

DEVELOPMENT OF EXPERTISE IN SELF-MANAGEMENT OF CHRONIC
ILLNESS: NARRATIVES OF OLDER ADULTS LIVING WITH
ATOPIC DERMATITIS, ASTHMA, AND ALLERGIES SINCE CHILDHOOD

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by

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Abstract

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The purpose of this qualitative study was to identify the knowledge, skills, and abilities needed and the resources used in self-management of atopy. The term atopy refers to several commonly comorbid medical diseases: atopic dermatitis (AD; also known as eczema), asthma, and allergic rhinitis (also known as hay fever) or anaphylaxis. Grounded theory and narrative methodologies were employed. Six adults aged 45-60 with early-onset conditions were each interviewed twice. They were asked to tell their stories of learning to manage all three conditions, starting in childhood when symptoms first occurred, through adulthood to their current age. Interviewed participants had severe or moderate AD and allergies, and mostly mild asthma. Previously gathered email data from an Internet support group for eczema patients was used to triangulate the interview data. Two broad types of knowledge, skills, and

abilities were identified: those related to psychosocial issues, and those related to symptom prevention, assessment, and treatment. Symptoms of the diseases were inter-related, supporting the medical concept of an atopic triad and prior calls for integrated treatment. Findings indicate that individuals living with atopy may need 30-50 years to develop self-management expertise. Adequate, accurate information is acquired piecemeal, at great effort, very slowly over time. Informative and compassionate physicians who grant sufficient time to answer questions are rarely found. Helpful resources include personal research on Western and alternative or complementary medicine, trial and error experimentation, mental health professionals, and peer support groups. Results were used to create a grounded theory that suggests there are age-related developmental stages in the learning process. Psychosocial maturity may be necessary for full development of self-management expertise. Critical challenges include the need to become proactive, learn healthy methods of stress reduction, find social support, understand the wide-range of inter-related biopsychosocial and environmental factors that can trigger or exacerbate symptoms, and overcome a sense of psychosocial deprivation due to the lifestyle restrictions imposed by atopy. To reduce the length of time needed to develop expertise in atopy self-management, patient education programs may be

needed. Diabetes patient education programs that combine psychosocial skills training and disease-related information may be a model.