

Session 2: What Matters to Us, Personalising support for people with CDH

Chairs: Laurent Storme and Judith Simpson

27th April 11.30 – 13.15

55 Prenatal Counseling for Congenital Diaphragmatic Hernia: A Qualitative Study of Provider Perspectives

Dr. Howard Jen¹, Dr. Howard Jen¹, Joseph Wertz¹, Evelyn Shen¹

¹*University of California, Los Angeles*

92 Congenital Diaphragmatic Hernia: Patient Parents As Partners

Ms Dawn Ireland¹, Mr Jason Miller¹, Dr Mahmoud El Fiky^{2,3}, Dr Brooke Newman, MSN¹, Mr Kamal Saleh¹, Mrs Tracy Meats¹, Miss Maria Harb¹, **Mrs Dawn Ireland**, Mrs Darlene Silverman¹

¹*CDH International*, ²*Cairo University*, ³*World Federation of Associations of Pediatric Surgeons (WOFAPS)*

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Mrs Beverley Power¹

¹*CDH UK*

Prenatal Counseling for Congenital Diaphragmatic Hernia: A Qualitative Study of Provider Perspectives

Dr. Howard Jen¹, Dr. Howard Jen¹, Joseph Wertz¹, Evelyn Shen¹

¹*University of California, Los Angeles*

Background

Counseling is an essential component of prenatal management of congenital diaphragmatic hernia (CDH). Research has demonstrated the value of prenatal counseling in improving parental anxiety and well-being even long after delivery. This project characterizes provider perspectives on and priorities for prenatal counseling of CDH.

Methods

Semi-structured interviews were conducted with attending physicians at an academic medical center. All interviews were audio recorded and transcribed. Transcripts were coded for themes and analyzed by two independent coders, and discrepancies were resolved through discussion.

Results

Of the eligible 25 attending physicians, interviews (n=10) were conducted with pediatric surgeons (n=4), maternal fetal medicine obstetricians (n=3) and neonatologists (n=3). Five core themes were identified (Table 1): 1) Parent education, 2) providing support, 3) preparing for uncertainty, 4) coordination of care, 5) navigating health system constraints.

Conclusion

Providers across specialties expressed a desire to communicate with parents in CDH prenatal counseling visits in a way that emphasized their individual needs in terms of technical information, emotional support, and guidance in decision-making. They likewise discussed the complexity of preparing parents for an experience that is variable and often unpredictable. Providers of different specialties emphasized different aspects of counseling as priorities, largely in line with differences in scope of practice. Variability was also noted in the level of emphasis placed on explaining possible chronic comorbidities and their impact on family life. Future research is needed to understand how effectively these provider priorities are communicated to and interpreted by parents themselves.

Images

Theme	Representative Quote
Parent education	"I think that relaying information is number one, telling them...how often I find it and what it actually means."
Providing support	"Then there's the emotional part of what you do with that...one of the important jobs of the physician is to be able to be empathic, be there, not just to give more information, to support them through their own journey."
Preparing for uncertainty	"A family has to decide for themselves what they think a poor quality of life is and what they think a good quality of life is, and that's going to be different for different families...even if you can pinpoint how likely or unlikely something is, you still have to plan for the possible outcomes if they're going to be unacceptable."
Coordination of care	"Some of these cases can be very, very complicated. And if each of us come up with our own opinion, but we don't talk to each other, it's a disaster, right. It's really a disaster...we can't operate in silos."
Navigating health system constraints	"Many people sort of see this prenatal counseling process as sort of a bit of a waste of time. I mean, we realize it's important, but we don't invest a lot of work into it. And I think it's very, very important because parents have a lot of choices in where they can get care at. And when you have a streamlined, committed approach from the beginning, all the way to the end, you're going to have better outcomes and families are going to trust you more."

Table 1

Congenital Diaphragmatic Hernia: Patient Parents As Partners

Ms Dawn Ireland¹, Mr Jason Miller¹, Dr Mahmoud El Fiky^{2,3}, Dr Brooke Newman, MSN¹, Mr Kamal Saleh¹, Mrs Tracy Meats¹, Miss Maria Harb¹, Mrs Dawn Ireland, Mrs Darlene Silverman¹

¹CDH International, ²Cairo University, ³World Federation of Associations of Pediatric Surgeons (WOFAPS)

Abstract: The purpose of this study is to evaluate the patient family experience in the care of Congenital Diaphragmatic Hernia. We looked at the financial and emotional toll on families who relocated for medical purposes versus those who did not. We asked the families how they felt about being a partner in their child's care and if they were given enough and appropriate information.

Purpose: To identify gaps in collaboration between Patient Parents and Medical Care Providers, and deficiencies in global Research and Awareness efforts for CDH.

Methods: We surveyed over 4513 CDH families who have voluntarily participated in the CDH Patient Registry, asking them about their child's care, their roles in the care team, and if they felt like a partner in that care. Out of the total number of patients, 2468 of these patients were survivors, 1292 non-survivors, and 697 unknown. Of the survivors, 2323 were over 18 years of age.

We also surveyed families on the overall general research of CDH and what they would like to see more funds and efforts focused on, as well as their opinion on a global Standard of Care for Congenital Diaphragmatic Hernia and a Standard Measurement of Mortality and Morbidity.

Results: An increasing number of respondents felt frustrated with the lack of Standards of Care and Measurements of Mortality and Morbidity, citing issues with insurance, school IEPs and the lack of accurate, unbiased information

Conclusion: There is still a disconnect between the Research Community and the Patient Community. The patient community desires more research focus on topics more beneficial to their ongoing care. They also would appreciate more collaboration among research institutions to create Standards of Care and Measurements of Mortality and Morbidity that will improve long-term quality of care and allow the patient community to make more informed decisions.

The CDH Patient Journey

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Background

Congenital Diaphragmatic Hernia is a malformation of the diaphragm resulting in further physiological problems. Mortality remains high, particularly where there are other issues involved.

Tracking a patient throughout their lifetime to understand the full impact on health and function is challenging.

CDH UK is a registered charity supporting anyone affected by CDH. It has over 25 years of experience and a broad range of patient experience and knowledge.

After embarking on the development of a new support resource, it realised there was no published 'patient journey' on which to base this development.

Aims

To develop a patient journey with timepoints of significance.

Methods

We studied our own data and looked at what we already knew from publications and medical advisors. We recruited a focus group, plotted out stages and timepoints through their 'lived' experiences using the Team Idea Mapping method. We then compared these experiences to our own data, to find out the common issues in daily life and care and created a visual map.

Outcome

We have developed a patient journey through the eyes of the patient and turned it into a patient friendly infographic. This can be used as a tool to help understand the CDH Journey throughout a patient's lifetime. CDH UK has already used this to create a first prototype of a mobile application. It has also further helped to recognise areas of patient concern and to improve services and resources.

Discussion

This can be used as a basis for care and research, including standards, benchmarking, transition and helping improvements in healthcare, education, family life and social settings. Potentially holding clues to the etiology and pathology of the condition and an opportunity to further explore theories and unanswered questions. It may help improve counselling and bereavement care, resulting in better general and mental health outcomes.