Growing up with hemophilia

*Health related quality of life and psychosocial functioning*

Limperg, P.F.

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Chapter 10

Psychosocial care for children with haemophilia and their parents in the Netherlands

P.F. Limperg, L. Haverman, M. Beijlevelt, M. van der Pot, G. Zaal, W.A. de Boer, K. Fijnvandraat, M. Peters, M.A. Grootenhuis

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Abstract

Introduction: Children growing up with haemophilia are at greater risk for psychosocial problems than their healthy peers. Providing psychosocial care to children with haemophilia and their families is indispensable, since psychosocial factors can have a significant impact on health and health-related quality of life (HRQOL).

Aims: Our aim was to give a description of psychosocial care provided by the multidisciplinary team of the Hemophilia Comprehensive Care Centre (HCCC) at the Emma Children’s Hospital in Amsterdam, the Netherlands. With this overview, other caregivers and hospitals can benefit in organizing their psychosocial care for children with haemophilia.

Methods: The focus of the psychosocial care provided by the multidisciplinary team is on preventing psychosocial problems and medical-related stress, and supporting and equipping the child with haemophilia and its parents with as many skills as possible to lead an independent life with a high HRQOL.

Results: Core elements of the psychosocial care are therefore monitoring and screening of HRQOL (e.g. in daily clinical practice via www.hetklikt.nu), psychoeducation (haemophilia camp, haemophilia school, disease-specific activities, meetings for girls, parent meetings), practical help (Emma at Work, an employment agency for adolescents and young adults; Educational Facility and school visits), psychosocial interventions (the On Track group intervention and the Haemophilia Coping and Perception Test) and individual care (psychological counselling and referrals).

Conclusion: By providing this overview of psychosocial support offered and by sharing this knowledge, psychosocial care can become more structured and consistent between HCCCs around the world. Potentially, processes and outcomes of care can be improved.
Introduction

Haemophilia is an X-linked bleeding disorder, caused by an inherited deficiency of clotting factor VIII (haemophilia A) or factor IX (haemophilia B) and leads to spontaneous and posttraumatic bleeds [1]. Since the introduction of prophylaxis and home treatment in the 1960s, severe bleeds occur less frequently and paediatric patients with haemophilia have a better health status than before. Children usually do not develop the marked impairments and disabilities that would have occurred in the past [1]. Prophylaxis and home treatment have led to significant improvement in the health-related quality of life (HRQOL) of children with bleeding disorders [2,3].

In the Netherlands, around 1600 patients are affected with haemophilia, of which approximately 400 are children. The Netherlands is one of the countries with the highest number of available prophylaxis (76–100%) and home treatment for patients with haemophilia [4]. Knowledge and experience is congregated in seven specialized Haemophilia Comprehensive Care Centres (HCCCs) [4,5]. Despite the optimal treatment, boys with haemophilia (BWH) still endure difficulties and impairments, such as hospital visits, frequent injections and limited participation in (sport) activities, which may have an impact on HRQOL and psychosocial functioning [6,7].

Haemophilia is a rare disorder that is complex to manage. Optimal care for patients, especially those with severe forms of the disease, requires more than the treatment of acute bleeding; attention to psychosocial functioning and HRQOL is needed as well since this can impact health and treatment. Therefore, pre-venting and treating medical-related stress and chronic complications, and achieving the highest HRQOL are the main goals of haemophilia management nowadays [8,9]. However, the challenge is to empower patients to manage their circumstances and challenges autonomously [8–10].

Psychosocial care addresses a wide range of physical, social and psychological issues related to promoting the health and development of children, adolescents and their families. Moreover, potentially traumatic medical events are frequent for children, and preventive interventions can be developed to address these common experiences [11]. Patients and parents
may benefit from monitoring and screening, psychoeducation, practical help, psychosocial interventions and individual care [8,12–14].

Children and adolescents go through several transitional phases, such as achieving personal identities, gaining independence from their parents, initiating employment and building significant relationships outside of their families, which can be challenging [15]. Children and adolescents with chronic illnesses are expected to pass similar developmental stages as healthy peers, but often have a delay in their developmental trajectory [16]. A recent study has shown that the process of achieving complete self-management in adolescents and young adults is not reached until a median age of 22.6 years [17]. Therefore, it is recommended that the paediatric team promotes self-management underpinned by psychosocial care and support in BWH early so that the transition process can be gradual [8,18]. However, psychosocial care and support is not always included in the care for people with haemophilia, especially in developing countries, mostly because of lack of financial resources and the emphasis on treating (life-threatening) bleeds [12]. A survey of haemophilia care in Europe, showed that 11 of the 19 countries surveyed (58%) did not offer psychosocial support to their patients either [4].

The Haemophilia Treatment Centre of the Emma Children’s Hospital in Amsterdam is one of the specialized HCCCs in the Netherlands, with the presence of a paediatric multidisciplinary team. The focus of the psychosocial multidisciplinary team is on supporting and equipping children or adolescents with congenital bleeding disorders and their parents with as many skills as possible to lead an independent life with a high HRQOL and optimal psychosocial functioning.

The goal is to provide an overview of paediatric haemophilia care to benefit other caregivers and hospitals in providing psychosocial care for children with haemophilia. This paper offers a framework for providing psychosocial care for children and families with haemophilia and other congenital bleeding disorders, based on research and clinical work by the HCCC of the Emma Children’s Hospital in Amsterdam, the Netherlands. By sharing this knowledge, psychosocial care can become more structured and consistent between HCCCs.
Potentially, processes and outcomes of care can be improved.

**Psychosocial care in the HCCC of the Emma Children’s Hospital/AMC, Amsterdam**

Approximately 100 BWH and 130 children with other congenital bleeding disorders (e.g. von Willebrand Disease and clotting factor deficiencies) are under treatment at the HCCC.

**The multidisciplinary team**

The paediatric multidisciplinary team consists of three paediatric haematologists, two paediatric haemophilia nurses, a paediatric psychologist, a social worker and a paediatric physiotherapist. The entire multidisciplinary team assembles monthly for the so-called ‘psychosocial team meeting’, where patients with psychosocial issues are discussed. Table 1 provides an overview of responsibilities of the multidisciplinary team of the HCCC.

<table>
<thead>
<tr>
<th>Team members</th>
<th>Role and responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric haematologist</td>
<td>Diagnosis, initiate psychosocial care, physical exam, infusion log, bleeds, treatment plan and any related questions.</td>
</tr>
<tr>
<td>Paediatric haemophilia nurse</td>
<td>Detect psychosocial difficulties; progress of infusion, stock of clotting factor and psychoeducation to children and parents; organize activities to enhance the self-management of patients.</td>
</tr>
<tr>
<td>Paediatric psychologist</td>
<td>Individual psychosocial counselling, improve self-management, treatment of BWH who experience social, emotional or behavioural problems; advice on how to cope with haemophilia in family, at school or social contexts.</td>
</tr>
<tr>
<td>Social worker</td>
<td>Psychosocial care regarding parents; coordinate care and mediate with authorities (e.g. questions related to finances, housing and health insurance).</td>
</tr>
<tr>
<td>Paediatric physiotherapist</td>
<td>Monitor (target) joints, assist in rehabilitation after a bleed, advice on prevention of bleeds, exercises and sport activities.</td>
</tr>
</tbody>
</table>

We will describe psychosocial care and interventions according to the degree of intensity and degree of priority, as depicted in Fig. 1, which was inspired by the Paediatric Psychosocial Preventative Health Model (PPPHM) [19]. When looking at the model in Fig. 1, we believe that the two bottom ‘tiers’ (monitoring and screening, and psychoeducation) include the most basic and important programmes due to their preventive character, also for centres with limited resources and no multidisciplinary team available. The upper three tiers are more specialized care programmes, which require the presence of a psychologist or social worker, which may not be the case in most centres.
However, we believe that psychological guidance can also be done outside of the HTC, by referral. Figure 2 provides an overview of psychosocial care according to age, including what team members are involved.

**Monitoring and screening**

Given the impact that haemophilia can have on HRQOL [20], the HCCC uses the ‘KLIK’ system (Dutch acronym for ‘quality of life in clinical practice’; www.hetklikt.nu) to monitor HRQOL patient reported outcomes (PROs) in the outpatient clinic. KLIK is a web-based tool to monitor and screen HRQOL over time, to be able to detect problems that arise for individual patients at an early stage, so tailored interventions can be offered before problems increase [21,22]. Prior to the consultation with the paediatric haematologist, children ages 8–18 years (and/or their parents if they are <8 years) complete online questionnaires at home. A generic HRQOL questionnaire (TNO-AZL Preschool Children Quality of Life (TapQoL) [23] or Paediatric Quality of Life Questionnaire (PedsQL) [24]), a disease-specific HRQOL questionnaire (Haemophilia Quality of Life; Haemo-QoL [25]) and a disease-specific Haemophilia Self-Efficacy Scale (HSES) [26] are completed (see Table 2). Moreover, to promote patient-centred care and
<table>
<thead>
<tr>
<th>Age</th>
<th>Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 yrs</td>
<td>KLIK: monitoring HRQOL in daily clinical practice (paediatric haematologist, paediatric haemophilia nurse)</td>
</tr>
<tr>
<td>6-7 yrs</td>
<td>KLIK: continue monitoring HRQOL in young adults</td>
</tr>
<tr>
<td>8-12 yrs</td>
<td>Carrousel outpatient clinic: comprehensive consultations linked to key ages (paediatric haematologist, nurse, psychologist, social worker, physiotherapist)</td>
</tr>
<tr>
<td>13-18 yrs</td>
<td>On-demand psycho-education to schools (paediatric haemophilia nurse)</td>
</tr>
<tr>
<td>19-25 yrs</td>
<td>Individual psychological counselling (paediatric psychologist)</td>
</tr>
<tr>
<td>26-30 yrs</td>
<td>Haemophilia Camp (haematologist, nurse, social work, psychologist)</td>
</tr>
<tr>
<td></td>
<td>Haemophilia Coping and Perception Test (psychologist, nurse)</td>
</tr>
<tr>
<td></td>
<td>On Track: group intervention (paediatric psychologist)</td>
</tr>
<tr>
<td></td>
<td>Haemophilia school (nurse)</td>
</tr>
<tr>
<td></td>
<td>Girls meeting (haematologist, nurse)</td>
</tr>
<tr>
<td></td>
<td>Activity day (haematologist, nurse)</td>
</tr>
<tr>
<td></td>
<td>Emma at Work: employment agency (professional)</td>
</tr>
<tr>
<td>PARENTS</td>
<td>Individual counselling (social worker)</td>
</tr>
<tr>
<td></td>
<td>Parent meetings (social worker, psychologist, paediatric haematologist/nurse)</td>
</tr>
<tr>
<td></td>
<td>Individual infusion training (haemophilia nurse)</td>
</tr>
</tbody>
</table>

Fig. 2. Overview of psychosocial care provided at the HCCC according to age.
Psychosocial care

Table 2. Overview of questionnaires in ‘KLIK’ and discipline discussing questionnaires.

<table>
<thead>
<tr>
<th>Questionnaires used in ‘KLIK’</th>
<th>Construct</th>
<th>Age child</th>
<th>Discussed by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent self-report</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sociodemographic</td>
<td>Sociodemographic information</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Distress Thermometer for Parents (DT-P) [28]</td>
<td>Distress experienced by parents</td>
<td></td>
<td>Social worker</td>
</tr>
<tr>
<td>Open question</td>
<td>Open question to team members</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parent proxy-report</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TapQoL [23]</td>
<td>Generic HRQOL</td>
<td>0-5 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>PedsQL [24]</td>
<td>Generic HRQOL</td>
<td>6-7 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Haemo-Qol [25]</td>
<td>Disease-specific HRQOL</td>
<td>4-7 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Hemophilia Self-Efficacy Scale (HSES) [26]</td>
<td>Disease-specific self-efficacy</td>
<td>1-7 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Strengths and Difficulties Questionnaire (SDQ) [30]</td>
<td>Behaviour</td>
<td>4-7 years</td>
<td>Psychologist</td>
</tr>
<tr>
<td>Pediatric Hemophilia Activities List (Ped-HAL) [31]</td>
<td>Physical functioning</td>
<td>0-7 years</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td><strong>Child self-report</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PedsQL [24]</td>
<td>Generic HRQOL</td>
<td>8-18 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Haemo-Qol [25]</td>
<td>Disease-specific HRQOL</td>
<td>8-18 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Hemophilia Self-Efficacy Scale (HSES) [26]</td>
<td>Disease-specific self-efficacy</td>
<td>8-18 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td>Strengths and Difficulties Questionnaire (SDQ) [30]</td>
<td>Behaviour</td>
<td>8-18 years</td>
<td>Psychologist</td>
</tr>
<tr>
<td>Pediatric Hemophilia Activities List (Ped-HAL) [31]</td>
<td>Physical functioning</td>
<td>8-18 years</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td><strong>School</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School questions</td>
<td></td>
<td>8-18 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td><strong>Emma at Work</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Questions about Emma at Work</td>
<td></td>
<td>15-18 years</td>
<td>Haematologist</td>
</tr>
<tr>
<td><strong>Open question</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Open question to team members</td>
<td></td>
<td>8-18 years</td>
<td>Haematologist</td>
</tr>
</tbody>
</table>

Questionnaires (1x per year): TapQoL/PedsQL, Haemo-Qol, HSES, school, Emma at Work, and open question.
Questionnaires carrousel outpatient clinic (every 3-4 years): TapQoL/PedsQL, Distress Thermometer for Parents, SDQ, Ped-HAL and open question.
The Ped-HAL is administered yearly in combination with the Hemophilia Joint Health Score (HJHS) [32].

To empower patients and parents, the so called KLIK ePROfile is provided to patients themselves as well and it is possible to add questions or remarks to the website, visible for a team member [21]. This way, communication about HRQOL between the team and the patient/parents is facilitated, as well as between the members of the multidisciplinary team. Research has shown that the use of KLIK ePROfile is effective in increasing communication on psychosocial topics [27]. KLIK is available for other diseases and has become standard care in five Dutch HCCCs; Amsterdam, Rotterdam, Leiden, Groningen and Nijmegen.

At least four times during childhood, linked to key ages of development, all children with bleeding disorders and parents are invited by the HCCC to attend the so-called ‘carrousel outpatient clinic’, where patients will be seen by all the members of the multi-disciplinary team in one morning. The main goal is to set up a multidisciplinary treatment plan for each patient and to offer psychosocial support to children and parents. Moreover, it is an unstrained way for patients and parents to get acquainted with the entire multidisciplinary team. Children and/or parents are invited within the first year of diagnosis, prior
to attending primary school (4 years old), prior to attending high school (11–12 years old) and prior to transitioning to adult care (16–17 years old). Because all disciplines are involved in the carrousel outpatient clinic, parents are asked to complete additional questionnaires via the KLIK website (see Table 2): the Distress Thermometer for Parents (DT-P) [28,29], the Strengths and Difficulties Questionnaire (SDQ) [30] and the Paediatric Haemophilia Activities List (Ped-HAL) [31]. The Ped-HAL is additionally administered yearly in severe patients in combination with the Haemophilia Joint Health Score (HJHS) [32].

Psychoeducation

BWH (5–12 years) with a moderate or severe form of haemophilia under treatment in Amsterdam, Groningen and Rotterdam can voluntarily attend the 3-day ‘Haemophilia Camp’ once a year. For children with chronic illnesses, meeting peers and fitting in with peer groups is very important [8]. Camps can support in improving practical skills and social outcomes, such as social interaction and acceptance [8,33]. The main goal of the haemophilia camp is therefore to facilitate peer contact, encourage self-management (e.g. practicing with infusions) and reduce (needle) anxiety. Approximately 95% of BWH join the camp at least once. Certified sports educators, haemophilia nurses, paediatricians, social workers and psychologists from all three HCCCs supervise the camp.

BWH (12–13 years) attend the 1-day ‘Haemophilia school’ at the HCCC. The Haemophilia school takes place during school holidays and BWH are urged to participate, in preparation for the process of transition; every boy with severe haemophilia should learn how to self-infuse. To enhance independency and self-management, during the day, knowledge is derived on how a blood clot is formed (by visiting the laboratory), how to manage medication and how to recognize and treat a bleed. Boys will practice with infusions (on a doll-arm, but also on the nurses and themselves), under supervision of haemophilia nurses.

Once a year, adolescent boys with all types of bleeding disorders (14–17 years) are invited to participate in an activity day with peers, during school holidays. Participation in physical activity and sports is associated with
not only better physical well-being, but also with more self-esteem and social interactions [6]. The main goals of this day are to meet peers with bleeding disorders, provide psychoeducation (e.g. about sports) and to be physically active under supervision.

Once a year, a meeting for girls (11–14 years) is organized at the HCCC. For girls, being a carrier of haemophilia with low FVIII/IX levels or having other clotting factor deficiencies can have an impact and girls rarely meet other affected girls [13]. The main goal is to enhance independency and self-management in girls. Also, this day provides the opportunity to meet other girls who have a bleeding disorder and to learn more about bleeding conditions, under supervision of a haemophilia nurse or paediatric haematologist.

Also, yearly parent meetings are organized at the HCCC for parents of children with congenital bleeding disorders. Peer support and the exchange of experiences is also very valuable for parents [8,12]. The main goal is to provide psychoeducation (e.g. about infusion, sports, letting go), to discuss specific themes and to provide peer support. Themes are chosen based on requests by parents and delineated per age group, under supervision of the social worker, psychologist and paediatric haematologist or nurse. Occasionally, a meeting for grandparents is organized.

In addition, a recently developed online guide for parents of chronically ill children has become available, the so called ‘Parent Compass’ (www.hetouderkompas.nl) [34]. This guide uses themes to help parents find (non-medical) answers and tips, related to their child’s situation. Parents often have questions regarding finances, work, family matters or their child’s condition. This website provides a source of reliable information.

Practical psychosocial care
Research has shown that haemophilia negatively affects employment, in terms of the quality of the job experience or the level of job relative to capabilities [35]. Guidance in finding a suitable education or employment is warranted in young adults with haemophilia [7,36]. Adolescents and young adults (15–25 years) with congenital bleeding disorders can be assisted in finding a (part-time) job
or internship that suits their capabilities and to gain professional experience, by the employment agency ‘Emma at Work’ (www.emma-at-work.nl) [37].

In case a child is hospitalized, child life specialists are available for all children under treatment during admission or during a visit at the outpatient clinic (e.g. in the case of needle phobia). The focus of child life specialists is on the prevention of developing psychosocial and child-rearing problems, as a consequence of a condition or hospital admission. For example the child life specialist contributes in daily care for the child and prepares children and parents for (painful) examinations and medical interventions. Moreover, the child life specialist assists in processing hospital-related and stressful experiences using games, conversations and relaxing activities. By observing the child, the child life specialist contributes to the treatment plan, taking pedagogical and developmental aspects into account. Observation can take place in a playroom, where individual and group counselling can be provided.

Children with congenital bleeding disorders can experience problems in school (e.g. due to absenteeism, feeling different from peers) which can lead to below average levels of academic achievement [38,39]. For children under treatment in need of school support, the Educational Facility is available. The Educational Facility is composed of professionals who provide educational support in case of hospitalization, and can facilitate communication with schools. Moreover, nurses can provide psychoeducation to schools or day cares about the disease (e.g. what to do in case of bleeds) and to reduce anxiety in teachers and caretakers.

Interventions
Psychosocial services are often based on referrals and include evidence-based interventions typically used by paediatric psychologists [40]. For those children (8–18 years) experiencing psychosocial problems or those wanting to meet peers with chronic illnesses, the On Track course has been developed; a group intervention programme [41]. The course is given twice a year by two trained psychologists and children with bleeding disorders can participate. The course has a six weekly programme, with the aim to learn active coping skills, to
promote resilience and to prevent psychosocial problems [42]. Parallel to the child sessions, parents learn how to stimulate their child in using active coping skills. On Track is based on cognitive behavioural therapy techniques and is proven to be effective in children and adolescents [41]. Different versions of the programme (face-to-face, online and age-specific) are available for children and their parents or siblings.

For BWH (8–12 years) experiencing distress or at risk for psychosocial problems, the *Haemophilia Coping and Perception Test* (HCPT) is developed by the HCCC [43]. The HCPT is a board game, which can be used by nurses or psychologists, and can be played in one-on-one or in a small group. The goal of the HCPT is to get insight into the knowledge, self-management, coping and perception of the disease and to provide tailored psychoeducation. The game provides a playful way to address gaps in knowledge to encourage the development of self-management skills in a manner that is accessible and appealing to BWH [43,44]. The HCPT is available in Dutch for all HCCCs. Literature has shown that techniques such as play therapy and peer group therapy can help BWH to adhere to treatment regimen [8].

**Individual tailored care**

For parents, a *social worker* is available at the HCCC to coordinate care, to mediate with authorities (e.g. questions related to finances, transport, employment, housing and health insurance), and to support connections to leisure and recreational activities, which contribute to parents’ quality of life [12]. For those children or families with persistent or escalating distress, a consultation with the *paediatric psychologist* is offered. The paediatric psychologist will give individual counselling, psychological therapy (for problems such as fear of needles, autonomy problems and non-adherence) as well as psychoeducation and referral services. For example when problems are not directly related to the disease or are “isolated” problems within parents (e.g. psychiatric problems), the psychologist will refer to external (expertise) centres. The main goal of the counselling is to empower patients and parents to manage their circumstances and challenges autonomously and improve HRQOL [8].
Discussion

Psychosocial support is an important part of comprehensive care for people with haemophilia and positive results of psychological support to families have been reported [8,13]. This paper provides an overview of psychosocial support offered by the HCCC in the Emma Children’s Hospital; by monitoring HRQOL and screening psychosocial functioning systematically, psychosocial problems can be identified early and deterioration of problems can be prevented. Psycho-education can lead to higher self-efficiency, which will help to overcome stress better and improve confidence in self-management. Interventions and individual counselling can improve adaptation, coping, specific skills, self-management, social-emotional outcomes and psychosocial well-being. Moreover, practical care can reduce stress and improve adaptation [12]. By sharing this knowledge, psychosocial care can become more structured and consistent between HCCCs. Potentially, processes and outcomes of care can be improved.

Communicating about the availability of psychosocial care is essential and several psychosocial interventions have been developed globally. For example in Italy, a group of 30 parents participated in a programme of counselling and psychological support. By the end of the programme, parents were able to better use problem-focused coping strategies. Other psychological aspects, such as depression and anxiety, were influenced positively as well [45]. In Spain, an educational intervention of physiotherapy in parents of BWH was evaluated and showed a reduction in the stressors perceived by parents and improved family cohesion and adaptability [46]. Moreover, the World Federation of Hemophilia (WFH) has supported the development of ‘HaemoAction’ – a tool to teach children how to prevent bleeds and manage haemophilia by playing while learning about the clotting process, types of bleeds and suitable physical activities [47]. Unfortunately, not all interventions are readily available internationally or lack translations and we therefore advocate a web-based platform where interventions can be shared and knowledge can be exchanged.

Obstacles for providing psychosocial care remain a challenge and should be identified. For example the biggest barrier perceived by patients in successful delivery of psychosocial services in the US was the distance from the
HTC [13,48]. To overcome such an obstacle, online interventions, such as the aforementioned On Track group intervention, can be helpful. Other obstacles that have been identified are resistance in one of the parents or patient, transportation problems, financial cost of services, service not available in community and clinic staff not having time to offer service [48]. Moreover, it is important to always consider the approach in the context of the characteristics of each society (e.g. cross-cultural validity) and the resources available [8]. For HTCs where resources are scarce, there are opportunities for psychosocial care (e.g. facilitating peer support) by other healthcare providers than psychologists or social workers [8].

We are aware of the fact that our HCCC is a privileged centre and that it has resources to use for psychosocial care. Still, there is room for improvement. For example the identification of families at risk at the HCCC can be improved by screening systematically with the Psychosocial Assessment Tool (PAT). This is a screening instrument designed to assess psychosocial risk in families of children newly diagnosed with cancer, based on the PPPHM [19], with potential clinical utility in haemophilia practice [49,50]. The PAT takes 10–15 min to complete, and could be included in the KLJK portal to be completed (once) before routine clinic visits to assess the risk for psychosocial problems. The PAT has been validated among multiple paediatric populations [50,51]. In addition, in organizations with limited financial resources for psychosocial support available, screening for psychosocial risk in families with the PAT can be recommended.

This overview of psychosocial support may be helpful to others to overcome barriers in forming psychosocial care and in applying these or other approaches to benefit their patients, families and services on several outcomes. In addition, in the future, it would be interesting to address the cost-effectiveness of the psychosocial care since interventions can have other desirable outcomes related to costs. For example interventions that promote adaptation to the illness and that promote adherence to treatment could potentially reduce hospital days, use of clotting factor and visits to the clinic [40]. Another cost-beneficial example can be the use of online interventions.
and networks, especially for adolescents. Modern communication technologies may offer health benefits through peer support and experiential learning gained through online social networking [52].

**Conclusion**

By exchanging knowledge, we provide a basis for interventions to be adapted into other languages and cultures. This way, psychosocial care can become more structured and consistent between HCCCs and processes and outcomes of care can potentially be improved.
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