

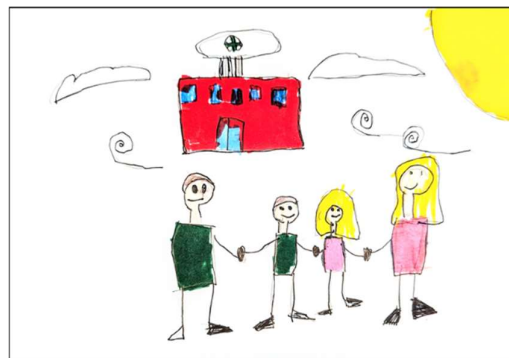


Invitation to PhD Dissertation Defence

Children with atopic diseases

Care pathways, experiences of care and influence on family life

Gitte Færk, MD



The defence will take place:

Thursday, December 12th, 2024, at 14:00

Centre for Health and Society (CSS), building 2, room 2.0.63

Øster Farimagsgade 5, 1353 Copenhagen K

After the defence, a reception will be held at CSS, building 24, room 24.0.73

(The lunchroom).

Assessment Committee:

Lene Heise Garvey, Professor

Bjarne Austad, Associate professor

Merethe Kirstine Andersen, Associate
professor

Supervisors:

Susanne Reventlow, Professor

Lone Skov, Professor

Kirsten Skamstrup Hansen, Chief physician

Jacob Pontoppidan Thyssen, Professor

Summary:

Atopic diseases such as atopic dermatitis, food allergy, asthma, and allergic rhinoconjunctivitis (hay fever) are frequent among children. The severity of these diseases vary both among children and over time for the individual child. During their journey children with atopic diseases often need to interact with various healthcare professionals, but there is a limited knowledge about their care pathways and how these can be improved. The objective of this PhD-project was to explore dimensions of care for children with atopic diseases that could be strengthened.

In the first study, we completed a questionnaire survey exploring the present referral pathways in the Danish healthcare system for children with atopic diseases. We found that there was not a direct pathway to the hospital for children with three or more atopic diseases, but they were more often referred to the hospital compared with children with one or two atopic diseases. In addition, food allergy and to a smaller degree asthma were found to be main contributing factors for referral to a hospital, whereas the number of diseases, atopic dermatitis and allergic rhinoconjunctivitis did not have the same effect. The second and third study were both based on individual interviews with parents of children with atopic dermatitis and another atopic disease (food allergy, asthma, and/or allergic rhinoconjunctivitis). In the second study, we examined parents' experiences with care and their children's care pathways within the healthcare system. The mapping revealed complexity and large variations in the children's care pathways even though they had the same atopic diseases. The allocation of responsibility, roles and tasks affected the interaction with healthcare professionals. The parents had a sense of care when the allocation of tasks and responsibilities matched both the families' expectations and experiences. The care pathway was experienced as segmented due to limited collaboration between healthcare professionals, which resulted in increased parental responsibility for coordination. The families felt supported, when healthcare professionals knew more about them than the child's diseases and individually adapted the level of provided care. In the third study, we examined how the atopic diseases affected family life including the tasks parents assumed in response to their child's conditions. Tasks directly associated with the child's treatment only played a minor role in the total workload. The parents carried out numerous other tasks to modify family life in response to the child's atopic diseases, which stemmed from their aspiration for their child to have a childhood as normal as possible.

In conclusion, these three studies contribute to the understanding of the care pathway for children with atopic diseases with focus on the parents' perspective. While accessibility is a key factor, continuity and trust are essential in the care pathway from the parents' viewpoint. Having a child with multiple atopic diseases impact the entire family, and the child's overall care pathway extends beyond encounters with healthcare professionals and the biomedical aspects. It is important for healthcare professionals be aware of these broader implications, as knowledge of these represents a significant step towards improving parents' experiences of the care pathway for their children with atopic diseases.