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Maternity care co-ordination for women with two or more long-term health conditions (MLTC): The need for joined up care

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By Zoe Vowles

Background

The MuM-PreDiCT study has found the number of women experiencing pregnancy with two or more long-term health conditions (known as multiple long-term conditions) is around 20%.[1] Confidential enquiries and reviews into deaths of women during or after pregnancy in the UK consistently find that women with pre-existing physical or mental health conditions, and those with multiple challenges or complexities, are more likely to die, experience serious illness and have poorer experiences of care during pregnancy and the postnatal period.[2,3]

It is increasingly recognised that people living with multiple long-term conditions (MLTC) have distinct needs in healthcare and their care should consider these.[4] The National Institute for Health and Care Excellence guidelines on the management of care for people with MLTC recommend an approach to care that focuses on the individual's needs and preferences; improving quality of life through reducing treatment burden and unplanned care; and ensuring co-ordination of care across different services.[5]

Pregnant women who are living with MLTC have specific needs that demand a multi-disciplinary team and care that may span both physical and mental health specialities, and require care across hospital sites and trusts.[6] Providing joined up care which does not place a burden on women and their families can be challenging as care is traditionally focused on single conditions and separates physical and mental health. This approach may detract from providing holistic woman-centred care which impacts upon women's satisfaction with care and outcomes. The time, cost, and work required for women to access appointments with many different services and healthcare professionals, and look after their health, can result in the burden impacting their life and wellbeing.[7, 8]

What did we find in MuM-PreDiCT about experiences and care of women with MLTC?

Within MuM-PreDiCT we undertook a study to understand the experiences and care of women with MLTC during pregnancy and after birth. Interviews were conducted with 57 women who were pregnant or had a baby within the last two years with MLTC, and with 51 staff who provided maternity care for those with MLTC.[9] Five themes were developed: (1) Need for teamwork across different health professionals; (2) Need for care coordinator; (3) Acknowledgement of multiple identities of women with MLTC in the perinatal period; (4) Acknowledgement of boundaries and limits of expertise; and (5) Need for improved information sharing and continuity. The full article is available here.

At times, the interviews highlighted a lack of, and need for, greater teamwork, involving the woman as a partner to provide more holistic, person-centred care, and a need for consistent information to support decisions around medication. A lack of continuity and co-ordination of care resulted in a significant burden of responsibility on women to share information with, and co-ordinate their care between different professionals. Input from a specialist such as obstetric physicians, specialist midwives or obstetricians improved this, however a lack of a designated coordinating professional in maternity was noted. Women felt there was little recognition of their different identities as a pregnant woman, new mother and someone with multiple health conditions or how their conditions and being pregnant would impact them. Women described a need for greater access to midwifery care to support birth planning and infant feeding choices.[9] Care was often fragmented and focused on individual conditions.

Experiences of postnatal care were particularly poor with a lack of continued co-ordination, specialist input and continuity of care and follow up for pre-existing health conditions in the postnatal period. Midwifery care which offers appropriate expertise in managing women's health conditions as part of a mult-disciplinary team was valued. Women also valued their expertise about their health conditions being recognised and health professionals being honest about the limitations of their knowledge and expertise when appropriate. Challenges in informational continuity, particularly when women were receiving care across sites and organisations were described which impacted upon coordination of care and required the woman to communicate with different teams and providers.[9] The MuM-PreDiCT study developed a longlist of care components from the interviews with women and staff which were explored and refined during four co-production workshops. A potential care bundle of key components was developed to improve care, support and outcomes for pregnant and postnatal women with MLTC. The bundle, which focuses on continuity, coordination, consistency and communication will be refined and tested in future research.

What does other evidence show?

Evidence reviews looking at continuity of midwifery care models find a lack of literature on use of these models for women with complexity such as MLTC.[10, 11] A systematic review exploring the association between having MLTC before pregnancy and poor maternal outcomes found a focus on single chronic conditions instead of an approach which recognises and actively considers MLTC.[12] Midwives were seen to be a core part of the multi-disciplinary team for women with MLTC with opportunities to support perinatal mental health, reduce health inequalities, provide leadership and enhance continuity and coordination of care.[13]

Changing Maternity Landscape

There have been changes in maternity care which impact on the co-ordination of care. The role of General Practitioners (GPs) in maternity care has changed with GPs less likely to have a role in routine antenatal care.[14] However, GPs continue to have an important role in holistic care of women with medical or mental health conditions.[15] There is a need for improved communication, collaboration and effective information sharing with GPs, particularly in the postnatal period when GPs resume responsibility for care and ongoing management of long-term health conditions.[16, 17] One such enterprise is the GPCPC (GPs Championing Perinatal Care), which is a network of UK General Practitioners (GPs), who have volunteered their time to work collaboratively on quality improvement in the field of perinatal care in primary care.

Maternal Medicine Networks have been established in England to streamline care and improve outcomes for women with pre-existing medical conditions, or those with medical conditions identified during pregnancy or in the postnatal period. The networks are responsible for ensuring women receive personalised, specialist care before, during and after pregnancy with care managed by an experienced multi-disciplinary team where appropriate.[18]

The importance of continuity and co-ordination of care

Effective co-ordination of care has been identified as an essential aspect of care in other settings where care involves a multi-disciplinary team such as in cancer care.[19] Co-ordinating clinical care has been identified as a key aspect of ensuring the right care for people with MLTC.[20] Nurse-led care coordination has been found to be effective in other specialities.[21] Research undertaken in Denmark compared a midwife-coordinated maternity care intervention with Standard Care for women with chronic health conditions. which included those with multiple health conditions. They found that, overall, women in the midwife-coordinated group were more satisfied with their care, although it did not change the length of their hospital stay.[22]

Maternity care policy has called for greater continuity of care, however this has been challenging to implement.[23] Continuity of care[24] includes a number of aspects such as the relationships women have with their clinical teams or care providers often known as 'relational continuity'; coordination of care; and continuity of information between different parts of the health system.[25] These are important for all women but particularly those with MLTC to avoid disjointed and fragmented care where multiple professionals, hospitals or trusts may be involved in their care. Continuity and coordination of care are global priorities to ensure health services meet people's needs, particularly those with MLTC.[26, 27] Women with chronic medical conditions have described a need for greater continuity in their maternity care.[6] There is extensive literature suggesting midwifery continuity of care models and co-ordination of care can improve the quality of care and outcomes for women and babies.[28, 29, 30, 31] However, previous studies focused on low-risk women. Further research is needed to understand the impact of MLTC on maternal health, improve care and make care more women-centred for those with MLTC12 My PhD exploring use of healthcare and experiences of midwifery care among pregnant women with MLTC aims to address this evidence gap.

The role of the midwife in care of women with MLTC

Midwives have a key role in the multi-disciplinary team, ensuring joined up care with obstetric and specialist services to meet women's needs. The MuM-PreDiCT study[9] found midwives were described as supporting co-ordination and holistic multidisciplinary team-care, particularly for women with medical, mental health and social complexities. Women valued care from midwives, particularly accessing information about breastfeeding, which they struggled to access from other professionals. Despite this, women didn't always have access to midwifery care during pregnancy and midwives sometimes lacked the appropriate experience and expertise. Although women with MLTC often need specialist care, which may be from an obstetrician, obstetric physician or other specialists or professionals, they also should have access to the holistic care offered by midwives. The recent World Health Organization Global Position Paper on transitioning to midwifery models of care described the importance of a collaborative interdisciplinary approach to care provided by midwives working in partnership with general or specialist medical practitioners and other members of the team to provide seamless and comprehensive care.[32]

Conclusion

Women with MLTC require care that is holistic and personalised to their individual needs and circumstances. Improved continuity and collaboration between different professionals and providers are required with an emphasis on postnatal care where experiences are particularly poor.

Author Bio: Zoë Vowles is a midwife and NIHR Doctoral Clinical Academic Fellow at Guy's and St Thomas's NHS Foundation Trust/King's College London. Her PhD is a mixed methods study exploring how pregnant and postnatal women with two or more long-term health conditions use health services and experience midwifery care, as part of multi-disciplinary maternity care.

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