

# Self-reported activity and participation in persons with haemophilia living in Sweden

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av

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## Avhandlingen baseras på följande delarbeten

- I. Brodin E, Baghaei F, Elfvinger P, Lindvall K, Sunnerhagen KS.  
The Swedish version of the Haemophilia Activity List.  
*Haemophilia* 2011 Jul;17(4):662-8.
- II. Brodin E, Baghaei F, Sunnerhagen KS  
Self-reported activity and functioning in daily life; the perspective of persons with haemophilia living in Sweden.  
*Eur J Haematol.* 2015 Oct;95(4):336-41.
- III. Brodin E, Hadzibajramovic E, Baghaei F, Sunnerhagen KS, Lundgren-Nilsson Å.  
Activity and Participation of Swedish Hemophilia Persons; change over 2.5 years.  
*Manuscript*
- IV. Brodin E, Sunnerhagen KS, Baghaei F, Törnbom M.  
Persons with Haemophilia in Sweden- Experiences and Strategies in Everyday Life. A Single Centre Study.  
*PLoS One.* 2015 Oct 2;10(10):e0139690.

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# Self-reported activity and participation in persons with haemophilia living in Sweden

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## **Abstract**

**Background:** Haemophilia is a hereditary disease caused by deficiency of clotting factor VIII or IX. Recurrent joint bleeding episodes can lead to haemophilia arthropathy, a condition affecting daily activities and participation in society. The Haemophilia Activity List (HAL), is a self-reported questionnaire that provides the person's own view of perceived difficulties in performance of daily activities. The overall aim of this thesis was to describe self-reported activity and participation in adult persons with haemophilia in Sweden and explore their experiences of living with haemophilia.

**Methods:** All adult persons with haemophilia in Sweden meeting the inclusion criteria were invited by letter to studies I+II and III (84 and 129 participated respectively) to validate Haemophilia Activity List and explore any difficulties in activity and participation. Sixty-one participated twice, first in studies I+II and then in study III. In study IV persons from the Haemophilia Treatment Centre in Gothenburg were recruited for interviews about their experiences living with haemophilia (14 participated). The interviews were analysed according to the empirical psychological phenomenological method described by G. Karlsson.

**Main results:** The most common difficulties reported were in physical activities involving the lower extremities such as e.g. rising from a chair, riding a bicycle, walking and running. Those with early treatment onset reported fewer difficulties than the group with later treatment onset. Over time the later treatment onset group reported increasing difficulties in leisure activities and sport. This indicates a greater need for rehabilitation for the later treatment onset group to help maintain their activity level in daily life. The participants interviewed valued the treatment with clotting factor and support from caregivers at the Haemophilia Treatment Centre. Preventing bleeds was a main objective for the interviewees with haemophilia. They adapted their social activities and strived for normality throughout life. The Swedish version of HAL has high internal consistency and excellent to good convergent validity and can be used as a complement to other clinical tests to establish the patient's self-perceived difficulties to perform activities of daily life.

**Conclusion:** The Swedish persons living with haemophilia reported most difficulties with activities involving the lower extremities and there was a difference between the groups with early and later treatment onset, where the later onset reported more difficulties over all. The interviewees with haemophilia adapted their social activities and strived for normality throughout life. They valued the treatment with clotting factor, and a major objective was preventing bleeds. The Swedish version of HAL can be used in the clinic and in research to gather information about the person's self-perceived activity and participation in daily life.

**Keywords:** Haemophilia, activity, participation, lived experiences, HAL, validity, interview, empirical phenomenological psychological method, coping