

# The Impact of Communication Surrounding Intrauterine Congenital Anomaly Diagnoses

## An Integrative Review

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### ABSTRACT

Congenital anomalies are the leading cause of infant death in the United States, accounting for 20% of the annual infant mortality. Advancements in ultrasound diagnostic technology allow practitioners to diagnose fetal anomalies as early as 11 weeks' gestational age, 75% of which are detected in low-risk pregnancies. Communicating a fetal anomaly diagnosis to parents and initiating perinatal end-of-life discussions are difficult for healthcare providers and parents alike. Furthermore, poorly communicated diagnoses have had long-term negative impacts on perinatal grief intensity, which can manifest into lifelong symptoms of adverse psychosocial outcomes such as anxiety, depression, substance abuse, and suicidal ideation. The purpose of this integrative review is to examine the impact of communication in discussing an intrauterine diagnosis of a fetal congenital anomaly on perinatal grief. An integrative review was conducted following the distinct 5-stage process of problem identification, searching the literature, evaluating data, analyzing, and presenting findings. A systematic literature review using the PICO model (Population, Intervention, Comparison, Outcome) and structured after

the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA). This framework was completed between November 2017 and May 2018 using PubMed, CINAHL, and PsycINFO databases. Of the 931 article results, 15 satisfied search criteria. Emerging themes included parental need for appropriate time to assimilate and understand the diagnosis, freedom to explore options and alternatives, and the need for clinicians with expert communication skills. The initial conversation communicating the diagnosis of a congenital anomaly impacts expectant parents for the remainder of their lives. Healthcare professionals are in a unique position to either positively or negatively impact the intensity of perinatal grieving reactions. The application of empathetic, sensitive communication may offer solace and promote healing surrounding perinatal end-of-life discussions.

**Key Words:** anencephaly, communication, congenital anomalies, grief, perinatal, shared decision-making

Congenital anomalies are the leading cause of infant death in the United States, responsible for 20% of the annual infant mortality.<sup>1</sup> Nearly 25% of women who experience perinatal loss develop adverse psychosocial outcomes including posttraumatic stress disorder (PTSD), depression, anxiety, substance abuse, and suicidal ideations.<sup>2–4</sup> Advancements in diagnostic imaging enable early detection of congenital anomalies, which may lead to difficult conversations between medical providers and expectant parents.<sup>5,6</sup> Many clinicians report discomfort and uncertainty when communicating a lethal intrauterine congenital anomaly diagnosis and feel ill-equipped to care for this patient population.<sup>6–8</sup> Furthermore, poor communication between expectant parents and healthcare professionals

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may precede the detection of fetal anomaly diagnoses, further potentiating adverse psychosocial outcomes surrounding perinatal loss.<sup>9</sup> Second-trimester ultrasound screening is performed at approximately 18 to 20 weeks' gestational age for the purpose of determining the number of fetuses, confirming gestational age, screening for placental location, and detecting fetal anomalies.<sup>10</sup> However, the majority of parents assume ultrasound scans are conducted solely for determining the sex of the fetus.<sup>9,11</sup> Most parents are unprepared to receive a diagnosis of a fetal anomaly, 75% of which are detected in low-risk or no known risk pregnancies.<sup>11-13</sup> As a result, unsuspecting parents, excited to discover the sex of the fetus, can be faced with devastating news.

Healthcare providers in the United States commonly base treatment recommendations for fetal congenital anomalies on associated survival rates of the fetal anomaly; thus, nearly 100% of providers discuss termination as the course of treatment when communicating lethal fetal congenital anomaly diagnoses.<sup>14-16</sup> However, nursing literature indicates that many parents choose to carry the pregnancy to term for deeply personal reasons, which include denial, prognostic uncertainty, religious beliefs, personal values, and viewing the infant on the ultrasound scan.<sup>7,9,13</sup> Approximately 20% to 40% of parents experiencing a pregnancy complicated by anencephaly, a uniformly lethal congenital anomaly, wish to carry the fetus to term.<sup>17</sup> Parents make these decisions to carry the fetus to term, knowing several options exist for pregnancies complicated by fetal anomalies other than termination, including organ and tissue donation, and perinatal palliative care, which may offer solace and meaning to an otherwise devastating experience.<sup>7,17,18</sup> Healthcare professionals may assist informed decision-making consistent with parents' personal beliefs and preferences through discussing available treatment options.<sup>9</sup> Recognition and respect of parental preferences concerning treatment options may facilitate the grieving process, potentially preventing long-term adverse psychosocial outcomes.

Communication plays an integral role concerning intrauterine fetal anomaly diagnoses.<sup>9,11,12</sup> Understanding the central role of communication and language in discussing a lethal congenital anomaly detected in utero with parents is vital. To prevent the possible development of long-term adverse psychosocial outcomes associated with complicated grief, it is critical to identify and address risk factors further contributing to intense perinatal grief. The purpose of this integrative review is to examine the impact of communication in discussing an intrauterine diagnosis of a fetal congenital anomaly on perinatal grief.

## BACKGROUND

Historically, the emotional impact that accompanies perinatal death was often overlooked. Unfortunately, affected parents were frequently neglected and ignored, suffering from PTSD, depression, anxiety, substance abuse, and suicidal ideation. The first documented case of perinatal grief was reported in 1968, with formal investigation beginning in the 1970s, when Kennel et al<sup>19</sup> recognized perinatal grief as its own distinct entity, sparking a proliferation of research on perinatal grief.<sup>19,20</sup> Subsequently, the Perinatal Grief Intensity (PGI) theory was developed.<sup>8,21-23</sup>

According to the PGI theory, incongruence between parental desire and the reality of pregnancy outcomes can result in intense, complicated perinatal grief.<sup>23</sup> Individuals experiencing perinatal grief have demonstrated higher-intensity grief in comparison with grief related to a terminal cancer diagnosis or surviving a traumatic injury.<sup>24</sup> Further evidence has found a negative correlation between intense perinatal grief and posttraumatic growth.<sup>24</sup> These results are indicative of specialized needs in caring for populations experiencing perinatal loss. While significant advancements in understanding perinatal loss have been made, there remains room for improvement.

The purpose of this integrative review was prompted from study findings that suggest poor end-of-life (EoL) communication and interactions between healthcare professionals and expectant parents have a significant negative impact on emotional and psychosocial well-being.<sup>9-12</sup> Lalor et al<sup>9</sup> highlight the necessity of improving practice when communicating intrauterine fetal anomalies to parents when first detected to decrease negative consequences of poor communication. Communication skills and training of healthcare professionals delivering bad news vary considerably.<sup>12</sup> While the communication of bad news was historically developed through trial and error, education programs have since been developed and implemented in medical residency programs.<sup>2</sup> However, there remains a lack of support for these programs despite the positive impact on long-term outcomes due to financial and time constraints.<sup>12</sup> Furthermore, nursing staff are equally rarely prepared for discussing bad news during pregnancy, yet they commonly become involved in such conversations during routine care of grieving parents.<sup>25</sup>

Intense perinatal grief, associated with long-term adverse psychosocial outcomes, requires specialized care.<sup>2,24,26</sup> Nurses and medical providers can further impact parents' experience by being sensitive not only through language and communication techniques during patient care, but also in recognizing parental culture, ethnicity, and values, which influence perinatal grief

reactions and inform decision-making.<sup>20</sup> Consequentially, adverse emotional reactions may be lessened or inadvertently potentiated through communication between expectant parents and healthcare professionals.<sup>27</sup>

## METHODS

Integrative reviews allow for the inclusion of diverse perspectives and methods, which can be helpful when developing knowledge around emerging practices, especially when little is known. This integrative review was conducted following the distinct 5-stage process of problem identification, searching the literature, evaluating data, analyzing, and presenting findings.<sup>28</sup> The PICO (Population, Intervention, Comparison, Outcome) model was used to guide the literature search as recommended by the Cochrane Handbook.<sup>29</sup> The study populations consisted of parents experiencing a pregnancy complicated by commonly lethal or uniformly lethal congenital anomalies that were detected by ultrasound diagnostic imaging. Interventions focused on investigating communication styles, techniques, and stances by healthcare professionals when communicating a fetal anomaly diagnosis detected in utero. Comparisons were then drawn upon varying degrees of perinatal grief reactions (outcome) associated with differing communicative interactions between healthcare professionals and the specified parent population.

Once the problem statement was created, a search of the literature was conducted through a systematic approach in the PubMed, CINAHL, and PsycINFO databases between November 2017 and May 2018. The search began with *a priori* inclusion and exclusion criteria, objectives, and method. Inclusion criteria included (a) peer-reviewed articles published in the English language, (b) during the last 10 years, (c) focused on some aspect of the communication of a lethal perinatal diagnosis. Experimental, quasi-experimental, and nonexperimental articles were considered, as were quantitative and qualitative designs. Exclusion criteria were restricted to non-English articles, articles published prior to 2008, gray literature, and articles that did not primarily focus on the communication of an anomaly (eg, articles that discussed the effects of a decision to terminate, types of fetal anomalies, and physiologic diagnosis of fetal anomalies). Key search terms included “communication” AND “fetal anomaly,” and “shared decision making” AND “fetal anomaly,” “communicating a terminal pregnancy diagnosis,” “communicating bad news concerning pregnancy,” and “delivering bad news during pregnancy.” After reviewing results with an expert librarian familiar with the primary author’s field of study, the key terms were revised to “communication of fetal anomaly,” and “shared

decision making and fetal anomaly,” “communicating a terminal diagnosis,” “communicating bad news,” and “delivering bad news,” as outlined in Table 1.

This search strategy resulted in 931 articles. Study selection followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) guidelines.<sup>30</sup> Titles and abstracts were reviewed, and inclusion/exclusion criteria were applied by the primary author. Articles satisfying predetermined criteria were reviewed in full ( $n = 21$ ). An additional 5 articles were found from hand-searching the reference lists of article included in the sample. Of these 26 articles subjected to critical evaluation, 15 satisfied inclusion/exclusion criteria and were included in this integrative review. Figure 1 outlines the data searching and evaluating process.

Each of the 15 articles was independently read multiple times by both authors. Key elements were abstracted and hand-entered into data matrixes<sup>31</sup> so that comparisons could be made. The authors then independently assessed and assigned the level of evidence (LOE) following the Johns Hopkins nursing evidence-based practice rating scale<sup>32</sup> to each article. In addition to assessing the LOE, each article was assessed for the level of knowledge (LOK) in following the process outlined by Polit et al.<sup>33</sup> The LOK<sup>33,34</sup> is useful for determining the state of the science. It is particularly valuable when identifying topics of interest in their infancy, thereby suggesting appropriate study designs to carry the state of the science forward. Upon independent completion of article evaluation, results were shared between authors electronically and discussed through telecommunication meetings. Discrepancies were resolved by mutual agreement after jointly reviewing criteria<sup>32-34</sup> and decision-making rationale.

Data were evaluated and analyzed in keeping with general principles of naturalistic research according to qualitative descriptive<sup>35-40</sup> techniques, endorsing focused attention on the complex social world in which people reside and an appreciation that observations provide invaluable evidence to real-life experiences.<sup>36,40,41</sup> Credibility, transferability, dependability, and confirmability were established by applying criteria as outlined by Lincoln<sup>40</sup> through peer debriefing, member checking, prolonged engagement, thick description, inquiry audit, and reflexivity. Electronic audit trails were recorded and maintained by the primary author of search results, decision matrixes, data reconstruction, and synthesis of thematic findings. Audit trails facilitated integrity and reflexivity of content analysis, in which findings were integrated into thematic representation of concepts, relationships, and interpretations.

Content analysis refers to a technique commonly used in qualitative research to analyze words or phrases

Table 1. Search strategy and key terms

Database	Search term	Results	Duplicates	Abstracts reviewed	Full articles reviewed	Articles included in review
CINAHL	"communication" AND "fetal anomaly"	4		5	3	3
	"shared decision making" AND "fetal anomaly"	66	1	6	4	4
	communicating a terminal pregnancy diagnosis	319		0	0	0
	communicating bad news concerning pregnancy	74		4	2	2
	delivering bad news during pregnancy	433		2	2	2
PUBMED	"communication" AND "fetal anomaly"	8	4	2	2	2
	"shared decision making" AND "fetal anomaly"	15	4	1	1	1
	communicating a terminal pregnancy diagnosis	0				
	communicating bad news concerning pregnancy	0				
	delivering bad news during pregnancy	3		0	0	0
PSYCINFO	"communication" AND "fetal anomaly"	7	4	0	0	0
	"shared decision making" AND "fetal anomaly"	1		0	0	0
	communicating a terminal pregnancy diagnosis	0				
	communicating bad news concerning pregnancy	0				
	delivering bad news during pregnancy	1		1	1	1
Total		931	13	21	15	15

in text documents. Directed content analysis was used to identify commonalities in the literature. This type of content analysis, used extensively by health investigators, further describes phenomena that are incomplete or would benefit from further description<sup>31</sup> and endeavor to answer the research question.<sup>34</sup> To examine the impact of communication in discussing an intrauterine diagnosis of a fetal anomaly on perinatal grief, the results of the integrative review are presented according to several themes that emerged from the literature based on qualitative experiences of parents. These were labeled as parental need for the following: appropriate time to assimilate and understand the diagnosis, freedom to explore options and alternatives, and the need for clinicians with expert communication skills.

Miles et al<sup>31</sup> outline more than a dozen techniques for assessing the quality of qualitative themes and conclusions. Objectivity or confirmability is conceptualized as relative neutrality and reasonable freedom from researcher bias. In the presentation of these themes, confirmability was addressed by (a) clearly describing the study's methods and procedures; (b) sharing the sequence of data collection, analysis, and presentation such as to create an audit trail; (c) being aware of personal assumptions and potential bias; and (d) presenting individual study findings in such a way

that are able to evaluate the fit of themes to results. The findings are presented according to each theme identified.

## RESULTS

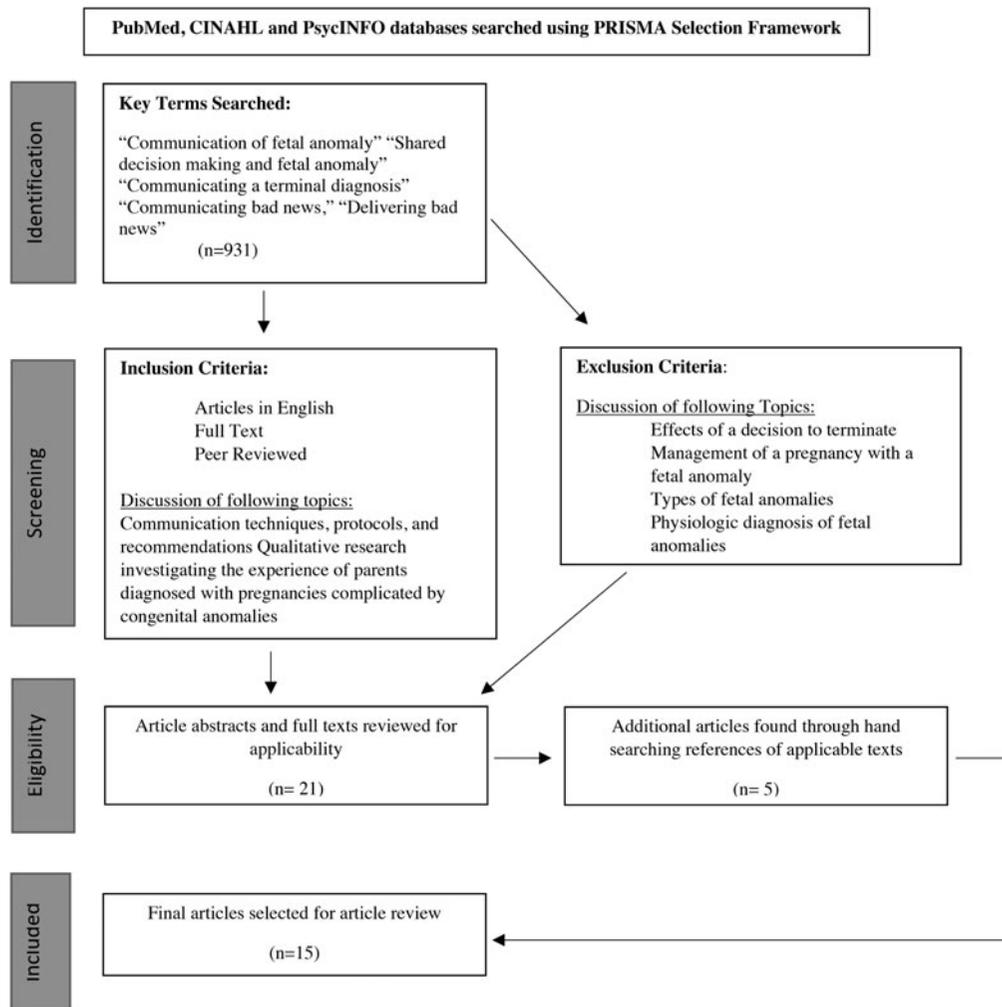
A total of 15 articles satisfied *a priori* selection criteria and comprised the sample in this integrative review. The majority of articles were published outside the United States ( $n = 10$ ; 67%).

All articles ( $n = 15$ ; 100%) were qualitative studies, representing an LOE ranging from 5 to 7. Table 2 outlines the characteristics of the study sample, as well as the LOE and LOK of each article.

## FINDINGS

### Parents need time to assimilate and understand the diagnosis

The theme that occurred with greatest frequency was *time*. This theme was labeled *appropriate time*, as there were 2 aspects of time associated with parental needs. First, parents overwhelmingly reported needing adequate time to absorb the information regarding the fetal anomaly diagnosis.<sup>9-11,20,27</sup> The initial shock of



**Figure 1.** PRISMA flow diagram modeled after Joanna Briggs Institute.<sup>30</sup>

receiving bad news inhibits parents' ability to process and understand information.<sup>27,42</sup> In addition, the health-care system is frequently impacted by limited time for face-to-face interaction with patients, often resulting from unrealistic patient to healthcare staff ratios. As a result, many parents feel that time constraints decrease the quality of communication.<sup>12</sup> Too much information provided in a short period of time is difficult for parents to process.<sup>27</sup> Studies have shown that dedicating extra time for answering questions positively impacts parents' experience in an emotionally challenging situation.<sup>11,27,42,43</sup>

Second, the length of time separating diagnostic and follow-up appointments further contributes to grief and anxiety among parents seeking answers.<sup>9</sup> Further diagnostic testing, referrals to maternal fetal specialists, and confirmation of an initial diagnosis may take weeks.<sup>7</sup> Providing appropriate time for parents to process devastating news, as well as decreasing time intervals

between follow-up appointments, may decrease anxiety while increasing understanding and facilitating informed decision-making.<sup>7,9,11,27</sup>

Third, receiving a diagnosis of a congenital anomaly is an extremely emotional event for parents.<sup>43</sup> This emotional reaction strongly influences and guides parental decision-making.<sup>44</sup> Parents have reported that being overwhelmed emotionally and mentally limits the decision-making capability.<sup>12</sup> Furthermore, women report having difficulty remembering, comprehending, or accessing information regarding the congenital anomaly, further contributing to feelings of anxiety and stress.<sup>9</sup>

Visual aids, such as images, diagrams, and percentile charts, were reported as being very helpful in increasing the level of comprehension of the congenital anomaly.<sup>9,11</sup> Frequent repetition of information, assessment of understanding of the diagnosis, and minimization of complex medical terminology and jargon

**Table 2. Characteristics of sample**

Study	Setting	Purpose	Design	Level of evidence	Level of knowledge
Carlsson et al (2016) <sup>13</sup>	Sweden	To explore the experiences and preferences of care following a congenital cardiac malformation diagnosis in utero	Qualitative (content analysis)	VI	Identification
Côté-Arsenault and Denney-Koelsch (2011) <sup>7</sup>	United States	To clarify responses and needs of families experiencing life-threatening fetal diagnoses	Qualitative descriptive	VI	Exploration
Dean and Willis (2016) <sup>25</sup>	United States	To present current communication protocols for perinatal end-of-life conversations, discussion of communication protocol (SPIKES <sup>a</sup> ), and recommendation for practice	Position paper	VII	Prediction and control
Greiner and Conklin (2015) <sup>11</sup>	United States	To provide a framework to break bad news of an anomalous fetus for physicians caring for pregnant women using the SPIKES <sup>a</sup> protocol	Position paper	VII	Prediction and control
Hodgson et al (2016) <sup>43</sup>	Australia	To describe parental experience and examine how to best provide support after a fetal anomaly diagnosis	Qualitative (narrative analysis)	VI	Exploration
Lafarge et al (2017) <sup>24</sup>	United Kingdom	To describe coping strategies used during and after termination for fetal anomaly	Qualitative (phenomenological analysis)	VI	Exploration
Labor et al (2007) <sup>9</sup>	United Kingdom (Ireland)	To explore the experiences of women's encounters with caregivers after the diagnosis of fetal anomaly on routine second-trimester ultrasound examination	Qualitative (constant comparison analysis)	VI	Description
Lisy et al (2016) <sup>27</sup>	Australia	To investigate the effectiveness, meaningfulness, and cultural appropriateness of care delivered to families experiencing stillbirth	Qualitative meta-synthesis	V	Exploration
Mccullough (2016) <sup>47</sup>	United States	To discuss ethical obligations of physicians when discussing bad news with parents experiencing perinatal loss	Position paper	VII	Prediction and control
Mcnamara et al (2013) <sup>20</sup>	United Kingdom (Ireland)	To provide a framework to guide physiologic, emotional, and spiritual care of patients carrying a fetus affected by a fetal anomaly	Position paper	VII	Prediction and control
Meaney et al (2015) <sup>44</sup>	United Kingdom	To explore parents perception of perinatal autopsy decision-making processes	Qualitative (phenomenological analysis)	VI	Description

(continues)

Table 2. Characteristics of sample (Continued)

Study	Setting	Purpose	Design	Level of evidence	Level of knowledge
Peters et al (2015) <sup>42</sup>	Australia	To promote and inform meaningful and culturally appropriate care to families experiencing stillbirth	Qualitative meta-synthesis	V	Prediction and control
Ryninks et al (2014) <sup>3</sup>	Switzerland	To describe a women's experience of spending time with her stillborn neonate	Qualitative (phenomenological analysis)	VI	Exploration
Üstündağ-Budak (2015) <sup>48</sup>	United States	To identify the meaning of stillbirth to women and its influence on consecutive pregnancies	Qualitative (phenomenological analysis)	VI	Descriptive
Xafis et al (2016) <sup>12</sup>	Australia	To identify communication difficulties between patients and providers discussing perinatal/neonatal end-of-life	Descriptive content analysis	VI	Prediction and control

<sup>a</sup>SPICES acronym represents the importance of setting, perception, invitation, knowledge, and empathy.

further facilitate comprehension.<sup>9,11,43,45</sup> Allowing parents time to process information that is presented using standard, nonmedical terminology facilitated comprehension of the diagnosis, increased decision-making capability, and an increased parental sense of control.<sup>12</sup>

### Parents need the freedom to explore options and alternatives

Healthcare professionals and parents alike hold preconceived assumptions influenced by culture, ethnicity, and personal values.<sup>9,11,20</sup> It is vital for healthcare professionals to recognize personal bias in order to avoid inadvertently negatively impacting parental experience during care surrounding perinatal loss.<sup>9</sup> Common assumptions made by healthcare professionals, as reported by parents, include assumptions of how parent(s) will react, assumptions that parents will wish to terminate the pregnancy, and assumptions that standardized care rather than individualized care is appropriate. Assumptions based on personal beliefs and bias—often unrecognized—risk healthcare professionals providing inappropriate care.<sup>9</sup> Furthermore, emotional and spiritual well-being is often overlooked, as care is focused on the physical aspects of the pregnancy and fetal anomaly.<sup>2,20</sup>

Without question, healthcare professionals are interested in the well-being of patients. Historically, inadvertent and unrecognized personal beliefs and assumptions have negatively impacted parental experience surrounding the diagnosis of a fetal anomaly.<sup>20</sup> To improve care, it is imperative to recognize personal beliefs and assumptions and the resulting influence these have on patient care.<sup>9,20</sup> Exploring parental desires allows healthcare professionals to deliver appropriate, sensitive care, thus facilitating informed decision-making.<sup>11</sup>

### Parents need clinicians with expert communication skills

The communicative stance and approach healthcare professionals adopt during communication include both verbal and nonverbal language and has been reported to impact parents' lives for years to come.<sup>12</sup> The crucial role of verbal language in communication was frequently repeated throughout the literature. Avoidance of medical jargon and terminology is imperative.<sup>9,11,20,42</sup> It is not uncommon for well-meaning healthcare professionals to unintentionally utilize complex medical terminology when communicating bad news to a patient.<sup>12</sup> Parents have reported feeling overwhelmed, confused, and inadequate when presented with medical jargon not commonly understood.<sup>12</sup> Ambiguity, abruptness, and technical language leave parents feeling anxious and alone.<sup>27</sup>

Nonverbal language can augment or weaken a parent's experience of receiving bad news during pregnancy.<sup>9</sup> The communicative stance of healthcare professionals can negatively influence a parent's understanding, decision-making capacity, and overall grief.<sup>12</sup> Grief may be compounded by perceived insensitivity in tone of voice, vocabulary usage, and perceived attitude, which may be interpreted as offhanded, uncaring, or indifferent.<sup>45</sup> Finally, assuming a stance of a listening attitude has resulted in positive outcomes.<sup>12</sup> Allowing prolonged periods of silence, in which healthcare professionals listen more than speak, demonstrated a caring attitude to the parents.<sup>12</sup>

Straightforward, open information concerning the diagnosis, prognosis, and treatment options available was found to facilitate both understanding of the fetal congenital anomaly and the grieving process of parents.<sup>20</sup> Parents reported appreciating honesty in communicating ambiguity associated with fetal anomalies, recognizing uncertainty is inevitable in predicting pregnancy outcomes.<sup>45</sup> An environment in which parents felt safe to ask questions and seek information regarding the nature of the fetal anomaly facilitated optimal decision-making capacity.<sup>11,12,25,27</sup> Sensitivity to the emotional state of the parents, as well as sensitivity in language chosen, positively impacted parental experience and informed decision-making.<sup>27</sup> Information communicated in an unbiased, nonjudgmental manner reportedly improved an overall negative experience for parents.<sup>20</sup> Ultimately, the emotional impact of receiving such a diagnosis can be lessened through clear, unbiased information communicated with sensitivity.<sup>43</sup> Remaining calm, showing empathy, and listening set a positive tone for the encounter, facilitating the communication of a fetal congenital anomaly diagnosis.<sup>11</sup>

## DISCUSSION

The key findings from this integrative review focused on themes identified as important to parents regarding the communication of an intrauterine diagnosis of a fetal congenital anomaly. These themes included allowing parents adequate time to process information, using language that is nontechnical and nonjudgmental, and incorporating empathetic, expert communications skills. Observation of these aspects of communication positively influences the experience of parents, enhancing comprehension of the diagnosis, and facilitating informed decision-making.<sup>9,11,20</sup> Key findings also identified several aspects that negatively influence parental experience, including extensive gaps in time between follow-up appointments, limited time available for providing patient education, fragmented healthcare, inconsistent training regarding communicating bad news dur-

ing pregnancy, and low referral rates to perinatal loss resources.<sup>7,11,27,46</sup>

Literature has demonstrated a significant gap in addressing communicating bad news during pregnancy, yet it is clear that such interactions have a lasting impact on parents' lives.<sup>9,11,12,45</sup> Despite a lack of formalized guidelines standardizing the communication of a diagnosis of an intrauterine fetal anomaly, literature does provide qualitative evidence through parental experience upon which to build a foundation for best practice. Furthermore, 2 communicative frameworks, linguistic theory and a modification of the SPIKES protocol, have been developed to guide healthcare professionals in discussing bad news with parents during pregnancy.<sup>12,25</sup> These frameworks address both positive and negative aspects associated with themes identified as important to parents during the communication of an intrauterine fetal congenital anomaly diagnosis. Application of these frameworks during the communication of a diagnosis of a fetal anomaly may improve communication, decrease parental anxiety, enhance provider-patient relationships, and facilitate informed decision-making.

Concerned by the lack of standardized training focused on EoL conversations in pediatric and neonatal practice, the resulting impact on parents, and understanding the central role of communication in the healthcare system, Xafis et al<sup>12</sup> proposed adapting linguistic theory as a framework to guide conversation when discussing terminal perinatal diagnoses. Linguistic theory suggests there are 4 general truths, or maxims, which are central to conversational dialogue, consisting of *quantity*, *quality*, *relation*, and *manner*.<sup>12</sup> The underlying principles observed by both the speaker and the listener enable efficient communication. However, breaching any of the maxims results in negative consequences, impacting both the provider-patient relationship and parental experience.<sup>12</sup>

The maxim of *quantity* is the unspoken agreement of sharing the full amount of information. Parents rely heavily on healthcare providers for information regarding the diagnosis of a fetal anomaly. Perceptions of receiving insufficient information to comfortably achieve informed decision-making may leave parents feeling anxious and frustrated.<sup>7,12,27</sup> Anxiety is furthered when the maxim of *quality*—the assumption of what the speaker says to be true is indeed true—is disrupted. However, open communication of evidence-based treatment options and honesty regarding the prognosis of the fetus is appreciated by parents. The maxim of *relation* requires continuity of care by the least number of healthcare professionals possible, as multisource communication may result in greater confusion for parents, breaching the maxim not only of relation but of quality

as well. Finally, the maxim of *manner* requires avoidance of medical jargon and terminology. Using simple terms and language parents are able to understand is imperative to facilitating informed decision-making.<sup>12</sup>

Greiner and Conklin<sup>11</sup> recommend adapting the SPIKES protocol to perinatal EoL discussions, understanding the significant impact of communication during informing parents of a fetal congenital anomaly diagnosis. Originally designed to inform oncology patients of a terminal diagnosis, the SPIKES protocol provides a framework for communicating bad news. The SPIKES acronym represents the importance of *setting, perception, invitation, knowledge, and empathy*.<sup>11,25</sup> The environment, or *setting*, in which the conversation occurs ought to maximize the comfort level of the patient. A quiet, private location with minimal distraction is ideal. *Perception* addresses the parent's understanding and impression of the diagnosis.<sup>25</sup> Assessing the perception a parent holds of the diagnosis allows for appropriate and individualized education. Asking the parents' *permission* to share information regarding the diagnosis of the fetus may provide a sense of control for parents.<sup>11,25</sup> Avoidance of medical jargon and terminology during these conversations enhances the *LOK* the parents are able to understand concerning the fetal anomaly diagnosis.<sup>11,25</sup> Finally, healthcare professionals can demonstrate *empathy* through adopting a communicative stance in which patiently and gently repeated information is provided while avoiding sentiments such as "I know what this must be like," which is often interpreted as insincere.<sup>11,27</sup>

Further suggestions to enhance the care of parents experiencing perinatal loss include developing specialized care measures for parents who receive a diagnosis of a fetal anomaly in utero and focused education for healthcare professionals caring for perinatal populations. Specialized standards may include expedited specialty referrals and extended appointment times dedicated to parental questions and education. Education for healthcare professionals regarding the impact and role of communication, best practice standards surrounding perinatal loss, and availability of perinatal palliative care resources may equip providers and nurses with the skills and knowledge necessary to care for populations experiencing intrauterine fetal congenital anomaly diagnoses.<sup>2,11,12,17</sup>

A critical next step in the research is to assess both current practice in communication and healthcare professionals' comfort level with their role in perinatal EoL discussions. From this knowledge, the development of standardized communicative protocols and education to perinatal healthcare professionals may be established. Failure to provide such guidance and education may have significantly negative impacts on both

healthcare professionals and parents. Therefore, it is necessary to equip providers and nurses alike with the skills necessary for effective communicative techniques concerning perinatal loss, to facilitate informed-decision making and positively impact the grieving process.

## LIMITATIONS

Several limitations are present in this integrative review. First, relatively few scholarly articles focus on communication techniques specific to perinatal EoL conversations and diagnoses. Although search terms were reviewed with a subject matter expert librarian, materials may have been inadvertently omitted. Second, few studies have been conducted in the United States concerning communication and care surrounding lethal congenital anomalies; therefore, a high percentage of articles included in this review were outside the American healthcare context. This is likely due to the increasing availability and legality of abortion in the United States. Laws prohibiting termination of pregnancy in countries such as Australia, Ireland, the United Kingdom, and Sweden provide healthcare practitioners with the opportunity to gain a more in-depth understanding in the intricacies of care and treatment of families carrying a terminal pregnancy. As a result, the majority of the literature included in this review was published in countries outside the United States. Third, communicative techniques, theory, and protocols have been borrowed from outside specialties and adapted to perinatal practice, which may limit their applicability to nursing care.<sup>12,25</sup> Fourth, all articles used in this review were qualitative. While qualitative research provides substantial guidance to nursing practice and patient care, this specialty field would benefit from the addition of quantitative studies to develop and strengthen the state of the science. Fifth, the LOE of each article ranged from 5 to 7, highlighting an opportunity for further research. Finally, to date, no guidelines used to standardize the communication of a fetal anomaly diagnosis to expectant parents were found. It is possible that crucial articles or guidelines were unintentionally left out of the sample through omission by the investigators, publication bias, or the delineators that were applied.

## CONCLUSION

Learning of an intrauterine fetal congenital anomaly is a devastating event for parents. Intense perinatal grief can develop into lifelong adverse psychosocial symptoms such as depression, anxiety, PTSD, substance abuse, and suicidal ideation. Interaction and communication with healthcare professionals can potentiate the

experience of parents, whether positive or negative, in a profound and lasting manner. Therefore, it is imperative to adopt a sensitive, empathetic communicative stance and apply techniques to facilitate open and empathetic communicating in the discussions surrounding intrauterine fetal congenital anomaly diagnoses.

## References

- Cole JCM, Moldenhauer JS, Jones TR, et al. A proposed model for perinatal palliative care. *J Obstet Gynecol Neonatal Nurs*. 2017;46(6):904–911. doi:10.1016/j.jogn.2017.01.014.
- Johnson OP, Langford RW. A randomized trial of a bereavement intervention for pregnancy loss. *J Obstet Gynecol Neonatal Nurs*. 2015;44(4):492–499. doi:10.1111/1552-6909.12659.
- Ryninks K, Roberts-Collins C, McKenzie-McHarg K, Horsch A. Mothers' experience of their contact with their stillborn infant: an interpretative phenomenological analysis. *BMC Pregnancy Childbirth*. 2014;14:203. doi:10.1186/1471-2393-14-203.
- Trinidad MX, Wick M. Neural tube defects. *Am J Obstet Gynecol*. 2017;95(76):1–9. doi:10.1097/AOG.0000000000002528.
- Wool C. Clinician confidence and comfort in providing perinatal palliative care. *J Obstet Gynecol Neonatal Nurs*. 2013;42(1):48–58. doi:10.1111/j.1552-6909.2012.01432.x.
- Wool C. Clinician perspectives of barriers in perinatal palliative care. *MCN Am J Matern Nurs*. 2015;40(1):44–50. doi:10.1097/NMC.0000000000000093.
- Côté-Arsenault D, Denney-Koelsch E. "My baby is a person": parents' experiences with life-threatening fetal diagnosis. *J Palliat Med*. 2011;14(12):1302–1308. doi:10.1089/jpm.2011.0165.
- Hutti MH, Myers J, Hall LA, et al. Predicting grief intensity after recent perinatal loss. *J Psychosom Res*. 2017;101:128–134. doi:10.1016/j.jpsychores.2017.07.016.
- Lalor JG, Devane D, Begley CM. Unexpected diagnosis of fetal abnormality: women's encounters with caregivers. *Birth*. 2007;34(1):80–88. doi:10.1111/j.1523-536X.2006.00148.x.
- Carlsson T, Mattsson E. Emotional and cognitive experiences during the time of diagnosis and decision-making following a prenatal diagnosis: a qualitative study of males presented with congenital heart defect in the fetus carried by their pregnant partner. *BMC Pregnancy Childbirth*. 2018;18(1):26. doi:10.1186/s12884-017-1607-y.
- Greiner AL, Conklin J. Breaking bad news to a pregnant woman with a fetal abnormality on ultrasound. *Obstet Gynecol Surv*. 2015;70(1):39–44. doi:10.1097/00019616-200203000-00015.
- Xafis V, Watkins A, Wilkinson D. Death talk: basic linguistic rules and communication in perinatal and paediatric end-of-life discussions. *Patient Educ Couns*. 2016;99(4):555–561. doi:10.1016/j.pec.2015.10.025.
- Carlsson T, Marttala UM, Mattsson E, Ringnér A. Experiences and preferences of care among Swedish immigrants following a prenatal diagnosis of congenital heart defect in the fetus: a qualitative interview study. *BMC Pregnancy Childbirth*. 2016;16(1):130. doi:10.1186/s12884-016-0912-1.
- Heuser CC, Eller AG, Byrne JL. Survey of physicians' approach to severe fetal anomalies. *J Med Ethics*. 2012;38(7):391–395. doi:10.1136/medethics-2011-100340.
- Moore L. Anencephaly. *J Diagnostic Med Sonogr*. 2010;26(6):286–289. doi:10.1177/8756479310386486.
- Hall JW, Denne N, Minardi JJ, Virginia W. Check the head: emergency ultrasound diagnosis of fetal anencephaly. *West J Emerg Med*. 2016;17(4):460–464. doi:10.5811/westjem.2016.5.30326.
- Chapman B. A case of anencephaly: integrated palliative care. *N Z Coll Midwives J*. 2013;48:5–8. doi:10.12784/nzcomjnl48.2013.1.5-8.
- Kavanaugh K, Roscigno CI, Swanson KM, Savage TA, Kimura RE, Kilpatrick SJ. Perinatal palliative care: parent perceptions of caring in interactions surrounding counseling for risk of delivering an extremely premature infant. *Palliat Support Care*. 2017;13(2):145–155. doi:10.1017/S1478951513000874.
- Kennell JH, Slyter H, Klaus MH. The mourning response of parents to the death of a newborn infant. *N Engl J Med*. 1970;283(7):344–349.
- McNamara K, O'Donoghue K, O'Connell O, Greene RA. Antenatal and intrapartum care of pregnancy complicated by lethal fetal anomaly. *Obstet Gynaecol*. 2013;15(3):189–194. doi:10.1111/tog.12028.
- Hutti MH, Armstrong DS, Myers JA, Hall LA. Grief intensity, psychological well-being, and the intimate partner relationship in the subsequent pregnancy after a perinatal loss. *J Obstet Gynecol Neonatal Nurs*. 2015;44(1):42–50. doi:10.1111/1552-6909.12539.
- Toedter LJ, Lasker JN, Janssen HJ. International comparison of studies using the perinatal grief scale: a decade of research on pregnancy loss. *Death Stud*. 2001;25(3):205–228.
- Potvin L, Lasker J, Toedter L. Measuring grief: a short version of the perinatal grief scale. *J Psychopathol Behav Assess*. 1989;11(1):29–45. doi:10.1007/BF00962697.
- Lafarge C, Mitchell K, Fox P. Posttraumatic growth following pregnancy termination for fetal abnormality: the predictive role of coping strategies and perinatal grief. *Anxiety Stress Coping*. 2017;30(5):536–550. doi:10.1080/10615806.2016.1278433.
- Dean A, Willis S. The use of protocol in breaking bad news: evidence and ethos. *Int J Palliat Nurs*. 2016;22(6):265–271.
- Hutti MH, Armstrong DS, Myers J, Armstrong DS. Evaluation of the perinatal grief pregnancy after perinatal loss. *J Obstet Gynecol Neonatal Nurs*. 2013;42(6):697–706. doi:10.1111/1552-6909.12249.
- Lisy K, Peters MD, Riitano D, Jordan Z, Aromataris E. Provision of meaningful care at diagnosis, birth, and after stillbirth: a qualitative synthesis of parents' experiences. *Birth*. 2016;43(1):6–19. doi:10.1111/birt.12217.
- Whittemore R, Knaff K. The integrative review: updated methodology. *J Adv Nurs*. 2005;52(5):546–553. doi:10.1111/j.1365-2648.2005.03621.x.
- Higgins JPT, Green S, eds. *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.handbook.cochrane.org. Accessed April 13, 2018.
- Peters MDJ, Godfrey CM, McInerney P, Soares CB, Khalil H, Parker D. *The Joanna Briggs Institute Reviewers' Manual 2015. Methodology for JBI Scoping Reviews*. Adelaide, SA: The Joanna Briggs Institute; 2015.
- Miles MB, Huberman AM, Saldana J. *Qualitative Data Analysis: A Methods Sourcebook*. 3rd ed. Los Angeles, CA: Sage; 2014.
- Newhouse R, Dearholt S, Poe S, Pugh LC, White K. *The Johns Hopkins Nursing Evidence-Based Practice Rating Scale*. Baltimore, MD: The Johns Hopkins Hospital, Johns Hopkins University School of Nursing; 2005.
- Polit DF, Beck CT. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Philadelphia, PA: Williams & Wilken; 2001.
- Polit DF. *Statistics and Data Analysis for Nursing Research*. San Francisco, CA: Pearson; 2010.

35. Sandelowski M. When a cigar is not just a cigar: alternative takes on data and data analysis. *Res Nurs Health*. 2011; 34(4):342–352. doi:10.1002/nur.20437.
36. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33(1):77–84. doi:10.1002/nur.20362.
37. Sandelowski M. Real qualitative researchers do not count: the use of numbers in qualitative research. *Res Nurs Health*. 2001;24(3):230–240.
38. Sandelowski M. Combining qualitative and quantitative sampling, data collection, and analysis techniques in mixed-method studies. *Res Nurs Health*. 2000;23(3):246–255.
39. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*. 2000;23(4):334–340.
40. Lincoln YS. Naturalistic inquiry. *Blackwell Encycl Sociol*. 2007. doi:10.1002/9781405165518.wbeosn006.
41. Denzin NK, Lincoln YS. *Handbook of Qualitative Research*. New York, NY: Sage; 1994.
42. Peters MD, Lisy K, Riitano D, Jordan Z, Aromataris E. Caring for families experiencing stillbirth: evidence-based guidance for maternity care providers. *Women Birth*. 2015;28(4):272–278. doi:10.1016/j.wombi.2015.07.003.
43. Hodgson J, Pitt P, Metcalfe S, et al. Experiences of prenatal diagnosis and decision-making about termination of pregnancy: a qualitative study. *Aust NZ J Obstet Gynaecol*. 2016; 56(6):605–613. doi:10.1111/ajo.12501.
44. Meaney S, Gallagher S, Lutomski JE, O'Donoghue K. Parental decision making around perinatal autopsy: a qualitative investigation. *Heal Expect*. 2015;18(6):3160–3171. doi:10.1111/hex.12305.
45. Wilkinson D, de Crespigny L, Xafis V. Ethical language and decision-making for prenatally diagnosed lethal malformations. *Semin Fetal Neonatal Med*. 2014;19(5):306–311. doi:10.1016/j.siny.2014.08.007.
46. Marc-Aurele KL, Hull AD, Jones MC, Pretorius DH. A fetal diagnostic center's referral rate for perinatal palliative care. *Ann Palliat Med*. 2018;7(2):177–185. doi:10.21037/apm.2017.03.12.
47. McCullough LB. Physicians' professionally responsible power: a core concept of clinical ethics. *J Med Philos (United Kingdom)*. 2016;41(1):1–9. doi:10.1093/jmp/jhv034.
48. Üstündağ-Budak AM, Larkin M, Harris G, Blissett J. Mothers' accounts of their stillbirth experiences and of their subsequent relationships with their living infant: an interpretative phenomenological analysis. *BMC Pregnancy Childbirth*. 2015;15:263. doi: 10.1186/s12884-015-0700-3.