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British Congenital Cardiac Association Fetal Cardiology Standards: impact of Patient and Public involvement exercise on the development of clinical standards

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Abstract

Objective: To examine the impact of a Patient and Public Involvement exercise on the development of British Congenital Cardiac Association Fetal Cardiology Standards 2021. *Design:* Open-ended, semi-structured interviews were undertaken to inform the design of a study to improve the quality of parents' experiences during antenatal and perinatal care of their child with CHD. This Patient and Public Involvement exercise was used to inform the final version of the drafted 'Standards'. *Setting:* One-on-one interviews with parents who responded to a request on the closed Facebook page of the user group "Little Hearts Matter": "Would you be interested in helping us to design a study about parents' experience on learning that their child had CHD"? *Patients:* Parents of children with single ventricle CHD. *Results:* Twenty-one parents (18 mothers, 3 fathers) participated. Parents responses were reported to have variably reinforced, augmented, and added specificity in the later stages of drafting to six of the seven subsections of Section C Information and Support for Parents including: "At the time of the Scan"; "Counselling following the identification of an abnormality"; "Written information/resources"; "Parent support"; "Communication with other teams and ongoing care"; and "Bereavement support". *Conclusions:* This Patient and Public Involvement exercise successfully informed the development of Standards after the initial drafting. It contributed to the establishment of face validity of the 'Standards', especially when consistent with what is reported in the literature. Further research is needed to explore approaches to involving and standardising Patient and Public Involvement in the development of clinical standards.

CHD is the most common single structural birth defect and is present in about 6–9 per 1000 live births in the UK each year.[1] Approximately half of the children requiring heart surgery in infancy are diagnosed antenatally, about 1000 cases per year[2] highest for the most complex defects, for example, hypoplastic left heart syndrome.

At the time of diagnosis, parents face complex and difficult decisions. For some, this will include a decision on whether to continue with the pregnancy. Research indicates that counselling, effective communication, and support during this time are crucial. The British Congenital Cardiac Association Fetal Cardiology Standards[3,4] aim to provide a framework for the development of tertiary services that can be adapted to fit with local models of delivery. The "Standards" cover national guidance for counselling, communication, and support of parents at antenatal diagnosis of a CHD.

The Standards were originally published in 2012 and then revised in September 2021 to reflect the significant changes in fetal cardiology during this period and to sit alongside the 2016 NHS CHD standards and specifications.[5] Commonly, clinical practice guidelines are formulated based on expert opinion and literature review. However, as we aim to describe, in the 2021 Standards, the British Congenital Cardiac Association also made use of information provided by a Patient and Public Involvement exercise.

The role and prominence of Patient and Public Involvement in research and quality improvement are increasing with Patient and Public Involvement informing the development of research projects on through to the dissemination of results. Using the revision of these "Standards" as an example, this article focuses on a relatively new area of patient, public involvement, its role in the development of clinical standards.

Methods

Study design

Open-ended, semi-structured interviews to elicit narrative accounts of patients' experiences of 20-week scan forward as well as their views and recommendations for design and implementation of a study to improve the quality of parents' experiences during antenatal and perinatal periods.

Inclusion criteria

Parents of children with a variety of single ventricle CHD.

Recruitment

Patients were recruited via an announcement "Would you be interested in helping us to design a study about parents' experience on learning that their child had a CHD" on the closed Facebook page of the user group Little Hearts Matter, a UK Charity established to help anyone affected by the diagnosis of single ventricle heart condition. The post was live for a month from February 2020.

Data analysis

Two researchers (SW, KV) independently listened to four of the 21 parent audio-recorded interviews, selected for diversity of gender, ethnicity/ religion, diagnosis, decision made, in order to prepare a list of words and phrases that could be used to index, that is, locate material on a given topic (e.g. communication of scan results, methods of data collection) for later retrieval, review and use in development of a proposal for a project to improve quality of parents' experience of antenatal diagnosis of complex congenital cardiac conditions.

The agreed Index was then applied to all 21 interviews. Two of the co-authors (SW and KV) independently indexed all cases and differences were resolved by MBL.

Using both self-identified characteristics of the patients as well as excerpts from the interviews retrieved through the Index, three of the authors (MBL, KV, SW) compiled a detailed report of the Patient and Public Involvement exercise and then reviewed and discussed it with the clinician authors (KB, AB, VJ), in order to plan a study of parents' experiences on learning that their child had a CHD.[6] VJ, as chair of the British Congenital Cardiac Association Fetal Cardiology Standards writing committee, proposed that the lessons learned from the Patient and Public Involvement exercise would be of value in "validating" (as in face validating) the committee's recommendations from a parent perspective and/or for suggesting areas where different and/or additional recommendations needed to be considered in the section of the standards titled "C: INFORMATION AND SUPPORT FOR PARENTS." (Appendix 1)

The Patient and Public Involvement exercise team (MBL, KV, SW, AB, KB, VJ) then examined the seven subsections of Section C in the draft 2021 British Congenital Cardiac Association Standards and considered and documented the parents' views on the issues and recommendations in drafted Section C. Parents' views from the Patient and Public Involvement exercise related to each applicable issue and recommendation were collated and fed back to the Standards writing committee by the chair and member of the Patient and Public Involvement exercise team, VJ. Where considered appropriate, the Standards were revised accordingly, reflecting patient and public input. Finally, the Patient and Public Involvement exercise team reviewed the completed Section C of the 2021 Standards and noted where the Patient and Public Involvement had influenced this final draft leading to changes as well as where Patient and Public Involvement validated content of the final draft.

As this was a Patient and Public Involvement exercise, ethics was not required. Signed consents were obtained.

Results

Patients and data collection

Originally planned as face-to-face interviews with one of the co-authors (MBL) at a location of patients choice, owing to lockdown, all interviews took place virtually. Parents were extremely forthcoming and welcoming of the opportunity to speak about their experience.

One author (MBL) interviewed 21 (18 mothers and 3 fathers) of the 29 parents (26 mothers and 3 fathers) who had expressed interest in participating via Zoom or FaceTime. Parents self-reported details of their child's conditions. Eight parents were unable to participate – all related to the pandemic (e.g. increased caregiving responsibilities, home schooling, illness). Interviews were audio-recorded and lasted between 40 and 95 minutes, with an average length of 78 minutes.

Impact of the parents' responses in the Patient and Public Involvement exercise on the development and finalisation of the Standards

Before the scan. Parents spoke of wanting information before the scan, more specifically what they were being referred for and why. This was addressed in 2012 Standards and unchanged in 2021 Standards.

At the time of the scan. Congruent with concerns parents expressed in the Patient and Public Involvement, the 2021 Standards provide explicit directions on what information should be provided at the time of the scan including: information on what to expect, how long it might take to gather all of the information, and that results will be discussed in a separate room.

Not raised by parents but covered in the Standards is a direction to "ensure parents understand the reason for the specialist evaluation as well as the limitations of such procedures as fetal echocardiogram".

Counselling following the identification of an abnormality. The opening statement declares that "following the detection of a problem, information, counselling and support should be provided". This statement provides the framework for 12 points that follow specifying what, where, and how information is to be given. Here, changes were influenced by the Patient and Public Involvement exercise. Salient among the parents' remarks about their experiences, and recommendations they would make about delivery of services, were reflected in 6 of the 12 points[4]:

Point 1 – Clear information about choices and implications provided by a specialist in fetal cardiology or paediatric cardiologist with experience of fetal congenital disease.

Point 2 – Look and location of a separate room for discussion.

Point 3 – Jargon free presentation delivered with empathy and compassion.

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Point 4 – Including "[providing] accurate description of the abnormality, information regarding the need for non-surgical or surgical intervention; potential surgical options available for the condition; timing and number of planned interventions likely to be required; associated mortality and morbidity and the short- and longer-term prognosis for the child".

Point 8 – [Parents] be made aware of all options available to them including, where relevant, information on termination of the pregnancy and relevant time limitations for decision making. Sufficient information and support must be provided to enable them to make an informed decision for their individual circumstances. Pregnancy options should be presented in an unbiased, non-judgemental manner.

Point 12 – "Individual values and beliefs of patients and the impact of these on decision making should be considered and respected".

Six points (Points 5, 6,7, 9, 10, 11) were reported as not having been influenced by the Patient and Public Involvement exercise. Several reasons were given for this assessment:

Point 6, 7, 9 – Recommendations that had to do with "the impact of extracardiac abnormalities with the cardiac abnormality (Point 6); "potential association of chromosomal or genetic abnormalities" (Point 7); and option of "postnatal comfort or palliative care" (Point 9) did not come up in the Patient and Public Involvement exercise.

Point 10 – Recommendation for cardiac nurse specialist or specialist fetal medicine midwife to be present at consultations was regarded as already standard practice

Point 5 – Parents opinions divided on recommendation for non-directive counselling.

Point 11 – Recommendation for clear documentation came up in another context as in documentation and communication of information from all health professionals involved (including specialist nurses and midwives) regardless of context (including between various services and institutions).

Written information/resources. Desire, request and recommendation for more information occurred repeatedly in the Patient and Public Involvement exercise. Parents expressed the need for sign posting to reliable sources of information as well as support groups that reflected their beliefs and values.

The naming in the Standards of specific sources for "trustworthy, accurate information as well as the recommendation including in types of independent counselling groups, relevant faith groups" was attributed to the Patient and Public Involvement exercise.

Parent support

Almost all of the Patient and Public Involvement exercise respondents, without prompting, mentioned the need for more information and emotional support. This is recognised in the 2021 Standards and reported from the writing group as addressed prior to review of the Patient and Public Involvement exercise. However, the exercise confirmed the value of the changes to the Standards.

Communication with other teams and ongoing care

Communication with other teams featured largely in parents' responses. Of greatest concern to them was not about appropriate referrals being made and actioned, an area of attention in the Standards, but rather about the lack of communication between teams and hospitals. This was cited as difficult to address in the Standards as thought to be beyond their purview to direct communication between other providers of aspects of patient care.

Also covered in this section is the possibility of discussions with other parents who have experienced an antenatal diagnosis of a congenital cardiac condition, something which many of the parents in the Patient and Public Involvement exercise said they would have appreciated. Specific suggestions for how this might be facilitated are part of the Standards.

Bereavement support

Parents who had terminated their pregnancy or had a child die in utero recommended additional support. Their suggestion that "support and opportunity for further discussion should be given to parents who have suffered a pregnancy loss may be provided by fetal cardiology or, if more appropriate, the fetal medicine team" is reflected in 2021 Standards.

Discussion

These findings came from a Patient and Public Involvement exercise conducted as part of the development of a research proposal about parent experiences with antenatal and perinatal care. They provided a serendipitous opportunity to use relevant parental feedback for review and finalisation of the 2021 British Congenital Cardiac Association Fetal Cardiology Standards. The main areas of influence were around information and emotional support. While there was a clear call for psychological/emotional support, parents called for support that was consistent with their values and beliefs, and in some instances not necessarily from psychologists per se.

Notably the parents' responses in the Patient and Public Involvement exercise were consistent with those found in previously published studies of parents' experiences. Parents would like better communication in interactions with clinicians[7] and better communication between the institutions where diagnosis and care are received.[8,9,10] Parents viewed individually tailored compassionate delivery of information as key to effective communication.[7,11,12,13,14]

Although parents were unanimous in wanting compassionate delivery of information, the style in which they would prefer information to be presented varied. The literature and these Standards focus on "non-directive counselling".[11,15,14] Some Patient and Public Involvement patients agreed with this notion, and others would have preferred a more directional approach to alleviate the anxiety of the decision-making.

Noted in both the Patient and Public Involvement exercises and in the literature were recommendations from parent interviews for improvement of the before scan experience (e.g. informing parents of the possibility of a congenital cardiac anomaly being detected).[16,10,17] This was an area which the Standards group did not necessarily think fell within their purview as this period would fall under the guidance of the fetal anomaly screening programme at the local hospital whereas these Standards are directed to tertiary fetal cardiac centres.

Specifically mentioned in both the Patient and Public Involvement exercises and literature[18,8,9] was a recommendation addressing parents' desire to be explicitly told in some detail what day-to-day life with their child would be like. Parents in both the Patient and Public Involvement exercise and literature commented that knowing this, along with their personal values and

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beliefs (cultural, spiritual), was a key factor in their decision-making.[11,12,14] Moreover, they wanted clinicians to ask about and understand their values and beliefs[14,12,11] and signpost them to helpful resources.[7,17,18,19,11,20,8,13]

Although not explicitly stated in the Standards, information on the day-to-day limitations that might be expected in a child with a CHD would be expected to form part of prenatal counselling. Parent support days, which are suggested by the guidance, often include a parent who has a child with CHD as well as signposting to support groups for parents of a child with CHD.

The necessary conversion of interviews to virtual rather than face to face, as a result of the pandemic, did not appear to negatively impact on the excercise. With the widespread use of online communication tools that have taken place in the past 3 years, a more detailed understanding of the impact of this on communication in many areas of medicine is evolving.[21,22,23,24]

Strengths and limitations

The Patient and Public Involvement exercise was never intended to be used to inform the development of the British Congenital Cardiac Association Standards. The convergence of the writing of Standards and preparing for a study occurred by chance, and as such while what was learned from the Patient and Public Involvement exercise reinforced and augmented the current Standards, a dedicated Patient and Public Involvement exercise might have increased the specificity. We support the regularising and routinising parent participation in the development of standards in all areas of perinatal, neonatal, and paediatric practice.

The sample for this exercise was recruited solely via the Little Hearts Matter closed Facebook page, thereby raising questions about sample size and diversity.

While 21 patients may be considered by some to be a small sample for an interview study, it is not at all small for a Patient and Public Involvement exercise. In fact, the number of respondents and depth of parents' responses in this exercise as compared to many qualitative research studies and most Patient and Public Involvement exercises, as well as the issues parents addressed and their consistency with other studies of parents of children with other complex CHDs; we see the results as having merit. A larger and more representative cohort would be desirable in future work, but at the very least the findings presented here contribute to the discussion of the use of Patient and Public Involvement in development and validation of practice standards, as well as their use in establishing benchmarks for improvement in quality of care at antenatal diagnosis of a complex CHD.

A major limitation is that it was not possible to obtain specific information on the CHD, pregnancy details, and outcome due to this being a Patient and Public Involvement exercise for which ethical approval is not required. The parents were recruited from a single ventricle charity and the details provided are the parental account at interview.

Further studies where the responses provided could be considered in the context of more detailed information of the specific cardiac diagnosis and counselling provided would be of value.

Also, and not insignificantly, the experiences the parents reported and their suggestions for improving experience came from their own unprompted self-structured narrative accounts of their journeys.

Conclusions

As demonstrated here, Patient and Public Involvement exercises can have an impact on the development of Standards of practice. They can bring to the fore what matters most to those who are seen to be the beneficiaries of the standards. They can serve to reinforce, augment, and add specificity to what has been drafted. They can contribute to the review and establishment face validity of what clinical experts perceive as helpful to parents, especially when the Patient and Public Involvement results are consistent with reports in the literature. Further research is needed to explore what is the best method and timing for involving and standardising Patient and Public Involvement in development of standards and in turn their use in benchmarking and assuring quality.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/S1047951123004298.

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