• **Title**

Death Talk: basic linguistic rules and communication in perinatal and paediatric end-of-life discussions

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Death Talk: basic linguistic rules and communication in perinatal and paediatric end-of-life discussions

Abstract

Objective: This paper considers clinician/parent communication difficulties noted by parents involved in end-of-life decision-making in the light of linguistic theory.

Methods: Grice's Cooperative Principle and associated maxims, which enable effective communication, are examined in relation to communication deficiencies that parents have identified when making end-of-life decisions for the child. Examples from the literature are provided to clarify the impact of failing to observe the maxims on parents and on clinician/parent communication.

Results: Linguistic theory applied to the literature on parental concerns about clinician/parent communication shows that the violation of the maxims of quantity, quality, relation, and manner as well as the stance that some clinicians adopt during discussions with parents impact on clinician/parent communication and lead to distrust, anger, sadness, and long-term difficulties coping with the experience of losing one's child.

Conclusion: Parents have identified communication deficiencies in end-of-life discussions. Relating these communication deficiencies to linguistic theory provides insight into communication difficulties but also solutions.

Practice Implications: Gaining an understanding of basic linguistic theory that underlies human interactions, gaining insight into the communication deficiencies that parents have identified, and modifying some communication behaviours in light of these with the suggestions made in this article may lead to improved clinician/parent communication.

Keywords

health communication; end of life care; consumer health information; decision making

"*A good doctor is someone who knows the content; a great doctor is how he interacts with the patient and the patients' families.*"

Father interviewee [1]

1. Introduction

End-of-Life (EoL) discussions are difficult and emotionally challenging but when such discussions are held with expectant parents or parents of children with life-limiting conditions, the difficulty is magnified for all parties involved and the emotional demand on parents is enormous.

The centrality of the role of communication in medicine is indisputable, as evidenced, for example, by the literature relating to breaking bad news to patients [2-5], doctor-patient communication [6-10] and communication skills training for clinicians [11-13]. Despite acknowledgement of the importance of communication in medicine and considerable focus in this area over many decades [9], parental concerns about communication in EoL discussions for their child are recurring and persistent.

Several issues may affect the progress made in this area. The quality of communication is greatly affected by the limited time healthcare professionals have at their disposal; the personal challenge health care professionals themselves face when dealing with parents also seems to play a role [14, 15], and, importantly, there is a lack of sustained training in communication [12, 14]. The focus of doctors' training has traditionally primarily been on the technical aspects of treatment and the preservation of life. It is only in very recent years that the focus of the role of medicine has shifted to a more holistic approach. Therefore, communication may still be impacted by this long tradition in medical training, especially given the variation in communication skills training. Where communication training is provided, it has been shown to be effective but such programs are not always available for all specialties [12] and are often local initiatives (for example, the web-based resources developed by the American Academy on Communication in Health Care, at www.aachonline.org). It has also been suggested that the long-term benefits of improved communication, while recognised, are not supported fully, as greater focus on improvements in this area produce increased financial costs in the short-term [10].

Linguistics is the scientific study of language and communication. Other studies have relied on linguistics to inform and develop programs or interventions [16-20] or develop a better understanding of established processes such a hospital handovers [21] but an analysis of

communication difficulties in perinatal and paediatric EoL discussions using linguistic theory has not been attempted previously. Drawing on linguistic theory about basic rules governing conversational exchanges provides a deeper understanding of persistent communication difficulties and their impact on parents, as reported by parents who have made EoL decisions for their child. This paper aims to clarify the nature of these communication difficulties and to provide communication strategies directly linked to the theory of communication. Previous studies have provided similar advice [10] without, however, providing evidence that it is supported by linguistic theory. Exposure to parents' lived experience coupled with an appreciation of basic linguistic conversational rules brings greater focus to such exchanges and highlights parental needs during such demanding exchanges as well as the impact on parents' decision-making and emotional wellbeing when communication is not optimal.

2. Methods

Grice's Cooperative Principle

Most people engaging in conversation successfully abide by unwritten rules that govern our conversational exchanges even if they are theoretically unaware of them, in the same way that they are able to string together grammatically correct sentences despite their unfamiliarity with the precise grammatical rules that govern such structures. The underlying general principle in any conversation is that both speakers and listeners are abiding by certain conventions that enable efficient communication and they make assumptions about each other's compliance with these rules [22].

Grice articulated a general principle governing conversational exchanges in the Cooperative Principle [23]:

> *Make your conversational contribution such as is required, at the stage at which it occurs, by the accepted purpose or direction of the talk exchange in which you are engaged.*

Further clarifying the nature of this unspoken agreement are four maxims that make effective communication possible [23] (Table 1): the maxims of Quantity, Quality, Relation, and Manner.

The maxims sound like commands or requests and could be misconstrued as a guide to good conversational etiquette even though Grice most likely adopted this form as a concise articulation of a complicated linguistic theory. The brevity with which they are articulated is useful for people with no specialist linguistic expertise who wish to better understand and observe basic rules that lead to effective and constructive communication (see Table 1).

Table 1. Grice's four Maxims

Category	Supermaxim	Maxim	Examples of the violation of the maxims in EoL discussions in parents' own words	How the Maxims have been violated
Quantity (amount of information provided)	n/a	1. Make your contribution as informative as required (for the current purposes of the exchange) 2. Do not make your contribution more informative than is required	1. A "Please keep parents informed. It seems a constant uphill struggle to obtain information, particularly in the hours immediately after delivery or transfer." [24] 1. B "I think they knew more than they wanted to tell me. Like the last day, I think they knew, and they weren't …they just didn't want to I guess…but sometimes they need to prepare that person. I would have been able to deal with it better; I would have been more prepared, my husband would have been there." [25] 1. C "We were very much on our own. We had a lot of questions and we didn't have anyone to answer them."[26] 1. D "It was very important for us to get some time with these very busy doctors. I think that on certain occasions the doctors should perhaps take the initiative to work out an agreement with parents such as: 'Shall I bother you with all the details that worry me, or shall I not say anything, or shall we try to find a good middle ground about what I tell you?' I had more than enough problems without having to worry about all the things that could go wrong." [27] 2. A "there was times where it was too much information."[1] 2. B Father did not want so much information because "point blank, I'm scared." [1]	The first four examples indicate parents' perception that too little information was made available. Violation of the first part of this maxim is evident in the described struggle to access information (1A), the sense that doctors were withholding details (1B), the isolation created by a lack of healthcare professionals to provide answers (1C) and the need to secure time with doctors (1D). Quote 1D also highlights the need parents might have for varying degrees of information provision and points to the need to check how the Maxim of Quantity should apply in this challenging context. Parents in 2A and 2B indicate that they found the information provision more detailed than desired thus pointing to the violation of the second part of this maxim. In 2B we are provided with an explanation of why too much information was unwelcome for this father; it was overwhelming and created fear.
Quality (factual accuracy of information provided)	*Try to make your contribution something that is true*	1. Do not say what you believe to be false 2. Do not say that for which you lack adequate evidence	1. A "Be honest with parents and don't be scared of telling the truth. People cope-they don't have a choice." [24] 1. B "I would like to know why, when there were so many physical signs that led us to believe that it was a very, very serious situation, why didn't they say that?"[28] 2. A "…the thing that bothered me the most is that she told me I am sorry for your loss…before they checked her heartbeat…Before they took me to the delivery room and she kept telling me I am sorry, I am so very sorry for your loss and then they found that she had a heartbeat." [29]	In 1A, the parent is making a request that the Maxim of Quality be observed in interactions with parents. Such a request usually only arises when a violation of the maxim has already been experienced. In 1B, the parent highlights the violation of this maxim by stating that the information they were given was contrary to the evidence/facts. In 2A, the healthcare professional made an assumption about the situation without verifying the evidence and caused distress in doing so.
Relation (pertinence of information provided to the matter at hand)	n/a	Be relevant	"[There were] too many doctors explaining things, there really should be just a few. It's too confusing." [30] "I think the doctors need to talk to one another. I think that is a very important thing to do" [28]	It is difficult for parents to ascertain which information they need to take into account to make decisions when there are multiple sources of information (which often differ both in content and focus). Parents here are requesting fewer sources of information so that they are better able to accurately relate the information to their child. The request for fewer sources of information points to the need for group consultations so differing views can be discussed, clarified, and differences can be resolved so parents do not have to question the relevance of multiple bits of information for their child (See section 3.3 for more detail)
Manner (clarity of information conveyed)	*Be perspicuous*	1. Avoid obscurity of expression 2. Avoid ambiguity 3. Be brief (avoid unnecessary prolixity)	1. A "There got to a point in our hospital stay when a certain doctor came in and I couldn't tell you a word he said. I know he was there, I couldn't tell you a word he said" [28] 2. A "No one ever told me the baby could die. I never understood what was happening medically. The doctor came out during the operation and asked my wife if they should stop or continue the operation. I didn't understand that the baby would die either way at that point. No interpreter came during this conversation."[31]	In 1A, the parent indicates they found the information so obscure that they retained none of it. This is a violation of part 1 of the Maxim of Manner but may also be a violation of part 2. In 2A the father indicates that part 2 of the Maxim was violated, as the information provided was ambiguous and did not clearly convey the expected outcome of the operation. His quote may also indicate that the information was obscure.(No examples were identified in relation to part 3 of this maxim)

Observing the Cooperative Principle, results in conversationally efficient communication because it enables us to make inferences beyond the stated words. For example, when the clinician who is talking to parents desperate to find treatment for their seriously ill child says, “We have the option of doing A or B.”, parents infer that options A and B would both yield beneficial results and that there are no other options available. If they were to then discover that option A would result in their child’s certain death or that there was a third option available but simply not communicated, confusion and distrust would emerge. Such feelings of confusion and distrust would result from the parents heavily relying on the Cooperative Principle.

3. Results

Grice’s maxims and EoL decisions for children

Numerous studies have focused on communication between healthcare professionals and parents who have made EoL decisions for their child. Many of these studies show parents’ sadness, anger, emotional distress, or disbelief about communication deficiencies relating to the care provided for their child. The following sections draw on studies involving parents who have made EoL decisions and demonstrate the ways in which a violation of the maxims has impeded communication.

3.1. The maxim of quantity

When engaging in such serious conversations about the life or death of a child, parents assume that healthcare providers will impart any information that will enable them to understand their child’s circumstances and make the best decision for their child.

Parents commonly complain about the amount of information they receive. While some parents do not wish to receive full information [1, 27] when making EoL decisions for their child a recurring theme in accounts from parents is that they have access to too little information and sometimes limited access to clinicians, the key providers of information [24-26, 28, 29, 32-42]. The commonest complaint is a lack of information relating to the outcome for their child [38, 43-45], information on the available options for their child [46], and information about the circumstances under which death occurred and autopsies [47, 48]. Parents of children who have died have indicated that having access to more information would have altered their decision pathway and would also have provided clarity regarding the cause of their child’s death [25].Others have complaints of an even more serious nature in cases where information was sometimes not made available to them at all [28, 34, 49].

The consequences of violating the maxim of quantity are profound and have been articulated by parents; a sense of distrust emerges when information is (or is perceived to be) withheld [28, 37, 48-50] with devastating consequences for clinician/parent relationships, for the decisions made, and for parents’ ability to live with their decisions and their experience overall. Conversely, comprehensive information, such as information on the child’s condition and prognosis, aids informed parental decision-making [25], reduces feelings of anger, distress and feelings of abandonment [42] and increases parents’ sense of control [1].

3.2. The maxim of quality

A fundamental assumption in conversation is that speakers are saying what they believe to be true. If either side perceives a lack of honesty, the exchange may simply end prematurely, disagreement may emerge, or arguments may erupt, depending on the nature of the people and the discussion. In

the EoL context, any perception of a lack of honesty in the information provided leads to anger [51] and a loss of trust [52], both of which can irreparably damage the clinician/parent relationship.

This maxim requires that healthcare professionals only communicate evidence-based, factual information and that they are honest about the child's circumstances. Parents often recognise and accept the uncertainties and unpredictability of their child's condition, which impacts on the potential outcomes and options for their child, and they appreciate it when healthcare professionals admit to the unpredictability involved [1, 30, 46, 53, 54]. In fact, studies have shown that parents do not wish to be given false hope when they are seeking information about their child [42]. They have also repeatedly indicated that they do not want to be stripped of all hope but, at the same time, do not welcome healthcare professionals providing false hope [32, 34, 37, 46, 53, 54].

Despite the difficulty clinicians may face when imparting bad news, it is vital for them to remember that parents consider it important to receive honest information even if it is negative in nature [24, 51, 55]. Some parents have identified the importance of receiving honest information as being linked to their ability to make informed decisions and to cope better following their child's death [30]. Observing the maxim of quality is important because when parents are provided with accurate information, they feel empowered (provided information is also timely and delivered sensitively) [24].

3.3. The maxim of relation

In most hospital systems parents will come in contact with numerous healthcare professionals and may not have a single, guiding clinician. Parents recognise that the more professionals involved, the more likely they are to receive information that is inconsistent so they advise that the smallest necessary number of professionals should provide information [54]. Parents have identified this multi-layered and multi-source communication as an issue of great confusion and concern [28, 30, 32, 34, 42, 48, 56], as they have to deal with both the information provided by each clinician and the various different ways in which it may be presented, while relating it to all other information provided. Where discrepancies are identified, confusion may emerge and parents become unsettled [56] as they are unable to determine which information is relevant to their child's circumstances and which information they need to bear in mind to understand the situation and make decisions. The view that professionals should share information more effectively with each other [28] also points to parents' desire to receive consistent information. Joint consultation involving a number of specialists simultaneously may minimise such inconsistencies.

Such inconsistency in information also greatly affects adherence to the maxim of quality. Inconsistencies arise from medical uncertainty and an inability to present definite answers because there may simply be none, but are also influenced by variations in clinical experience and clinician values. The uncertainty of information in itself does not result in the violation of the maxim of quality but the presentation of uncertain information as factual does. There is also evidence that many parents may not be influenced by the facts and figures so beloved of doctors, focusing instead on the need to maintain some hope for either cure or a better outcome [57].

3.4. The maxim of manner

Language that is obscure, ambiguous or verbose is difficult to understand and creates distance between the speaker and listener, as the speaker is perceived as obstructive and unwilling to help the listener to understand. Obscure and ambiguous language can also make the listener feel

inadequate. This has implications for parents involved in EoL discussions who may be disempowered at a critical time, when they must advocate for their child.

Parents report that this maxim is often violated because clinicians use medical terms parents have difficulty comprehending (especially in the initial phases of their contact). Parents suggest that easy-to-understand non-technical language is very helpful [43, 58] but some acknowledge that a sensitive manner of delivery is also important [31]. There is some variation in parental preferences regarding the use of jargon across countries with some parents less inclined to think that simplified terminology would improve communication [45]. Despite this finding, however, parents have indicated repeatedly that they find medical jargon confusing and overwhelming and recognise that this creates difficulties in their ability to properly assess information [28, 34, 39, 41, 42] and therefore make informed decisions. The difficulties are further magnified when parents have limited English [31, 42] and when they lack basic medical knowledge and do not know what questions to ask [39, 41, 49] to seek clarification.

Observing the maxim of manner in EoL discussions is central to informed decision-making but also has an impact on parents' emotional wellbeing; one study showed that parents felt they were more in control and less fearful when information was uncomplicated and delivered in simple terms [54].

Doctors' use of jargon may also reflect their own struggle. It has, for example, been shown that junior medical staff in neonatal intensive care units resort to medical jargon and language which achieves "detachment" when feeling insecure or threatened [59].

4. Discussion and Conclusion

4.1. Discussion

Factors impacting on parental EoL decision-making

When more than one maxim is violated, communication is severely impeded. If we also take into account parents' turbulent emotional state, it is not difficult to imagine that they suffer significantly reduced capacity for optimal decision-making. Parents indicate that it is difficult to engage in rational decision-making at a time when they are not functioning well physically and mentally [60] or in a time of crisis [27]. In addition, parents found that they had limited decision-making capacity as a result of the paucity of information they received (violation of the maxim of quantity) and their comprehension of information was hampered by the jargon used (violation of the maxim of manner), as well as the difficulty in understanding and retaining complex explanations of the child's condition (violation of the maxim of manner) [41, 61].

Other important communication features

Parents recognise that some healthcare staff lack the skills to communicate effectively [49]. This paper has thus far focused exclusively on Grice's Cooperative Principle and associated maxims. The parent EoL literature, however, reveals additional aspects of communication difficulty that seem unrelated to Grice's maxims. For example, some parents found their interactions with healthcare professionals frustrating, as they perceived indifference from them and an unwillingness to listen to parents [29, 34, 54, 55], answer their questions, or address concerns they had about their child, and, for some, a condescending attitude was a source of distress [34, 50]. A range of healthcare professionals' behaviours influenced parents very negatively and caused them to feel coerced and bullied into making decisions about their child [32]. Such behaviours included the tone of voice, the words used when discussing the baby, body language, and an unwillingness to take into account

parents' goals and their need for explanations [32]. In addition, some parents experienced distress when they perceived a negative attitude towards disability or when healthcare professionals spoke disrespectfully about the unborn child during prognostic testing [32, 33, 62]. Also causing distress was an uncaring offhand attitude from healthcare professionals announcing bad news to parents [28, 56]. This attitude caused some parents to question whether they were being told the truth [56].

Clinicians' treatment of parents plays an important role in parents' ability to better cope with such great distress and parents have made numerous suggestions. For example, parents appreciate a general empathetic and sensitive attitude from the medical professional [48, 63], especially when difficult information is delivered [31, 64, 65] and they request a sensitive attitude regarding parental needs after the loss of their child [24]. Parents reveal that clinicians' acknowledgement of the difficulty of their situation [66] and being able to speak to the doctor, not as a professional, but as a human being [56] help them accept their decisions. Other parents have emphasized the importance of medical personnel being humble and understanding [27].

> What parents are referring to in these studies is the *stance* or attitude that some healthcare professionals adopt towards parents who find themselves in such difficult circumstances. Such concerns are important, as attention to patients' emotional needs and patient/clinician relationship has been shown to impact on perceptions of satisfying patient/clinician communication [67].

Communicative stance [59] is the attitude or emotion we express in communication with others thorough words or phrases (linguistic means) and/or through the tone and pitch of our voice, our body language, and facial expressions (paralinguistic means) [68]. This stance reveals people's underlying beliefs and values. It is, however, also influenced by what other speakers are contributing and *their* communicative stance [69:701]. We contend that communicative stance is also conveyed through omissions. For example, if the clinician ignores parents' contributions and steadfastly pursues the expression of his own content, this limits the parents' ability to make use of the exchange. The following quotes from parents of children that died in intensive care illustrate the impact of communicative stance.

> "He came across very cold almost like he was trying to impress the residents that he was with. That was a horrible incident especially for my wife, well for me too. Just the way he presented the information in such a matter-of-fact tone. Without any real consideration for what he was really talking about. It's like he did not have a concept that he was talking about a human being" [28].

> "I was so upset. I was just mad that he…because he just talked about it like it was casual, you know, 'I have your child's heart and lungs laying here.' And that's how it was, very crude more or less. Kind of heartless, you know. I was astonished. I was baffled…my mouth was wide open and tears were flowing." [25]

As seen from the literature, communicative stance is of central importance in EoL communication and impacts on how all content is received as well as on the healthcare professional's ability to develop a good relationship with parents. It is also important to note, however, that communicative stance may be variously interpreted depending on the cultural background of conversational participants.

Another feature which impacts on communication in settings where speakers are from different social backgrounds, including the clinical setting, is a process referred to as *communication/linguistic accommodation* [70, 71]. Communication/linguistic accommodation involves speaker-initiated modifications to a number of language features including vocabulary, grammar, speech rate,

pausation etc. in order to reduce differences between speakers, facilitate communication, and help the speaker gain social approval from the listener [70, 71]. This is known as *convergence* while behaviours that create distance between speakers, for example because one wants to display superiority, is referred to as *divergence* [70]. Linguistic accommodation in the clinical setting is particularly important given the imbalance in power, knowledge, and often social status between clinicians and parents.

Additional issues that impact on parents in EoL contexts are issues such as the ordering of good and bad news delivery with apparent differences between preferred deliverer and recipient ordering [72]. People delivering news seem to prefer delivering good news prior to bad news, as this eases their own distress [72]. However, recipients of news prefer the reverse order [72]. This has important implications for EoL communication where bad news about, for example, limitation of treatments needs to precede and be balanced with good news about treatments and comfort that can be offered to the child.

4.2. Conclusion

Linguistics has not been formally applied to EoL communication previously. This paper aims to apply a particular linguistic lens to existing evidence about EoL communication, the literature on which is voluminous. The paper aims to assist healthcare professionals in two ways: first, it provides a concise account of communication deficiencies that parents themselves have identified and their impact. Knowledge of these issues in addition to clinical experience may provide a deeper understanding of the parents' perspective, which is often neglected in the whirlwind of clinical demands. Second, relating these communication deficiencies to linguistic theory provides clarity regarding the rules governing conversational exchanges and a reminder of how to remedy persistent difficulties. When Grice's maxims and other linguistic phenomena are known, they seem intuitive, as we are all party to their implementation (or not) in our daily interactions.

There are numerous other factors which impact on the quality of our communication with others and the resulting relationships that develop or suffer. We have brought attention to some of these with reference to the EoL parent literature but have not examined them in any great linguistic depth. Mere insight into these communicative features may bring greater awareness in healthcare professionals' interactions. Future research could focus on this area, as well as on developing a communication evaluation instrument to measure the quality of exchanges in the EoL context and provide feedback to clinicians.

4.3 Practice implications

Gaining an understanding of basic linguistic theory, gaining insight into the communication deficiencies that parents have identified in the EoL context and modifying some communication behaviours in light of these with the suggestions made in this article may lead to improved clinician/parent communication.

Improved communication in the challenging EoL setting can be achieved with attention to certain aspects of communication parents find important and which parents themselves have often identified. These suggestions are not novel but when linked to linguistic theory may better resonate with healthcare professionals. Healthcare professionals should:

- establish the level of detail and complexity desired by families and adapt the information to their needs (maxim of quantity)

- give the facts available, then discuss the issues resulting from these facts (maxim of quality)
- acknowledge uncertainty (maxim of quality)
- present facts honestly (but compassionately), even if devastating, and avoid providing false hope (maxim of quality)
- conduct joint consultations involving a number of specialists simultaneously (maxim of quality/relation)
- use simple language and explanations , pause and ask questions to check understanding and how the information is being processed or perceived, both cognitively and emotionally (maxim of manner).

Finally, healthcare professionals should bear in mind that their compassion, understanding, and respectful attitude towards parents making EoL decisions for their child are crucial to parents' emotional wellbeing long after their child has died. The way healthcare professionals communicate and the stance they adopt when communicating is so powerful that it impacts on parents' lives for the rest of *their* lives. Such great responsibility for another human being's life surely deserves an effort to improve certain aspects of communication.

Author Contributions

VX conceived and synthesised the article, conducted the literature search, drafted the article, critically revised it, and approved the final version submitted.

AW contributed to the design of the article, critically revised it, and approved the final version submitted.

DW contributed to the design of the article, critically revised it, and approved the final version submitted.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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