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Original Article

Breaking bad news: an interview study of paediatric cardiologists

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Abstract Technical developments in paediatric cardiology over the last few decades have increased expectations on professionals, demanding of them more emotional competence and communicative ability. The aim of this study was to examine the approach of paediatric cardiologists in informing and communicating with the family of the patient. *Method:* A qualitative interview method was first tested in a pilot study with two paediatric cardiologists. There were nine subsequent semi-structured interviews that were carried out with paediatric cardiologists. A researcher performed all the interviews, which were taped, transcribed, decoded, and analysed. *Results:* Among paediatric cardiologists, how to break bad news to the family is an important concern, evident in findings regarding the significance of trust and confidence, the use of different emotional positions, and a common ambition to achieve skills to handle the situation. There is a need for reflection, education, and sharing of experiences. The cardiologists desire further development of teamwork and of skills in medical students and residents for delivering bad news. *Conclusions:* Doctors are expected to cope with the complexities of diagnoses and decisions, while simultaneously being sensitive to the feelings of the parents, aware of their own emotions, and able to keep it all under control in the context of breaking the bad news to the parents and keeping them informed. These conflicting demands create a need to expand the professional role of the doctor by including more training in emotional competence and communicative ability, beginning in medical school and continuing through consultancy.

Keywords: Counselling; patient relations; medical education; professional role

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PAEDIATRIC CARDIOLOGY HAS PROGRESSED SIGNIFICANTLY over the last few decades,[1] and technical developments have brought both positive and negative consequences for professionals within the field. The chances of offering effective cure and survival have improved substantially, but expectations have also been raised and demands have grown, causing increased stress.[2] Cardiologists rarely have time to reflect after, or to develop coping skills before, encounters characterised by emotionally loaded communication with parents of children with congenital cardiac diseases.[3] This situation demands changes in the professional work of cardiologists within this field. The doctor is expected to cope with the complexities of diagnoses and care decisions, simultaneously be aware of the feelings of the parents and his or her own emotions, and know how to keep everything under control in the context of breaking the bad news and keeping the parents informed. These conflicting demands create a need to expand the professional role of the doctor by including more of emotional competence and communicative ability. Especially with the more severe cardiac abnormalities, successful counselling is crucial.[4] The paediatric cardiologist usually delivers the bad news, and consequently their professional approach is very important.[5,6] Knowledge, strategies, and experience in this field need to be further investigated.[4]

The aim of this study was to elucidate the methods of counselling in the encounter between the paediatric

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cardiologist and the family, especially concerning parental guidance and supportive management.

Materials and methods

There were nine experienced paediatric cardiologists counselling families with a child with congenital heart disease who were interviewed during the period from January to May, 2008. The interviews reflected counselling of parents and patients throughout the cardiologists' entire careers and regarded parents whose infants were considered to have complex congenital cardiac disease requiring some kind of interventional procedure. The interviews took place at a Paediatric Cardiology Unit, a tertiary centre, at a University Hospital, in Sweden. All nine doctors, consultants in paediatric cardiology at the Paediatric Cardiology Clinic, were interviewed for 1.5–2.5 hours. These interviews were preceded by two pilot interviews not included in the study. All interviews were carried out by the first author, a qualified social worker and experienced interviewer, specialising in consultation and communication.

The interviews were semi-structured around preliminary themes with follow-up questions and opportunities for the interviewee to add personal reflections.[7] One main theme focused on the doctors' presentations of themselves and their professional attitudes. The other main theme focused on the encounter with the parents and the message given. Both themes included topics such as access to evidence-based knowledge, emotive reactions, and ambivalence between proximity and distance in the meetings with the clients. The interviews were taped, transcribed, decoded, and analysed for units of meaning and themes and sub-themes arising from the data. There were two researchers, a medical sociologist experienced in qualitative data analysis and a paediatric cardiologist, who read and independently analysed the decoded data and identified the main themes. The coding framework was achieved through consensus. The method was characterised by a flexible design in which the analysis moves back and forth between the collected data and the analytic frames.[8]

The analysed data and results were presented, discussed, and reflected upon with the interview participants to confirm the findings and to ensure that the study met three current criteria of qualitative research: credibility, transferability, and dependability.[9,10] Credibility refers to the believability of the results as credible interpretations of the data. We brought our findings back to the interview group for confirmation, which found the study to be credible. The transferability of our results to areas beyond the study is increased by describing our method and results in enough detail for the reader to make informed choices about their applicability in other contexts. Dependability, as well as the quality and integration of study design, data collection, and analysis, was bolstered by the collaborative nature of the analysis, our in-depth discussions, and confirmation by the interview group.

The study was approved by the Regional Ethical Review Board at Umea University, and informed consent was obtained from the informants prior to the study.

Results

Most of the cardiologists have referred to encounters with families receiving a newborn baby with complex congenital cardiac disease who needed intervention or who did not survive. Some cardiologists have described communication with older children with complex chronic cardiac disease before proceeding to another surgical intervention, for example, patients with univentricular heart or patients awaiting cardiac transplantation. The anatomical diagnoses varied but all were categorised as complex.

The doctors interviewed unanimously stressed the importance of communication in meetings with families, but their strategies for creating a good meeting varied.

Doctors' meeting strategies varied in terms of structure, relationship, and formality: from a very structured information meeting to a more flexible format; from reliance on guidelines to the use of their own personal experiences; and from adherence to factual information to the acceptance of the emotionally charged nature of the meetings. Despite the potential for many different strategies, we identified the following patterns of attitudes and communication styles in the group of doctors interviewed.

Method of providing information

All the cardiologists in our study considered it very important to give correct medical information about the cardiac disease. Most drew a sketch to illustrate the malformation, and then the communication methods diverged.

One of the strategies in informing the parents was *solid structure*:

> "I go straight forward and then pick up what is left of the family."
> "I want to be honest even if it hurts."
> "Clarity creates confidence."

The majority of the cardiologists, however, used a more *flexible format*:

> "I try to add information depending on the reactions of the parents."

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"From the reactions I get, I try to face them in their critical situation."
"I am prepared for all types of reactions, and then I estimate what kind of information they can handle."

The former strategy was more general, and the latter more context dependent.

All interviewees stressed the lack of education on how to provide this information. Consequently, their methods were developed individually, but here we also identified some common patterns. Owing to the lack of support or education in this area, the cardiologists used their *own personal qualities*:

"I have an intuitive attitude."
"You have to go through trial and error."
"I use my finger-tip feeling, my instinctive feeling."
"Keep your antennae out; what kind of signals do they collect?"
"Using your own personality, you have to be very conscious of your reactions in different situations."

Another method within this personal model was developed almost scientifically:

"I followed the families of the first 20 children I met who died. I made home visits once or twice after the death to learn how the families reacted, how they managed the crises and I learned how to support them. Personal experience guided my way of coping with the situation."

As opposed to the use of their own personal qualities or inquiries when breaking bad news, the doctors expressed a generally hesitant attitude to *guidelines*:

"Guidelines could maybe be useful for younger colleagues."
"Perhaps some very elementary keystones to rely on."
"I think it is very difficult to have guidelines in these situations."
"Since everybody works so hard with his/her personality in these contacts, a general model cannot be applied."

Emotional position

The cardiologists mediated a broad spectrum of variable emotional positions, from intimate to distant. The most intimate position includes the *doctor's own needs*:

"Often you get some kind of reward…you can get a hug…and the parents express that they understand that the doctor feels sad."
"You have the right as a doctor to be a human being."
"Sometimes the consultation is like a family situation…you can give a hug and get something back."

The most distant emotional position represented in this group relies on the *doctor's role as a professional*:

"I want a professional distance."
"I am careful not to get too close."
"Friendship is unprofessional."
"It is important to keep a well-defined border."

In spite of these large apparent differences, the most common pattern included a little of each attitude in a more *balanced approach*:

"To follow the family alongside the roller coaster they are riding without being too close."
"To be at an empathic distance…in order not to drain your own strength."
"I know my limits, how much I can manage; I am conscious not to exceed the limits."

Creation of confidence

The question of how to create confidence formed an essential part of the strategies for providing information. All the cardiologists in our study emphasised the importance of creating confidence, but the strategies chosen varied from "[being] open-minded, honest, not try[ing] to conceal something, dar[ing] to admit that you are not all-knowing", to being "clear, straight on, reliable, and trustworthy" or to stressing "the reciprocal confidence". Many cardiologists emphasised the importance of bilateral agreement concerning communication and information.

Interaction

Initially, almost all of the cardiologists assessed the *communicative abilities of the parents*:

"I am prepared for the parents' diversity; some are emotional and some are focused on the problem."
"I use my [emotional] scanner and depending on what signals the scanner picks up, I handle the situation."

Some of our informants described the encounter with the parents as "an attempt to read them".

To assist parents in realising and handling the crisis, many doctors *repeated the information* and usually multiple follow-up encounters for information and counselling were arranged:

"We have to give them a new world picture."

The majority of the cardiologists stressed the importance of further follow-up encounters throughout the hospital stay to make sure that the parents had received the information.

Success and failure

The doctors were posed the question: "When are you successful or unsuccessful in your work with the child and the family"? The most striking finding was their unanimous opinion about what constitutes failure in their work: either making an

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incorrect diagnosis or having a "communication breakdown", "sometimes leading to exchange of doctors, even if it hurts".

The most important factor in the doctors feeling successful in work was the "presence of trust", or "to follow the parents from chaos to trust".

Strategies for handling the situation

"We have to prepare ourselves continually to manage our exposed position." Having access to a mentor was mentioned by most of the interviewees as a way of managing the challenge when they lacked confidence. "I have a mentor with whom I can be unconfident." Supervision was described as a way of continually improving the ability to break bad news. "I can accept that there is a need for supervision even if I was hesitant in the beginning." The doctors also mentioned the importance of time for reflection, individually and in groups. Most of the cardiologists insisted on the necessity of developing the dialogue in the colleague group: "We need to think together". The majority expressed their thoughts about their contribution to building up common values: "we need a common approach". They also stated that "we need a strategy" and many of the doctors wanted joint meetings to further develop the colleague team and the whole professional health-care team: "frequently recurring, mutual management discussions are necessary". It is obvious that our interviewees looked for evidence-based knowledge, and with a lack of scientifically grounded recommendations they searched for shared experiences generated in their clinical work.

Discussion

Meeting children with heart disease and their parents is a professional challenge for which doctors receive little if any education. Paediatric cardiologists were acutely aware of their lack of training in this area and they recognised, as do family members interviewed in a related study,[11] the vital role of communication in these meetings. Earlier, doctors were initiated into a system that was almost entirely self-governing.[12] Communication today, however, takes place in a world with rapid technical development and an increasingly complex, ever-changing society. The raised expectations placed on doctors reflect the high expectations put on all professions in a differentiated, complex society.[13] Studies have shown that professional work presumes, besides theoretical and practical professional skills, also the conscious use of one's own personality. This requires self-knowledge, empathy, and the ability to make ethical decisions.[4,14]

Data from this study indicate clearly that being professional implies not only a strict medical perspective but also an emotional one. Many authors discuss a common tendency in society for the professional standpoint to aim at being more coherent in including both cognitions and emotions in an effort to support the patient.[15] Increasing demands from a complex society focus on elaborating a new professional approach.[16,17] The cardiologists' means of handling this can be visualised on a palette where the same colours are available to all, but the specific hues and shades vary. An apparent common strategy was using "your own personal skills". Despite the lack of scientifically grounded recommendations in information methods, the cardiologists have developed a professional approach demanded in high quality care.[18]

Bone found that the combination of "invisible" emotional work and clinical administrative tasks was considered very stressful.[19] In this study, we found a broad spectrum of different emotional positions that pose very different individual demands. However, the majority of the cardiologists showed a *balanced pattern* of emotional position, and even this position seemed to be stressful.

Creating confidence is a central and essential part of communication, and a primary aim in meetings with the parents is to build trust.[20] It has been stated that modern society presumes that people trust each other and that this trust holds good even for strangers.[21] If the encounter between the cardiologist and the parents does not succeed, if the professional is not capable of meeting the parents' expectations, trust will be impaired both for the parents and the cardiologist. In this study, the cardiologists demonstrated different strategies for building trust: being present; being open-minded; being straightforward or distinctly structured. Some of the cardiologists also combined and adapted various strategies.

A central part of the communication with the parents was the doctor's delivery of the message concerning the child's heart disease. All the interviewees saw this meeting as extraordinarily important, to be followed by continuing interaction with the parents that often extended over years.

Many cardiologists emphasised the importance of agreement between doctors and parents about communication and information, regarding it as a joint venture. Communication breakdown was regarded as one of the greatest failures and it was evident that there was a need for further improvement of communication skills. All the interviewees stressed the lack of education and requested more training rather than guidelines. Several authors emphasise the importance of recognising the education needs of the consultants in creating effective role

models for medical students.[22] It is also important that medical education programmes provide models to teach skills for delivering bad news.[22]

The cardiologists also discussed the importance of reflection, a need that has been mentioned by several authors. To be able to meet the demands of patient families and society, it is essential for doctors to have an opportunity to explore and evaluate the current professional standpoint.[4,23,24]

Supervision or coaching was mentioned as an additional strategy for handling the situation and managing the challenge of breaking the bad news. Other suggestions focused on increasing opportunities for doctors to discuss their contacts with patients, for example in groups based on the work of Balint,[25,26] where the participants develop their ability to search for constructive communication with the parents/patients. The ideal object would be to combine experience-based emotive and personal skills with education and training.

Besides individual approaches to improve communication and information, the cardiologists emphasised the importance of team meetings and teamwork, an instructional book for which is available as a resource.[27] An earlier study has shown that patients and their families require service from a wide range of health professionals.[28] The assembled competence in the professional healthcare team must be further developed.

Limitations

We interviewed a small number of paediatric cardiologists working at the same Swedish department of paediatric cardiology. The results may be local and limited, but with the theoretical framework as a background, we find the conclusions to be generally applicable. Another limitation is the lack of gender balance because, at the time of the interviews, all consultants in the department were male.

Conclusions

Among paediatric cardiologists, we found

- unanimous emphasis on the importance of how bad news is communicated;
- agreement about the significance of trust and confidence in relation to the families and the use of different emotional positions;
- a common ambition to achieve better skills for handling the situation;
- a need for reflection, education, and coordination of efforts through joint reflection and sharing of experiences.

Recommendations

To meet these needs, there is a requirement for the development of teamwork and for programmes in medical education to develop the skills of medical students and residents in delivering bad news.

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