

Women's Experience of Managing Pre-Existing Lymphoedema during Pregnancy and the Early Postnatal Period

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Abstract : Lymphoedema is a chronic condition caused by dysfunction of the lymphatic system, which limits the drainage of fluid and tissue waste from the interstitial space of the affected body part. The normal physiological changes in pregnancy cause an increased load on a normal lymphatic system which can result in a transient lymphatic overload (oedema). The interaction between lymphoedema and pregnancy oedema is unclear. Women with pre-existing lymphoedema require accurate information and additional strategies to manage their lymphoedema during pregnancy. Currently, no resources are available to guide women or their healthcare providers with accurate advice and additional management strategies for coping with lymphoedema during pregnancy until they have recovered postnatally. This study explored the experiences of Australian women with pre-existing lymphoedema during recent pregnancy and the early postnatal period to determine how their usual lymphoedema management strategies were adapted and what were their additional or unmet needs. Interactions with their obstetric care providers, the hospital maternity services, and usual lymphoedema therapy services were detailed. Participants were sourced from several Australian lymphoedema community groups, including therapist networks. Opportunistic sampling is appropriate to explore this topic in a small target population as lymphoedema in women of childbearing age is uncommon, with prevalence data unavailable. Inclusion criteria were aged over 18 years, diagnosed with primary or secondary lymphoedema of the arm or leg, pregnant within the preceding ten years (since 2012), and had their pregnancy and postnatal care in Australia. Exclusion criteria were a diagnosis of lipedema and if unable to read or understand a reasonable level of English. A mixed-method qualitative design was used in two phases. This involved an online survey (REDCap platform) of the participants followed by online semi-structured interviews or focus groups to provide the transcript data for inductive thematic analysis to gain an in-depth understanding of issues raised. Women with well-managed pre-existing lymphoedema coped well with the additional oedema load of pregnancy; however, those with limited access to quality conservative care prior to pregnancy were found to be significantly impacted by pregnancy, including many reporting deterioration of their chronic lymphoedema. Misinformation and a lack of support increased fear and apprehension in planning and enjoying their pregnancy experience. Collaboration between maternity and lymphoedema therapy services did not happen despite study participants suggesting it. Helpful resources and unmet needs were identified in the recent Australian context to inform further research and the development of resources to assist women with lymphoedema who are considering or are pregnant and their supporters, including health care providers.

Keywords : lymphoedema, management strategies, pregnancy, qualitative

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