**Review:**

**Challenges of Having a Child with Thalassaemia Major: A Phenomenological Study**

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Motherhood can be an extremely stressful experience for women across different cultures and economic and social settings. This paper provides an insightful account of the challenges experienced by mothers of children with Thalassaemia in Jordan and clearly illustrates how the specific role of mothers creates additional stress which has an impact on their quality of life.

The authors begin by presenting the cultural significance of Thalassaemia as a genetic disorder and the key contribution of consanguineous marriage is clearly established from the outset. However, the issue of compulsory pre-marriage screening and risk assessment, together with the national media programmes to highlight the risks of consanguineous marriage, appear to have limited impact since this type of marriage remains popular.

Using a descriptive phenomenological approach the authors recruited and interviewed 23 mothers from two major Thalassaemia clinics in Jordan. One of the strengths of this paper is its emphasis on the methodological approach and the audit trail presented with the use of quotes drawn from the identified themes. Emphasis on rigour is elaborated with the consideration of bracketing, where the researchers acknowledge and set aside their individual values and beliefs at the beginning of the study; and the discussion of strategies to achieve trustworthiness are clearly stated. Including the interview questions is really helpful as it enables the reader to understand how the interviews were guided and how the themes were generated.

Another strength of this paper is the way in which the authors have presented their key findings, focusing on the debilitating psychosocial distress experienced by mothers. The authors carefully discuss the findings highlighting the key themes and subthemes generated from the data within the Jordanian context. The quotes used clearly illustrate the emotional burden carried by mothers, and how they assume key responsibility for their child or children. Alarmingly however, the deficits in knowledge and understanding of the condition appear to increase the stress even further, which have implications for their mental wellbeing and quality of life.

The authors have successfully explored and illustrated the challenges experienced by mothers which they acknowledge may be unique to the Jordanian community. This is certainly implied in the absence of references to the role of fathers within the mothers’ interview data. Whilst the authors identify the key implications for practice in relation to the provision of holistic care for mothers including information and support, and the role of healthcare providers in facilitating this; the role played by fathers in the provision of support remains an area of interest. Whilst the authors suggest that the amount of support offered by fathers at home is unknown, further work is needed to understand how fathers negotiate their roles in relation to having a child or children with a chronic condition.

This research has given mothers a voice, enabling them to share their thoughts and fears and in this way has revealed gaps in knowledge and the need to develop support services further. In this way, this paper makes a significant contribution to the literature and has major implications for the development of services.

Sarah Church (PhD, MSc, RGN, RM, PGDipEd, SFHEA, PGCert (Research Supervision)) is an Associate Professor and Reader in Midwifery, in a joint appointment with London South Bank University and Barts Health, NHS Trust. She is an experienced midwife, educator and researcher. Sarah has extensive experience in the development and teaching of undergraduate, postgraduate programmes and educational courses for midwives and healthcare professionals. She supervises MSc, PhD and Professional Doctorate students' research. She is a qualitative researcher, particularly the use of phenomenology and reflexive autobiography. Her PhD focused on gender identity and explored the reproductive identities and experiences of midwives and mothers. Her current research areas include lesbian motherhood, perinatal mental health, cancer in pregnancy, and migration and midwifery, especially the mobility of midwives. Sarah has contributed journal articles and book chapters on issues within the sociology of reproduction and childbirth. Sarah is an active member of COST Action group IS1405, "Building Intrapartum Research through Health - an interdisciplinary whole system approach to understanding and contextualizing physiological labour and birth (BIRTH)".