

Background

Cardiovascular diseases (CVD) are currently the leading cause of mortality in pregnant women. To date, the majority of empirical studies and guidelines include an assessment of clinical status, prognosis and outcomes of these women. However, we currently lack an in-depth understanding of the needs, expectations and experiences of women regarding the follow-up they receive during their pregnancy journey.

Aim(s)

The current study aimed (i) to gain an in-depth understanding of experiences of women with cardiovascular disease and (ii) to describe barriers and facilitators of the received follow-up throughout their pregnancy.

Methods

This qualitative phenomenological study included data collection using semi-structured interviews, performed at a tertiary centre comprising a cardio-obstetrics outpatient clinic. Purposive sampling was performed. A thematic analysis of the transcribed interviews was done until data saturation was achieved.

Results

Five main themes were identified. Awareness of the disease came for many patients when they experienced symptoms or when delivery was premature and their baby was admitted to neonatal care. Facilitators were caregivers' skills, such as delivering humane care and providing congruent information, thus ensuring continuity of care. Barriers were that patients often had to seek help themselves and felt lonely in their journey. Patients had the feeling that they were not listened to when being symptomatic or felt something was off leading to potentially detrimental, but preventable, complications. Due to a lack of visibility, the Heart Pregnancy team was not widely known to care providers in referring hospitals. The entire patient journey had an important impact on patients' psyche, unfortunately the current psychological follow-up was experienced as insufficiently addressing their needs.

Discussion

More visibility and knowledge about this condition as well as the implementation of a structured, patient-centred care pathway, with special attention to psychological support, will better meet patients' needs.

Implications and future perspectives

With these results, the perspective of cardio-obstetric patients can be incorporated into guidelines and the development of an integrated care pathway.