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Prioritized knowledge- and development needs within child- and adolescent inpatient psychiatric care

A COLLABORATIVE PROJECT BETWEEN THE SWEDISH AGENCY FOR HEALTH TECHNOLOGY ASSESSMENT AND ASSESSMENT OF SOCIAL SERVICES (SBU) AND THE NATIONAL BOARD OF HEALTH AND WELFARE (SOCIALSTYRELSEN).

Summary

Purpose

The purpose of this project is to identify areas within child and adolescent inpatient psychiatric care that need improvement and increased knowledge. A collaborative approach by SBU and National Board of Health and Welfare aims to achieve this by obtaining relevant information from former patients, their relatives, and professionals in the area. Child and adolescent psychiatry in Sweden is termed ”BUP”, which is a term that will be used throughout the rest of this document.

FOTO: SHUTTERSTOCK

The results of this project could aid in the improvement and further development of the child psychiatric inpatient care sector by influencing decision-makers, care facilities and professional associations. The result can also be of use for researchers and research funder founding bodies when initiating new research projects.

Background

In Sweden, approximately 2,500 children are admitted to inpatient BUP care every year. More than half of those are girls. The majority are in their teens, but younger children are also in inpatient BUP care. While most of the children are admitted to short-term inpatient care voluntarily following emergency events, in some cases children and young people can spend up to several months in inpatient BUP care. Children can also be placed into psychiatric care against their own will, so-called compulsory care, with the support of the Act on Compulsory Psychiatric Care (shortened LPT in Swedish), whereby the child can be subject to coercive measures. In 2019, approximately 340 children in Sweden were cared for with the support of LPT within inpatient BUP care.

In 2017, the result of a Swedish state investigation focusing on child psychiatric inpatient care and on coercive measures were published [1]. Results from this investigation led to the Swedish government commissioning the National Board of Health and Welfare to strengthen the national development work within this field and generate more support to the child and adolescent psychiatric activities providing inpatient care. As a results, the National Board of Health and Welfare and SBU initiated a collaborative project to identify important knowledge and development needs within inpatient BUP care.

Method

The methodology used in this project is developed by the British organisation James Lind Alliance [2]. The method focuses on patients, relatives and professionals highlighting the knowledge and development needs that they, from their perspectives, consider most important. The method has an inclusive perspective where the participants work together as equals and where a common result is achieved based on consensus principles.

The project’s structure is divided into two parts, an inventory part where the knowledge and development needs are collected and listed by the project managers, and a priority part where participants highlight what they consider most important based on the inventory step (Figure 1). The inventory part was carried out through an open survey on SBU’s website and was directed to those with experience in inpatient BUP care, either as a patient, relative, clinicians, researcher, or other relevant stakeholders such as professional and user organizations. A total of 282 people responded to the survey in the inventory part.

Following the inventory part, the project managers reviewed the inventory answers and put similar answers together creating a list of 62 overall knowledge and development needs (Table 2). The list was sent out to the working group consisting of 83 people who signed up for the priority part. The working group consisted of former patients, relatives, and professionals with experience from BUP inpatient care. In two consecutive prioritization surveys, all participants could choose 10 of the 62 listed knowledge and development needs that they considered to be the most important. Following these prioritization surveys, 23 knowledge and development needs that the working group deemed important were identified and discussed at a final digital prioritization meeting.

The prioritization meeting was attended by 18 people, during which the participants were divided into four smaller discussion groups, with each group consisting of 4–5 participants. In all groups, patients, relatives, and professionals were represented. Each group selected 10 out of 23 remaining knowledge and development needs that they thought were most important. This resulted in a list with the most prioritized knowledge and development needs, Table 1. All individuals who participated in the prioritization meeting were given a chance to submit comments on the final list.

Results

The knowledge and development needs that were top ranked at the prioritization meeting are presented in Table 1. They were divided into three different categories 1–3 based on how high priority they were given at the meeting, with Priority 1 assigned a highest rank.

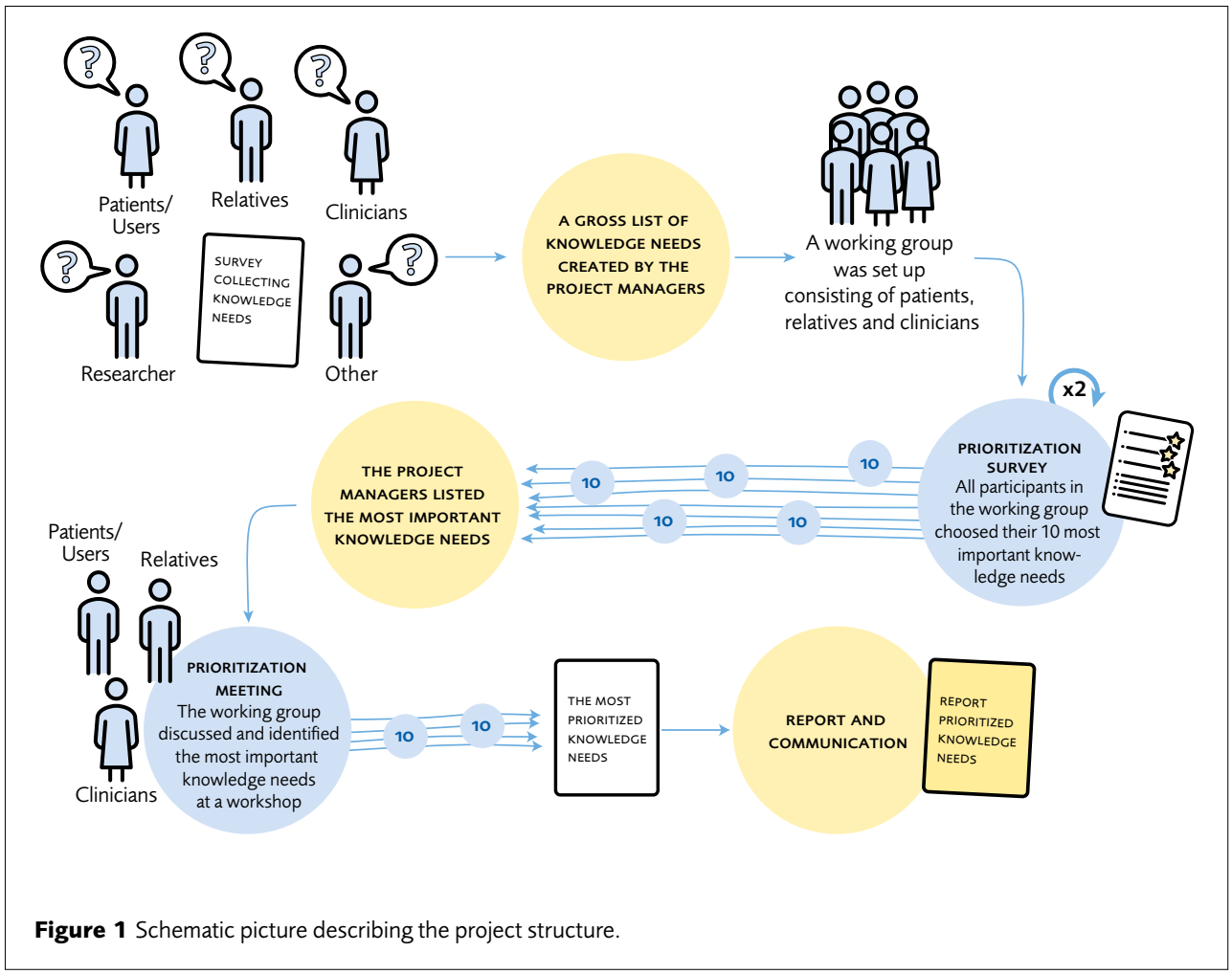

Figure 1 Schematic picture describing the project structure.

Table 1 The highest priority knowledge and development needs (priority 1–3).

PRIORITY 1 The knowledge and development needs that were given the highest priority (prioritized by all four groups at the priority meeting).	
1	Knowledge regarding treatment of various diagnoses, as well as difficulties and comorbidities that occur in inpatient BUP care patients, e.g. eating disorders, self-harming behaviours and autism.
1	Knowledge of how to address persons within inpatient BUP care with different psychiatric diagnoses and problems.
1	Which care is meaningful in an inpatient setting, i.e. how can the content of inpatient BUP care be set up and developed?
1	Knowledge of how the collaboration can be organized between different actors outside health care (social services, school, police) and with outpatient care during hospitalization, treatment and follow-up within inpatient BUP care.
PRIORITY 2 The knowledge and development needs that were prioritized second highest (prioritized by two to three of the groups at the prioritization meeting).	
2	What is the effect of coercive measures (e.g., tube feeding or belting) in inpatient BUP care and what are the experiences of the patients and their relatives?
2	How are conditions created to stimulate a good physical, mental and social care environment, i.e., premises, activities, atmosphere, feeling of well-being, etc. within inpatient BUP care?
2	Knowledge of in-depth investigation that lasts shorter or longer during the treatment period within inpatient BUP care that also includes social factors e.g., home conditions and life situation that may affect the child's mood.
2	What is the effect of being cared for in inpatient BUP care and the significance of the length of the care period? When should patients be discharged?
2	What is the effect of mixing patients with different types of diagnoses, age, and difficulties in inpatient BUP care and what are the patients 'and relatives' experience of this?
2	What support should relatives receive when the admission is ongoing within inpatient BUP care?
2	Which professional categories are needed within inpatient BUP care, what roles should they have and what skills are required to conduct inpatient care with good quality? For example, the importance of the participation of psychologists and social care workers, the effect of specialization of nurses as well as the staff's knowledge in child-adolescent psychiatry.

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Table 1 continued

PRIORITY 3 The knowledge and development needs that were prioritized as the third most important (prioritized by at least one group at the prioritization meeting)	
3	Knowledge of what creates a feeling of security or insecurity for patients and relatives in inpatient BUP care.
3	Specific knowledge about assessment methods for eating disorders and the need for hospitalization within inpatient BUP care.
3	Knowledge of differentiation of diseases with similar symptoms (differential diagnosis) in complex diagnostics within inpatient BUP care.
3	Knowledge of treating patients who have been exposed to violence, abuse, or traumatic events (both before and during the care period of inpatient BUP care).
3	Knowledge of which patients need inpatient BUP care and the criteria for admission to care.
3	Knowledge of what causes coercive measures to increase and what causes coercive measures to decrease (preventive) in inpatient BUP care.

Discussion

Inpatient BUP care is an advanced and complex care system which aims to provide support for children and young people with serious psychiatric illnesses. Part of what makes care complex is the wide range of diagnoses, the age range of patients and, in most cases, need for collaboration with other branches, such as outpatient care, social services and schools.

Based on the results presented herein, it appears that there is a consensus between what patients, relatives and those who work in the area consider to be important knowledge and development needs. All of those involved highlighted the special need for further development in terms of BUP inpatient care organisation, mission, purpose, content, and execution. They also emphasize that there is a need for knowledge and development regarding collaboration of inpatient BUP care with other areas within and outside healthcare.

The knowledge needs that are addressed as particularly important in the current project relate to organizational- and care-development of various kinds, for example how the content of inpatient care can be set up and developed, how the implementation of existing knowledge can take place, and what know-

ledge-enhancing initiatives should be undertaken to strengthen the professionals´ competence.

In some cases, more research including systematic reviews needs to be conducted, for example to investigate the effect of different treatments, coercive measures and how patients and their relatives experience the provided care.

This report also highlights areas within the field of inpatient BUP care that require further development and emphasizes on the importance of the collaboration between decision makers, child psychiatric institutions and user associations to achieve these improvements.

Table 2 All 62 overall knowledge and development needs that were included in the prioritization.

ID	Total list of knowledge and development needs for prioritization
Diagnosis, investigation and admission	
1	** Knowledge of which patients need inpatient BUP care and the criteria for admission to care.
2	Are there diagnoses, symptoms or groups of patients that are systematically not assessed and enrolled for care within inpatient BUP care, e.g. because of gender, being asylum seeker or being cared for by The National Board of Institutional Care?
3	* Knowledge of which assessment instruments and estimation forms are the most reliable in inpatient BUP care?
4	Specific knowledge about assessment of anxiety and depression and need for hospitalization in inpatient BUP care.
5	* Specific knowledge about assessment of autism and other comorbidities and the need for hospitalization in inpatient BUP care.
6	** Specific knowledge about assessment methods for eating disorders and the need for hospitalization within inpatient BUP care.
7	Specific knowledge about assessment of suicide risk and the need for hospitalization within inpatient BUP care.
8	Specific knowledge about assessment of self-harming behaviour and the need for hospitalization within inpatient BUP care.
9	* What effect does user-controlled hospitalization (self-hospitalization of patients) have within inpatient BUP care?
10	** Knowledge of in-depth investigation that lasts shorter or longer during the treatment period within inpatient BUP care that also includes social factors e.g., home conditions and life situation that may affect the child's mood.

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Table 2 continued

ID	Total list of knowledge and development needs for prioritization
11	What effect do structured diagnostic programs have for inpatient BUP care and what parts are needed for different types of diagnostics?
12	** Knowledge of differentiation of diseases with similar symptoms (differential diagnosis) in complex diagnostics within inpatient BUP care.
Treatment	
13	** Which care is meaningful in an inpatient setting, i.e. how can the content of inpatient BUP care be set up and developed?
14	** What is the effect of being cared for in inpatient BUP care and the significance of the length of the care period? When should patients be discharged?
15	How can inpatient BUP care be evaluated, on the basis of patients' and relatives' experience of the care?
16	** Knowledge regarding treatment of various diagnoses, as well as difficulties and comorbidities that occur in inpatient BUP care patients, e.g. eating disorders, self-harming behaviours and autism.
17	** What effect does psychological treatment have within inpatient BUP care, e.g., counselling, cognitive behaviour therapy, or dialectical behaviour therapy?
18	What effect does drug treatment have within inpatient BUP care?
19	* What effect does treatment other than medication and psychological treatment have within inpatient BUP care? For example, image therapy, physical activity, animal therapy, electroconvulsive therapy (ECT).
20	** What support should relatives receive when the admission is ongoing within inpatient BUP care?
Attitudes of health care personnel towards patients and relatives and patient experience	
21	** Knowledge of how to address persons within inpatient BUP care with different psychiatric diagnoses and problems.
22	Effect of methods used for dealing with and responding to threats and violence in inpatient BUP care, e.g. The Safewards and Bergen model?
23	** Knowledge of the meaning of a successful treatment during hospitalization and during the treatment period within inpatient BUP care, from a patient perspective.
24	** Knowledge of treating patients who have been exposed to violence, abuse or traumatic events (both before and during the care period in inpatient BUP care).

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Table 2 continued

ID	Total list of knowledge and development needs for prioritization
25	** Knowledge of how to meet the needs of the patient´s relatives / entire families in crisis when assessing the need for hospitalization and during the treatment period within inpatient BUP care.
Information and participation for patients and relatives	
26	** Knowledge of how to provide clear information regarding the purpose of admission and contents of the treatment plan, to both caregivers and the patient admitted to inpatient BUP care.
27	Knowledge of how information is given in a good way to patients and relatives in inpatient BUP care and what it should contain.
28	Knowledge of how patients can be involved in their inpatient BUP care.
29	* Knowledge of how the patient´s relatives / parents can be involved at BUP inpatient care.
30	Knowledge of methods and approaches that can be used to increase the participation for patients and their relatives in inpatient BUP care, including care meetings / care planning meetings and motivational talks (MI).
31	Knowledge of how collaboration with relatives / parents and inpatient care can take place based on the child's wishes and needs during hospitalization and treatment within inpatient BUP care.
Care environment and patient safety	
32	Knowledge of the impact that the treatment environment may hold, for example interior design and its importance for creating a good care environment within inpatient BUP care.
33	What is the effect of giving patients outdoor access during inpatient BUP care?
34	** How are conditions created to stimulate a good physical, mental and social care environment, i.e., premises, activities, atmosphere, feeling of well-being, etc. within inpatient BUP care?
35	** Knowledge of the importance of food and the environment in which it is served within inpatient BUP care.
36	** Knowledge of what creates a feeling of security and insecurity for patients and their relatives in inpatient BUP care.
37	What measures are effective in reducing the risk of patients being exposed to violence, threats, sexual abuse or harassment in inpatient BUP care?

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Table 2 continued

ID	Total list of knowledge and development needs for prioritization
38	Knowledge of the definition of patient safety in inpatient BUP care and the routines and guidelines supporting safety measures. For what purpose should deviations be reported and how should it be documented?
Work environment, organization, resources and professional skills	
39	* What is a good working environment for the staff within inpatient BUP care and how does it affect the ability to provide care?
40	** Which professional categories are needed within inpatient BUP care, what roles should they have and what skills are required to conduct inpatient care with good quality? For example, the importance of the participation of psychologists and social care workers, the effect of specialization of nurses as well as the staff's knowledge in child-adolescent psychiatry.
41	Does working in professional teams improve the investigation and treatment within BUP inpatient BUP care?
42	* What effect has continuity on personal contacts during investigation and treatment within inpatient BUP care?
43	Knowledge of how information transfer can be improved between staff about patients in inpatient BUP care.
44	* What forms of competence development are needed and how to enable competence development within inpatient BUP care?
45	What effects do education, support, supervision, and time to reflect have on the staffs´ ability to promote a good treatment of patients and relatives in inpatient BUP care?
46	* How does the organization and resources (e.g., staffing, coordinated staff, care places) within inpatient BUP care affect the ability to provide good quality care?
47	How to handle patients' and relatives' experience of not getting a place for hospitalization or being sent home from inpatient BUP care due to too few places or insufficient resources?
48	How are long waiting times reduced and the environment in waiting rooms for patients and relatives improved when admitted to inpatient BUP care?
49	** What is the effect of mixing patients with different types of diagnoses, ages and problems in inpatient BUP care and what are patients 'and relatives' experience of this?

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Table 2 continued

ID	Total list of knowledge and development needs for prioritization
50	What is the effect of mixing children with adult patients in inpatient BUP care and what are the experiences of patients and relatives of this?
	Collaboration with other actors when deciding on admission and treatment
51	* Knowledge of what is required in the organization within inpatient BUP care in regards to collaboration with other actors and how can new forms of collaboration be developed?
52	** Knowledge of how collaboration can be organized between different actors outside health care (social services, school, police) during hospitalization and treatment within inpatient BUP care?
53	** Knowledge of how collaboration with outpatient care can be organized during hospitalization and treatment and during follow-up after inpatient BUP care.
54	Knowledge of how collaboration between inpatient BUP care and other care departments (e.g. the emergency room, or other somatic health care) can be organized?
55	Knowledge of how inpatient BUP care and adult psychiatry can work together during the transmission period.
56	Knowledge about collaboration between different municipalities or regions around a patient and how the care is affected by the fact that not all regions provide inpatient BUP care?
	Compulsory care and coercive measures
57	* Knowledge of how the law on compulsory care should be interpreted and how it should be applied within inpatient BUP care.
58	** Knowledge of what causes coercive measures to increase inpatient BUP care and what causes coercive measures to decrease (preventive) inpatient BUP care.
59	What is the effect of receiving compulsory care within inpatient BUP care and what are the experience of patients and relatives to these measures?
60	** What is the effect of coercive measures (e.g., tube feeding or belting) in inpatient BUP care and what are the experience of patients and relatives to these measures?
61	* Knowledge of how interventions and treatment of patients can be further developed during and after coercive measures within inpatient BUP care.
62	Knowledge of how patients and relatives receive information about compulsory care and compulsory measures within inpatient BUP care and how they can be involved in the care.

*Knowledge and development needs marked with * and ** proceeded from the first priority round to the second priority round (35 knowledge and development needs). Those marked with ** also proceeded to the final discussion at the priority meeting (the workshop) (23 knowledge and development needs).*

References

1. SOU 2017:111. För barnets bästa? Utredningen om tvångsåtgärder mot barn i psykiatrisk tvångsvård. Statens offentliga utredningar. Stockholm: Elanders Sverige AB. [updated Jan 12 2018; accessed May 24 2021]. Available from: https://www.regeringen.se/48e3dc/contentassets/c67ed758215e444b8cd4ef42a1d73997/sou-2017_111_for-barnets-basta.pdf.

2. James Lind Alliance (JLA). Southampton: National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre (NETSCC). James Lind Alliance. Available from: http://www.jla.nihr.ac.uk/.

Project management, working group and external reviewers

The working group that prioritized knowledge needs consisted of 83 people, of which 18 people participated in the digital prioritization meeting. These 18 people consisted of 6 patients, 4 relatives and 8 professionals (3 specialist physicians in child and adolescent psychiatry, 3 nurses, one psychologist and one health and medical care curator).

The project management group

- Susanne Buchmayer (Expert Specialist in Child and Adolescent Psychiatry, PhD, Chair of Swedish Society for Child and Adolescent Psychiatry)
- Nathalie Sundberg (Patient Expert, Ambassador at the user organisation Hjärnkoll)
- Karin Rydin (Project Manager, SBU)
- Marie Österberg (Project Manager, SBU)
- Birgitta Lindelius (Project Manager, Socialstyrelsen)
- Sara Fundell (Project Administrator, SBU)

External reviewers

- Anne-Katrin Kantzer (Specialist in Pediatrics and Child and Adolescent Psychiatry, PhD)
- Fanny Åberg (Patient Expert)

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