

Editorial Comment

Qualitative research: what it is and what it can contribute to cardiology in the young

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“It’s not so much the challenge that he gives you; it’s the challenge you have within yourself to forget about the problem and just treat him like a normal child.”

IN THIS ISSUE OF *CARDIOLOGY IN THE YOUNG*, Rempel and colleagues¹ present a study using qualitative research that gives new insights into how mothers and fathers parent children with hypoplastic left heart syndrome who have survived the Norwood surgical procedure. Using interviews with parents, the study conveys the wide range, and intensity, of challenges faced by parents as they dealt with complicated emotions about the illness of their children. With great happiness and joy that their child has survived, the parents sought to maintain normality amidst ongoing uncertainty and anxiety over the future developments for their offspring. Health professionals did little to address the emotions, concerns, and needs of the parents. As a result, over years, the parents often felt unsupported.

This study addresses not only a vulnerable young population, but also provides insights for health professionals about the experiences and needs of parents which can inform clinical practice. The methods used in the study, however, may raise some curiosity or concern. What is qualitative research? And how should its quality be judged? How can any research based on a small number of participants be trusted? How can change to practice from a study that is not a randomized control trial even be contemplated?

What is qualitative research?

Qualitative research was originally developed in the social sciences, but has been more common since the mid-1990s in medicine, nursing, psychology, political science, social work and education.² Qualitative research uses non-numerical data to explore how humans behave, experience and understand.³ Data are most often collected by a researcher through interviews, focus groups, or from systematically recorded observations.^{4–6} Usually, the collection of data involves discussing with people in a non-judgmental and open way aspects of their behaviours, perceptions, meanings, knowledge, beliefs, and decision-making. Other methods can involve observing people in social situations. Participants in such studies are often those with direct experience or insight into the topic of the research. In the study of Rempel and colleagues,¹ interviews with a researcher were carried out with a sample of parents of children with the particular congenital cardiac malformation. Questions related to their thoughts, emotions and experiences related to the conditions of their children, and the health system, over time. Health professionals can also be participants, for example, when the research focuses directly on practice behaviours or patient-clinical interactions.⁷

Qualitative methods can also be used in combination with quantitative data – an approach known as ‘mixed-methods’ research.⁸ This is when numerical data is collected based either on, or as a result of, qualitative data. For example, qualitative research can be undertaken prior to a survey to identify key topics for inclusion in a questionnaire. Conversely, qualitative research may be undertaken based on a quantitative study to explore reasons for the results.⁹

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Qualitative research assumes that humans are complex individual, social, and cultural beings. Human behaviour is seen to be influenced by many factors, including values, beliefs, knowledge, cultural background, relationships with others, social norms, and aspirations. The influence of macro factors affecting populations is also important. A good example is the exploration of how gender or age influences their experience or behaviours. While qualitative research has become increasingly more common, what does it offer to improve the care of young patients with cardiac disease?

The contribution of qualitative research to cardiac care for the young

Over the last 15 years, health professionals have been advised to practise in accordance with evidence derived from research, and to place greatest reliance on findings from randomized control trials and meta-analysis.¹⁰ There continue to be concerns, nonetheless, that evidence must recognize the complexity of patients not only in clinical terms, but also in relation to their values, preferences, and experiences.^{11,12} Being an effective health professional not only involves prescribing treatments, but also extensive interpersonal interactions and support.¹³ Qualitative research is well suited to addressing these areas, because it addresses how people behave, see, experience, or react in a manner which captures the personal and social complexity of people and their context. Insight into these factors can then be used to improve care and support.

Understanding and better supporting young patients

Adult non-health professionals with cardiac disease often have very different beliefs and knowledge than those held by health professionals. These disparities include marked differences in

- perceptions and understanding of risk and risk factors¹⁴
- causes of and the biological nature of heart ailments,¹⁵
- the importance of and tasks needed for self care¹⁶ and medication consumption.¹⁷

Perspectives held by patients in these areas are informed by a very wide variety of sources, including the mass media, the internet, other patients, preconceptions, intuition, and health professionals.^{14,18,19} For people with cardiac disease these facets are not just intrinsically important, but are salient because they influence the outcomes for health via self care, compliance, decision-making,

and will also affect psychosocial well being and quality of life.^{17,20,21}

Providing cardiac care for the young patient with cardiac disease brings added challenges for the health professional. Support should be provided that is appropriate to each young patient and their family. Professionals must seek to communicate with patients not just across professional-patient boundaries, but across boundaries of age and development. Qualitative studies indicate that many young patients do not even have a basic understanding of their condition. When children and adolescents with congenital or acquired cardiac disease were interviewed to ascertain their knowledge, only a minority knew their disease by name, or understood what it was.²² This occurs even when the children and adolescents have been given explanations by health professionals about their disease.²² How can this happen? Other qualitative studies illustrate that children and adolescents experience and relate to cardiac disease in terms of their own language, beliefs, values, and aspirations. After transplantation of the heart, qualitative research has shown that children have a strong sense of their personal hopes, support needs, challenges, and concerns as they try to live a life they see as being normal.²³ Similarly, adolescents interviewed about growing up with a congenitally malformed heart report dealing with many identity, gender, and social dimensions of being an adolescent with congenital cardiac disease.²⁴

To address these experiences, qualitative research into the perspectives of young patients on their condition can be used to develop health services that are more responsive to the needs and perspectives of these young patients. Qualitative research can also provide knowledge of who should be included in these services. A qualitative study of young people aged 8 to 18²⁵ identified that friends and teachers can play a key role in helping the young patients deal with their condition. Such findings have implications for how different agencies and groups can work together to provide more responsive support.

Understanding and supporting better the families of young patients

As with young patients, the families and significant others of young patients can have diverse and different perspectives on the nature and management of heart conditions. Since the 1960s, it has been recognized that being the parent of a child with a congenitally malformed heart is stressful.²⁶ A high degree of anxiety is associated with having a child with a cardiac problem.²⁷ Qualitative research has shown that over the course of the life of these young patients, the parents of children living with

the congenitally malformed heart continually question if and how their child can attain “normality”.²⁸ They often feel anxious about shame, and have concerns at different stages of school and social life about which other people involved in the life of their children should be told about the cardiac condition. Dilemmas are experienced related to the need to protect the child from demanding physical and social situations versus the risk of social isolation from peers and recreation.²⁸

These findings provide further indications of the complex emotions and extensive psychosocial needs of parents and families. Qualitative research has also shown that health professionals have expectations of parents that are often at odds with those held by parents themselves. In a study based on interviews about the needs for information, and roles, of parents,²⁹ there were common and large mismatches between the expectations voiced by the health professionals and the parents of the information and support needed by the parents. Other qualitative research has detailed the wide range of information that parents feel is needed by both themselves and their children.³⁰ This included information about

- past procedures and ailments
- the current situation, including diagnosis, side effects of medication, and relating to lifestyle and recreational issues
- issues of recovery related to scarring
- statistics relating to survival and how other patients with the same condition fare.

Unmet emotional needs of parents included needing additional support from health professionals about the specifics of the condition suffered by the child, and how to link with other similar parents. This knowledge can also be used to inform the support provided by health professionals and services to families.

What is quality in qualitative research?

Qualitative research, therefore, can provide insights and knowledge that other methods cannot, and is now well accepted by most general medical journals.^{31–33} As with all research, prior to guiding decisions in practice, the quality of research studies must be appraised, and the transferability of findings to patients and populations assessed.

Agreement on what factors are most important in the appraisal of qualitative research has emerged over the last decade^{8,32,34} though disagreements persist, particularly around the use of checklists.³⁵ A commonly used appraisal tool that is sufficiently generic to be widely used but is also reliable was developed by the Critical Appraisal Skills Programme.³⁶ This tool

focuses on three main issues. First, the tool addresses whether the qualitative study used thorough and appropriate methods. This examines the degree of match between the question and the method of the research. Second, the tool examines whether the findings are well presented and meaningful. This speaks to the substantiation, sophistication and resonance of the findings. Third, the tool addresses the relevance of the findings, specifically how useful or transferable are the results likely to be to different patients and settings.

Qualitative research studies tend to be small in size due to the large volume of data that is collected, and the need to analyse these data in a deep fashion. This does raise the issue of the trust that can be placed in any research study based on a small number of participants. Qualitative research does not seek to be statistically generalizable in the manner of trials or other quantitative evidence. Rather, qualitative research can generate new insights and understanding into aspects of human beings and their behaviour that were previously only poorly or partially understood.

Conclusion

Qualitative research can increase insight into the range and complexity of perspectives and needs of young patients with cardiac problems and their parents. This knowledge can be used to inform clinical practice so as to improve the quality of care for young patients and their parents. Qualitative methods are rigorous and accepted ways of increasing insight and understanding into the views, challenges, and experiences of young patients and their families. The methods can also be used to inform the development of practice and services that are more responsive to the needs, and perspectives, of the young patients and their parents.

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