the Child* and *Precious Lives* emphasized maximizing quality of life as an overarching aim for care, whereas *Dreams and Dilemmas* depicted the parents struggling to make the "right" decision about care for their children. *Portraits* focused on the coordination of care, symptom management, and prioritizing the family's goals in making care decisions. Each video included a discussion of how the families' priorities and values shape their decisions about their child's care. All but the *Portraits* video explicitly discussed that medical decisions should be made based on Goals of Care and family priorities, guided by the child's experience and prognosis. *Dreams and Dilemmas* and *Follow the Child* depicted and discussed

the decision to pursue medical interventions versus comfort care, respectively. Decisions about care in both instances were made in consideration of the child's prognosis. All four videos included a discussion of how goals and priorities of care shift over time as the child's condition progressed and the child responded to different interventions.

3.2.2. Goals of care content related to the World Health Organization Domains of Health [Table 3]

Table 3 summarizes the content of the evaluated videos related to the World Health Organization Domains of Health: physical health and independence, psycho-spiritual, social and environmental. *Follow the Child* discussed the importance of managing physical symptoms, while *Dreams and Dilemmas* discussed physical health and independence as related to the child's prognosis. *Portraits* addressed this component of health by describing the impact that the child's health has on the family's independence, and *Precious Lives* emphasized how children's physical health and independence evolve as diseases progress. Three videos (*Dreams and Dilemmas*, *Portraits* and *Precious Lives*) incorporated the psycho-spiritual component of health, specifically how spiritual beliefs influence family decisions and how having a child with complex medical needs may impact a family's faith. The child's role in the family and community were highlighted as social domains of health. Only *Portraits* and *Precious Lives* addressed the

Table 2
Summary of the goals of care content in the evaluated videos.

| Content | Follow the Child | Dreams and Dilemmas | Portraits | Precious Lives |
|---|--|---|---|---|
| Length of Video | 10 minutes, 26 seconds | 48 minutes, 47 seconds | 54 minutes, 50 seconds | 41 minutes, 48 seconds |
| Intended Audience | Clinicians, Family Caregivers | Clinicians and the Public | Clinicians, Educators, and the Public | Clinicians |
| Visuals | Drawings and Interview clips | Live-action, documentary style film | Live-action, interview clips and photos, documentary style film | Live-action with interview clips |
| Types of Characters | Outlined drawings of animated people Heterosexual white couple, single white mom, female white child life specialist | Neonatologist and team, white heterosexual couple and their premature twin boys | Diverse families; primarily white female interprofessional palliative care team | Four white heterosexual couples |
| Clinical Context | Variety of prognoses and diagnoses. | Prognostic uncertainty in neonatal intensive care. | Range of diagnoses. | Variety of prognoses and diagnoses. |
| Language | English; Does not use phrase "Goals of Care" | English; Does not use phrase "Goals of Care" | English with some Spanish; Does contain phrase "Goals of Care" | English; Does contain phrase "Goals of Care" |
| Other Important Focus | Following the child's lead when making care decisions; focus on inclusion of child. | Anticipatory grief; hopes and fears; parents grappling with care decisions. | Palliative care team describing overarching goals of palliative care with seven family experiences. | Description of family needs in complex care, Goals of Care discussion starts more explicitly 25 minutes into the film, palliative care. |
| Overarching Aims for Medical Care | Video address quality of life as care focus; child experience should inform and guide care. | Video depicts parents striving to make the "right" medical decision; portrays uncertainty. | Video focuses on palliative care model, addresses family goals, pain and symptom management, and bridging gaps in the child's care. | Video emphasizes maximizing child's quality of life; discusses uncertainty. |
| Values and Priorities | Goals of Care should be assessed as decisions are being made. If quality of life is highly prioritized, care options should be evaluated based on how they would impact a child's quality of life. | Parents determine values and priorities based on their children's diagnosis and prognosis, faith, and anticipated quality of life. | Families discussed their values and priorities guiding care. | Parents discuss what they hope for their children's lives and how that informs medical decisions. |
| Medical Decisions | Child experience helps inform family decision-making. | Clinical team discusses immediate care options in medical context without family present; then shows parents considering larger picture of child's future. | Lacks specific discussion of how medical decisions tie into Goals of Care, emphasizes role of coordinated care (facilitated by palliative care team). | Discussion of which medical interventions should be pursued if child's condition deteriorates based on family's goals. |
| Dichotomous vs. Inclusive | Tracheostomy or comfort care; ongoing reassessment of interventions and goals. | Parents choosing care based on dichotomous options, electing comfort care for one twin and a full ICU stay with interventions and surgery for the other twin. | Describes the home-based, community care that the children with complex, chronic needs receive. | Palliative care for quality focus and also interventions that prolong life. |
| Clinician role in formulating/actualizing Goals of Care | Clinicians can encourage Goals of Care considerations with families; child life specialists as a conduit in forming and actualizing Goals of Care. | Clinicians make medical recommendations and guide the parents in their decision, some discussion within the clinical team about the 'right' decision, discussion about code status. | Clinicians helping families make decisions families are comfortable with and providing bereavement resources. | Couple recounts painful interaction with clinician making medical recommendations. |
| Evolving Goals over time | Priorities in care can change over time which impacts how decisions are made, as illustrated in the first interview and the interview with the child life specialist. | As the twin's health condition changes, Goals of Care change. Interventions are evaluated on an ongoing basis based on how the child responds. | Portrays examples of evolving goals, including a family changing their mind about a trach/vent and end-of-life decisions. | Parents discuss priorities changing as disease progresses, moving from wanting a cure to loving the child as they are and for who they are. |

Table 3
Summary of goals of care content in videos related to the World Health Organization Domains of Health.

| WHO domain | Follow the child | Dreams and dilemmas | Portraits | Precious lives |
|----------------------------------|--|---|---|---|
| Physical Health and Independence | Discussion of the importance of keeping symptoms managed and the child comfortable. | Discussion of what the prognosis might be after brain injury, and how that affects the decisions that are made about care. | Discussion of the impact that the child's physical health has on the family. | Discussion of how children's physical health has changed over the course of illness and how physical health affects independence. |
| Psycho-spiritual | None | Mother of the twins incorporates her faith into her decision making, stating that God will give them a sign when it is time to transition care. | One parent discusses the how her child's special needs impacted her spirituality, some discussion of the role of spirituality in palliative care. | A set of parents discussed their spiritual belief in afterlife. |
| Social | Discussion of the child's role and place within their family (the relational role of the child). | Depicts parents discussing the impact that other family member's opinions have on their decision making, and how their day-to-day life might look brining the twins home from the NICU and caring for them while caring for other children. | Family narratives convey the impact that the special needs child has on the family's social situation and impact on siblings; one parent discusses that their child is able to go to school and church. | Discussion of inability of the child to communicate and play, parents recount how the child interacts with the family at home and how the child impacts the family's day-to-day life. |
| Environmental | None | None | Discussion of the extensive tangible needs that the family needs to meet (medical equipment, etc). | Discussion of the home environment in different households (caregivers, siblings, etc.) and how they impact the child's care and family life. |

environmental component of health, including discussions of the home environment and provisions for the child's tangible needs such as durable medical equipment.

3.3. PEMAT-A/V - understandability and actionability [Table 4]

Table 4 describes the collective video scores on the PEMAT tool, related to the understandability and actionability of the materials. The videos scored higher in the PEMAT-A/V categories for content and layout and design and scored lower in the actionability section. The average of the content and layout and design scores was 0.8 out of 1, while the average of the scores in the actionability section was 0.2 out of 1.

Of the four videos, three explicitly stated the video purpose either in written subtitle or via voice introduction at onset. Each video employed conversational language in active voice with medical terms stated sparingly. All videos contained segments or sections which flowed in a logical sequence. Half of the videos included written headers to differentiate the video sections. Two videos clearly identified a practical behavior the viewer could engage in based on video content, though none shared explicit steps to take toward follow-up action. For example, while a video shared the idea of having a family meeting with the health care team, the video did not suggest tangible action items such as preparing a list of questions or coordinating attendance with key staff.

Table 4
Collective patient education materials assessment tool (PEMAT) video scoring.

| | Videos with Score 0 | Videos with Score 1 | Videos with N/A response |
|---|---------------------|---------------------|--------------------------|
| The material makes its purpose completely evident. | 1 | 3 | 0 |
| The material uses common, everyday language. | 0 | 4 | 0 |
| Medical terms are used only to familiarize audience with terms. | 0 | 4 | 0 |
| The material uses the active voice. | 0 | 4 | 0 |
| The material breaks or "chunks" information into short sections. | 0 | 4 | 0 |
| The material's sections have informative headers. | 2 | 2 | 0 |
| The material presents information in a logical sequence. | 0 | 4 | 0 |
| The material provides a summary. | 4 | 0 | 0 |
| The material uses visual cues to draw attention to key points. | 0 | 0 | 4 |
| Text on the screen is easy to read. | 0 | 4 | 0 |
| The material allows the user to hear the words clearly. | 0 | 4 | 0 |
| The material uses photos and illustrations that are clear and uncluttered. | 0 | 2 | 2 |
| The material uses simple tables with short and clear row and column headings. | 0 | 0 | 4 |
| The material clearly identifies at least one action the user can take. | 2 | 2 | 0 |
| The material addresses the user directly when describing actions. | 4 | 0 | 0 |
| The material breaks down any action into explicit, manageable steps. | 4 | 0 | 0 |
| The material explains how to use any diagrams to take action. | 0 | 0 | 4 |

4. Discussion and conclusion

4.1. Discussion

Goals of Care conversations have the potential to promote patient-centered care and align treatment plans with care preferences [40]. Use of Goals of Care video tools for adult patients and their family caregivers has shown improved preparation for treatment choices and subsequent receipt of goal-concordant care [41-44]. While Goals of Care conversations may be emotionally laden due to the nature of a child's diagnosis or prognosis, they have potential to improve knowledge and raise awareness about care options to then provide decisional support for families [2,45].

4.2. Goals of care framework – adaptable for video tool storylines

A relevant framework for considering Goals of Care in pediatrics includes the concept of goals as "overarching aims" which are "informed by the patient and family underlying values and priorities" [2]. Pediatric Goals of Care frameworks include concepts such as "big picture" so that Goals of Care encompass an "aim, purpose, direction, or telos" to help guide and direct clinical care [46]. Using this existing framework of Goals of Care as a longitudinal narrative, video-based communication tools have the potential to depict each medical intervention or care decision within the larger Goals of Care captured in a video-based storyline [4].

4.3. Comparison with existing modalities

Pediatric-specific Goals of Care texts account for <4% of published Goals of Care materials [2]. Goals of Care content in pediatrics commonly depicts the setting of disease progression or worsening clinical status [3,47]. Written tools for pediatric Goals of Care tend to focus on end-of-life decisions with an emphasis on advance care planning or code status [48-49]. The video modalities differed than existing written Goals of Care materials for children recognizing goals as important even during phases of seeming wellness. By depicting scenes from the family's life, videos contextualized the role for values content not only as an end-of-life consideration but as relevant to the larger narrative arc of the child's life to include happy, healthy days outside of the hospital. Written Goals of Care decisional tools are combined with intervention education and thus presented as separate tools specific to individual interventions such as gastrostomy tube, tracheostomy, or other procedural steps rather than a larger arc of Goals of Care grounded in quality-of-life content [50]. The ability of videos to span conversations and timepoints should allow for Goals of Care considerations to be portrayed in videos as a trajectory rather than separated into individual medical decisions. However, the existing videos that were identified in the current review lacked explicit and concrete discussion of Goals of Care, with relevant content scattered throughout broader family narratives. Only two videos actually used the phrase "Goals of Care." This lack of explicit and targeted discussion limits the potential of the videos to guide families in verbalizing care priorities for their children [51].

4.4. Valuable role for families

Our overall conclusion is that video tools are highly valuable tools with the potential to help pediatric families process and articulate their Goals of Care; yet they are not readily available. Given this lack of availability, parents may turn to privately posted content on the internet or social media for information and perspectives. While this content may also portray family experiences, there is also a risk for bias or medical misinformation.

Parents making critical care decisions or formulating goals for their child's medical care often find themselves disoriented as if in a labyrinth, with no clear path forward [52]. Rather than being clear, discrete decisional steps, Goals of Care decisions are structurally complex and multidimensional, contextualized within the parents' relationship to the child and their personal sense of duty.

While video narratives lack the interactive and reciprocal nature of a peer support model, they nonetheless have the potential of reducing the viewer's feelings of isolation. They may be especially apt at capturing this complexity by allowing the viewer to bear witness to similar families' journeys that are deeply emotional and often characterized by some periods of clinical improvement and hope and other periods of clinical decline and grief [53]. Clinical teams often provide families with population-based prognoses or medically focused consequences of interventions for a child. Family video narratives can contextualize this information via accounts that are deeply personal and tangible—almost experiential. This family-centric information may help clarify for parents how the lived outcomes of various medical decisions may fit within their preferences and values for their child. Importantly, videos narratives that capture families' time in the medical setting and in the home environment respect the non-clinical dimensions of a family's experience with their child's illness. Frequently, these narratives are also stories of resilience, adaptation, intense gratitude and love; as such, they may help to expand parent and clinician perspectives on family life with a medically complex child [34,36-38].

4.5. Valuable role for clinical teams

Though the target audience for Goals of Care videos may be families, these tools may also increase understanding and empathy of clinical teams. Medical trainees and pediatric clinicians identify Goals of Care discussions as professionally and personally challenging, partially due to

feeling unprepared for the conversational content [54-56]. A paper from the neonatal intensive care unit documented an increase in clinician moral distress after Goals of Care conversations with families [57]. High-quality practices in Goals of Care conversations include engaging in patient-centered communication patterns and active silent space for listening—skills which can be modeled through video examples [58-60]. An analysis of Goals of Care use in the existing medical literature reveals the term is "most often assumed with its context centered on the needs of the health care system and linked to a specific medical topic" [4]. Clinical teams may be approaching these conversations with a narrow perspective of providing facts or giving medical data, while families express a preference for investment in the therapeutic relationship and engagement with their narrative [61].

4.6. Study strengths and limitations

Strengths of the study include rigorous adherence to reporting guidelines (Appendix B), the use of a systematic review organizational software, and partnership with a parent researcher (MN) and reviewers in various stages of medical training (pediatric resident and faculty) for inclusive perspectives. Study limitations include search terminology occurring in English with restricted access to global films, although reviews of empirical studies have shown no evidence of systematic bias from the use of language restrictions in conventional medicine [62]. Additional study limitations include low number of video reviewers (four members of the study team) and lack of validated video assessment instruments. The final papers were all countries where intensive medical resources are available and where shared decision-making is the cultural norm. Further work should be done to explore and expand culture-specific materials regarding Goals of Care communication.

4.7. Innovation

Historically, pediatric Goals of Care communication resources have been written materials such as brochures, decision aids with algorithms, or descriptive websites [2,51]. This study is the first to describe the landscape of video tools as a particularly promising intervention for pediatric Goals of Care opportunities. This review reveals a stark paucity of video-based Goals of Care tools for the pediatric population and limited scholarship describing or evaluating those tools. Study team access to existing videos tools required multiple rounds of communication with the producers and/or cost waivers—barriers that likely reduce access for families.

This study contributes content analysis of the existing video tools. To evaluate the thematic content of the videos, the study team had to develop a content analysis tool. The existing tools most frequently used to assess video content were developed for written consumer health materials. The lack of instruments available to measure the educational and emotional components of videos warrants future development of a standardized tool to assess the "verbal, vocal and visual" elements of videos developed for clinical use [63].

4.8. Conclusion

Goals of Care video development warrants engagement of families, videographers, and clinical teams as collaborating partners to ensure relevant, targeted, and accessible tools. The increasing number of family-produced videos highlighting aspects of a loved child's medical journal on social media sites and YouTube reveals the desire of families to share and receive narrative in film format. Ideally, rather than medical teams creating communication tools in isolation from family input and families showcasing experiential films in isolation, healthy and mutually respectful partnerships can translate into carefully and intentionally produced video content to foster Goals of Care conversations. A video tool co-created with mutual insight from key stakeholders carries powerful potential to serve as a springboard for additional collaborative conversations specific to the context and circumstances of the viewer. Each stakeholder brings a unique lens to the

film content and the final video message ideally reaches all audiences relevant in the child's care. There is currently a lack of such video tools despite their tremendous potential to educate and facilitate communication between parents and clinicians. The development of video tools for both parents and clinicians, targeting the processing and articulating Goals of Care, can help ensure that children's care is being guided by the principles most important to families.

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Registration and protocol

This review is registered in PROSPERO, ID number CRD42022303505.

Declaration of Competing Interest

No known conflicts of interest. Dr. Weaver contributed in a private capacity. The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the U.S. Department of Veterans Affairs, the U.S. Government, or the National Center for Ethics in Health Care.

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Appendix. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2022.100029>.

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