CONCLUSIVE REPORT FOR MODIAB-WEB: A PERSON-CENTERED PROJECT

The overall aim of the MODIAB-Web research project was to investigate well-being and diabetes management in women with type 1 diabetes mellitus (T1DM) during pregnancy and in early motherhood in the first six months after childbirth.

This was studied through explorative, observational studies, a qualitative interview study, and through an intervention using a randomized controlled trial (RCT) design. In the RCT, we tested a web-based support programme directed to the women with T1DM during pregnancy and up to six months after childbirth. The study is reported in 14 scientific papers[1-14], 11 Abstracts in proceedings of scientific conferences (7 poster and 4 oral presentations), one PhD thesis, 4 Master's theses, and two popular scientific publications.

To capture the needs and usefulness, content and layout of the Web support was developed based on a synthesis of existing scientific evidence including a specific questionnaire to the target group[11], and including essential theories, and through a participatory design. Participating stakeholders were project managers, advisory and scientific reference groups, technical producers, and mothers with T1DM[3]. Overall guiding theoretical perspective for the web-based support was to have a person-centered approach[10]. Guiding theories focused on: participatory design, learning ("communities of practice"), salutogenesis, social support and transition to motherhood[9,10]. In a sub-study we described and compared the MODIAB- Web project with another three person-centered internet-based support projects, although with different target groups and different theoretical perspectives[14].

The Web-based support consisted of three main components[2,3]: 1) specific information about pregnancy, childbirth, and early motherhood in relation to type 1 diabetes[7,13]; 2) a self-care diary, including a device for documenting and evaluating blood glucose levels, insulin doses, food intake, physical activities, and overall well-being; and 3) a forum for communication between women with type 1 diabetes in the childbearing period. The software prototype was pilot tested by a group of mothers with T1DM[1] and some minor changes were made in the final version of the web- support. The RCT with web-based support in addition to usual care compared to only usual care was offered in the RCT November 2011 to March 2016, first at two hospital-based antenatal care units, and successively another four hospital-based antenatal care units in Sweden were added. No changes of the web support was done during the study period, except adding some specific information on miscarriage[13]. The hypothesis was that women receiving web-based support in addition to usual care to a higher degree should manage their diabetes and have a higher degree of well-being[2,3] at 6 months after birth compared to the control group receiving only standard care[2].

In early pregnancy, a higher degree of diabetes management correlated positively with self-perceived health and well-being and with less worry about diabetes distress and hypoglycemia. This was found in the whole composite group, both control group and intervention group, measured before the web-based support was offered[8].

The web-based support and standard care was not superior to standard care alone in terms of general well-being or self-efficacy of diabetes management at six months postpartum. Few participants had a high activity level[5]. We critically analysed the adherence to the technological elements and study design in the web-based intervention and found that technology and study design do matter and might mutually influence each other, particularly when it includes components of social support. We also made some essential recommendations when planning for and running a study of a web-based person-centered support programme and also questioned if it is optimal to evaluate such interventions by conducting an RCT[12].

Associations between well-being, diabetes management and breastfeeding postpartum were investigated in the composite group of control- and intervention group. Women who experienced less negative impact of breastfeeding on daily diabetes management routines reported significantly better well-being, sense of coherence and self-efficacy of diabetes management. A higher degree of unstable blood glucose levels was associated with a lower degree of well-being two months after childbirth. Participants with lower scores of general well-being and sense of coherence expressed a need for more professional support to manage their diabetes than they were provided[6]. A qualitative study on the episode after birth identified that becoming a mother was a turning point towards a greater awareness and acceptance of prioritizing diabetes management and health. To reprioritize life comprised three parts: adjusting to motherhood, taking command of the diabetes, and seeking like-minded women. There was a gap in provision of diabetes care after birth and during the time of early motherhood compared with during pregnancy[4].

In conclusion: Becoming a mother is related to increased demands for women with type 1 diabetes mellitus, and the findings confirm that well-being and diabetes management are closely linked during the childbearing period[5,6,8]. Women who received web-based support did not show any higher degree of diabetes management and wellbeing[5], but this can be explained by study design, technical devises and the contemporary development of medico-technical devises for managing diabetes[12]. More research is needed to identify the needs for support in everyday living, also to identify the most vulnerable women with T1DM in pregnancy as well as the first months after having given birth. Providing alternative sources for health information and peer support could improve the situation during this season of life. Further evaluated interventions are needed to identify optimal models of perinatal care for women with diabetes mellitus.

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