



# Towards improving the lived experience of adult congenital heart patients: suggestions for health care practitioners

## Original Article


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### Abstract

What steps may clinicians looking after adult congenital heart patients take to improve the care they provide? An adult with complex congenital heart disease (CHD) who required a Fontan circulation has developed a discussion paper with the help of his attending clinicians. Drawing on his personal experience and that of others that he has represented, the paper highlights the problems in communication between such patients and their physician, followed by suggestions as to how to improve patient engagement, empowerment, and enablement. Attention to those suggestions may well benefit all in the care provided for this growing population.

Health care providers caring for adult congenital heart disease (CHD) patients need to improve the clinical experience, in order to uplift the patient's quality of life outcomes, potentially achievable with small changes in their clinical approach.<sup>1</sup> As someone (JM) who has remained well into my late forties with CHD that has required multiple operations, electrophysiology studies, a pacemaker, etc., and having advocated for,<sup>2,a,b</sup> surveyed,<sup>3</sup> and immersed myself in the patient community for the last 25 years, I have here distilled some clear gaps, that if addressed may not only improve a patient's quality of life but also improve a health care provider effectiveness and job satisfaction.<sup>4</sup> These involve shifting the clinical approach towards interpersonal engagement, patient empowerment, and enablement.

The adult CHD community has voiced their concerns around the uncertainty of life expectancy which requires clearer communications around outcomes, though recognising that this may not always be possible.<sup>1,3</sup> Much of the practical solutions suggested herein will be obvious, align to practising critical allyship<sup>5</sup> and, if applied, will help alleviate the anxiety and depression felt amongst teens and adults with CHD. Failing to mind these systemic gaps by well-intentioned practitioners will continue to facilitate several negative impacts experienced through patients' mental health.

### Methods

While mainly written in the first person, this paper evolved over the last 3 years with repeated discussions with my attending clinicians reviewing the challenges faced by adult CHD patients to determine what else practitioners may do to be more helpful. A participatory research methodology has been used incorporating direct collaboration between the affected adult with CHD and his health care providers—working together to understand the problems faced by both to bring about better outcomes.<sup>6</sup>

### Results

#### *Suggestions for health care practitioners*

##### *Start with your patient's level of understanding*

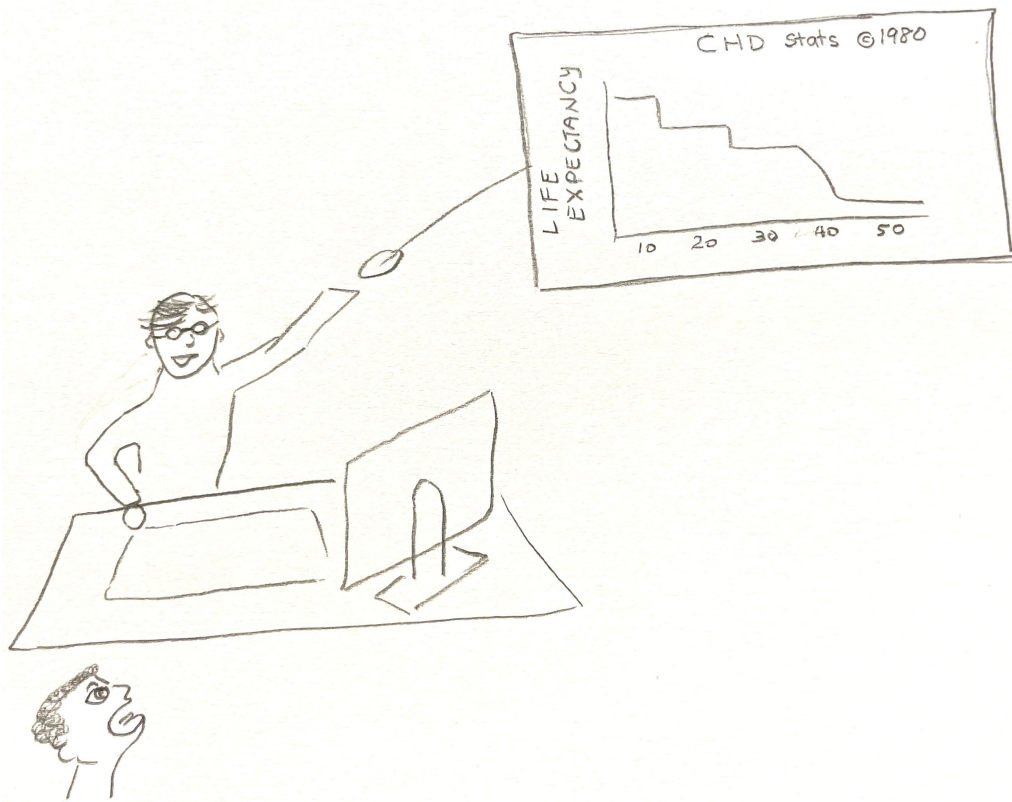
Like a good job interview, a clinical assessment should be a two-way conversation. Likewise, to be most effective, the clinician should first seek to uncover the patients' understanding of their own condition, key concerns affecting their lifestyle, an assessment of the patients' grasp of health literacy and how much information they are able to take in. By tailoring language, pace and developing a shared understanding of goals and outcomes, the clinician can start to address patient needs beyond just their clinical condition.

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**Figure 1.** Chart shock - attempts to be transparent with recent data may create significant anxiety for patients.

### *Ask better questions, and ask them upfront for both the patient and health care provider*

Are your patients satisfied with the answers to their many questions and leave with an improved understanding? Sadly many are not.<sup>1</sup> When we do not receive answers or feel we cannot ask questions, the result can be a sense of disempowerment and a feeling of hopelessness.<sup>4</sup> When practitioners ask “Do you have any questions?,” though well meaning, it is often delivered in an automated fashion, maybe because of time pressures and skill constraints. That question often signals a wrap up of the session leading to closure rather than disclosure. A better question to learn from a patient’s experience would be “What do you want to know more about?,” or “What do you think you need at this time?.” These questions may add significant empowerment and more meaningful engagement if asked at the start of the consultation, as it suggests that the patient’s needs take precedence over the clinician’s agenda. Whilst the patient’s level of advocacy will vary between individuals, the need is the same, and if enabled by the clinician, provides a real choice even if not taken up.

### *Unintended consequences of presenting data*

Some practitioners may fall into the trap of touting research statistics or referring to recent studies without clear explanation. Patients do not typically follow journals or understand postgraduate academic language, nor would they be likely to have the ability to appreciate statistics and interpret research findings’ relevant to their situation. Showing charts with a declining trajectory concerning life expectancy or health outcomes can cause incredible trauma and extinguish hope. No matter what words accompany the presentation, patients (and carers) will likely plot themselves on the trajectory and assume their life journey will

follow a similar pattern leading to a highly paralysing perspective (see Fig. 1). People in my community have experienced anxiety and depression and/or committed suicide after being confronted by these data sets. Here again, clinicians need to draw out and gently build on the patient’s level of understanding about their condition, medical literacy, and current treatment expectations.

### *Best practice*

**Communication coordination.** Empowerment can be enabled by clinicians by giving patients a variety of perspectives and providing open communication when making referrals. Patients need know why they are being referred to other specialists and what specific information is being sought from them. Commonly, there is a gap regarding referrals and the level of communication and transparency. In the workplace regardless of the setting, colleagues are typically provided a warm introduction when being referred to or moved to another team. Yet this courtesy is rarely practised for patients, whereas a three-way consult, video chat, or open letter as a warm introduction would be empowering, inclusive and helpful.

**Supporting an informed choice.** One trait which I value highly with my medical team, but rarely hear echoed from fellow patients, is the willingness to explain, discuss, and explore the options before us, and the encouragement to take up second and third opinions.<sup>1</sup> Patients have every right to know what their options are. Being party to the decision-making gives them a feeling of empowerment. Yet it is important to provide clear recommendations wherever possible to help the patient make an informed decision. On the other hand, placing the full onus on the patients themselves to make a decision may well be overwhelming and counterproductive.<sup>7</sup>

**Treatment plans and impact transparency.** Practitioners can often order a battery of investigations without patient consultation or explanation which may lead to a cascade of interventions that the patient may not choose to undertake if what was being planned was clearly outlined. Health care providers need to consider the patient's perspective and experience, present the treatment plan and explore how that relates to the patient's condition, identify the primary and secondary medical concerns, followed by open discussion before proceeding. That discussion need include the potential harm of such investigations, such as the exposure to radiation, the need for sedation and/or anaesthesia etc.<sup>1</sup> At the same time, it would be important to spell out the information that the investigation, especially if invasive, may provide as well as its overall accuracy.

**Community connection.** Social media offers increasing access to others who have similar conditions. The clinician should acknowledge the opportunity to reduce the sense of isolation and ask patients if they have connected with others or considered this option.<sup>1,8</sup> There are many community-based organisations available to guide introductions for patients to support networks. Practitioners may do well to prompt the awareness for patients or better still, suggesting connecting with them to close the patient community and research feedback loop.

#### Participatory research

Medical education teaches technical skills, less so the application and consideration of the patient experience. In order to close the gap between what clinicians are taught and what is experienced by patients, it is necessary to shed light on the patient experience as early as possible in the learning journey. Medical training should include participatory research where students are working directly with patients over a period of time to build an understanding of the challenges experienced.<sup>4,9</sup> Patients should be working with researchers to help drive the research agenda and identify important research questions.

#### Discussion

This paper is an example of participatory research that was written over teleconference interviews (2019- 2022) with a doctor in training (AN), starting with the question, "What do CHD patient's need?" inspired by my cardiologist (SM). By working together towards a common goal to improve patient experience and outcomes, we have unpacked the gaps and solutions summarised in this paper. I also have worked in partnership with researchers on participatory stories, exploring the question, "How can I have hope?" to build a video library of CHD patient interviews to share their lived experiences and perspectives on life with CHD.<sup>10</sup> These projects have provided rich

insights and behavioural changes for all involved, including the breaking down of barriers, deeper empathy, and sharpening the focus on human centred healthcare and patient outcomes.

#### Conclusion

Clinicians, especially those involved in adult CHD patients, are urged to prioritise a patient-orientated care agenda over the clinical care agenda. Start by applying the practical steps outlined herein to work on communication and empowerment strategies to foster a partnership approach and replace the existing power displacement in the relationship between patients and their practitioners. Further study as evidenced by a recent paper from Canada may further validate the importance of the issues canvassed above.<sup>11</sup>

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