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# **SELF-ADMISSION AS A TREATMENT TOOL IN SEVERE ANOREXIA NERVOSA**

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**Karolinska  
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# Self-admission as a treatment tool in severe anorexia nervosa

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

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To Maria



## ABSTRACT

Self-admission to psychiatric inpatient treatment is an innovative collaborative approach to healthcare rationing that invites patients to play a more active role in deciding when they need a higher level of care. In self-admission, patients with a history of high utilization of inpatient treatment are offered the choice to decide for themselves when an episode of brief hospital admission—usually 3-7 days at a time—is warranted. Self-admission has been offered in mental healthcare in Scandinavian countries and the Netherlands for over a decade as a tool in the treatment of severe and enduring mental illnesses such as schizophrenia, bipolar disorder, and borderline personality disorder. In self-admission, high-utilizers of healthcare are offered “fast lane” access to earmarked beds to make use of as they see fit, without waiting time and risk of being sent home by a psychiatric emergency service. Patients eligible for self-admission typically present with a history of multiple and prolonged episodes of hospital admission. By encouraging self-monitoring of their mental health status and promoting swift help seeking, the delay between the first signs of deterioration and subsequent hospital admission can theoretically be minimized, ultimately reducing the total time spent in hospital—if patients are invited to act early in response to subjective cues that might not prompt admission if assessed through a regular emergency service, they can potentially avoid further deterioration and lengthier hospital admissions.

This thesis is an evaluation of the self-admission program targeted to patients with severe anorexia nervosa at the Stockholm Centre for Eating Disorders, employing a mixed methods approach integrating qualitative, quantitative, and health economic components. For the qualitative component of the thesis, 16 participants were interviewed about their experiences in the self-admission program. For the quantitative component, outcomes in terms of healthcare utilization, eating disorder morbidity, health-related quality of life, and sick leave for 29 participants were compared to a group of 113 non-participants matched according to age, duration of illness, and body mass index. For the health economics component, the healthcare resources reallocated within the program were analyzed relative to the reduction in days spent in inpatient treatment seen among these 29 participants, in order to identify any potential crowding out effects.

In sum, the findings show that self-admission to inpatient treatment is a viable and effective treatment tool for individuals with severe anorexia nervosa in terms of strengthening patient autonomy and reducing the total number of days spent hospitalized. The introduction of the self-admission program led to a more than 50% decrease in the total number of days that participants spent in inpatient treatment during 12 months in the program. In comparison, only small and statistically non-significant changes over time were observed in low- and moderate-utilization comparison groups. However, no significant effects were seen in terms of the number of days spent in involuntary inpatient treatment or the number of visits to the outpatient clinic. Moreover, the introduction of self-admission did not have any significant or clinically relevant effects on participants’ self-rated eating disorder morbidity or body mass index. In terms of health-related quality of life, mixed results were seen. Whereas participant interviews pointed

to marked improvements in agency, motivation, and autonomy that made a real difference in patients' everyday lives, these changes were not mirrored by improvements on health-related quality of life as measured by standard quantitative self-rating instruments. A beneficial tendency was seen for participants in terms of number of days on sick leave; this finding, however, did not reach statistical significance. Importantly, the reallocation of hospital beds earmarked for self-admission was offset by an overall reduced need for inpatient treatment among participants, resulting in a net increase in available hospital beds for non-participants.

These findings imply that self-admission in anorexia nervosa may be most useful as a tool within a recovery model framework—an approach where the primary goal is not necessarily to achieve full symptom remission and recovery in a traditional sense, but instead to improve symptom management, strengthen the overall levels of functioning and social inclusion, and maintain a community-based treatment focus. Thus, the self-admission model underscores how hospitalization can serve as a complement to community treatment rather than a substitute. For patients with longstanding illness and pervasive difficulties in maintaining community-based treatment contacts, self-admission can be used as a tool in striving for a higher level of functioning in everyday life. Not least, the self-admission approach may help promote an understanding of the hospital ward as a safe and helpful sanctuary in times of need rather than a place implicitly associated with crisis and coercion. In its proper context, the self-admission model holds the potential to transform the delivery of healthcare from crisis-driven to pre-emptive, and to strengthen autonomy for severely ill patients.



# POPULÄRVETENSKAPLIG SAMMANFATTNING

Självvald inläggning är ett nydanande sätt att använda sig av psykiatrisk heldygnsvård som ger patienter ett ökat inflytande. Modellen går ut på att personer med ett sedan tidigare känt stort behov av heldygnsvård – dvs inneliggande vård på en vårdavdelning – erbjuds tillgång till öronmärkta vårdplatser och möjligheten att själva bestämma när de ska läggas in under en kortare period. Vanligtvis rör det sig om mellan tre och sju dagar åt gången. När patienterna önskar lägga in sig kontaktar de avdelningen direkt och behöver alltså inte söka vid en akutmottagning eller kontakta sin läkare för ställningstagande till inläggning. Deras egna skäl till att vilja lägga in sig ifrågasätts heller inte – patienterna är välkomna att använda sig av självvald inläggning av vilken anledning de vill, oavsett om det handlar om ett faktiskt försämrat mående, oro för att en försämring kan vara på gång, en önskan att få en tydligare struktur i vardagen eller andra skäl. Förhoppningen är att modellen ska uppmuntra personer med långvarig psykisk ohälsa att vara vaksamma på försämringar i måendet och raskt söka hjälp när de så behöver. Att på detta vis ta tidiga tecken på försämring på allvar och snabbt få tillgång till en plats inom heldygnsvården utan risk för att bli avvisad kan innebära att ett negativt förlopp hejdas innan läget hunnit bli riktigt allvarligt. Därmed kan en längre period av sjukhusvård i bästa fall förebyggas och det totala behovet av heldygnsvård minska.

Självvald inläggning används sedan tidigare inom psykiatrin i Norge och Nederländerna och infördes 2014 på olika håll i Sverige. Vanligtvis riktar sig modellen till patienter med långvarig psykossjukdom, så som schizofreni, eller till patienter med självskadeproblematik. I denna avhandling utvärderas självvald inläggning för vuxna personer med svår och långvarig ätstörningssjukdom – huvudsakligen anorexia nervosa – vid Stockholms centrum för ätstörningar (SCÄ), som är en klinik för specialiserad ätstörningsvård i Region Stockholms regi. Detta är första gången som patienter med ätstörningssjukdom har erbjudits självvald inläggning som en del av vården.

I studien intervjuades deltagare i programmet för självvald inläggning vid SCÄ om sina erfarenheter av och tankar om modellen. Deltagarna rapporterade här att de överlag upplevde självvald inläggning som en stor trygghet i vardagen. Vetskapen om att de vid behov hade snabb tillgång till heldygnsvården vid SCÄ upplevdes som ett ”skyddsnät” och ett stöttande verktyg att ta till i perioder av försämrat mående. Deltagarna uppskattade det ökade medbestämmande över vården som självvald inläggning medför och beskrev att deras motivation, autonomi och livskvalitet påverkades i positiv riktning. Samtidigt kunde deltagarna beskriva hinder som emellanåt gjorde det svårt för dem att fullt ut använda sig av självvald inläggning på ett konstruktivt vis. Många patienter med en ätstörning upplever att det är mycket svårt att ”trotsa sjukdomen” och acceptera att man behöver hjälp och stöd. Denna ambivalens inför att söka och delta i vård utgjorde ett tydligt hinder för många deltagare – trots att det i teorin var enkelt för dem att använda sig av självvald inläggning så var det inte alltid så lätt att i praktiken på eget bevåg kontakta avdelningen och be om inläggning. En hjälpsam faktor kunde här vara att ha stöd av anhöriga eller behandlare som uppmuntrade ett aktivt användande av självvald inläggning.

I studien analyserades också hur deltagarnas vårdkonsumtion, ätstörningssjukdom, självskattade livskvalitet och sjukfrånvaro förändrades under deras första år med självvald inläggning. Deltagarna jämfördes här med en ur patientregister matchad grupp av personer med likartad ätstörningssjukdom som inte haft tillgång till självvald inläggning. I fråga om det totala behovet av heldygnsvård sågs en tydlig minskning. Även om deltagarna var inlagda *fler* gånger då de fick möjlighet att själva styra över detta så var perioderna på avdelningen avsevärt *kortare* än året innan, så att man som helhet såg en minskning av antalet dagar inom heldygnsvården med över 50%. Någon motsvarande förändring sågs inte i jämförelsegruppen utan tillgång till självvald inläggning. Själva ätstörningssjukdomen påverkades dock inte på samma gynnsamma vis – varken deltagarnas ätstörningssymptom eller kroppsvikt förändrades i någon kliniskt relevant utsträckning. I fråga om livskvalitet mätt med självskattningsskalor sågs en tvetydig bild: som helhet skattade deltagarna att deras livskvalitet hade blivit bättre men då man tittade på enskilda delar av livskvaliteten (daglig funktionsnivå, ångest och nedstämdhet, smärta m.m.) sågs inte samma förbättring. Deltagarnas sjukfrånvaro tenderade att påverkas i gynnsam riktning i jämförelse med den matchade gruppen, men denna förändring var inte statistisk signifikant.

Avslutningsvis analyserades också vad självvald inläggning innebär i fråga om prioriteringar inom vården och om modellen är hälsoekonomiskt hållbar. Då befintliga vårdplatser öronmärks för deltagarna så minskar ofrånkomligen antalet platser för icke-deltagare, dvs för alla andra patienter på kliniken. Detta kan medföra att den ”vanliga” kön till avdelningen blir längre. Om deltagarna med hjälp av de öronmärkta vårdplatserna kan minska sin tidigare höga vårdkonsumtion så att de inte är inlagda lika långa perioder så kan dock platser frigöras för icke-deltagare, så att deras tillgång är oförändrad eller i bästa fall ökar. På SCÄ innebar införandet av självvald inläggning att deltagarna minskade sitt behov av heldygnsvård så pass mycket att detta med råge kompenserade för de öronmärkta vårdplatserna. Genom omfördelningen av vårdplatser som följde på införandet av självvald inläggning ökade således tillgången till avdelningsvård för både deltagare och icke-deltagare.

Sammanfattningsvis kan självvald inläggning utgöra ett stöd i vardagen för personer med svår och långvarig ätstörningssjukdom. Självvald inläggning bör i första hand ses som ett verktyg för att minska det totala behovet av heldygnsvård och för att stärka vardaglig funktionsnivå, livskvalitet och autonomi. Modellen påverkade dock inte deltagarnas ätstörningssjukdom som sådan och utgör på intet vis någon helhetslösning för patienter med stort vårdbehov. För personer med långvarig psykisk ohälsa kan det naturligtvis vara nog så viktigt att tillägna sig verktyg för att förbättra sin vardag *trots* kvarstående sjukdomssymptom. När självvald inläggning tillämpas på rätt sätt tycks modellen kunna bidra till ett mer förebyggande och förutsägbart nyttjande av vården och minska behovet av akuta krisinsatser och långa perioder på sjukhus för svårt sjuka patienter inom ätstörningsvården.

## LIST OF SCIENTIFIC PAPERS

- I. Strand, M., Bulik, C. M., von Hausswolff-Juhlin, Y., & Gustafsson, S. A. (2017). Self-admission to inpatient treatment for patients with anorexia nervosa: the patient's perspective. *International Journal of Eating Disorders*, 50, 398–405. <https://doi.org/10.1002/eat.22659>
- II. Strand, M., & Sjöstrand, M. (2019). Self-admission in psychiatry: The ethics. *Bioethics*, 33, 132–137. <https://doi.org/10.1111/bioe.12501>
- III. Strand, M., Bulik, C. M., Gustafsson, S. A., von Hausswolff-Juhlin, Y., & Welch, E. (2020). Self-admission to inpatient treatment in anorexia nervosa: Impact on healthcare utilization, eating disorder morbidity, and quality of life. *International Journal of Eating Disorders*, 53, 1685–1695. <https://doi.org/10.1002/eat.23346>
- IV. Strand, M., Bulik, C. M., Gustafsson, S. A., & Welch, E. (2020). Self-admission in the treatment of eating disorders: an analysis of healthcare resource reallocation. Manuscript submitted for publication.

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## LIST OF ABBREVIATIONS

ADD	Attention-deficit disorder
ADHD	Attention-deficit/hyperactivity disorder
AN	Anorexia nervosa
ANOVA	Analysis of variance
ARFID	Avoidant/restrictive food intake disorder
BED	Binge eating disorder
BMI	Body mass index
BN	Bulimia nervosa
CBA	Cost-benefit analysis
CBT	Cognitive-behavioral therapy
CEA	Cost-effectiveness analysis
CHEERS	Consolidated Health Economic Evaluation Reporting Standards
CI	Confidence interval
CIA	Clinical Impairment Assessment Questionnaire
CUA	Cost-utility analysis
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition
EDE-Q	Eating Disorder Examination Questionnaire
EDQOL	Eating Disorders Quality of Life
EDwell	Eating Disorders Well Being Questionnaire
FBT	Family-based treatment
HRQoL	Health-related quality of life
ICD-10	International Classification of Diseases, 10th Revision
ICD-11	International Classification of Diseases, 11th Revision
ICER	Incremental cost-effectiveness ratio
IMRaD	Introduction, Methods, Results, and Discussion
LISA	Longitudinal Integrated Database for Health Insurance and Labor Market Studies
OSFED	Other specified feeding or eating disorder
QALY	Quality-adjusted life year

MHCPQ	Mental Health Consumer Participation Questionnaire
RCT	Randomized controlled trial
SCÄ	Stockholm Centre for Eating Disorders
SE-AN	Severe and enduring anorexia nervosa
SE-ED	Severe and enduring eating disorder
SF-36	Short Form-36
SIAS	Swedish Social Insurance Agency
SRQR	Standards for Reporting Qualitative Research
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TAU	Treatment as usual
VAS	Visual analog scale
WHODAS	World Health Organization Disability Assessment Schedule





# 1 INTRODUCTION

## 1.1 SELF-ADMISSION AT A GLANCE

The past decades have seen a gradual transformation of mental healthcare, favoring outpatient and community-based treatment rather than prolonged periods of institutionalized care for individuals with severe mental illness (Engstrom, 2012; Killaspy, 2006; Thornicroft & Tansella, 2013). As part of this process, promoting patient participation has increasingly come to be regarded as an integral part of psychiatric treatment (Storm & Edwards, 2013). Striving for larger patient involvement in healthcare decisions challenges the paternalistic assumption that clinicians' professional knowledge per default puts them in a position to tell what is in the best interest of their patients (Coulter, 1999). Participatory efforts have been shown to improve patient satisfaction with healthcare; however, the impact in terms of clinical outcomes is inconclusive (Duncan, Best, & Hagen, 2010). Importantly, strengthening patient control and autonomy may also be seen as having intrinsic value—i.e., as a goal in its own right—providing a new yardstick for assessing healthcare quality (Berwick, 2009).

However, the implementation of models of patient participation and shared decision making in inpatient settings have proven particularly complicated (Storm & Edwards, 2013). This thesis focuses on the very first step in ensuring that a patient receives inpatient treatment—the hospital admission. Even in settings where efforts have been devoted to strengthening patient participation, the process of having a patient admitted to an inpatient ward is typically under the strict control of the healthcare provider. Patients may of course ask for inpatient care if they believe that they would benefit from it, but the actual decision to admit a patient is firmly in the hands of the clinician. The rationale behind this type of gatekeeper model is reasonable. The healthcare provider can be expected to make a professional assessment of what the optimal level of care is in a clinical situation and is also in a position to monitor the available resources, e.g., the number of unoccupied beds at the ward, and to triage based on severity. Avoiding unnecessary hospitalization by promoting community-based interventions and follow-up—i.e., healthcare provided in outpatient clinics, physicians' offices, public health units, outreach programs, workplaces, or people's homes rather than at a hospital—is often heralded as a wise priority, not least since the number of psychiatric inpatient beds has decreased in many countries (Systema, Burgess, & Tansella, 2002).

Even so, the traditional gatekeeper model may also have a negative impact. Patients who present for clinical evaluation in the early phases of a process of deteriorating mental health may not display signs and symptoms that allow the clinician to fully realize the potential malignity of the situation, even though the patient senses that their clinical status is deteriorating. An urge to promote community-based care may result in an unfortunate delay in delivering adequate treatment and, as a secondary consequence, ultimately prolong the total time spent hospitalized once the acute symptoms have escalated. Moreover, the hierarchy of power inherent to the gatekeeper model may exacerbate destructive conflicts between patient and clinician—for example, a negative spiral may ensue when patients feel forced to accentuate their most dra-

matic symptoms in order for the clinician to appreciate the need for inpatient treatment. Certain psychiatric disorders may prove particularly challenging in this regard. The optimal way of utilizing the hospital ward in the treatment of borderline personality disorder has been a topic of debate, on the grounds that patients may not benefit from inpatient treatment in the long run (National Institute for Health and Clinical Excellence, 2009; Paris, 2004b). However, there is also a risk that negative stereotyping and stigmatization of patients with borderline personality disorder may result in overzealous withholding of inpatient treatment (Kealy & Ogrodniczuk, 2010).

Self-admission to inpatient treatment is an innovative model that invites patients to play a more active role in deciding when they need a higher level of care. In self-admission, patients with a history of high utilization of inpatient treatment are offered the choice to decide for themselves when a brief hospital admission episode—usually 3-7 days at a time—is warranted (Strand & von Hausswolff-Juhlin, 2015). A central part of the self-admission concept is that the specific reason behind an individual's choice to self-admit is not questioned. Participants are free to make use of the hospital ward because of deteriorating mental health, acute crisis, poor everyday structure, loneliness, or any other reason. Hence, the traditional admission model with the healthcare provider operating as gatekeeper is bypassed. Importantly, self-admission is designed as an add-on tool, not a replacement of other treatment options. Thus, admission through regular procedures is still available if the situation warrants.

Notably, some have argued that the increased emphasis in recent years on outpatient and community-based care has resulted in diminished interest in the therapeutic possibilities of inpatient treatment, such that inpatient care has come to be seen as the “backyard of psychiatry”—a “necessary evil” that is seldom invested in (Jacobsson, 2013). It has even been suggested that inpatient treatment should deliberately be made as unattractive as possible so that other modes of crisis management are favored (Paris, 2004a). Here, self-admission could help in reaffirming the beneficial potential of the inpatient milieu.

The current self-admission program at the Stockholm Centre for Eating Disorders (SCÄ) can be used to illustrate the concept (Strand, Gustafsson, Bulik, & von Hausswolff-Juhlin, 2015). Here, two out of eleven hospital beds on the adult inpatient ward have been earmarked for self-admission; thus, they are available only for participants in the self-admission program and are never occupied by regularly admitted patients. Participants are given access to self-admission for 1 year at a time, without restriction in the total number of admission episodes during that year. They may self-admit for a maximum of 7 consecutive days and are free to discharge when they so wish. Upon arrival at the ward, they briefly discuss their current mental health status and their immediate treatment goals with a nurse, but they are not routinely assessed by a consultant psychiatrist. To be eligible for the program, patients must maintain outpatient or day treatment contact at the clinic, they must have been admitted for specialized inpatient treatment at least once in the previous 3 years, and they must have the ability to follow the basic treatment framework at the ward. Moreover, regular hospital admission remains available when needed.

The rationale behind self-admission is multifold. Proponents of the concept hold that self-admission can strengthen patient autonomy and agency, reinforce the asylum role of the inpatient ward, prevent coercive measures, and reduce the total time spent hospitalized due to early help-seeking (Strand & von Hausswolff-Juhlin, 2015). Participants typically have a history of multiple and prolonged episodes of inpatient treatment. By encouraging self-monitoring of their mental health status and promoting early help-seeking, the delay between the first signs of deterioration and hospital admission can theoretically be minimized, ultimately reducing the total time spent hospitalized. Designating existing hospital beds for self-admission inevitably means that fewer beds are available for regular admissions; however, it is argued that if this re-allocation of available resources can aid patients with high healthcare utilization in reducing their total time spent in hospital, the overall availability for all patients could hypothetically remain unchanged or even improve.

Until now, self-admission has been offered primarily to patients with severe and enduring mental illness such as schizophrenia and other psychotic disorders, bipolar disorder, and borderline personality disorder. The rationale varies somewhat across these diagnostic groups. For individuals with schizophrenia or bipolar disorder, self-admission has mainly been used to improve everyday functioning and maintain community-based efforts (Strand & von Hausswolff-Juhlin, 2015). For patients with borderline personality disorder, however, it has been suggested that practicing using self-admission as a constructive coping strategy could positively affect the underlying disorder and promote recovery (Helleman, Goossens, Kaasenbrood, & van Achterberg, 2014a). A distinction has been suggested between recovery *from* a mental disorder and recovery *in* a mental disorder (Davidson & Roe, 2007). Whereas the notion of recovery *from* a disorder assumes a traditional view of recovery as equated with full symptom remission, the focus on recovery *in* a disorder suggests that recovery must not necessarily involve a “cure” and a “return to normal”. Instead, promoting ideals of patient autonomy, self-mastery, and symptom management—all clearly correlated with health-related quality of life (HRQoL) (Connell, Brazier, O’Cathain, Lloyd-Jones, & Paisley, 2012)—is seen as a form of recovery in its own right, even if the formal diagnosis does not change.

At first sight, the rationale behind the self-admission model may not seem to apply to patients with severe anorexia nervosa (AN). A basic requirement behind the idea of promoting early intervention in a phase of acutely deteriorating mental health is that the individual is able to identify and act upon subtle signs of relapse. When psychiatric symptoms are experienced as alarming and undesirable, which is typically the case in patients suffering from psychotic or affective disorders, this may be a fairly straightforward task. In contrast, signs of deterioration in AN—such as weight loss—are often experienced by the patient as desirable and even stabilizing, at least during the initial phase. Naturally, this could interfere with the ability to make active use of self-admission or any other intervention that requires a certain level of insight into the problematic nature of one’s symptoms. Moreover, whereas other psychiatric disorders can be associated with a strong tendency to seek hospitalization (as discussed with regards to borderline personality disorder above), healthcare providers and relatives often have to put considerable effort into making severely ill AN patients accept any treatment at all. Patient groups

that are generally reluctant to voluntarily request inpatient treatment may thus benefit less from the self-admission approach.

Despite these potential obstacles, there are good reasons to believe that individuals with AN could make use of the self-admission concept. Similar to the programs targeting individuals with borderline personality disorder, the self-admission approach could promote reflection on subjective motives and barriers among participants with AN and, by extension, enhance abilities and strategies that can have positive influence on the course and prognosis of the disorder. Research has shown that patients suffering from AN are indeed able to request inpatient treatment once the initial period of reinforcement—i.e., positive feelings of achievement associated with weight loss—has passed and the negative aspects of the core symptoms become more prominent (Gorse, Nordon, Rouillon, Pham-Scottez, & Revah-Levy, 2013). As patients' awareness of their loss of control over AN symptoms and of their ambivalence towards engaging in treatment gradually increases, they may become less reluctant to ask for help. For patients with severe and enduring illness this process may take several years, but it is nonetheless a realistic trajectory. Hypothetically, this process of successively increased awareness could be further promoted by providing patients with the hands-on tool of self-admission, which requires them to practice self-monitoring, develop agency, and dismantle ambivalence.

In the literature, varying terminology has been used to describe the self-admission model. In Norway, the concept has often been referred to as *user-controlled admission* (“brukerstyrt inleggelse”), mirroring its origins within the service user movement and broader attempts to increase user participation in Norwegian healthcare. When the model was introduced in Sweden, a working group within the Stockholm County Council discussed various options and ultimately decided on *patient-controlled admission* (“patientstyrd inläggning”) as the formal term. This term was therefore used when the model was piloted at SCÄ in 2014. Since patients and staff have subsequently come to use the somewhat wieldier *self-admission* (“själv-inläggning”), this is the term used in this thesis. Furthermore, it should be noted that *self-referral* has sometimes been used in reports on the self-admission model. However, in healthcare, referral is a broader term—a physician may refer a patient to a specialist outpatient service, for example, and patients can often also self-refer to various healthcare services—whereas admission and self-admission refer specifically to the act of being admitted to inpatient treatment at a hospital or a similar healthcare facility.

## **1.2 PROMOTING PATIENT PARTICIPATION IN PSYCHIATRY**

A core idea behind self-admission is promoting and strengthening patients' influence over their treatment options. The self-admission programs that have been piloted in Norway are part of a broader initiative undertaken by healthcare authorities in the past decades to promote patient participation and involvement in psychiatry (Larsen, Aasheim, & Nordal, 2006; Storm, Hausken, & Knudsen, 2010). In the literature on patient participation, a variety of partly overlapping terms are used: participation, involvement, inclusion, empowerment, etc. Moreover, concepts such as patient participation, patient-centered care, and shared decision making are sometimes used interchangeably and are not always intuitively distinguished from one another.

In general, *patient-centeredness* is concerned with providing healthcare in a way that is mindful of and responsive to the patient's subjective preferences, values, needs, and goals (Storm & Edwards, 2013). This may also include patient involvement in policy making and in the development of clinical guidelines (Harding, Pettinari, Brown, Hayward, & Taylor, 2011). Within an overarching context of patient-centered care, *patient participation* can be applied as an approach for strengthening patients' influence in making decisions related to their treatment. This may involve—on a scale of increasing levels of autonomy—providing patients with adequate information, offering them the opportunity to express their views, redistributing some power over decision making to patients, and allowing for patients to make decisions without involving other people (such as a clinician) (Storm & Edwards, 2013). A specific tool of patient participation is *shared decision making*, whereby healthcare choices regarding treatments etc. are made collaboratively by a healthcare professional and the patient. In this view, patients are seen as experts based on their own lived experiences (Tambuyzer, Pieters, & Van Audenhove, 2014), whereas the clinician contributes with professional expertise regarding the available options. For example, shared decision making is often employed in managing psychotropic medication and has been shown to increase adherence (Nott, McIntosh, Taube, & Taylor, 2018).

Another term that is frequently encountered in the literature on patient participation is *empowerment*. Importantly, it has been emphasized that empowerment is a personal process and that any discussion of issues related to power needs to acknowledge that power can be gained or lost, but not given (Tambuyzer et al., 2014). Thus, patients cannot *be* empowered by a clinician; the clinician can merely provide an environment within which empowerment is possible. This may involve different levels of a healthcare organization. Patients can be involved on an individual level (i.e., in decisions regarding their treatment), on a healthcare service level (e.g., as patient representatives in the board of advisors), and/or on a policy level (Storm & Edwards, 2013; Tambuyzer et al., 2014). Moreover, patients may also be involved in research and education (Tambuyzer et al., 2014). Patient involvement initiatives have been successfully implemented in high-income settings as well as in low- and middle-income countries, although the evidence base for benefits in terms of patient-level outcomes is generally weak (Semrau et al., 2016). It can, of course, be argued that patient involvement should be seen as a valuable goal in its own right, regardless of secondary outcomes.

There is, however, also criticism and concern about how patient participation in mental healthcare is currently conceptualized. Some critical voices describe psychiatry as more or less inherently paternalistic and hold that efforts to increase patient participation and involvement often retain a hierarchic and potentially excluding biomedical focus (Joergensen & Praestegaard, 2018; Stickley, 2006). In this view, seeking to make patients ascend the “power ladder” (Stickley, 2006, p. 571) merely reinforces the dominant discourse and may amount to little more than the ticking of politically correct boxes for the yearly report. Moreover, a *consumerist* perspective, whereby patients are invited to choose among services without actual influence over the healthcare contents, is sometimes seen as a core component of the surge of patient participation initiatives (Tambuyzer et al., 2014). However, although there are probably examples

of token patient involvement, this view seems overly cynical. It is far from certain that viewing the patient as an inherently subversive agent is necessarily seen as helpful by most individuals who seek help from psychiatry. In fact, when asked about it, patients do not always *want* to be actively involved as participants in all clinical decision making—surely, patients want to be treated with respect and dignity and to be seen as individuals, but they also tend to emphasize the need for competent professional advice (Solbjør, Rise, Westerlund, & Steinsbekk, 2011), not least in situations where their own capacity for partaking in complex treatment decisions may be impaired. The preferred level of participation among patients may vary across individuals and at different phases of illness (Storm & Edwards, 2013). When symptoms improve, patients tend to display an increased interest in participation. This, however, is another criticism of how patient participation is implemented on an institutional level: that those individuals who partake in organizational policy making are often currently well and that they may therefore not be representative of the majority of people receiving mental healthcare services (Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Storm et al., 2010).

Clinical barriers that impede active patient participation include impaired insight, low mood and energy levels, and lack of verbal ability during episodes of severe mental illness (Solbjør et al., 2011). Interestingly, sometimes patient involvement is also hindered by *self-stigma*; i.e., the anticipation of being treated badly and unjustly based on self-perception and/or previous experiences in healthcare (Edin Renberg & Sandlund, 2019). Four abilities have been highlighted with regard to patient capacity: the ability to understand relevant information, the ability to make sense of that understanding for personal purposes, the ability to engage in logical reasoning about various treatment options, and the ability to express a subjective choice (Tambuyzer et al., 2014). The capacity to grasp the relevance of medical information in relation to one's own current situation—i.e., insight into the severity of one's illness—may be especially impaired in eating disorders, where core symptoms often have an egosyntonic character that makes it difficult for patients to acknowledge them as problematic (Gorwood, Duriez, Lengvenyte, Guillaume, & Criquillion, 2019; Konstantakopoulos, Tchanturia, Surguladze, & David, 2011). Other psychiatric disorders may involve elements of passivity or rapidly changing mind states that hinder effective decision making (Solbjør et al., 2011). Still, in situations such as these, clinicians can promote patient involvement by other means; for example, even severely ill patients can often be engaged in everyday *microdecisions* that affect their lives at the hospital ward, such as choice of activities, environment issues, or food (Edin Renberg & Sandlund, 2019). Even if patient preferences cannot always be met, it is important to allow for patients' voices to be heard in a systematic way.

In the past decades, discussions about patient-centeredness and patient participation in psychiatry have often focused on concepts on community care, including how community-based efforts could diminish the need for psychiatric hospitals (Systema et al., 2002; Thornicroft & Tansella, 2013). For example, so-called *assertive community treatment* is now an established model in the management of severe mental illness, although challenges regarding optimal implementation still exist (Thorning & Dixon, 2020). Current models of psychiatric inpatient treatment have little evidence base and it has not clearly been shown that hospitaliza-

tion is more effective than other approaches to treatment (Clarke & Glick, 2019). On the other hand, it has been argued that there is also scarce evidence *against* contemporary hospital psychiatry and that favoring community-based treatment is largely based on memories of past abuse in the lunatic wards of older days, even though the rejection of institutional care does not automatically foreclose the risk of further abuse (Perera, 2020). It has been suggested that the dichotomy between hospital and community psychiatry is unnecessary and potentially unhelpful (Perera, 2020; Thornicroft & Tansella, 2013). In fact, there appears to be a clear correlation between the supply of psychiatric outpatient and inpatient treatment across (high-income) countries:

“Generally, countries with high levels of inpatient care also provide high levels of outpatient care (e.g., the Netherlands, France, Switzerland, Germany). Meanwhile, the countries that provide the least amount of inpatient care (e.g., the United States, New Zealand, Denmark, and Sweden) tend to provide the least amount of outpatient care as well.” (Perera, 2020, p. 965)

In some places, unfortunately, a lack of inpatient beds contributes to a situation where severely ill patients are shuttled between emergency departments, shelters, and various types of correctional facilities instead of being offered proper treatment and continuity of care (Clarke & Glick, 2019). However, the boundaries between inpatient and outpatient treatment are often not clear cut—for example, hospitals often organize outpatient and community mental health programs (Perera, 2020). Several hybrid models that integrate elements of out- and inpatient treatment exist, such as partial hospitalization, day patient programs, and intensive outpatient programs. A case can be made for a balanced model where community-based treatment and inpatient treatment are seen as complements instead of substitutes and are coordinated accordingly (Perera, 2020; Thornicroft & Tansella, 2013). For example, brief episodes of hospitalization at times of need with the explicit aim of optimizing the chances for resuming community care and ensuring a smooth transfer between services are recommendable (Clarke & Glick, 2019). Furthermore, for community-based efforts to be successful, broader integration of individuals with severe mental illness into the job market and society at large must be prioritized (Leff & Warner, 2006; Thornicroft & Tansella, 2013).

## **1.3 PREVIOUS RESEARCH ON SELF-ADMISSION**

### **1.3.1 Early attempts**

Besides the Scandinavian and Dutch models described in more detail below, there are no previously published descriptions of large-scale structured self-admission models. However, examples of similar approaches exist. A British study from 1995 presents a model where adolescents hospitalized after a suicide attempt were offered a “green card” that would serve as a passport for immediate readmission to a local hospital if a bed was available, should new suicidal thoughts occur (Cotgrove, Zirinsky, Black, & Weston, 1995). Here, the main goal was to reduce the number of further suicide attempts and self-injury. The green card concept was meant to offer the adolescents a temporary escape from a possibly destructive and intolerable home

environment, comparable to an “asylum” function, until the immediate crisis could be resolved. Of the 47 adolescents in the treatment group, only five (11%) made use of their green card in the follow-up period of 1 year. In the treatment group, three patients (6%) made a further suicide attempt in this period of time, whereas amongst the 58 adolescents in the control group, seven (12%) made a subsequent suicide attempt. However, this difference was not statistically significant. None of the patients in the treatment group who actually made use of their green card made a further suicide attempt during follow-up.

An Australian case report from 1999 describes a patient with a complex picture of schizophrenia, borderline personality disorder, and polysubstance abuse who had previously had several lengthy and tumultuous hospital stays (Little & Stephens, 1999). As one component of a community-based approach to crisis management, the patient was offered a “voucher” permitting five inpatient days over the next year. The agreement was that at a time of crisis, he would contact a community nurse who could assist him in finding adequate coping strategies. However, he was also free to use his voucher at will and if he chose to do so, he would be admitted the next day; this slight delay was introduced in order to promote further community-based solutions before entering hospital. Unfortunately, very sparse outcome data are offered. After receiving the voucher, the patient in question had only one brief admission episode in 13 months, compared to four lengthy hospital stays in the preceding 6 months. The case report then ends rather brusquely when the patient suddenly decides to move to another part of the continent.

In the literature on self-admission for patients with borderline personality disorder, a number of other studies are often referenced as prior examples of similar concepts. However, although the goals of the interventions may be similar to those of self-admission, these models differ from self-admission in that brief admissions were either offered after acute consultation with a case manager or an emergency room physician (Berrino et al., 2011; Morgan, Jones, & Owen, 1993; Nehls, 1994b, 1994a; Wong, Wong, & Tye, 2005) or planned in advance for the patients as a preventive measure based on previous utilization of inpatient treatment (Koekkoek, van der Snoek, Oosterwijk, & van Meijel, 2010). Moreover, there are examples of studies assessing open-door vs. locked-door policies on inpatient wards (Crabtree & Grossman, 1974; Efkenmann et al., 2019), which primarily concern patients that are already admitted.

### **1.3.2 Scandinavian experiences**

In a context of a broader political emphasis on patient participation in healthcare, self-admission to inpatient treatment has been offered in Norway since the early 2000s. At the outset of this thesis project, a systematic review of previous studies on the topic was performed (Strand & von Hausswolff-Juhlin, 2015). Six articles, published from 2008 and onwards, reporting findings from four different Norwegian programs of self-admission were reviewed. Most of the studies included could be described as early pilot projects and, hence, the quality of the evidence was generally limited. Variations of the same basic model of self-admission were employed. At inclusion, a “contract” was drafted in collaboration with the patient, an outpatient clinician, and staff at the designated hospital ward, outlining practical matters and the



purposes behind self-admission. Patients with a self-admission contract were allowed to admit themselves for a maximum of 5 days. At the inpatient ward, the participants were mainly offered basic supportive therapeutic interventions, such as help with emotional containment and a structured daily schedule (Heskestad & Tytlandsvik, 2008). No changes in medication were allowed during these brief admissions episodes. Interestingly, three of the four study sites had introduced a quarantine rule, whereby participants were made to wait 14 or 21 days after discharge before they could self-admit again (Heskestad & Tytlandsvik, 2008; Sollied & Måsø Helland, 2010; Støvind, Hanneborg, & Ruud, 2012). This rule was established in hopes that it would help prevent overly frequent admissions and support patients in maintaining a focus on their everyday lives in the community.

These Norwegian self-admission programs specifically targeted patients with high previous healthcare utilization and a history of prolonged hospital admissions. As an illustration of the severity of their mental illness, the 18 included participants in one of the studies (Heskestad & Tytlandsvik, 2008) had suffered from a psychotic disorder for 9 years on average and had been admitted to a mental hospital ten times for a mean total inpatient period of 20 months. None of the participants were employed; 16 of them were receiving disability pension.

Quantitative outcomes were reported from three of the Norwegian study sites. Notably, they all compare the intervention period with a control period of equal length prior to enrollment in the self-admission program—hence, participants serve as their own controls (i.e., a study design that is not typically seen as a controlled study). Follow-up periods varied between 8 (Hanneborg & Ruud, 2011; Støvind et al., 2012) and 19 months (Heskestad & Tytlandsvik, 2008) on average. The studies do not report common variables such as effect size, statistical significance, etc. The quantitative data from these studies are summarized in Table 1. In sum, these early data show that the number of participant admission episodes increased but that the corresponding number of days spent hospitalized decreased considerably at all three study sites.

The experiences reported by participants in these Norwegian self-admission programs were mostly positive. Participants displayed an improved confidence in making use of various coping strategies to manage their symptoms and they seemed to have access to a larger and more innovative cognitive toolbox (Rise et al., 2014). Whereas non-participants discussed using coping strategies mainly as a way to adapt to the illness, participants in the self-admission program showed a stronger ability to use these skills “in order to grow, to break barriers and to take opportunities” (Rise et al., 2014, p. 5). Moreover, participants expressed less overall resignation and powerlessness, in contrast to non-participants who gave a more passive and helpless impression. Participants in the self-admission program had more often made efforts to change the trajectory of their lives, such as enrolling in educational programs. Non-participants, on the other hand, tended to talk about education and other life goals in a more negative way, i.e., as distant and unattainable.

Patient interviews also revealed that access to self-admission early on in a process of deteriorating mental health made them feel safer and more secure in everyday life (Tytlandsvik & Heskestad, 2009). Even those participants who never actually made use of the opportunity

to self-admit during the study period experienced the program as helpful, since merely knowing that they could contact the inpatient ward at will made them feel safer. Participants also described a greater level of freedom in everyday life—for example, they reported that they were more likely to explore new activities in everyday life, since the self-admission program served as a safety net (Sollied & Måsø Helland, 2010).

	Akershus	Tromsø	Jæren
<b>Number of admissions (total)</b>			
During control period	46	n/a	69
During intervention period	70	n/a	178
Change	+52%	n/a	+158%
<b>Number of involuntary admissions</b>			
During control period	8	n/a	37
During intervention period	4	n/a	23
Change	-50%	n/a	-38%
<b>Number of psychiatric emergency admissions</b>			
During control period	16	n/a	n/a
During intervention period	9	n/a	n/a
Change	-43%	n/a	n/a
<b>Days/weeks in inpatient care</b>			
During control period	1560 days	1099 days	265 weeks
During intervention period	684 days	854 days	178 weeks
Change	-56%	-22%	-33%
<b>Days/weeks in involuntary inpatient care</b>			
During control period	122 days	n/a	181 weeks
During intervention period	47 days	n/a	88 weeks
Change	-61%	n/a	-51%
<b>Days/weeks in psychiatric emergency care</b>			
During control period	198 days	76 days	n/a
During intervention period	52 days	20 days	n/a
Change	-74%	-74%	n/a
<b>Bed occupancy rate during intervention period</b>			
	n/a	30.7%	28%

**Table 1.** Quantitative data from Norwegian pilot studies (adapted from Strand & von Hausswolff-Juhlin, 2015). All numbers given are total numbers for all study participants.

Some barriers were also mentioned. Several participants experienced that self-monitoring their health status was too demanding, as they were afraid of both under- and overestimating their current need for inpatient treatment (Sollied & Måsø Helland, 2010). Previous negative experiences of inpatient treatment could also make participants hesitant to contact the ward; moreover, some participants were afraid that they would be turned away and not be allowed to self-admit after all despite being in the program (Hanneborg & Ruud, 2011). Participants described feeling uncertain that their subjective reasons for admission were legitimate in compared to those of others in the program whose needs may be greater (Sollied & Måsø Helland, 2010). Some of them missed traditional elements of inpatient care, such as regular assessments by a psychiatrist (Tytlandsvik & Heskestad, 2009). The quarantine rule was also seen as stress provoking and counterproductive (Hanneborg & Ruud, 2011; Tytlandsvik & Heskestad, 2009).

Interviews with staff members prior to the introduction of self-admission showed that they were often worried that participants in the program would misuse the initiative, so that they would demand to be admitted very frequently once they were offered free access. Concern was also raised that participants would choose to contact the ward mostly during evenings, weekends, and holidays (Hanneborg & Ruud, 2011; Tytlandsvik & Heskestad, 2009) when there are fewer staff members. This, however, turned out not to be the case—it appears that healthcare professionals may sometimes overestimate the allure of psychiatric inpatient treatment. At the end of the study period, staff members displayed a significantly more positive view of the self-admission concept. The fact that staff could now more often genuinely welcome patients to the ward instead of “guarding” the available beds was described as a main advantage. They also noted that there was less “drama” in times of crisis (Sollied & Måsø Helland, 2010). Staff members experienced that participants invested more effort into making the hospital stay useful, now that they had chosen for themselves to admit. A remaining concern, mainly raised by psychiatrists, was that the self-admission model may not be appropriate from a patient safety perspective—not least, it was seen as unclear who would be held responsible if negative events occurred during a self-admission episode (Hanneborg & Ruud, 2011).

After this systematic review of the field in 2014–2015, a number of new studies of higher quality have been published that have contributed to a somewhat more nuanced picture of self-admission. In two Norwegian randomized controlled trials (RCTs) published in 2016, no differences were seen between intervention and control groups in terms of total time spent hospitalized. During the initial 4 months in the self-admission program, the 26 participants were admitted more frequently than the 27 controls; however, both groups displayed a similar total use of inpatient treatment and outpatient consultations (Moljord et al., 2016). A 12-month follow-up study by the same team of researchers revealed that whereas participants reduced the total time spent in inpatient treatment by around 40% during the intervention period, so did the control group (Sigrunarsen, Moljord, Steinsbekk, Eriksen, & Morken, 2016). In a recent Norwegian pre-post study (i.e., an uncontrolled study) comprising 57 participants, a marked reduction in the total number of inpatient days was observed (Nyttingnes & Ruud, 2020)—however, due to the lack of control group, the authors conclude that it cannot be ruled out that the findings was not simply caused by regression towards the mean.

In a prospective cohort study of Danish self-admission programs published in 2018 (Thomsen et al., 2018), an intervention group comprising 422 patients, mostly diagnosed with schizophrenia, was compared with 2 110 propensity score matched controls being subjected to treatment as usual (TAU). At 12-month follow-up, it was observed that while the participants in the intervention group were able to reduce their total number of days spent in hospital, so were the TAU group—in fact, those patients subjected to TAU reduced their utilization of inpatient care even more. During the intervention phase, participants in the self-admission program spent on average 58.2 days in psychiatric inpatient treatment compared to 75.2 days in the previous year; the corresponding numbers in the TAU group was 29.8 days compared to 65.4 days in the previous year. Hence, these findings do not simply represent a regression towards the mean; they reveal that participants in self-admission programs actually fared slightly worse than non-participants.

Another Danish study comprising 190 participants in self-admission programs across the country showed a generally high patient satisfaction with the model; however, those who expected more active optimization of their medication during hospital admission or an overall more intensive level of care were less satisfied (Ellegaard, Bliksted, Lomborg, & Mehlsen, 2017). A questionnaire study by the same authors comprising 252 mental health professionals revealed that while these staff members also held a favorable view of the self-admission model, the opinions regarding what constituted a successful self-admission episode differed somewhat compared to those of the participants (Ellegaard, Mehlsen, Lomborg, & Bliksted, 2017). Thus, the authors highlight that healthcare providers should be aware of the fact that patients may self-admit and self-discharge for other reasons than those that seem most obvious from a provider perspective. Yet another study by the same research group focused on mental health professionals' experiences of the implementation of the self-admission model, emphasizing a process of gradually increased awareness and comprehension of the intricacies of the concept (Ellegaard, Bliksted, Mehlsen, & Lomborg, 2018). Moreover, in interviews with 26 patients, safety was highlighted as a focal point in the self-admission model: the increased access to inpatient treatment and their familiarity with the ward strengthened participants' feelings of safety, but this safety could also be undermined by experiences of being overlooked by staff or feeling uncertain about what would happen after the self-admission episode (Ellegaard, Bliksted, Mehlsen, & Lomborg, 2020).

A number of Swedish reports on self-admission have also been published, mainly from programs targeted to patients with emotional instability and self-injury. Experiences from the self-admission program at the Northern Stockholm Psychiatry service demonstrate that self-admission can be a useful tool in managing self-injurious behaviors (Eckerström, 2017). Interviews with 15 program participants showed that they experienced that access to self-admission could provide a time-out when life is rough, that it helped them to see their difficulties from a new perspective, and that it could encourage a more active personal responsibility (Eckerström, Flyckt, Carlborg, Jayaram-Lindström, & Perseus, 2020). A clearly established treatment plan, an easy-to-follow admission procedure, and a welcoming attitude among hospital staff were seen as key components in ensuring successful use of the model. Moreover, in a qualitative study where eight hospital nurses were interviewed, it was shown that their professional role

shifted with the introduction of self-admission, from mainly “handling problems” to a focus on establishing caring relationships and exploring the meanings of recovery (Eckerström et al., 2019).

Data on patient experiences from a similar program in Skåne in the southern part of Sweden have also been published (Helleman, Lundh, Liljedahl, Daukantaitė, & Westling, 2018), although this report—similar to the Dutch reports described in more detail below—focuses on brief admission in a broader perspective rather than on self-admission specifically. A manual on training and clinical implementation of self-admission targeted to patients with borderline personality disorder and/or self-injurious behaviors has also been published (Liljedahl, Helleman, Daukantaitė, & Westling, 2017). Interviews with twelve healthcare providers in the Skåne region showed that they experienced that self-admission contributed to increased predictability and safety, strengthened bonds between outpatient and inpatient services, and promoted an overall shift from conflict to collaboration (Lindkvist et al., 2019). Seven participating patients in the Skåne program have also been interviewed, demonstrating that self-admission could provide a more “worthy” alternative to traditional admission models that the patients experienced as rigid and counterproductive (Lindkvist, Westling, Liljedahl, & Landgren, 2020). However, in an RCT of self-admission for patients displaying self-injurious behaviors or recurrent suicidality and a minimum of three diagnostic criteria for borderline personality disorder, the intervention group did not fare significantly better than the control group—both groups decreased the total number of days spent hospitalized in equal proportions (Westling et al., 2019). In contrast, the intervention group displayed a reduction in days spent in compulsory treatment as well as in non-suicidal self-injurious behaviors.

### **1.3.3 The Dutch model**

Self-admission targeted to patients with borderline personality disorder has reportedly been offered in the Netherlands for quite some time (Helleman, Goossens, van Achterberg, & Kaasenbrood, 2018). However, the Dutch literature on this intervention is surprisingly sparse. Data from only one Dutch self-admission project have been published, focusing mostly on active components of brief admissions in a broader perspective and relatively little on the self-admission component specifically. Personal communication with the main researcher behind this project in search of further published data has not revealed any additional reports, neither in English nor in Dutch.

In the published Dutch self-admission model (Helleman, 2017; Helleman, Goossens, Kaasenbrood, & van Achterberg, 2014b), patients with borderline personality disorder were offered a framework of self-admission with somewhat individualized practical details. Upon arrival at the hospital ward, the patient would briefly discuss the goals with the current admission, discharge date, and other practical questions with a nurse; no psychiatrist or medical doctor would be involved at this stage. During the stay at the hospital, the patient would not partake in the structured therapy groups at the ward but could request conversations with a nurse. Self-admission participants were usually responsible for their medication at the ward. The overarching goals were to prevent self-injury or suicide and to support patients in regaining control

in times of crisis. Other goals were to avoid prolonged episodes of hospital treatment and to prevent dropout from outpatient or community-based treatments. By inviting patients to draft the brief admission contract in a collaborative manner, the program aimed to encourage active patient involvement in problem-solving and planning, which could ideally promote growth in terms of autonomy and self-esteem. Nevertheless, the authors note that patients with borderline personality disorder will most likely experience further crises during treatment, regardless of their overall autonomy level. The concept of self-admission could serve to prevent a total loss of control in these situations and promote a swift return to everyday life. In addition, the model may by extension modify actual symptoms of the underlying disorder, such as poor affect regulation, defective coping skills, etc.

No quantitative outcome data—i.e., data on healthcare utilization, remission, HRQoL, etc.—from the Dutch project have been reported. Only qualitative data from participant interviews (Helleman et al., 2014b), as well a single-case descriptive study outlining the practical use of brief admissions for a 37-year old woman suffering from borderline personality disorder and posttraumatic stress disorder over 6 years (Helleman, Goossens, Kaasenbrood, & van Achterberg, 2016), have been published. These reports focus on broader experiences of useful and not-so-useful components of being admitted to a psychiatric ward, but relatively little on self-admission specifically. Notably, participants repeatedly mention how the ward came to serve as an “asylum” where they could gain respite from difficult life situations. Being engaged in pleasant, distracting activities at the hospital was seen as helpful in this regard and the clear structure of the ward, with fixed mealtimes etc., was also important. Knowing that access to this environment was possible at all times helped the patients feel safer in their everyday lives.

## **1.4 EATING DISORDERS**

### **1.4.1 Diagnostic categories, epidemiology, and treatment**

In the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) (American Psychiatric Association, 2013) three primary eating disorder diagnoses are described: AN, bulimia nervosa (BN), and binge-eating disorder (BED). AN is characterized by a restricted energy intake resulting in a significantly low body weight; an intense fear of weight gain (so called “weight phobia”); and a distorted experience of one’s own body weight or shape, an undue influence of body weight or shape on self-image, or a persistent lack of recognition of the seriousness of the current low body weight. AN can be further subdivided into restricting type AN, in which weight loss is accomplished mainly through dieting, fasting, and/or excessive exercise, and binge-eating/purging type AN, which also involves recurrent episodes of binge eating or purging behaviors. BN is characterized by recurrent episodes of binge eating (which involves loss of control eating and consumption of unusually large amounts of food over a brief period of time) unhealthy compensatory behaviors to prevent weight gain (such as vomiting, laxative use, or excessive exercise), and an overemphasis on weight or shape in self-evaluation. BED is characterized by recurrent episodes of binge eating without compensatory behaviors. Furthermore, the DSM-5 section on feeding and eating disorders includes the diagnosis avoidant/restrictive food intake disorder, commonly abbreviated as ARFID, which is character-

ized by restricted energy intake due to factors other than body image concerns, such as low appetite, sensory sensitivity, or dysphagia. In addition to these diagnostic entities, other specified feeding or eating disorder (OSFED) is a category that captures eating disorder presentations that do not meet threshold diagnostic criteria for any of the prototypical diagnoses outlined above; it may, for instance, be used in atypical AN where an individual meets all diagnostic criteria for AN except that their weight remains within or above the normal range despite significant weight loss.

Individuals with eating disorders are a very diverse group when it comes to age, ethnicity, gender, socioeconomic status, etc. (Schaumberg et al., 2017; Treasure, Duarte, & Schmidt, 2020). AN typically debuts in adolescence or young adulthood (Hudson, Hiripi, Pope, & Kessler, 2007). In contrast, BN and BED presentations dominate the clinical picture in adults (Treasure et al., 2020). Diagnostic crossover between eating disorder diagnoses over time is frequently seen (Eddy et al., 2008; Schaumberg et al., 2019); for example, an eating disorder may debut as AN and then develop into BN over time. In the DSM-5, the 12-month prevalence of AN is estimated to 0.4% and that of BN to 1.0-1.5% among young women. The 12-month prevalence of BED in adults is estimated to 1.6% for women and 0.8% for men (American Psychiatric Association, 2013). More recent estimates based on a large United States sample indicate a lifetime prevalence of 0.80%, 0.28%, and 0.85% for AN, BN, and BED, respectively; corresponding 12-month prevalence estimates are 0.05%, 0.14%, 0.44% (Udo & Grilo, 2018). In this study, the prevalence of all three eating disorders were markedly greater for women than for men, although the ratio was more similar between women and men in BED compared to AN and BN. However, the occurrence of subthreshold disordered eating in the absence of a full eating disorder is much more common: a study on adolescents showed that 24% of girls and 16% of boys reported some eating disorder symptoms (Hautala et al., 2008). Reliable prevalence estimates for ARFID are not available; a study of a non-clinical sample of Swiss school children indicated that as many as 3.2% may fulfil diagnostic criteria (Kurz, van Dyck, Dremmel, Munsch, & Hilbert, 2015).

The notion of a surge in eating disorders is a contested topic. Recent figures point to a stable incidence rate for AN in the past decades, a somewhat declining incidence rate for BN, and a rising incidence rate for BED and OSFED (Treasure et al., 2020). Globally, however, there appears to have been a sharp rise in eating disorder prevalence in the past decades (Treasure et al., 2020), not least in an East Asian context (Pike & Dunne, 2015). This rise has partly been attributed to westernization and urbanization (Doris et al., 2015; Keel & Klump, 2003); however, an increased recognition of eating disorders may of course also affect help-seeking patterns and incidence rates observed in healthcare settings.

Disordered eating can give rise to a broad range of medical complications, such as cardiac dysfunction, gastrointestinal problems, reduced bone mineralization, and serious electrolyte imbalances (Misra & Klibanski, 2011; Norris et al., 2016; Sachs, Harnke, Mehler, & Krantz, 2016; Treasure et al., 2020). Moreover, eating disorders are typically accompanied by psychiatric comorbidity (Treasure et al., 2020). Most commonly, this involves mood and anxiety disorders,

neurodevelopmental disorders such as attention-deficit/hyperactivity disorder (ADHD), attention-deficit disorder (ADD), or autism, personality disorders, and substance use disorders. Eating disorders are associated with substantially elevated mortality rates. Two large meta-analyses have estimated the standardized mortality ratio in AN at 5.9 and 5.2, respectively (Arcelus, Mitchell, Wales, & Nielsen, 2011; Keshaviah et al., 2014). Notably, these estimates are substantially higher than rates reported in schizophrenia, bipolar disorder, or major depressive disorder. The elevated rates are partly explained by a markedly increased risk for suicide in individuals with AN (Keel et al., 2003; Keshaviah et al., 2014). Treatment-refractory AN is undoubtedly a life-threatening condition.

The underlying mechanisms in the development and maintenance of eating disorders are still not fully known, despite active research (Treasure et al., 2020). Biological factors such as genetic predisposition, susceptibility to appetite dysregulation, and metabolic vulnerability are commonly thought to interact with psychological factors and personality traits such as rigidity, perfectionism, alexithymia, intolerance of uncertainty, and a high ability to delay reward. Moreover, psychosocial and sociocultural factors such as peer pressure, thin idealization, culturally embedded body ideals, family attitudes towards eating, and psychological trauma are often implicated in the development of eating disorders (Becker, 1995; Copeland et al., 2015; Fitzsimmons-Craft et al., 2014; Keel & Klump, 2003; Rijkers, Schoorl, van Hoeken, & Hoek, 2019; Treasure et al., 2020). Once established, an eating disorder often becomes self-perpetuating (Fairburn, 2008). Notably, a very common theme in interviews with individuals with AN is a subjective ambiguous experience of being in control while simultaneously being controlled by the illness:

“It takes control of you, but it can also feel very safe. It’s a very confusing illness, because at the moment it’s probably got a lot of control over me, in certain ways, and I just want to get away from it, I’m just sick and tired and I’m exhausted, but then it kind of protects you as well, I think, from coping with other things.” (Tan, Hope, Stewart, & Fitzpatrick, 2003, pp. 632-633)

“[Patients] experienced pleasure and disgust, were empowered and disempowered, felt safe yet constantly threatened, were both pure and dirty, and when sickest felt at their best. Anorexia was a constant process of becoming and unbecoming, of having a life by moving toward death.” (Warin, 2010, p. 4)

Importantly, early intervention is associated with favorable outcomes and thus, rapid initiation of specialized treatment rather than watchful waiting is essential (Treasure et al., 2020). For children and adolescents, family-based treatment (FBT) is usually recommended across the spectrum of eating disorders (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; National Institute for Health and Clinical Excellence, 2017; Wallin, af Sandeberg, Nilsson, & Linne, 2015), although the solidity of the evidence base behind this has been debated (Fisher, Skocic, Rutherford, & Hetrick, 2018). For adults with BN and BED, cognitive-behavioral therapy (CBT)—delivered either by therapist or by guided self-help—is recommended as the treatment of choice (Brownley et al., 2016; National Institute for Health and Clinical Excellence, 2017;



Shapiro et al., 2007; Treasure et al., 2020; Wallin et al., 2015). This is sometimes augmented by pharmacotherapy, including the use of selective serotonin reuptake inhibitors, anticonvulsants, and (in the case of BED) lisdexamfetamine (Aigner, Treasure, Kaye, & Kasper, 2011; Brownley et al., 2016; Shapiro et al., 2007; Treasure et al., 2020). For adults with AN, the treatment recommendations are somewhat less clear cut. In large trials, little or no difference has been found between CBT, focal psychodynamic psychotherapy, and so-called specialist supportive clinical management (SSCM), all of which have proven effective (Treasure et al., 2020). Interestingly, SSCM was developed as an active control condition for a trial of psychotherapy in AN but proved to be effective in its own right (McIntosh et al., 2006); this treatment approach focuses on non-specialized supportive psychotherapy and clinical management. No specific pharmacological treatments have proven effective in altering the progress of AN; however, medication aimed at alleviating anxiety and treating comorbid psychiatric conditions, such as selective serotonin reuptake inhibitors or atypical antipsychotics, are often used (Aigner et al., 2011; Lebow, Sim, Erwin, & Murad, 2013). For individuals with ARFID, an adapted CBT approach has been suggested, bearing in mind that it may not be realistic that patients with homeostatic low appetite and/or sensory selectivity will achieve fully normalized eating (Thomas & Eddy, 2019).

Patients typically refer to therapeutic alliance as a central component in what distinguishes a successful treatment episode from a not-so-successful attempt (Gulliksen et al., 2012; Hay & Cho, 2013; Venturo-Conerly et al., 2020). A positive therapeutic alliance is also highlighted as an integral part of the SSCM approach to treatment (Jordan, McIntosh, & Bulik, 2019). In contrast, the role of treatment motivation in eating disorders is somewhat contested, as there is little evidence that interventions aimed at increasing patient motivation are effective in eating disorders (Waller, 2012). Furthermore, it has been argued that achieving improvement in eating disorder pathology at an early stage in treatment is what *creates* therapeutic alliance, not the other way around (Turner, Marshall, Wood, Stopa, & Waller, 2016), and that a therapist's focus on achieving alliance at the expense of rapid behavioral change actually risks delaying and obstructing treatment (Waller & Turner, 2016).

It can be noted that similar diagnostic categories as those described above are found in the *International Classification of Diseases, 11th Revision* (ICD-11) (World Health Organization, 2019). Sweden is officially obliged to use ICD codes in formal diagnostic registers; however, ICD-11 has not yet formally come into effect and the diagnostic codes in the *International Classification of Diseases, 10th Revision* (ICD-10) (World Health Organization, 2004) are therefore currently used. In the case of AN, the ICD-10 retains a description of “deliberate weight loss” as a core component; this framing of AN as intentional has, however, been dropped from the DSM-5.

#### **1.4.2 Specialist eating disorder inpatient treatment**

Hospitalization is sometimes necessary in the treatment of eating disorders. It is estimated that about 20-40% of adult outpatients with AN are at an immediate risk for complications or do not respond adequately to outpatient treatment, necessitating a higher level of care, i.e., in-

patient or day treatment (Treasure et al., 2020). Swedish national guidelines recommend that inpatient treatment is reserved for two groups of patients with eating disorders: those who present with a critically low body mass index (BMI) and are at risk for severe medical complications, and those with longstanding malnutrition who have not benefited from outpatient or day treatment (Wallin et al., 2015). Similarly, British national guidelines recommend that patients whose physical health is severely compromised should be admitted to inpatient treatment for medical stabilization and to initiate renourishment when other treatment options have proven unsuccessful (National Institute for Health and Clinical Excellence, 2017). However, the guidelines also underscore that absolute weight or BMI thresholds should not be employed when deciding who should be admitted. Furthermore, British guidelines specifically designed for the clinical management of severely ill patients with AN recommend that these individuals receive inpatient treatment in units specializing in eating disorders, as far as possible (Royal College of Psychiatrists, 2014). When no such facility is available, the choice between admitting a patient to a medical or a general psychiatric inpatient unit must be made on an individual basis, whereby variables such as the clinical state of the patient, the need of monitoring, and the experience of available psychiatric units in managing malnutrition must be considered. The British guidelines also state that inpatient treatment should not be used solely to provide psychological treatment; i.e., a focus on medical stabilization should be maintained (National Institute for Health and Clinical Excellence, 2017). On the other hand, patients should not be discharged solely because they have reached a healthy weight—their ability to maintain any positive changes made in treatment must be assessed in order to avoid rapid readmission.

Specialist eating disorder inpatient treatment is typically focused on renourishment and weight restoration. Therefore, a central component of this treatment is meal support (Treasure et al., 2020), with active mealtime aid and encouragement from staff and (for children and adolescents) parents. This may involve nutritional supplements or, for some patients, nasogastric feeding at times when adequate normal feeding is not possible (Rizzo, Douglas, & Lawrence, 2019). A large variety of protocols for renourishment in a hospital setting exist, some of which are more cautious whereas others favor a more rapid approach (Agostino, Erdstein, & Di Meglio, 2013; Garber et al., 2016; Treasure et al., 2020). In any case, due to the risk of so-called *refeeding syndrome*, which is a potentially lethal condition caused by phosphate depletion, blood phosphate levels should be carefully monitored during renourishment (Kohn, Madden, & Clarke, 2011). Parenteral nutrition is not recommended (Garber et al., 2016), since an integral part of treatment is the establishment of eating behaviors that are viable in an outpatient setting. Inpatient meal support is usually augmented with psychosocial, educational, and pharmacological treatment approaches (Treasure et al., 2020)—a typical inpatient/residential treatment program may, for example, include various forms of group therapy, individual therapy, physiotherapy, art therapy, and medical management.

Due to the necessarily prolonged nature of renourishment, inpatient treatment for patients with AN is typically lengthy; hospitalization of 4 months or longer are not uncommon (Meule et al., 2020; Strik Lievers et al., 2009). However, two RCTs have shown that for adolescents, models in which a brief hospitalization focused on medical stabilization was followed by day or out-

patient treatment displayed similar outcomes to a longer inpatient treatment aimed at full weight restoration (Herpertz-Dahlmann et al., 2014; Madden et al., 2015). Since day treatment is typically less costly than inpatient treatment, the sequential models were also favorable from a health economic perspective.

Relatively little is known about factors that influence the need for hospitalization and re-admission in AN. A study of patient application letters requesting inpatient treatment (Gorse et al., 2013) revealed a process of awareness, whereby individuals with AN gradually developed a more realistic understanding of their own loss of control over the disorder and the toll it was taking on their health. Here, an initial sense of control manifested in the form of rigid AN behaviors was gradually replaced by feelings of helplessness that prompted the individual to eventually seek adequate help. It has also been shown that life events associated with maturation and transition, such as marriage and childbearing, may reduce the need for hospitalization and readmission over time in individuals with an eating disorder (Tabler & Utz, 2020). Similarly, studies on general psychiatric inpatient treatment have shown that the need for re-admission may be more influenced by individual-level factors than clinical and/or organizational factors (Tedeschi et al., 2020) and that early psychiatric readmission is better predicted by socioeconomic factors, such as residential and employment status, than by illness severity (Schmutte, Dunn, & Sledge, 2010). Interestingly—and perhaps counterintuitively—a more favorable outcome during inpatient treatment has been associated with less favorable outcome after treatment for patients with eating disorders (Lowe, Davis, Annunziato, & Lucks, 2003).

### **1.4.3 Severe and enduring anorexia nervosa**

The majority of patients with AN can be treated successfully (Keel & Brown, 2010; van Son, van Hoeken, van Furth, Donker, & Hoek, 2010). Still, a prolonged trajectory with enduring disability is seen in as many as 20-30% of individuals with AN (Ciao, Accurso, & Wonderlich, 2016; Dobrescu et al., 2020; Eddy et al., 2017). The state of prolonged AN is now commonly referred to as *severe and enduring AN* (SE-AN) (Broomfield, Stedal, Touyz, & Rhodes, 2017); sometimes the term severe and enduring eating disorder (SE-ED) is used to indicate that eating disorder presentations other than AN may become prolonged (Treasure, Stein, & Maguire, 2015). However, broad agreement on a formal definition of this condition is lacking (Ciao et al., 2016; Hay & Touyz, 2018; Wildes et al., 2016; Wonderlich, Bulik, Schmidt, Steiger, & Hoek, 2020)—for example, suggested SE-AN minimum illness durations range from 3 to 10 years. Unfortunately, there is still little evidence regarding an optimal model of inpatient treatment for individuals with longstanding AN (Hay, Touyz, & Sud, 2012; Wonderlich et al., 2020). Some AN patients require prolonged periods of hospital treatment and relapse after discharge is common, a scenario that may evolve into a “revolving door” pattern (Eckert, Halmi, Marchi, Grove, & Crosby, 1995; Wonderlich et al., 2020). Unlike what has been observed in general psychiatry in recent decades, the hospitalization rate for this patient group has not been substantially diminished (Papadopoulos, Ekbom, Brandt, & Ekselius, 2009).

Little is known about why some individuals develop a longstanding eating disorder. Young age at onset and rapid initiation of treatment are generally seen as the two factors most strongly

associated with a favorable outcome (Treasure et al., 2020); conversely, older age at onset and a lengthy treatment delay may entail a more prolonged course. A large number of perpetuating factors in the development of SE-AN have been suggested; these include neurobiological and genetic factors, the presence of comorbid psychiatric conditions, interpersonal and family dysfunction, and the potentially adaptive functions of AN behaviors in managing low self-esteem, issues around identity formation, or trauma symptoms (Brewerton & Baker Dennis, 2016). As with any learned behavior, it can be enormously difficult for an individual with AN to change their restrictive dietary pattern once it has become established, not least considering that repeated behaviors such as these affect neural reward systems in ways that make them less sensitive to the receipt and valuation of reward feedback over time (Steinglass & Foerde, 2016). Moreover, sociocultural factors such as the idealization of thinness or athleticism, peer pressure, and social reinforcement may also influence the course of AN (Brewerton & Baker Dennis, 2016). For example, in the past, marketing strategies focused on idealized bodies used to mainly be directed towards young consumers. Nowadays, however, thinness and athleticism continue to be important societal ideals well into midlife (Bulik, 2013), which may potentially contribute to a prolonged course of illness for individuals with eating disorders.

A large body of literature addresses the issue of medical futility in the treatment of individuals suffering from SE-AN (Geppert, 2015; Lopez, Yager, & Feinstein, 2010; O'Neill, Crowther, & Sampson, 1994; Russon & Alison, 1998; Trachsel, Wild, Biller-Andorno, & Krones, 2015; Westmoreland & Mehler, 2016; Williams, Pieri, & Sims, 1998). However, the main focus in these papers has typically been on patient cases with extremely severe undernutrition where giving up active treatment efforts may result in imminent death from cardiac arrest or multiple organ failure. A more prevalent clinical dilemma is how to best support those SE-AN patients who have “tried everything” without success—i.e., cases of prolonged illness and a permanently low BMI where numerous treatment attempts have not lead to lasting remission (Wildes et al., 2016). After repeated unsuccessful treatment attempts, SE-AN patients may simply be dismissed and left to fend for themselves, a scenario that typically results in further clinical deterioration and an acute need for resumed treatment. A vicious circle characterized by periodically intensified treatment, partial remission, and new dismissal due to insufficient treatment motivation may ensue (Wonderlich et al., 2020), adding to the overall sense of futility and frustration. On the other hand, a fear of what will happen to the patient if treatment is terminated may also result in continued ineffective interventions that neither patient, nor therapist, truly believes in, for lack of viable alternatives (Waller, 2009).

Treatment and/or management of SE-AN requires careful considerations. There is agreement that treatment interventions should be modified according to the particular needs of patients with SE-AN, but there is little empirical research to guide recommendations (Ciao et al., 2016). In particular, CBT (Pike & Olmsted, 2016) and SSCM (Hay, McIntosh, & Bulik, 2016) have been suggested as potential avenues for treatment of this patient group, and both treatment approaches have resulted in significant improvements in RCTs (Touyz et al., 2016). Overall, there appears to be consensus among clinicians and researchers in the field that a multidisciplinary team is necessary to provide the support needed, and that traditional treatment goals for

AN (such as full weight restoration etc.) may not be realistic and achievable for all SE-AN patients (Ciao et al., 2016). Moreover, whereas empathy, patience, and acceptance are certainly vital parts of the therapeutic stance, the need for limit-setting in terms of medical complications to ensure patient safety is also highlighted (Ciao et al., 2016).

The literature on SE-AN commonly focuses on trying to improve patients' HRQoL as a primary treatment goal (Dawson, Rhodes, & Touyz, 2014; Franko, Murray, Mancuso, & Eddy, 2016). In some cases, an implicit idea behind this approach is that improvements in patients' everyday level of functioning may also induce a new outlook on life that can, in turn, lead to renewed efforts to achieve traditional treatment goals such as weight restoration (Molin, von Hausswolff-Juhlin, Norring, Hagberg, & Gustafsson, 2016). Qualitative research shows that HRQoL may have a greater influence on eating disorder symptoms than vice versa and that enhancing HRQoL may therefore aid in promoting recovery (Mitchison, Dawson, Hand, Mond, & Hay, 2016). Nevertheless, the fact that HRQoL levels in SE-AN patients have been found to be equal to those seen in patients with schizophrenia means that treatment will often need to be prolonged and focused on symptom management rather than clinical recovery (Touyz & Strober, 2016). Not least, SE-AN patients themselves point to a common mismatch between the treatment alternatives that are readily available to them and their subjective perception of what they actually need. Interestingly, they describe a simultaneous need for realistic and attainable treatment goals in order to avoid a sense of repeated failure *and* a future-oriented therapeutic stance in which they are challenged to progress instead of merely being monitored (Bamford, Mountford, & Geller, 2016).

Much like the debate about hospitalization in borderline personality disorder (National Institute for Health and Clinical Excellence, 2009; Paris, 2004b), the usefulness of repeated episodes of inpatient treatment for patients with SE-AN can be questioned. As noted above, a revolving door pattern may emerge where any improvement seen during hospitalization is rapidly reversed after discharge such that another episode of inpatient treatment becomes necessary (Eckert et al., 1995; Wonderlich et al., 2020). Even so, inpatient treatment can be a meaningful component in the clinical management of SE-AN. For example, in contrast to typical lengthy hospital admissions aimed at weight restoration for patients with AN, it has been suggested that the use of brief admissions focused on stabilization and treatment of physical symptoms may be a more useful approach in SE-AN (Bamford et al., 2016; Woodside, Twose, Olteanu, & Sathi, 2016).

## **1.5 AN INTRODUCTION TO HEALTH ECONOMICS**

### **1.5.1 Why health economics?**

Regardless of existing differences between countries in how health services are financed, available healthcare resources are inevitably scarce. Therefore, informed choices need to be made about the allocation of these resources in order to optimize health and healthcare equity. Health economics is concerned with issues related to effectiveness, value, and behaviors in the production and consumption of healthcare. As a branch of economics—a relatively old discipline—

the systematic application of health economics is fairly new and has gained influence only during the last 40 years (Guinness & Wiseman, 2011).

A quite common view of health economics among healthcare providers and staff is that it is somehow unethical; that the study of costs and benefits ultimately implies *denying* some individuals treatment from which they may in fact benefit (Cairns & Fox-Rushby, 2005a). Prioritizing among healthcare services and treatment options within a limited budget inevitably means that there will be healthcare needs which are not fully met. Of course, it may seem like the problem in such situations is that the healthcare budget simply is not large enough. The argument that investments in the healthcare sector are needed certainly holds truth in many settings. However, no economy will ever have the resources necessary to exhaust all possibilities to produce a positive health benefit at the margin. Moreover, larger healthcare expenditures do not automatically lead to better health outcomes—a case in point is the United States, where healthcare costs are considerably higher than in other high-income countries without being matched by equally great health outcomes (Papanicolas, Woskie, & Jha, 2018). There are also other ways to improve the health status of a population besides healthcare, such as a strengthened educational sector, improved housing and sanitation, better nutrition, and a cleaner environment. Health economics is crucial in trying to determine how to allocate limited resources so as to create the greatest benefits, within the healthcare sector as well as on a broader societal scale. Ultimately, the application of a health economic perspective recognizes that the opportunity costs of treating one patient or group of patients implies benefits foregone for other patients.

It is sometimes argued that health economic analyses are too crude—that they mostly rely on standardized economic outcome measures and thereby fail to capture what is truly important to patients (Cairns & Fox-Rushby, 2005a). Similarly, health economic analysis often involves making broad assumptions based on available clinical data, sometimes building complex models on relatively limited clinical evidence. Health economics may also seem overly technical: “decision-makers can find economic evaluations are a bit of a ‘black box’—they can see what goes in and the results that come out, but can’t see how it works” (Cairns & Fox-Rushby, 2005a, p. 234). It is true that health economic analysis does not necessarily reflect everything that is of importance to patients, healthcare providers, and policy makers—see, for example, the discussion about equity below. An economic evaluation should not be seen as providing a definitive action plan for healthcare decision-making. Health economics is a tool in summarizing relevant information regarding resource allocation; however, policy makers may of course want to use additional tools in order to grasp the full picture.

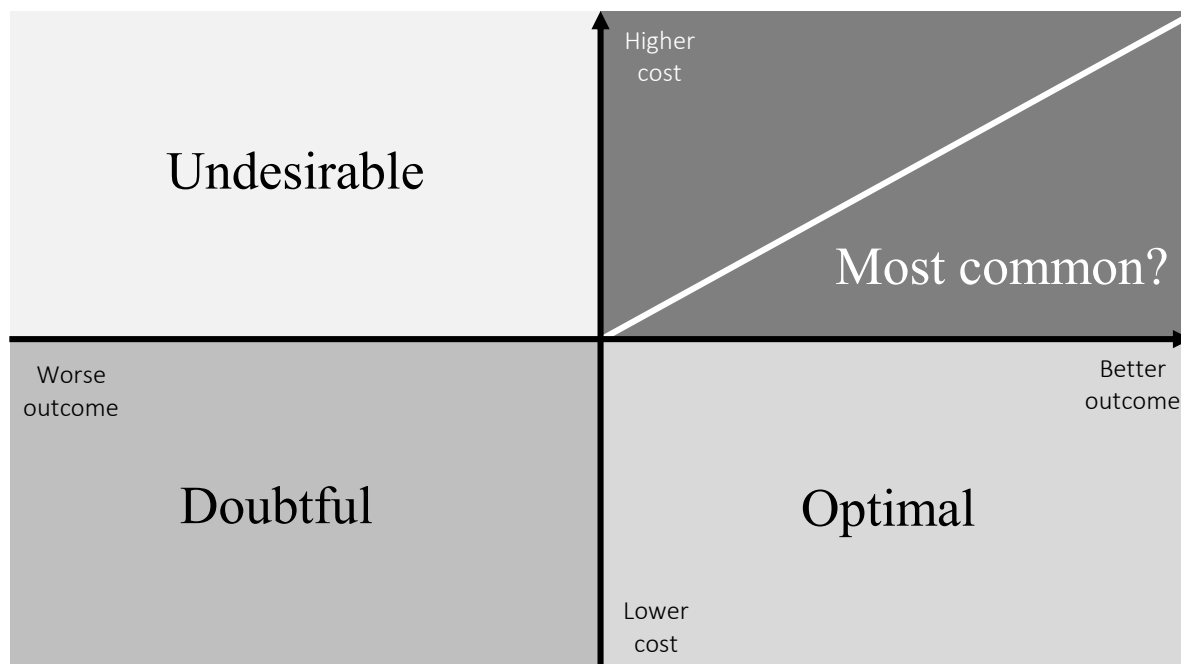
### **1.5.2 Types of economic evaluation**

The three main approaches to health economic evaluation—*cost-effectiveness analysis* (CEA), *cost-utility analysis* (CUA), and *cost-benefit analysis* (CBA)—are based on distinct assumptions about economy and equity and are appropriate in different situations and contexts in which specific types of comparisons are sought. Notably, many other types of analyses are also described in the literature, such as *cost-consequences analysis*, *cost-minimization analysis*, *be-*

*havioral cost analysis, budget-impact analysis, cost-efficiency analysis, cost-value analysis, health intervention and technology assessment, and relative effectiveness assessment* as well as a substantial number of CEA subcategories (*distributional CEA, sectoral CEA, etc.*) (Culyer & Chalkidou, 2019). In practice, however, CEA, CUA, and CBA remain the most common analytical approaches in health economic evaluation and will be the main focus here.

In a CEA, the costs of two or more healthcare interventions are related to a common outcome measure that may differ in magnitude between programs (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015b). As an illustration, one might want to compare the cost-effectiveness of inpatient treatment and a structured day treatment program for patients with AN, where common outcome measures could be, for example, symptom remission according to various rating scales, body weight restoration, or remission rates. Providing inpatient treatment is probably more expensive than a day treatment program, but may possibly also be associated with greater gains in terms of remission. Alternatively, the fact that inpatient treatment is costlier may to some extent be offset by more rapid gains, so that costs for a relatively brief hospital admission are not so much higher than the costs for a longer course of day treatment. In comparing these alternatives, an incremental cost per unit of effect is calculated; this is usually presented as an incremental cost-effectiveness ratio (ICER), where predefined thresholds can be applied to evaluate whether or not the different alternatives are to be seen as cost-effective.

One way to illustrate ICERs and to compare two or more interventions is using a *cost-effectiveness plane* (see Figure 1). In a cost-effectiveness plane, differences in effectiveness are plotted on the horizontal axis and differences in costs are plotted on the vertical axis (Cairns & Fox-Rushby, 2005c). Thus, if a novel treatment is more effective but also costlier than an older intervention, it will end up in the north-east quadrant—this is the most common scenario in evaluating novel interventions. In the south-east quadrant, the novel intervention dominates the old intervention in terms of both effectiveness and costs. In contrast, in the north-west quadrant, the old intervention is both more effective and cheaper than the new intervention (in practice, this is fairly uncommon, since novel interventions that fare worse in terms of effectiveness than older ones rarely reach the stage of economic evaluation). Finally, in the south-west quadrant, the novel intervention is cheaper but also less effective than the old intervention. Examples of this situation could involve, for example, online delivery of psychotherapeutic interventions, which may hypothetically be slightly less effective than face-to-face psychotherapy, but where the lower associated costs could mean that the intervention can be delivered to a larger number of patients, making it a worthwhile healthcare investment in spite of the differences in effectiveness. If, on the other hand, a novel treatment intervention is indeed both more effective and costlier than the old intervention, various techniques exist to evaluate whether it is “worth it” or not (Bala & Zarkin, 2002). Ultimately, one may have to resort to national or non-governmental organization guidelines outlining predefined cost-effectiveness thresholds (Culyer, 2015; Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015e; Marseille, Larson, Kazi, Kahn, & Rosen, 2015).



**Figure 1.** Cost-effectiveness plane. The four quadrants represent different combinations of changes in cost and changes in outcome, where the most common scenario for a novel intervention is probably that it is both more effective and more expensive than the old intervention. The diagonal line represents the ICER, which varies in different contexts.

A CEA is most valuable in situations where a decision maker is considering several available options in a specific field and within a limited budget (Drummond et al., 2015b). A limitation is that generic outcome measures are rarely used in CEAs, meaning that it is difficult to compare the relative cost-effectiveness of programs with unrelated outcomes that may still be administered within the same health care budget.

In order to solve this problem, a CUA can be employed. A CUA is usually described as a variant of a CEA, with the only difference being that in a CUA, generic outcome measures of health gain are used in order to enable cross-program comparisons (Drummond et al., 2015b). A common outcome measure in a CUA is quality-adjusted life years (QALYs)—a generic approach that integrates gains in terms of both reduced morbidity and mortality into one single measure (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015d). In the example described above, one could evaluate the effects of the different approaches to the treatment of AN in terms of both HRQoL (measured with rating instruments that can be combined with population-generated preference weights to yield a numeric outcome) and reduced mortality. The outcome in terms of QALYs gained may then be compared with programs in order fields, such as various treatment options for depressive disorder, in order to ascertain where available budget resources are best put to use. Because of the benefits of generic comparisons between different fields, CUAs are nowadays the most common published form of economic evaluation (Drummond et al., 2015b).



In a CBA, outcomes are instead translated into monetary value, which makes it possible to compare the costs and benefits of a single intervention, program, or policy in isolation and decide whether or not it is “worth it”—i.e., if the benefits outweigh the costs (Drummond et al., 2015b). Naturally, CBAs of several different programs can also be compared, but this is not necessarily the aim of an individual analysis. Traditionally, the CBA approach has mostly been employed in fields outside of healthcare, such as in evaluating costs and benefits of large infrastructure projects or of implementing environmental policies where an intervention has broad implications and “ripples on the surface” affecting several other areas can be expected (Cellini & Kee, 2015).

The main limitation in conducting a CBA in the healthcare sector is the difficulties associated with assigning monetary values to intangible health outcomes, such as QALYs gained, the prevention of long-term negative consequences of a certain condition, increased workforce productivity, or reduced need for unpaid assistance from relatives (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015c). In the example above, employing a CBA would involve valuing benefits such as patients with AN being able to return to work or school, reduced stress levels and increased workforce productivity of parents or caregivers, the prevention of potentially severe and disabling long-term complications such as enamel erosion or osteoporosis at a young age, etc. Needless to say, this is a very complex task involving lots of uncertainty which would have to be accounted for through careful sensitivity analysis (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015a).

Importantly, in framing a health economic evaluation, one must consider who the main audience is and what viewpoint to apply (Fox-Rushby & Cairns, 2005). For example, if the evaluation is intended to be used in policy-making in a broader societal setting (e.g., in comparing different budget sectors), one needs to include a fairly large number of relevant costs and benefits, such as opportunity costs for patients and their relatives and effects on sick leave. In contrast, a decision maker belonging to a specific organization, such as a hospital or a third-party payer, may prefer a narrower perspective that merely evaluates the optimal way of allocating resources within a healthcare service and disregards the broader societal costs and benefits.

An economic evaluation must also take into account that costs change over time. Therefore, in order to enable comparisons of costs and effects that differ in time, measures of discounting may need to be included in the analysis (Cairns & Fox-Rushby, 2005b). Discount rates are typically determined by the decision-making context, particularly the country in question. Although discounting may seem to be a highly technical issue, it also involves ethical considerations. For example, it is sometimes suggested that discounting is unfair to future generations (Cairns & Fox-Rushby, 2005b). The current generation may implicitly choose to underinvest in projects that would generate large benefits to future generations, simply because the smaller immediate returns does not make them seem worthwhile. Similarly, the current generation may attach little weight to distant costs that do indeed become burdensome for future generations.

The impact of the many assumptions typically made in an economic evaluation and the uncertainty of available clinical data need to be accounted for by undertaking a sensitivity analysis

(Claxton, 2008). Various techniques may be used depending on what type of uncertainty that needs to be assessed. A sensitivity analysis begins with the identification of all parameters or modelling approaches that involve uncertainty—usually, those variables that are the most uncertain, have the greatest sampling variability, are based on the weakest evidence, and influence the largest share of costs and effects are chosen for inclusion. A basic sensitivity analysis may then proceed with a one-way or multi-way exploration, whereby parameter numbers are altered within reasonable ranges one or many at a time to see how they influence the outcome of the evaluation (Walker & Miners, 2005). Threshold analysis (i.e., determining at what cut-off levels the conclusions of the evaluation change) or best-/worst-case scenarios may also be employed. Alternatively, for model-based evaluations, methods for probabilistic sensitivity analysis could be employed. This involves the consideration of all uncertain parameters simultaneously through a very large number of simulations, such as in a Monte Carlo analysis.

### 1.5.3 Underlying assumptions

One of the most interesting—and challenging—aspects of economic evaluation is the underlying assumptions about economy, equity, and society inherent to the various types of analyses described briefly above. Here, the concepts of *welfarism* and *extra-welfarism* as distinct analytical frameworks shape the scope of CBA, CEA, and CUA.

The welfarist approach to economic evaluation usually takes the form of a CBA, whereby program costs as well as health outcomes are valued in monetary terms, something that is often reflected in the use of willingness-to-pay methods (Coast, Smith, & Lorgelly, 2008). Welfarism is typically built around the idea of individuals rationally ordering available options and then choosing the one that maximizes their welfare (which may not necessarily be the same as maximizing health), a view that assumes that individuals themselves are best fit to judge what contributes most to their utility (Brouwer, Culyer, van Exel, & Rutten, 2008). Thus, the “goodness” of any given situation is derived solely by evaluating individual-perspective utility levels. This approach, however, can become problematic from a societal perspective in which the distribution and equity of utilities are important. Clearly, the heavy reliance on willingness-to-pay in measuring welfare in CBA may skew healthcare resources towards the wealthy (Coast et al., 2008).

Welfarism dominated health economics in the 1960s and 1970s, but from the 1980s and onwards, the extra-welfarist approach has become more favored (Buchanan & Wordsworth, 2015). In extra-welfarism, the exclusive focus on utility-derived notions of welfare present in traditional welfarism is rejected (Brouwer & Koopmanschap, 2000). Much of the literature concerned with extra-welfarism is based on the influential ideas of Indian economist and philosopher Amartya Sen. In the early 1980s, Sen introduced the concept of *capabilities* (Sen, 1987)—i.e., “the extent to which an individual is able to function in a particular way, whether or not he or she chooses to do so” (Coast et al., 2008, p. 1191)—as the important “entity” upon which to base an evaluation. Here, clearly, “goodness” is not only to be measured in the form of outcomes or utilities but rather in terms of freedom, equity, and capabilities. In the case of healthcare, the principal output according to an extra-welfarist framework is health; this stands

in contrast to traditional welfarism, where health is principally of interest only insofar as it results in increased individual utility through the consumption of healthcare (Coast et al., 2008).

In contrast to the welfarist emphasis on individual value—e.g., in employing willingness-to-pay techniques to elicit preferences—public or community preferences are usually the main focus in an extra-welfarist analysis (Coast et al., 2008). This interest in distributional welfare and equity means that even though preferences are still important in an extra-welfarism framework, a number of stakeholders other than the primarily affected individuals (e.g., the public/community or decision makers) are seen as more appropriate informants when assigning values. For this reason, extra-welfarism has been described as “inherently paternalistic” (Brouwer et al., 2008, p. 333). Views differ as to whether this is a good thing or a bad thing. The aim of economic analyses grounded in extra-welfarism (i.e., CEAs or CUAs) is to determine the least costly way to reach a particular goal, which has been predefined as important and worthwhile by somebody else than the primarily affected individuals. In a welfarist CBA approach, however, one of the goals is to determine whether the goal is at all worth achieving from an individualistic point of view (Buchanan & Wordsworth, 2015). With this in mind, it is obvious that a CEA/CUA approach is not just a less complicated version of a CBA, but in fact represents a distinctly different view on economy, health, and health-related preferences.

In sum, the differences among CBA, CEA, and CUA are not merely of a technical nature. Even if as a health economics analyst one may choose to approach these methods from a pragmatic point of view, one should be aware of the specific assumptions and ideologies that make up the foundations of the different analytical frameworks. In relation to the relatively rudimentary analysis of resource reallocation presented below, this introduction to health economic approaches may perhaps appear overly detailed. Even so, it is important to be mindful of the context and framework within which a health economic evaluation takes place in order to understand the specific conditions underlying the present self-admission program.

#### **1.5.4 And what about equity?**

In health economics as well as in medical ethics, *equity* refers to the fairness by which healthcare resources are distributed. Arguably, equity is an important area of economic evaluation for several reasons: it is usually a prominent policy objective, it is often at least partially incompatible with efficiency objectives, and it has far-reaching implications for resource allocation (Jan & Wiseman, 2011). The fact that equity is fundamentally about justice and fairness means that it will typically have different meanings for different people and in different contexts—no correct universal definition of equity exists.

Justice is one of four areas commonly described as cornerstones of medical ethics—the other three being respect for autonomy, non-maleficence (i.e., avoiding the causation of harm), and beneficence (i.e., benefitting others directly and/or relieving harm) (Beauchamp & Childress, 2013). Naturally, justice is an important aspect of many decisions in healthcare, in policy matters as well as in everyday clinical encounters. However, deciding on what is fair, just, and equitable is not a straightforward task. In discussions concerning priority setting and rationing,

two broad approaches can be outlined: a *utilitarian* strategy that aims to maximize benefits for patients and society, and an *egalitarian* strategy that highlight equal treatment and fair opportunities. These two approaches often emphasize different criteria in rationing scarce healthcare resources. In terms of medical priority-setting, the prospect of success is typically an important factor—in order not to waste valuable resources, this criterion demands that they should primarily be distributed to patients who have a reasonable chance of benefit (Beauchamp & Childress, 2013). Perhaps most evidently, *medical utility* is a factor of immediate relevance on many levels in medical decision-making, from emergency ward triage decisions to broader healthcare investments. According to this largely uncontroversial principle, those patients whose medical needs are greatest and/or most urgent are to be prioritized (Persad, Wertheimer, & Emanuel, 2009). In contrast, a highly controversial factor is *social utility*; e.g., prioritizing patients according to their perceived instrumental “worth” for society. However, in particular situations, such as prioritizing healthcare professionals for immunization during an outbreak of pandemic viral disease so that they can in turn provide healthcare for others, this principle is seen as less problematic (Beauchamp & Childress, 2013). Ultimately, most healthcare systems rely on many different principles for equitable allocation of healthcare resources simultaneously—a number of these are explored in more detail in the discussion of Study II below.

Importantly, equity is not the same thing as *equality*. For example, equal sharing of a good (such as healthcare resources) among groups may not at all be considered fair if one of the groups is disadvantaged from the outset. In many countries, distribution of healthcare resources is weighted so as to reflect the greater needs of certain groups in society, be it children, the elderly, immigrant or refugee populations, or indigenous people. Indeed, when governments intervene in the healthcare sector, it is often for reasons of ensuring equity (Jan & Wiseman, 2011). In discussing equity, the term *horizontal equity* is used to describe situations in which the objective is to treat people in equivalent circumstances in the same manner. In contrast, *vertical equity* refers to the notion of treating people differently when their level of need differs, i.e., “trying to lessen the gap between the ‘haves’ and the ‘have nots’ through preferential treatment of the latter” (Jan & Wiseman, 2011, p. 253). In practice, vertical equity is often more difficult to implement, due to the complex considerations involved when it comes to meeting various needs differentially. However, horizontal equity may also be complicated to achieve; for example, individuals who are provided with the same access or opportunity to use healthcare resources may comply to different degrees, resulting in different patterns of utilization among those with equal needs.

## 1.6 AIMS AND HYPOTHESES

In August 2014, the self-admission program at SCÄ was launched as part of a broader self-admission initiative in the Stockholm County Council. This is the first time that self-admission has been offered to patients with an eating disorder. Most participants suffer from treatment-refractory AN, but the program does not exclusively target this group; it is fully possible that patients with long-standing BN or other eating disorder presentations may be able to make use of the model too.

The overarching aim of the present thesis project was to explore whether self-admission to inpatient treatment is a viable and effective intervention in the treatment of patients with severe AN. As described in more detail in the Methods section, a mixed methods approach was employed to allow for the simultaneous evaluation of the self-admission program from multiple viewpoints and the integration of various types of outcome data.

The specific objectives of **Study I** were to explore patients' experiences of participating in a self-admission program at a specialist eating disorder service and to identify helpful aspects, barriers, and areas of potential improvement.

The objectives of **Study II** were to explore the implications of the novel concept of self-admission from the perspectives of medical ethics, resource allocation, and priority setting in healthcare. Hence, Study II can be described as a formative study, setting the stage for the health economic evaluation presented in Study IV.

The objectives of **Study III** were to evaluate quantitative outcomes in terms of healthcare utilization, eating disorder morbidity, HRQoL, and sick leave. Thus, for Study III, a number of variables were assessed at inclusion and after 12 months in the program, making use of rating instruments as well as data from national healthcare and social security registers. Here, it was hypothesized that—similar to the outcomes observed in the Norwegian pilot studies on patients with mainly psychotic or affective disorders—participants would reduce their overall utilization of inpatient treatment (in terms of days spent hospitalized). Moreover, it was hypothesized that their HRQoL would be improved and that the days spent in sick leave would be reduced. It was also hypothesized that participation in the self-admission program would promote at least modest improvement in terms of eating disorder morbidity (i.e., a reduction of eating disorder cognitions as reflected by disorder-specific self-rating instruments and improved BMI).

The objectives of **Study IV** were to utilize the information and data generated by studies II and III in order to create a model for the economic evaluation of the self-admission program. The main focus was to establish whether, from a healthcare service provider perspective, the reallocation of resources associated with the introduction of self-admission is justified, so that the reduction of hospital beds available for regular patients on the waiting list is offset by the observed reduction in healthcare utilization for the program participants. Here, it was hypothesized that participants' utilization of inpatient treatment would be reduced to such an extent that more resources would ultimately be made available to non-participants.



## 2 METHODS

### 2.1 SETTING: SELF-ADMISSION AT THE STOCKHOLM CENTRE FOR EATING DISORDERS

This thesis project was undertaken at SCÄ, which is a public sector specialist service for the treatment of eating disorders in Stockholm, Sweden operated by the Stockholm County Council. The catchment area is Metropolitan Stockholm with a population of 2.2 million. Treatment at the hospital is publicly funded, with only minor patient fees in consonance with all Swedish public healthcare. The per diem patient fee for inpatient treatment (regular as well as self-admission) is currently equivalent to 10 United States dollars.

Treatment at SCÄ is offered in outpatient, inpatient, and/or day patient format. Separate outpatient services treat adults; children, teenagers, and their families; and adult patients with severe and enduring illness. One inpatient ward treats adults and one treats children and teenagers who are typically hospitalized along with their parent(s). Two different day patient programs serve patients aged 16 years and older: one intensive program where patients are in treatment every weekday for three months, and one interval program where patients are in treatment every third week over a longer period of time. For children, teenagers, and their families, SCÄ offers a day treatment program with a multifamily therapy focus. For adult patients, treatment at SCÄ is based on CBT in accordance with national guidelines (Wallin et al., 2015), whereas treatment for children and teenagers usually focuses on FBT.

Since 2014, two hospital beds out of eleven at the adult inpatient ward—i.e., 18.2% of available beds—are reserved for patients in the self-admission program. Regular admissions to the remaining nine beds are mainly initiated by the outpatient units on an elective basis; these are usually voluntary admissions, although involuntary commitment according to Swedish law also occurs. Due to the often prolonged nature of these regular admissions, the patient turnover at the ward is low and there is typically a several weeks wait for regular admissions. No emergency admissions are available; instead, emergency cases are routinely handled by general psychiatry or somatic healthcare. Treatment at the adult inpatient ward is reserved for the most severely ill patients; this typically involves patients with severe AN but patients suffering from other eating disorders are also hospitalized occasionally. Treatments revolve around renourishment aided by meal support, various forms of group therapy, individual therapy, physiotherapy, and medical management. Overall, the inpatient treatment provided at the hospital is best described as *residential care* in some countries; the environment at the ward is more homelike than in a typical hospital ward, patients sleep in regular beds rather than in hospital beds, and there is a hobby room with plenty of art supplies.

To be eligible for the self-admission program, patients must maintain continuous treatment contact at the adult outpatient or day treatment units. They must also have had at least one treatment episode in the adult inpatient ward within the past 3 years, so that they are familiar with the treatment framework. Exclusion criteria for the program are current suicidal or high-risk self-injurious behavior, the presence of an untreated substance use disorder, and/or medical in-

stability requiring urgent somatic inpatient treatment. These are the same exclusion criteria used for regular inpatients at the ward. No criteria specifically related to BMI are applied. Usually, participation in the program is suggested by a patient's treatment contact at the inpatient ward or outpatient clinic and an in-depth discussion of the rationale behind the model takes place before the patient makes a decision about participation.

Participants can admit themselves at will for a maximum of 7 days by contacting the ward directly. Admission is possible between 8 AM and 7 PM, due to staff working hours that make it difficult to assign a nurse for the intake procedure during evenings and nights. If both designated self-admission beds are already occupied by another patient in the program, a waiting list is established. There is no explicit limit on how often participants can self-admit—in theory, patients can discharge and readmit themselves right away as long as there is no other patient on the waiting list. Upon arrival at the ward, they do not see one of the ward consultant psychiatrists, as would be the case in a regular admission. Instead, for self-admitted patients, one of the ward nurses conducts a brief intake interview focused on the main reasons for admission and what the patient hopes to achieve during their stay. Importantly, the patients' motives for choosing to self-admit are not questioned. Naturally, if the nurse notes that the patient is severely emaciated or that s/he displays suicidal intention, a consultant psychiatrist or a physician on call can always be asked to see the patient and decide if a different level of care is needed.

The self-admission contract is valid for 12 months, with the possibility of renewal annually—some patients have participated in the program for several years, whereas others choose to end their participation after the first year. Importantly, self-admission is constructed as an add-on treatment option and regular admission is still available for participants if necessary.

## **2.2 OVERALL STUDY DESIGN: A MIXED METHODS APPROACH**

In mixed methods research, elements of qualitative and quantitative research methodologies are combined for the purpose of achieving a greater breadth and depth of understanding (Curry & Nunez-Smith, 2015). Traditionally, a quantitative research approach has dominated medical research. However, many contemporary phenomena and tendencies in healthcare are difficult or even impossible to explore with the use of solely quantitative methods. The integration of research approaches rooted in different disciplines and traditions “enables researches to seek a more panoramic view of their research landscape, viewing phenomena from different viewpoints and through diverse research lenses” (Shorten & Smith, 2017, p. 74). This usually requires collaboration among team members trained in various disciplines, application of diverse perspectives, and use of different professional languages—naturally, this can be a challenge, but also an extraordinary asset.

Importantly, mixed methods research goes beyond the mere use of different methodologies side by side. A mixed methods approach requires a purposeful study design in terms of timing of and relation between the different study components and an iterative integration of qualitative and quantitative findings. The aim is synergy, where a combination of methodologies



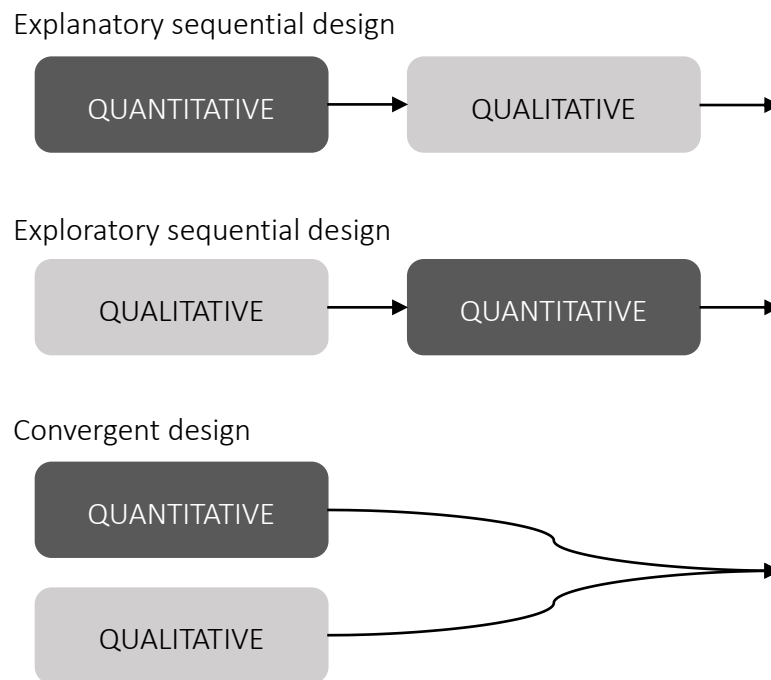
ideally results in an in-depth multifaceted understanding that could not be achieved by simply conducting a quantitative and a qualitative study in parallel.

Qualitative and quantitative research approaches have a number of fundamental differences that need to be carefully considered (Curry & Nunez-Smith, 2015). For example, the starting point in quantitative research is typically a number of known premises that, taken together, result in a logical conclusion in a “top-down” manner. In contrast, insights in qualitative research are typically reached “from the ground up” so that specific observations are used to reach a conclusion of more general nature. Quantitative research explores the *breadth* of a phenomenon generated by sampling units and test hypotheses, whereas qualitative research aims to produce a *depth* of understanding generated by studying cases and to generate hypotheses. In quantitative research, the setting can be either *experimental* or *naturalistic*; in qualitative research, the setting is typically *naturalistic*. Ideally, sampling of the study population is *random* in quantitative research, whereas qualitative research relies on *purposeful* sampling (also known as non-probability sampling) where the researcher deliberately includes informants with direct experience of the focal topic. In quantitative research, the sample size needs to be large enough to establish *representativeness*; in qualitative research, sample sizes are typically smaller, guided by data *saturation*. Quantitative research makes use of *numerical* data, whereas qualitative research typically utilizes *narrative* data. Data analysis in quantitative research relies on *statistical methods*; in qualitative research, data such as interview transcripts are *iteratively interpreted*. Finally, in quantitative research, *external validity* and *generalizability* of the findings are sought; i.e., it should be possible to make inferences from the sample population that are valid in the population at large. In contrast, qualitative research focuses on *transferability*, where the readers are invited to make connections between the study setting and their own context to decide if the findings are relevant for them.

These differences can make direct comparison or merging of quantitative and qualitative data difficult. However, in mixed methods research, the different perspectives can ideally be used in a complementary way so that the qualities of each method are emphasized and enhanced in relation to the overarching research question. Inconsistencies between quantitative and qualitative data in mixed methods research may in fact highlight important areas of discovery that need to be further examined (Curry & Nunez-Smith, 2015). (See, for example, the Discussion section of this thesis for a discussion of discrepancies between quantitative and qualitative HRQoL data among participants in the self-admission program.)

Combining qualitative and quantitative data requires careful consideration when it comes to study design and timing. Generally, three different mixed methods designs can be used (see Figure 2) (Curry & Nunez-Smith, 2015). In an *explanatory sequential* design, the quantitative study component precedes the qualitative component. Here, collection and analysis of quantitative data are completed first, typically generating findings that are incomplete or difficult to interpret. The qualitative component is then conducted in order to clarify and explain the quantitative findings. In contrast, in an *exploratory sequential* design, the qualitative study component occurs first, generating hypotheses that can then inform the quantitative component. Third,

in a *convergent* design, the quantitative and qualitative components are conducted simultaneously. After the parallel data collection, various approaches to the subsequent integration of findings, such as *merging* or *embedding*, exist. Additionally, embedding a qualitative component in a quantitative study of a complex intervention has become increasingly popular—here, the qualitative component can shed light on, for example, why the intervention did or did not work and how real-world circumstances promoted or limited its use (Curry & Nunez-Smith, 2015).



**Figure 2.** Mixed methods designs (adapted from Curry & Nunez-Smith, 2015).

In the case of the self-admission program at SCÄ, quantitative, qualitative, and health economic perspectives were all seen as important facets to study. Quantitative components, such as studying changes in terms of healthcare utilization, eating disorder morbidity as reflected by symptom rating scales and BMI, HRQoL as measured by self-report instruments, and sick leave, can of course illuminate important aspects of the self-admission intervention: How does self-admission affect the overall healthcare utilization in patients with severe AN? Can it, in spite of the brief nature of the self-admission episodes, somehow aid participants in striving for recovery? Does it in fact, as hypothesized, improve their self-rated HRQoL and promote the ability to maintain workplace contact?

Qualitative components can give insight into important aspects of how participants experience and make use of the self-admission program: What aspects of the program are seen as particularly helpful? Are there, in contrast, aspects that hinder an optimal use? Has the self-admission program been implemented and delivered as intended in the real-world setting of the SCÄ adult inpatient ward?

The health economics component—integrating findings generated through quantitative, qualitative, and ethical analyses—can provide the evidence that service providers and healthcare policy makers need in order to justify and plan further health services changes: Is the reallocation of healthcare resources associated with the introduction of a self-admission program justified? Does the program target the severely ill group that it is intended for? Are there any crowding out effects for non-participants?

All things considered, evaluating the self-admission program at SCÄ is a prime example of a task that calls for a mixed methods study (Curry & Nunez-Smith, 2015). For the present study, a convergent design was used where collection of quantitative and qualitative data was begun and performed simultaneously. However, since not all participants were included in the self-admission program at once but rather sequentially over the period of several years, data saturation in the qualitative component was reached at a much earlier point than the completion of the quantitative component. This meant that findings from the qualitative component were indeed possible to use in order to inform the interpretation of the quantitative component as well as in the design of the health economic evaluation, resembling an exploratory sequential design.

Unfortunately, even though self-admission can be characterized as an experimental approach per se, it was not feasible to conduct a formal experimental study (such as an RCT) of the self-admission program at SCÄ. Inspired by the promising results from the Norwegian pilot studies, the Stockholm County Council decided early on that self-admission should be made widely available and rolled it out on a broader scale, although the clinical effectiveness of the model had not yet been fully established. This decision meant that it was not possible to randomly allocate eligible patients to different study arms—i.e., active participation in the self-admission program or a control condition such as TAU—since this would have involved offering patients treatment on unequal terms, which is not usually seen as acceptable once a treatment intervention has been established and confirmed by government agencies as the treatment of choice and a standard option. Instead, the self-admission program at SCÄ had to be evaluated using a cohort study design. The highly naturalistic setting of the study is reflected in the design of all study components: quantitative, qualitative, and health economic.

## **2.3 QUALITATIVE METHODS**

### **2.3.1 Informants**

For the qualitative part of the study, the first 16 participants in the self-admission program at SCÄ (15 women and one man) with a mean age of 31 years (range 18-56, median 27) were enrolled as informants. At inclusion, these informants had been suffering from a restrictive eating disorder for a mean of 15 years (range 3-42, median 11) and their mean BMI was 15.8 kg/m<sup>2</sup> (range 10.2-20.6, median 15.5). During their first 6 months in the program, 14 of these informants had made use of the opportunity to self-admit, while two of them had not.

### **2.3.2 Interview procedure**

All informants were interviewed at 6 months after inclusion in the self-admission program, regardless of whether they had actually self-admitted. A semi-structured interview manual was prepared, defining the research questions that were to be investigated during the interviews. Certain questions in the interview manual differed based on the individual informants' use of their contract; for example, those informants who had never actually self-admitted during their time in the program were asked specific questions about the reasons behind this, whereas they could naturally not be interviewed about their experiences of the admission process and being a self-admitted patient at the ward. All interviews were conducted face-to-face by a single interviewer, who was not involved in the treatment at the inpatient ward. During the interviews, an open interview technique was applied whereby all informants were asked the same opening question ("Could you please tell me about your experiences so far in the self-admission program?"), after which they were asked open-ended follow-up questions appropriate to the topics brought up in the conversation ("Are there any positive aspects of self-admission?", "Are there any negative aspects of self-admission?", "Has your participation in the program affected your everyday life in any way?").

### **2.3.3 Qualitative content analysis**

All interviews were audio recorded and transcribed verbatim by the interviewer. The transcribed interviews were analyzed using the qualitative analysis software program NVivo 11. A qualitative content analysis approach was applied (Hsieh & Shannon, 2005; Schreier, 2012) whereby those excerpts of the interview text that was regarded as meaningful in relation to the research questions were coded and labelled according to a "bottom-up" principle. In an initial round of content analysis, the interviews were coded freely by me, yielding 72 separate coding categories. The two persons mainly responsible for data coding then jointly reviewed these categories and grouped them into main themes and subthemes. There were no predefined criteria (e.g., number of informant statements needed) to aid in determining what would constitute a separate theme or subtheme; instead, after the initial "bottom-up" approach had yielded a number of statement categories, meaningful clusters were identified and developed inductively by analyzing patterns and interrelations and labelled so as to reflect nuances within the themes. Using this preliminary data coding scheme, the two analysts separately re-analyzed the interviews and modified the coding scheme accordingly, adding newfound themes and re-grouping the theme hierarchy when needed. A data coding scheme with four main themes, each with a number of subthemes (see Results), was eventually agreed upon. With this updated data coding scheme, me and my co-analyst went back and separately re-coded the interviews in a "top-down" approach to make sure that the coding scheme was now accurate and reliable. At this point, an interrater reliability of 91% was reached. For those statements where the analysts differed in their coding, consensus was reached through discussion. After 12 interviews, no new codes emerged and the interview material was thus considered as saturated; i.e., even if more interview material would increase the amount of information, it was unlikely to lead to the emergence of new topical themes.

The quotes used in the Results section were translated from Swedish into English by the interviewer and verified by the rest of the author group behind Study I.

## **2.4 QUANTITATIVE METHODS**

### **2.4.1 Participants and comparison groups**

For the quantitative part of the study, the outcomes at 12-month follow-up for participants in the self-admission program were analyzed alongside those of two comparison groups in a cohort study design. All 34 patients who were offered to participate in the self-admission program at SCÄ between August 2014 and February 2019 were invited to participate in the quantitative study. None declined to have their healthcare utilization data collected, although a few did not actively participate in completing baseline or follow-up questionnaires. Therefore, *n* varies somewhat for different quantitative outcome parameters presented in the Results section. Six participants ended up staying in the program less than 6 months (due to ending the treatment contact at SCÄ because of remission, suicide attempt, or substance use) and were not assessed at 12-month follow-up. Therefore, a total of 29 participants constituted the participant cohort for the quantitative part of the study. One patient committed suicide after 11 months in the program; her data up until that point were included in the analyses. For the remaining 28 participants, data on their first 12 months in the program were included. All participants had an AN diagnosis as defined in the ICD-10 (albeit in some cases in partial remission). Many, but not all, fulfilled suggested criteria for SE-AN (Wonderlich et al., 2020).

A larger comparison group was established using the nationwide eating disorder database Stepwise, which has been found to be valid and reliable (Birgegård, Björck, & Clinton, 2010; Emilsson, Lindahl, Köster, Lambe, & Ludvigsson, 2015). During the years covered by this study, data on patients in treatment at specialist eating disorder services throughout Sweden were routinely entered into Stepwise, and individuals from this source thus represent a TAU population in comparison to the participants who received eating disorder specialist treatment with self-admission as an add-on tool. By definition, the individuals identified in the Stepwise register were enrolled in eating disorder specialist treatment and had access to inpatient treatment, although the exact access may vary somewhat according to geography. Participants and the comparison group were matched based on age, duration of illness, and BMI. An attempt to use gender as a matching parameter was made, but this was not possible due to a low number of men in corresponding age spans. Eating disorder diagnosis was not used as a matching parameter; it was assumed that since all participants had an AN diagnosis, using BMI as matching parameter would result in an adequate diagnostic match. Ethical permits allowed for a 1:10 ratio of participants to comparison group; however, due to a scarcity of individuals with matching severity of illness in the register, a 1:4 ratio was achieved. However, for two participants it was only possible to identify two and three adequate matches, respectively. Thus, the comparison group comprised 113 individuals in total who were included in the Stepwise register between 2013 and 2017.

As described in the Results section, although a satisfactory baseline match was achieved in terms of age, gender, duration of illness, and BMI, the two groups differed in terms of previous healthcare utilization—this was largely due to the fact that a majority of individuals in the comparison group had no days in inpatient treatment in the 12 months prior to inclusion in the Stepwise database. Therefore, the larger comparison group is referred to as the “low-utilization comparison group”. Separate sensitivity analyses were performed whereby only those individuals in the larger comparison group who had received inpatient treatment in the 12 months before baseline were included. In the following, this group, comprising 27 individuals who were a somewhat better match in terms of days spent in inpatient treatment, is referred to as the “moderate-utilization comparison group”.

Additional data on comorbidity were retrieved from the National Patient Register (see below). Data on the occurrence of binge-purge behaviors as part of a patient’s eating disorder were retrieved from the Stepwise register.

## **2.4.2 Outcome measures**

### *2.4.2.1 Healthcare utilization*

For analyzing healthcare utilization, this study makes use of the high-quality nationwide registers maintained by the Swedish government, which covers the Swedish population in its entirety (Ludvigsson et al., 2016). Specifically, data on the number of days in and frequency of inpatient treatment, number of days in involuntary inpatient treatment, and number of outpatient visits during 12 months prior to and after baseline were retrieved from the National Patient Register, kept by the Swedish National Board of Health and Welfare. Specific data on participants’ self-admission episodes were retrieved from patient records.

### *2.4.2.2 Eating disorder morbidity*

To evaluate impact on eating disorder morbidity, changes in BMI, Eating Disorders Examination Questionnaire (EDE-Q) 6.0 scores, and Clinical Impairment Assessment Questionnaire (CIA) 3.0 scores between baseline and 12-month follow-up were assessed. EDE-Q is a self-report instrument consisting of 28 items and three additional questions that measures features of psychopathology related to an eating disorder, generating a global score and scores on four subscales: restraint, eating concern, shape concern, and weight concern (Fairburn & Beglin, 2008, 1994). CIA is a 16-item self-report instrument measuring the severity of psychosocial impairment due to an eating disorder (Bohn et al., 2008; Bohn & Fairburn, 2008). EDE-Q and CIA have both been translated and validated for use in a Swedish setting (Welch, Birgegård, Parling, & Ghaderi, 2011). Moreover, the Global Assessment of Functioning (GAF) scale included in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 1994) was used. Unfortunately, the number of individuals in the comparison groups with available follow-up data on eating disorder morbidity and GAF were too small to allow for meaningful statistical analyses.

#### 2.4.2.3 *Health-related quality of life*

To evaluate impact on participants' HRQoL, the generic preference-based self-report instruments EQ-5D-3L (from here on referred to as EQ-5D) and the Short Form 36 (SF-36) were used, both of which are widely used measures of general health in clinical studies throughout the world. EQ-5D assesses five attributes of health—mobility, self-care, usual activities, pain/discomfort, and anxiety/depression—on three severity levels (Drummond et al., 2015d). The instrument also contains a visual analog scale (VAS) where respondents rate their overall health state on a 0-100 scale. The respondent answers on EQ-5D can be transformed into a single-index health status value, which has been developed using a time trade-off approach (Drummond et al., 2015d). In the present study, country-specific experience value sets for Sweden were used (Burström et al., 2014). SF-36 consists of 36 items generating eight dimension scores and two summary scores for physical and mental health. These scores can then be transformed into a single-index measure known as SF-6D, which has been developed based on standard gamble measurements (Drummond et al., 2015d). Since no country-specific SF-6D preference value set is available for Sweden, utility scores developed in the United Kingdom and licensed by the University of Sheffield were used (Brazier, Roberts, & Deverill, 2002). Participants' HRQoL was assessed at baseline and at 12 months follow-up; however, it was not possible to obtain HRQoL data for the comparison groups.

#### 2.4.2.4 *Sick leave*

Data on sick leave for participants and comparison groups were retrieved from the Longitudinal Integrated Database for Health Insurance and Labor Market Studies (LISA) at Statistics Sweden, which comprise aggregated data from the Swedish Social Insurance Agency (SIAS). All Swedish residents aged 16-64 years are covered by universal health insurance and receive economic support if their ability to work is limited due to sickness, injury, or disability. Various forms of benefits exist. For the present study, data on sick leave, sick leave for rehabilitation, and disability leave (from here on collectively referred to as “sick leave”) were collected. The first day of sick leave is not compensated and the 13 days that follow are compensated by the employer. After this, the benefits are paid for by SIAS. Therefore, periods of sick leave shorter than 14 days are not registered in the database, except for students and the unemployed. At the time of analysis, data on sick leave up until 2017 were available in the LISA database. For a small number of participants who were included after January 1, 2018, additional sick leave data were obtained from patient records.

### 2.4.3 **Statistical analysis**

An a priori estimation of statistical power using G\*Power 3.1.9.2 based on the medium effects sizes seen in available Norwegian data (Strand & von Hausswolff-Juhlin, 2015) and assuming a two-sided null hypothesis of no effect suggested that power above 80% would be achieved at a level of 26 participants.

For all statistical analyses, IBM® SPSS® Statistics 26 was used. For data on eating disorder morbidity and HRQoL before and after inclusion, paired t-tests were performed. For data on

healthcare utilization during the 12 months before and after inclusion, exploratory analyses revealed that the differences between pairs were generally not normally distributed. Thus, for these data, Wilcoxon signed-rank tests were performed.

Regarding sick leave, aggregated data are available in the LISA database at full-year level only. Thus, in the assessment of changes in sick leave, data were analyzed over three time-points: the full year before inclusion, the full baseline (inclusion) year, and the full year after inclusion. Mauchly's sphericity test showed that sphericity could be assumed for participant and moderate-utilization comparison group data but not for the low-utilization comparison group data. A repeated measures analysis of variance (ANOVA; with Greenhouse-Geisser correction for the low-utilization comparison group) was then performed.

In all analyses, an  $\alpha$  level of  $< .05$  was considered statistically significant. Bonferroni corrections were also applied to account for multiple comparisons. For statistically significant paired t-tests, Cohen's  $d$  effect sizes were calculated, considering values around 0.2 as small, 0.5 as medium, and 0.8 as large (Fritz, Morris, & Richler, 2012). For statistically significant Wilcoxon signed-rank tests, the matched-pairs rank-biserial correlation suggested by Kerby was chosen in assessing effect sizes (Kerby, 2014).

## **2.5 HEALTH ECONOMIC METHODS**

### **2.5.1 Perspective, participants, and data collection**

For the health economic analysis, a healthcare provider perspective on the resource reallocation associated with self-admission was adopted. All participants in the quantitative component of this thesis were included in the health economic analysis. For analyzing changes in healthcare utilization, additional data on participants' self-admission episodes and number of participants in the program were retrieved from patient records. Naturally, as described in the section on health economics above, changes in eating disorder morbidity—such as increased BMI or symptom remission—and HRQoL can impact on cost-effectiveness from a service provider perspective as well as from a patient perspective. However, since these outcomes turned out to be largely unaffected by participation in the self-admission program (see results from Study III below), they were not included as parameters in the economic evaluation.

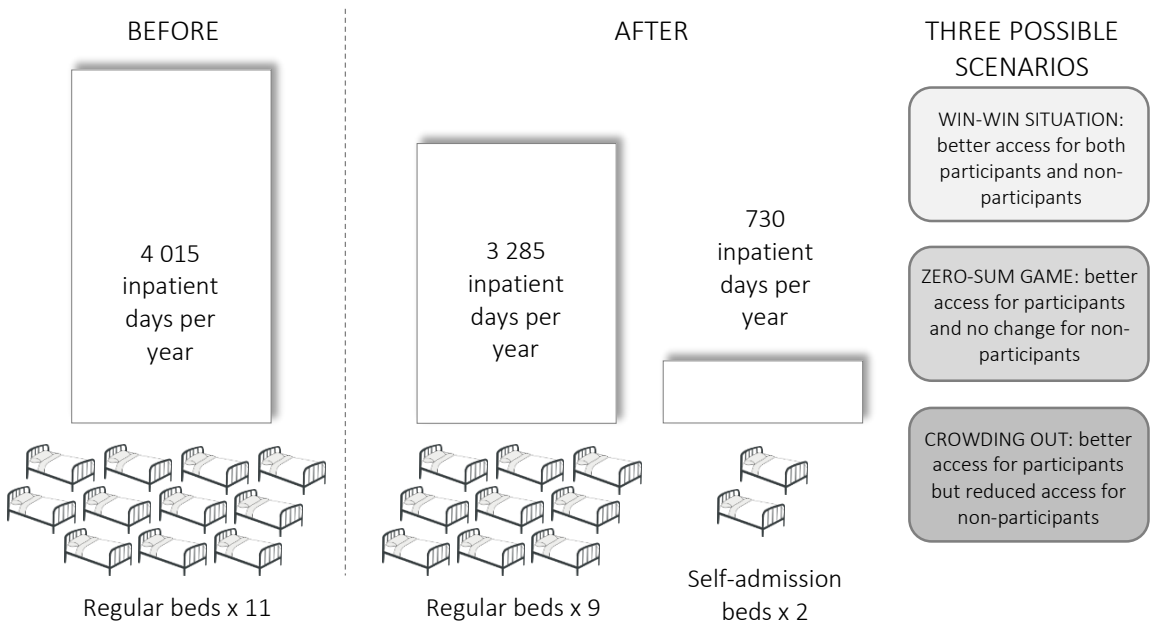
### **2.5.2 Costs**

From 2014, when the self-admission program at SCÄ was launched, until the end of 2018, the costs associated with regular hospital beds and self-admission beds were remunerated differently within the purchaser-provider model employed by the Stockholm County Council. For regular hospital beds, SCÄ (i.e., the service provider) received a fixed sum per inpatient day and the remuneration therefore varied according to bed occupancy. For self-admission beds, in contrast, remuneration was received as a fixed sum based on full bed occupancy—without such an arrangement, incentives for overuse of the self-admission beds would be created, since self-admission presupposes that the designated beds are not always occupied. In practice, however, regular hospital beds at SCÄ are always fully utilized due to high demand and low patient turn-



over as described above. Therefore, the separate models of remuneration did not lead to any overall differences in costs per inpatient day between the self-admission program and regular inpatient treatment. Since 2019, after renegotiated purchaser-provider contracts, both forms of inpatient treatment are remunerated in the same manner, as fixed sums. On the whole, this change had no net effect on the data used here.

Start-up costs in the program mainly included staff education and the printing of patient information material. As self-admission is based on reallocation of existing resources, no additional inventorial costs were accrued. Even so, although the self-admission intervention is not technically complicated, it represents a novel way of thinking about healthcare rationing and patient involvement that staff may be unaccustomed to. Therefore, certain initial efforts are needed to familiarize them with the model. However, experiences from SCÄ (Strand, Gustafsson, Bulik, & Hausswolff-Juhlin, 2017) show that it was fully possible to incorporate these activities into regular staff meetings and continuous education. Likewise, the printing of patient information folders represented a very minor cost. Overall, the start-up costs in a self-admission program are negligible and have not been included in the present analysis.



**Figure 3.** Resource reallocation in the self-admission program at SCÄ.

Taken together, although there are no direct costs associated with the self-admission program—the fixed healthcare service budget remains the same and no resources (financial or other) are added—there are opportunity costs from displaced activities in the form of 730 inpatient days per year (2 beds x 365 days) that are no longer available for regular patients at SCÄ (see Figure 3), regardless of how many of these inpatient days that are in fact instead utilized by program participants. The health economic analysis is primarily concerned with whether this opportunity cost is offset by a large enough reduction in the number of days that program participants

spend in inpatient treatment. Although limited in scope, this approach is somewhat similar to a distributional CEA in that it takes into account equity concerns related to the opportunity cost of displaced activities within a fixed healthcare service budget (Cookson et al., 2017). However, a traditional CEA—i.e., establishing an ICER by relating costs to clinical outcomes—was not feasible, due to the fact that the main clinical outcome variables apart from healthcare utilization (i.e., eating disorder morbidity and HRQoL) turned out to be largely unaffected.

### **2.5.3 Time horizon**

In the reallocation of resources associated with self-admission, opportunity costs and benefits (i.e., reduction in participants' time spent hospitalized) are generated over the same time horizon—in this particular study, over the course of 12 months. An exception may be the initial startup costs, which are negligible (see above). Accordingly, no discounting has been applied in the analysis.

### **2.5.4 Statistical analysis**

As noted above, in analyzing the cohort study data that Studies III and IV are based on, Wilcoxon signed-rank tests were performed for changes in healthcare utilization due to the fact that the differences between pairs were generally not normally distributed. This notwithstanding, for the health economic evaluation paired t-tests were also performed in order to calculate a 95% confidence interval (CI) for sensitivity analysis purposes. Utilizing paired t-tests or Wilcoxon signed-rank tests did not alter the statistical significance of the findings. To account for stochastic parameter uncertainty, 95% CIs for the healthcare utilization estimates were then used.

## **2.6 ETHICS, PREREGISTRATION, AND ADHERENCE TO REPORTING GUIDELINES**

All procedures were conducted in accordance with the Helsinki declaration. The study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Nos. 2014/1586-31, 2015/1537-32, 2018/1184-32, and 2020-00831). Informed consent was obtained from all participants prior to inclusion. The study protocol was preregistered at ClinicalTrials.gov (ID: NCT02937259). Notably, the protocol was later updated and aligned with other studies in the field to allow for the use of matched comparison groups as described above. In reporting the findings, relevant guidelines have been adhered to: for Study I, the Standards for Reporting Qualitative Research (SRQR) recommendations (O'Brien, Harris, Beckman, Reed, & Cook, 2014); for Study III, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement (von Elm et al., 2007); and for Study IV, the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement (Husereau et al., 2013).

## 3 RESULTS

### 3.1 STUDY I: QUALITATIVE COMPONENT

Four themes and 16 subthemes emerged from the interview data (see Figure 4). In general, the participants described a high level of satisfaction with the self-admission program and they all said that they would recommend enrollment to others in similar situations. Participants appreciated the agency and flexibility associated with the model and described a number of potential benefits of self-admission in various life situations. However, they also highlighted personal and/or contextual requirements that should ideally be met in order to make use of self-admission in an optimal way. Moreover, several participants had experienced barriers—logistic and otherwise—that needed to be transcended.

#### 3.1.1 Agency and flexibility

A number of participant statements described advantages as well as potential pitfalls associated with the emphasis on agency, responsibility, and flexibility in the self-admission model. Two

Agency and Flexibility ( <i>n</i> =16)	<ul style="list-style-type: none"> <li>•Agency (<i>n</i>=15)</li> <li>•Flexibility (<i>n</i>=14)</li> </ul>
Functions ( <i>n</i> =16)	<ul style="list-style-type: none"> <li>•Security (<i>n</i>=13)</li> <li>•Boosting healthy routines (<i>n</i>=13)</li> <li>•Preventing deterioration and prolonged hospital admissions (<i>n</i>=13)</li> <li>•Motivational support (<i>n</i>=13)</li> <li>•Getting a break (<i>n</i>=9)</li> <li>•Relieving relatives (<i>n</i>=11)</li> </ul>
Barriers ( <i>n</i> =14)	<ul style="list-style-type: none"> <li>•Ambivalence (<i>n</i>=14)</li> <li>•Other patients (<i>n</i>=10) <ul style="list-style-type: none"> <li>•Others may be in greater need (<i>n</i>=5)</li> </ul> </li> <li>•Triggering environment (<i>n</i>=9)</li> <li>•Difficult being a select group/role model (<i>n</i>=4)</li> <li>•Admission presupposes deterioration (<i>n</i>=6)</li> <li>•Fear of being forced to stay longer (<i>n</i>=3)</li> </ul>
Applicability ( <i>n</i> =16)	<ul style="list-style-type: none"> <li>•Simultaneously requires and fosters motivation and maturity (<i>n</i>=14)</li> <li>•Requires encouragement (<i>n</i>=13)</li> <li>•Risks becoming self-destructive (<i>n</i>=10)</li> <li>•Risks impeding independence (<i>n</i>=5)</li> </ul>

**Figure 4.** Themes and subthemes, including data on how many of the participants that raised each theme/subtheme.

subthemes emerged. First, “Agency” was seen as a core feature of the self-admission concept. Participants described how the focus on patient participation and involvement lead to novel ways of thinking about treatment and about themselves as patients:

“It’s very important for me. I have a high level of integrity. And that’s what’s so fantastic about this: it’s a whole new approach.”

“Now when you talk to a doctor at the ward, they listen to what you say and actually reflect upon it instead of just looking at you like you’re trying to fool them or like you have ulterior motives.”

Even so, a few participants also brought up potential risks associated with shared decision making in inpatient treatment:

“If you could decide everything for yourself when you’re at the ward it would be just like being at home, and then what’s the point?”

“I get to decide a lot, but when it comes to my eating disorder I don’t think I should have too much say, because it’ll be bad for me.”

“Flexibility” was mentioned as another core element of the self-admission model. Comments on this subtheme emphasized how participants could tailor the brief admission episode so that it allowed for different logistics based on their current life situation:

“I tested combining self-admission with my job training. I was at the ward, then I went to my workplace, then I came back to the ward.”

“It was also more of a freedom, not feeling that I had to sit there and watch the clock and be like ‘right, three hours left until next meal’ and then ‘now it’s two hours left’—that institutional feeling. This way, it’s almost like going to work: you do what you’re supposed to do and then you go home.”

“It felt good, because I could leave for a few hours every day. For my afternoon snack. So it wasn’t as confined as I had thought. Those hours made a big difference, it wasn’t like being at a closed ward.”

### **3.1.2 Function of the self-admission program**

Six subthemes were related to how participants made use of self-admission in a beneficial way. “Security” was highlighted by those participants who had actually utilized their self-admission contracts as well as by those who had not. Participants in the latter group described self-admission as a “safety net” or as providing an “alternative”, contributing to an increased sense of security in their everyday lives:

“I think this contract gives me an enormous sense of security because [...] I can try on my own and if it doesn’t work out, I always have a backup plan. You know you won’t just fall headlong.”

“Yes, it affects my everyday life 24/7, just knowing that I have the opportunity.”

“Boosting healthy routines” was mentioned by several participants as a hands-on opportunity of making good use of the brief nature of the self-admission episodes:

“Then I found myself in a situation where I didn’t eat food, only liquid supplements. So I admitted myself for a week just to get out of that supplement swamp and start eating regular meals again. [...] That was really a good admission, probably my first sound admission where I’ve felt like I was actually ‘on board’ myself. I’ve been treated against my will a lot, but this time I really set a goal, totally focused on it, and used this week to get back to regular meals again.”

“I’ve been to the ward just to update my sense of a regular portion size. And it works.”

“Preventing deterioration and prolonged hospital admissions” was raised as an important function by most of the participants. Here, participants admitted that they were not eager to admit themselves and spend time as inpatients, but they thought that it was still worth it if it meant that they could avoid longer hospitalization periods:

“Before, whenever things started going downhill and it became more difficult to eat, it would get really bad before I could get help and then it’s so much harder getting back up in the saddle again. But now it hasn’t been that hard because I’ve been able to get back to my usual routines and stop these behaviors before they go too far.”

“I don’t need to be there for eleven months—if I just ask for it in time, it can be eleven days instead. [...] If you just sacrifice two weeks, you gain ten months of freedom. It’s a pretty big thing.”

“Motivational support” involved descriptions of how merely knowing that self-admission existed as an option made participants more likely to stay focused and keep on striving towards behavioral changes at home:

“A few times this spring I’ve had minor setbacks. And so I’ve said to myself: –Do you want to go back to the ward again? Is that what you want? –No, no, no, I don’t! –Well, then behave! [...] But at the same time, I know that if it doesn’t work out, I can always go in for ‘a short one’.”

“The ward can be sort of a walking companion; I don’t have to drag everything along all by myself. I’ll do it on my own but I’m never alone, because the ward is there just in case.”

Furthermore, a few participants said that they had used self-admission for motivation by daring to try new and difficult things and expand their horizons. For example, one participant had dared to go on a brief holiday trip abroad for the first time in many years because she felt safe in the knowledge that if things did not go well during the trip, she would have swift access to the inpatient ward once she returned home.

The helpfulness in “Getting a break” was brought up both in a wider sense as well as in somewhat more specific ways:

“To get just a few days at the ward—shutting the rest of the world out, handing over choices and letting go of control [...]. To be treated so fantastically was really valuable to me.”

“Days when I just don’t feel like cooking, I can go there and eat.”

For some participants, making use of the opportunity to self-admit at times of crisis allowed for some rest and relief from the overwhelming demands of their everyday lives:

“It was sort of an escape from my reality, a break from all those hard things, even if it’s really difficult being at the ward. Just to get away from family demands and things like that.”

Most of the participants had informed their close relatives about their access to self-admission. Accordingly, “Relieving relatives” was described as a beneficial function in the interviews:

“[My mother] thinks it a relief knowing that I have this opportunity and that I don’t have to be on an admission queue for several months if I actually need help right away.”

“My brother thinks it’s one step towards a healthier future, just being able to acknowledge that I need help. That’s how he sees it.”

Simply knowing that there was now swift access to specialized treatment at the hospital ward meant that family members—who had often been actively involved over many years in trying to arrange professional and acceptable treatment for the participants—felt more at ease.

### **3.1.3 Barriers**

A number of barriers that hindered optimal use of the self-admission model were also raised. Here, four subthemes emerged. “Ambivalence” was frequently mentioned by the participants, who typically saw it as inherent to the AN illness:

“God, I’d just like to admit myself and get some rest and get taken care of, but I discharge simply because I can. And now when I’m back—well, as you can see I’m in a wheel chair and I’m not allowed to do anything, so now I can only regret... Damn, why can’t I have the strength to use self-admission in a sensible way?”

“There’s always resistance to being admitted. But somehow you have to reason with yourself and realize that this isn’t going to last. You need help to understand you need help. So I think about: Is this the life I want, [...] to never be able to eat food? What kind of life is that? [...] So you list your ‘pros’ and ‘cons’, and when the ‘pros’ get strong enough you seek help.”

“Of course, [self-admission] has been there as an option and somehow felt like a relief or a comfort, sort of. But at the same time it feels impossible.”

The experience of “Other patients” as a barrier was subdivided into three additional subthemes. Several participants said that they often reflected about whether other participants in the self-admission program might need the earmarked beds more. Notably, this often appeared to interact with and strengthen ambivalence:

“There’s also a danger in knowing if someone else is on the waiting list, because then you might feel like that person probably needs it more and I’ll just wait a little longer. Otherwise I’ll feel guilty about someone else deteriorating and becoming really ill. [...] So I’ll wait and call back the next day to see if they admitted themselves. You’re sort of holding back all the time.”

Moreover, participants described how the ambiance at the ward—i.e., being around other individuals with severe AN— was not necessarily supportive and that, at worst, it could trigger AN symptoms:

“It’s kind of like a microcosm in there. You’re supposed to focus on your own treatment, but [...] it’s impossible to not be affected by the atmosphere. Sometimes it’s like a reality show in there, for real.”

One participant also said that admitting yourself to the ward for a new episode of inpatient treatment, however brief, could bring about feelings of despondency:

“That’s one of the most difficult things about being there: that you’re sitting there with the same people—myself included—that were there a year ago. Nine out of ten patients are the same and no one has made any progress. It makes you feel a bit hopeless.”

Some participants had experienced feeling as a brief “visitor” at the ward, as if they were somehow “disturbing” the regular patients by self-admitting. The mere fact that the program participants had made an active choice to contact the ward and admit themselves could make them feel uneasy and ambiguous:

“To come there as a role model for health, so to speak, and admit voluntary to a ward that’s currently infected with triggering and stuff like that. It can feel a bit paradoxical. [...] I haven’t felt like some kind of sponsor of recovery when I use self-admission, but it’s so obvious for all the others that might be there involuntarily that ‘she comes here and admits herself by her own free will, how can you do that?’ When I might still feel as bad as they do, only I want to get better.”

The subtheme “Admission presupposes deterioration” was also somewhat equivocal. A number of participants mentioned that it was important for them that it would be “understandable” to others (e.g., staff members or fellow patients) that they were in acute need of treatment once they chose to self-admit. This could, for example, mean that they would restrict their eating even more before contacting the ward, in order to feel certain that their deterioration would be

visible. Participants also described AN as possessing a will of its' own; that the illness “wanted” to squeeze the last drops out of them before treatment at the ward was sought:

“Such difficult challenges await at the ward, so the illness wants to take what it can get from you before you go against it.”

Some participants described feeling as a “failure” if they chose to self-admit and return to the very ward that they might recently have been discharged from:

“It’s like coming back with your tail between your legs. You’ve met the staff during the months you’ve been hospitalized and have gotten to know them. They’ve followed your journey [...] and then you return in slightly worse shape and it feels difficult having to meet them.”

A few participants also mentioned that people around them would automatically assume that their health status was deteriorating when they chose to self-admit, even though that was not necessarily the main reason:

“It was a bit awkward when I got there, because everybody reacted like: ‘My god, it’s so great that you come in when things are feeling hard.’[...] Everyone assumed I was there because things were going bad [...] and then I started to feel like I had to confirm that.”

A small number of participants also brought up “Fear of being forced to stay longer” as a barrier, associated with prior experiences of coercive treatment:

“I’ll always be a little scared, since my very first experience was that I wasn’t actually allowed to discharge when I wanted to. So I’ll always have that fear, unfortunately.”

### **3.1.4 Applicability**

A recurring theme related to what the participants saw as requirements for being able to make proper use of the self-admission model. Here, four subthemes emerged. Most participants emphasized that the success of self-admission is dependent on individual-level factors such as motivation, awareness, and maturity. Interestingly, whereas the idea that a certain level of insight and responsibility is required of program participants was often brought up, so was the experience that the self-admission model could in and by itself foster these same skills and traits. These notions were brought together into the single subtheme “Simultaneously requires and fosters motivation and maturity”—not seldom, participants brought up both ideas within the same sentence. In particular, low levels of motivation were described as a risk factor:

“It’s almost a survival mechanism: we [patients with AN] withdraw if we can. And you have to get over that threshold before you’re given the opportunity of self-admission. Otherwise it becomes self-destructive.”

“I couldn’t have had this contract ten years ago. Or, I could have had it but I wouldn’t have used it. No way. It’s like I have matured and realized that I have to ask myself:



What are my goals? What do I want? And to reach those goals I may need to accept getting help.”

Still, many participants also emphasized how the flexibility of the self-admission framework made it easier for them to “bypass” previously experienced barriers:

“Once you’ve been offered a contract, it means that you have a very severe eating disorder. [...] My eating disorder doesn’t have to prove anything.”

“Even if I don’t do everything with joy when I’m [at the ward], I know that I’m doing it because I’ve chosen it myself. And then maybe I can show others that have even greater difficulties that it’s possible to do it by your own free will. That it’s ok to like the food.”

For some participants, self-admission was helpful in promoting self-awareness and active help-seeking behaviors:

“I don’t have to get to a BMI of 9; the point is to [admit yourself] in time. [...] It can be tough and there’s no way around it. It’s all about rising above it and accepting that you’re doing it for your own sake. And I did.”

“For me, it has also been useful to ask for help. [...] And it gets easier and easier every time. If you’ve done it once you know how it works.”

A number of participants highlighted how self-admission had facilitated an internal process of reconsidering what it means to lead a healthy life and what personal goals that are realistic and worth striving for:

“It’s now easier to dare believe that I could live a life in balance. Now I don’t have to be so busy with maintaining a façade of healthiness any more—instead, I can work with what’s really relevant.”

“My goal is just to find some kind of eating habits that will still be very disordered, that’s just how it is. But just being able to eat and maintain a weight that I feel is ok and that isn’t life threatening. [...] I used to think that this, the illness, was just make-believe. That oh well, someone else will fix this for me. But I’ve realized that I have to take responsibility for feeding myself. [...] My wish is to maintain a decent everyday life with the help of self-admission.”

Under the subtheme “Requires encouragement”, participants emphasized that it was often very helpful to have somebody who knew them well—typically a therapist, although this could also involve a friend or relative—who would actively encourage them to make use of the opportunity to self-admit in times of ambivalence:

“[My therapists] can sometimes urge me to come in for a week, because they recognize when I’m losing it. Because I still have an illusion of being able to cope.”

“Since it's kind of hard for me to make decisions on my own, it's a relief that I don't have to. I don't think I would've contacted the ward if my therapist hadn't said 'come on, give them a call!'.”

“Risks becoming self-destructive” included participant statements acknowledging the delicate balance between making use of the flexibility and freedom that is at the core of the self-admission model and giving the AN illness more leeway:

“Perhaps you need to be careful with it because when you get to decide; very often it's the eating disorder talking. Maybe there needs to be an open dialogue so that the staff is alert about what is the illness and what is really favorable in going forward with this contract. [...] It's so easy to believe that 'well, she's here voluntarily, she really wants to get better' but that's not always the case.”

“Like Fatima... You could see she wasn't following the rules; she went out to eat every day—but no. And also, I follow her on Instagram so I know she didn't go out and eat. [...] For the staff to be fooled like that, I just think that's super weird.”

A few participants mentioned that they had indeed made note of this risk and therefore made a conscious decision to not actively seek to maximize flexibility (e.g., maintaining contact with school or work, sleeping at home, or going out for meals) once they had self-admitted to the ward:

“I think I'll try to be here as much as possible. So that every day looks the same, because that's how I need to run my life. It's good to allow for flexibility, absolutely, but I think I'll be here the whole time.”

“Even if someone would say 'Can't we have lunch today?'—a friend or somebody—then I'd say 'No, I'm going to be at the ward'. It's better to eat there, that way I know I'll get what I need.”

Finally, under the subtheme “Risks impeding independence” some participants brought up the idea that having access to self-admission may actually be counterproductive, since it may presumably not fully allow participants to “let go” of the ward and explore life outside of hospital:

“One of the main reasons why I don't want to go back to the ward is that I've just started getting by on my own. [...] I'm scared to death that I would somehow become dependent again, dependent on others.”

“If you feel that you want to break free—from the illness, that is—then this is kind of like a shackle. You still have one foot in the ward.”

### **3.1.5 Lessons on implementation**

The participant interviews also yielded a lot of data that did not primarily concern patient experiences of the self-admission program in relation to AN, but that touched upon logistical issues regarding the implementation of the program. Therefore, as an addendum to Study I, an article

describing patient experiences of the implementation of the program was published (Strand et al., 2017); this article, however, is not formally a part of this thesis. The fact that certain problems arose during the initial implementation of the novel self-admission model is hardly surprising. In several ways, self-admission represents a break with traditional ideas of treatment at a psychiatric hospital ward, which meant that staff members had to become acquainted with new ways of thinking about and dealing with patient issues. An early issue was contradictory statements from different member of the staff, due to misunderstandings and inexperience with the model. For example, a bed earmarked for self-admission was “double booked”, i.e., two participants were told that they could have the bed, on at least one occasion. Minor mishaps like these are to be expected, but they can nevertheless have negative impact on participants’ ambivalence about self-admitting. On a more conceptual level, the brief nature of the self-admission episodes meant that it was not always possible for participants to see a certain staff member continuously during their stay at the ward, due to scheduled rotation of staff. This lack of staff continuity was brought up as a barrier by some participants, who felt that they needed to know specifically whom among the staff they could turn to for support. Moreover, a number of participants highlighted that even though they appreciated the focus on patient involvement, autonomy, and agency “in theory”, they felt little confidence in handling this somewhat unfamiliar responsibility. In hindsight, a few of them described that they had probably entered the self-admission program with an unrealistic view about what to expect and about their own abilities.

### **3.2 STUDY II: FORMATIVE STUDY ON PRIORITY SETTING AND RESOURCE REALLOCATION**

In contrast to Studies I, III, and IV, but similar to many studies in the field of medical ethics, Study II does not adhere to the IMRaD (Introduction, Methods, Results, and Discussion) structure. As outlined above, Study II can be described as a pre-study to the health economic evaluation presented in Study IV, setting the stage for the analysis of resource reallocation presented there. Although many of the basic assumptions about the intricacies of healthcare rationing associated with the self-admission model are taken for granted in Study IV, they were far from self-evident at the outset of this thesis project. In contrast, they have been assembled in a highly iterative process, where Studies I and II as well as a previously conducted review of the field (Strand & von Hausswolff-Juhlin, 2015) were instrumental in creating the framework for the subsequent health economic evaluation.

#### **3.2.1 Priority setting in self-admission**

As described in the Introduction section, various principles for the allocation of scarce health-care resources exist (Persad et al., 2009). These principles are inspired by different schools of thought in medical ethics and assign different value to a collection of commonly referenced priority-setting tools, including treating all people equally (e.g., allocation by lottery or “first come, first served”), favoring the worse off (e.g., treating the most severely ill or the youngest first), maximizing total societal benefit (e.g., saving the largest number of lives or life-years), or rewarding social usefulness (e.g., prioritizing those whose occupational skills are seen as

more important for the society as a whole). Although these principles can sometimes be mutually exclusive, there are common tendencies. In real-world discussions, outside of the medical ethics seminar, a *principle of need* is typically emphasized in healthcare, stipulating that those individuals who are in greatest need of healthcare services and medical treatment should be prioritized and receive it first. The principle of need commonly informs the allocation of healthcare resources in countries with publicly funded healthcare. It is integrated into Swedish law (Swedish Ministry of Health and Social Affairs, 1995) and appears to have solid support among the population at large—a finding that has been observed in various settings and cultures (Ryynänen, Myllykangas, Kinnunen, & Takala, 1999). Prioritizing those individuals who display the greatest acute need of treatment is at the center of healthcare triage systems and is probably often taken for granted by most medical professionals.

Naturally, *need* can be defined in a number of ways. Even so, a core assumption in healthcare is that everything else equal, an individual who is more severely ill should be prioritized for treatment in situations where healthcare resources are limited (i.e., most situations) (Hasman, Hope, & Østerdal, 2006). At a psychiatric emergency ward or at an outpatient mental health service, the severity of symptoms that a patient displays and the gravity of her/his medical history are typically the fundamental aspects that guide a clinician in deciding what level of care to recommend. Thus, if the number of available hospital beds are limited and several patients need to be admitted, those patients who are worse off in terms of current mental illness will be given priority. If no beds are available and a severely ill patient still needs urgent inpatient treatment, a less severely ill inpatient may need to be discharged in order to free up a hospital bed.

An analysis of self-admission programs in terms of priority setting needs to acknowledge the fact that the concept of self-admission bypasses this fundamental principle, at least insofar as the assessment of illness severity is to be performed at the very moment of admission. In self-admission, program participants are given “fast lane” access to earmarked beds to make use of as they see fit. Moreover, once participants have self-admitted, they can stay for a fixed number of days without risk of early discharge—usually, the brevity of these self-admission episodes is stressed, but one might just as well emphasize the fact that participants at SCÄ are guaranteed to stay at the inpatient ward for 7 days regardless of clinicians’ opinions. Importantly, since those beds that are reserved for self-admission are taken from the pool of regular beds, i.e., no extra resources are added to the equation from a healthcare provider perspective, the establishment of a self-admission program inevitably means that a smaller number of hospital beds than before are to be shared among the non-participants that make up the bulk of the patients at SCÄ. Hence, a scarce resource in healthcare—psychiatric hospital beds—is funneled towards a highly select group of patients. As outlined in Study I, participants in the SCÄ self-admission programs display an overall satisfaction with the program. However, given that they are offered increased access to a scarce resource, this may not be very surprising—individuals who are offered something “extra” are often satisfied. In terms of priority setting in healthcare, however, it must be analyzed whether this reallocation of resources is justified.

Granted, those AN patients who are targeted by the SCÄ self-admission program are some of the most severely ill patients treated at the clinic. Even so, it is not certain that they are actually the *most* severely ill. For example, the exclusion criteria that are applied means that patients with a comorbid substance use disorder or with suicidal and/or serious self-injurious behaviors—factors that are likely to reflect a very severe overall clinical picture—are not given access to the program. The same holds true for those patients who are unlikely to be able to independently adhere to the everyday routines at the ward, due to impaired insight, intellectual disabilities, or other reasons. This is not to say that the inclusion and exclusion criteria in the self-admission program are misconceived, merely that there may very well be severely ill, non-eligible patients at SCÄ who are actually made worse off by the establishment of the program. Moreover, challenges may remain even if the most severely ill patients are indeed given priority in the program. For example, among the participants with access to the earmarked beds, these extra resources are distributed on a first come, first served basis. This approach may intuitively seem to treat people equally, but in practice it risks benefitting less severely ill patients by favoring “people who are well-off, who become informed, and travel more quickly, and can queue for interventions without competing for employment or child-care concerns” (Persad et al., 2009, p. 424). In Study I, participants with teenage children did mention that they had to arrange for someone to look after them before they could self-admit, although no overall pattern of unequal access within the group was observed. Furthermore, individuals living with severe mental illness are more likely to find it difficult to self-monitor their health status and engage in active help-seeking (Andrade et al., 2014). These barriers may be further reinforced by mental health-related stigma (Schnyder, Panczak, Groth, & Schultze-Lutter, 2017).

One way that self-admission may in fact benefit *all* patients with severe illness is if the establishment of self-admission programs results in a more efficient delivery of healthcare at the level of the entire service unit—in this case, the adult inpatient ward at SCÄ—so that additional resources are also made available to non-participants. For this to happen, the participants in the self-admission program must reduce their total days spent in inpatient treatment equal to or more than the number of days lost to the program and unavailable to non-participants due to the earmarking of hospital beds. For SCÄ, as described in more detail in Study IV, this amounts to 730 days of inpatient treatment (365 days per year x 2 earmarked hospital beds) that must be made available for non-participants when high utilizers are removed from the general hospital queue. However, this delicate balance may just as well result in crowding out of non-participants, so that they ultimately have to share fewer available inpatient days between them.

### **3.2.2 Three possible scenarios of resource reallocation**

To briefly reiterate, the self-admission framework described above rests upon reallocation of existing hospital beds rather than on increased funding and capacity expansion. Thus, when existing hospital beds are earmarked for self-admission and designated to be used solely by participants in the program, the number of hospital beds that non-participants must share is inevitably reduced. Only if those high utilizers of inpatient care who are offered increased access to admission are able to make use of this tool so as to quite dramatically reduce the total number

of days they spend at the inpatient ward, the regular hospital queue for non-participants may be shortened to the extent that the loss of the reallocated beds is offset.

With this equilibrium in mind, the introduction of self-admission could hypothetically result in three different scenarios (see Figure 3). First, having lost healthcare resources that were previously available to them, the non-participants could be subjected to crowding out and end up in a worse off situation than before. Second, a “zero-sum game” can be imagined, whereby the benefits accrued by participants do not have negative impact on availability for non-participants. Third, a “win-win situation” could hypothetically be created, in which increased access and better outcomes for participants means that hospital beds are freed up to be used by non-participants.

Here, it must also be noted that those hospital beds that are reserved for the participants in the self-admission program are not meant to be occupied all of the time, the way regular hospital beds would ideally be. This is because of the “safety net” function of the self-admission beds: if participants could not count on these beds to be available at need and thus largely unoccupied, a core component of the self-admission program would be lost. Moreover, considering that a rationale behind the model is that participants may reduce their overall time spent hospitalized, one successful outcome of introducing self-admission would be that nobody used it—in this highly unlikely hypothetical scenario, participants would feel so much more safe and secure in the knowledge that they could access inpatient treatment at will that they went about with their lives outside of the hospital with greater agency and autonomy, improved HRQoL, and markedly reduced symptom severity. As implausible as this may seem, it nevertheless illustrates the fundamental logic behind the self-admission concept as well as the pedagogical difficulties associated with trying to “pitch” self-admission to policy makers. Needless to say, a low utilization of the self-admission beds could also reflect a general dislike of the program by participants. The important point to notice is that the discussion about health services efficiency with regards to self-admission is fundamentally *not* about whether the designated hospital beds should primarily be offered to regular patients or solely to those who participate in the program, but rather about whether they should be offered to regular patients or largely remain empty and ready for use by participants once they need them. Once healthcare policy makers realize this, they may find it difficult to justify keeping sought-after hospital beds in “standby mode”.

### **3.3 STUDY III: QUANTITATIVE COMPONENT**

The baseline characteristics of the participant and comparison group cohorts are provided in Table 2, including the moderate-utilization subgroup. An appropriate match in terms of gender, age, duration of illness, and BMI was achieved. In contrast, the groups displayed quite different patterns of comorbidity, the most noteworthy discrepancy being that the occurrence of a personality disorder was considerably more common in the moderate-utilization comparison group; here, one out of four patients was diagnosed with a personality disorder, compared to one out of fifteen among participants. Also, patients in any of the comparison groups more often engaged in binge-purge behaviors as a part of their eating disorder. The most notable pat-

	Participants	Low-utilization comparison group	Moderate-utilization comparison group
<i>n</i>	29	113	27
% women	93.2	98.2	96.3
Years of age	29.7 (10.6)	27.8 (10.4)	30.2 (12.3)
Duration of illness in years	13.4 (10.6)	11.7 (10.5)	14 (12.3)
BMI	15.8 (2.3)	16.5 (1.8)	15.8 (1.6)
EDE-Q global score	3.3 (1.2)	3.5 (1.4)	3.6 (1.7)
CIA score	30.0 (10.4)	31.1 (10.4)	34.3 (10.3)
% with binge-purge component	10.3	39.8	25.9
% with affective disorder	55.2	30.1	44.4
% with anxiety disorder	41.4	31.0	51.9
% with OCD	13.8	8.8	14.8
% with personality disorder	6.9	9.7	25.9
% with ADHD/ADD	10.3	4.4	3.7
% with autism	6.9	1.8	3.7

**Table 2.** Baseline characteristics of participants and comparison groups. Values are means unless otherwise indicated. Standard deviations are presented in parentheses wherever applicable.

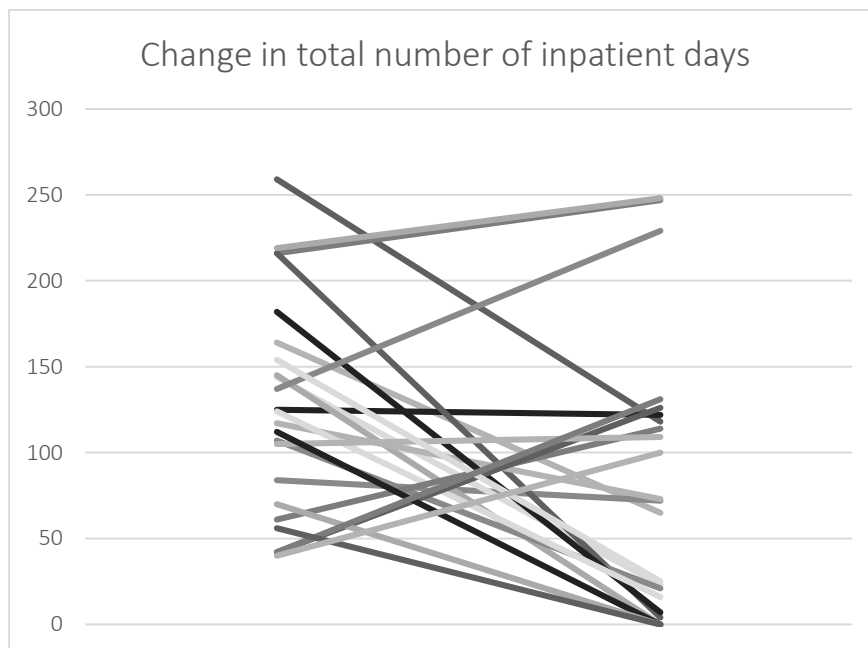
tern of comorbidity among participants was that they were diagnosed with ADHD/ADD or an autism spectrum disorder more often than patients in the other groups.

### 3.3.1 Changes in healthcare utilization

The overall patterns of utilization of inpatient treatment when the 12-month intervention period was compared to the 12 months prior to inclusion are shown in Figure 5. As seen, whereas the admission frequency—i.e., the number of discrete admission episodes—sharply increased, a substantial reduction of the number of days spent in inpatient treatment was observed. However, as illustrated in Figure 6, there was great variation in how individual participants changed their healthcare utilization in the program. Changes in healthcare utilization across the three groups are shown in Table 3. In sum, the participant group reduced their utilization of inpatient treatment by 51%, compared to smaller and statistically non-significant changes in both comparison groups. This reduction corresponded to a medium-to-large effect size of 0.73 and remained significant after Bonferroni correction. In contrast, no significant effects were seen in terms of the number of days spent in involuntary inpatient treatment or the number of visits to the outpatient clinic.



**Figure 5.** Participants' yearly inpatient treatment utilization before and after inclusion, where the vertical midline represents baseline. A sharp increase in admission frequency corresponds to a reduction of the total number of days spent in inpatient treatment. It can be noted that 145 self-admission admission episodes correspond to merely 795 days in hospital, a smaller share of the total days spent in inpatient treatment than the 37 regular admission episodes accumulated by participants.



**Figure 6.** Variation in changes in participants' total number of inpatient days during the 12-month intervention phase compared to the 12 months before baseline. Each line represents an individual participant in the study.



		Before				After				% change	<i>p</i>
		Mean	25th pctl.	50th pctl.	75th pctl.	Mean	25th pctl.	50th pctl.	75th pctl.		
Participants ( <i>n</i> =29)	Days in inpatient treatment	139.7	80.5	124.0	180.0	68.2	3.5	31.0	119.0	-51.1	0.001
	Number of admissions	2.3	1.0	1.0	3.0	6.3	1.0	4.0	11.0	+171.7	0.001
	Days in involuntary inpatient treatment	10.3	0.0	0.0	0.0	9.4	0.0	0.0	0.0	-9.3	0.917
	Number of outpatient visits	11.5	5.5	8.0	13.0	12.8	6.5	11.0	16.0	+11.7	0.330
Low-utilization comparison group ( <i>n</i> =113)	Days in inpatient treatment	17.0	0.0	0.0	0.0	22.9	0.0	0.0	2.5	+34.7	0.259
	Number of admissions	0.5	0.0	0.0	0.0	0.7	0.0	0.0	1.0	+36.8	0.108
	Days in involuntary inpatient treatment	4.4	0.0	0.0	0.0	3.2	0.0	0.0	0.0	-28.0	0.838
	Number of outpatient visits	3.4	0.5	1.0	4.5	4.0	1.0	2.0	6.0	+18.5	0.157
Moderate-utilization comparison group ( <i>n</i> =27)	Days in inpatient treatment	71.0	4.0	32.0	112.0	62.4	0.0	24.0	105.0	-12.1	0.336
	Number of admissions	2.2	1.0	2.0	3.0	2.1	0.0	1.0	3.0	-6.7	0.746
	Days in involuntary inpatient treatment	18.4	0.0	0.0	0.0	6.1	0.0	0.0	0.0	-70.0	0.310
	Number of outpatient visits	6.7	2.0	5.0	9.0	6.5	2.0	4.0	9.0	-2.8	0.761

**Table 3.** Changes in health care utilization among participants and comparison groups (pctl. = percentile). *p*-values are shown prior to Bonferroni correction.

### 3.3.2 Changes in eating disorder morbidity

Data on eating disorder morbidity and GAF among participants are shown in Table 4. Here, a significant but modest increase in BMI was seen, which corresponded to a medium effect size of 0.45. However, this increase did not remain significant after Bonferroni correction—moreover, it is doubtful whether a 6% increase in BMI can be considered a clinically meaningful outcome. A significant 33% increase in GAF scores was also observed, corresponding to a medium effect size of 0.61.

### 3.3.3 Changes in health-related quality of life

Data on HRQoL among participants are shown in Table 5. As seen, no major changes in terms of the overall EQ-5D scores or the SF-36 scores were observed. Upon separate analysis of the item-level distribution of EQ-5D data, slight improvements in terms of “usual activities” and “anxiety/depression” but no major changes were observed (see Table 6). However, in terms of

	Before	After	% change	<i>p</i>	<i>n</i>
BMI	15.8 (2.3)	16.7 (2.5)	+6.1	0.023	29
EDE-Q global score	3.2 (1.2)	2.9 (1.2)	-8.1	0.203	23
EDE-Q restraint	2.8 (1.7)	2.6 (1.7)	-7.1	0.492	23
EDE-Q eating concern	2.4 (1.1)	2.1 (1.0)	-10.3	0.308	23
EDE-Q weight concern	3.3 (1.3)	3.1 (1.4)	-6.1	0.411	23
EDE-Q shape concern	4.2 (1.3)	3.9 (1.4)	-9.0	0.095	23
CIA	30.0 (9.0)	27.5 (8.4)	-8.3	0.272	18
GAF	31.2 (11.0)	41.5 (16.7)	+33.0	0.007	24

**Table 4.** Changes in eating disorder symptomatology and GAF scores among participants. Values are means unless otherwise indicated. Standard deviations are presented in parentheses wherever applicable. *p*-values are shown prior to Bonferroni correction.

	Before	After	% change	<i>p</i>	<i>n</i>
EQ-5D single- index value	0.7682 (0.1328)	0.8024 (0.1528)	+4.4	0.084	23
EQ visual analogue scale	44.8 (15.3)	56.2 (21.0)	+25.6	0.001	22
SF-36 standard gamble health state variation	0.614 (0.053)	0.639 (0.086)	+4.2	0.056	22

**Table 5.** Changes in participants' HRQoL. Values are means unless otherwise indicated. Standard deviations are presented in parentheses wherever applicable. *p*-values are shown prior to Bonferroni correction.

EQ VAS, a significant 26% improvement was found, which corresponded to a large effect size of 0.78.

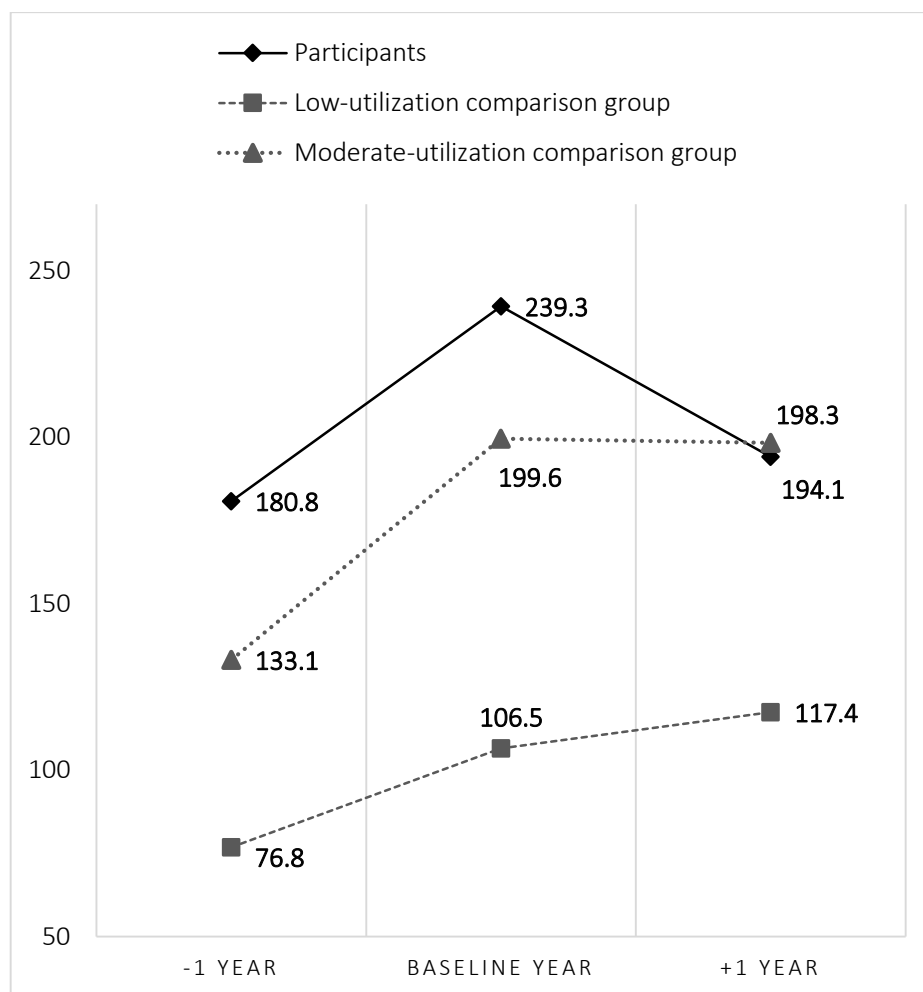
### 3.3.4 Changes in sick leave

Three time-point longitudinal data on sick leave among participants and comparison groups are shown in Figure 7. A discrepant pattern was observed in the participant group vs. comparison groups. In all three groups, an increase in the number of days on sick leave between the year prior to inclusion and the baseline year was found. Thereafter, the low-utilization comparison group displayed a further—if somewhat less steep—increase between the baseline year

and the year after inclusion, whereas the level of sick leave remained more or less unchanged in the moderate-utilization comparison group. In contrast, the number of days on sick leave among participants during the same phase displayed a parallel decrease. This decrease, however, was statistically non-significant at  $p = 0.090$ .

Level	Mobility		Self-care		Usual activities		Pain/discomfort		Anxiety/depression	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1	22 (96%)	20 (87%)	23 (100%)	23 (100%)	8 (35%)	12 (52%)	16 (70%)	16 (70%)	0	3 (13%)
2	1 (4%)	3 (13%)	0	0	10 (43%)	8 (35%)	6 (26%)	6 (26%)	17 (74%)	15 (65%)
3	0	0	0	0	5 (22%)	3 (13%)	1 (4%)	1 (4%)	6 (26%)	5 (22%)
Total	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)	23 (100%)

**Table 6.** Item-level distribution of participants' EQ-5D data.

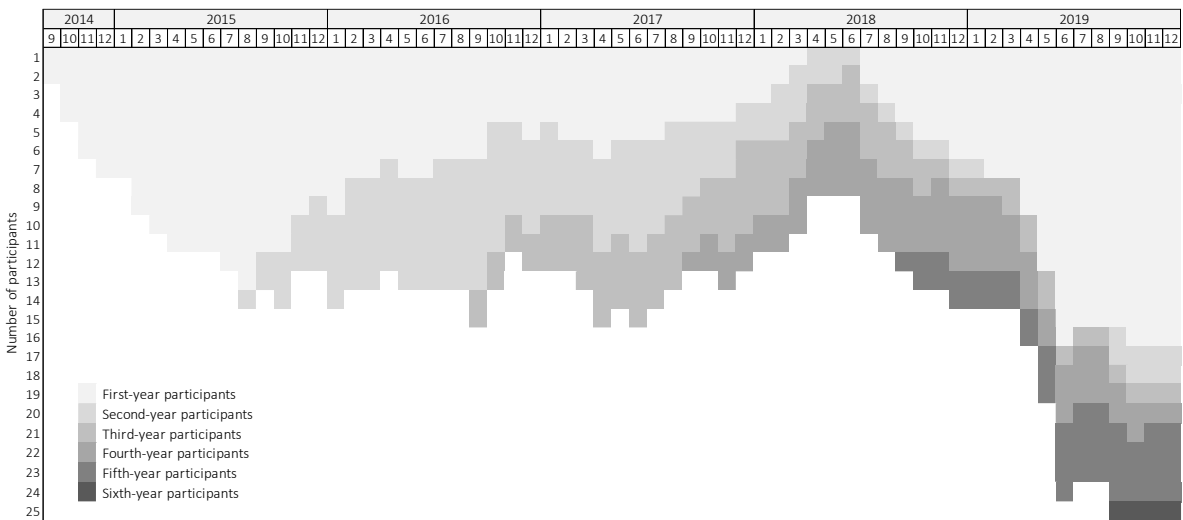


**Figure 7.** Changes in the mean number of days on sick leave over three time-points.

### 3.4 STUDY IV: HEALTH ECONOMICS COMPONENT

#### 3.4.1 Impact of resource reallocation

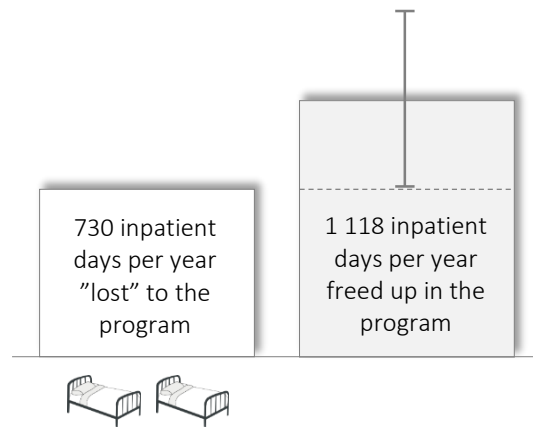
Patterns of utilization of self-admission over time in the program are shown in Figure 8. Over the entire study period, 41 patients were enrolled in the program (although not all of them had reached the 12-month follow-up point at the end of the study period). The mean number of program participants at any given time since the launch in August 2014 until December 2019 was 13.2. Since participants were included consecutively, there was a gradual increase in the number of participants in the first year, followed by a stabilization. The increase during the last part of the observation period was most likely due to the fact that several original participants remained in the program for “safety net” reasons even though they did not actively make use of the self-admission option, which allowed for the further inclusion of new participants.



**Figure 8.** Participants over time in the self-admission program at SCÄ.

The mean number of regular inpatient days at SCÄ for participants during the 12 months before and after inclusion were 127.1 and 42.5, respectively, corresponding to a 66.6% reduction in regular inpatient days at SCÄ specifically (excluding utilization of other healthcare services). Thus, on average, the utilization of regular inpatient treatment at SCÄ for participants was reduced by 84.7 days (95% CI: 55.7-113.7;  $p < 0.001$ ). Assuming a yearly average of 13.2 participants, this resulted in a net increase of available regular inpatient days of 1118.0, outnumbering the available regular hospital days “lost” to the program (i.e., 730 days; see Figure 9) by 53.2%. Therefore, a clear “win-win situation” was observed.

The mean total number of inpatient days at SCÄ (including both regular and self-admission) for participants during the 12 months after inclusion was 69.9, corresponding to a 44.1% reduction. Thus, on average, the total utilization of inpatient treatment at SCÄ for participants was reduced by 57.3 days (95% CI: 21.7-92.9;  $p = 0.003$ ). The mean number of self-admission days during the 12 months after inclusion was 27.4. Assuming a yearly average of 13.2 partici-



**Figure 9.** Net increase in available regular hospital days outnumbering the days “lost” to the program.

pants, the earmarked beds were actively utilized during 361.7 self-admission days out of the available 730. Thus, the earmarked beds were utilized 49.5% of the time available.

### 3.4.2 Sensitivity analysis

Utilizing the low end of the 95% CI—i.e., a reduction of the utilization of regular inpatient treatment at SCÄ for participants by 55.7 days—for a sensitivity analysis resulted in an increase of available regular inpatient days of 735.2, i.e., just above the 730 days “lost” to the program annually. Utilizing the high end of the 95% CI—i.e., a reduction of the utilization of regular inpatient treatment at SCÄ for participants by 113.7 days— resulted in an increase of available regular inpatient days of 1500.8, exceeding the number of available regular hospital days “lost” to the program by 105.6%. Thus, across the entire 95% CI, the self-admission program resulted in a “win-win situation” (see Figure 9).



## 4 DISCUSSION

### 4.1 SELF-ADMISSION IN ANOREXIA NERVOSA: WHAT TO EXPECT

#### 4.1.1 Summary of findings

The findings from this thesis project show that the introduction of a self-admission program for patients with AN at a specialist eating disorder service resulted in a more than 50% decrease in the total number of days that participants spent in inpatient treatment during 12 months in the program. Thus, despite a steep rise in admission frequency—i.e., the participants more often made use of the opportunity to admit—the overall outcome was a reduction of the time spent hospitalized, due to the brief nature of these admission episodes. In comparison, only smaller and statistically non-significant changes over time were observed in low- and moderate utilization comparison groups. In contrast to these findings, no significant effects were seen in terms of the number of days spent in involuntary inpatient treatment or the number of visits to the outpatient clinic.

However, the introduction of self-admission did not have any significant and clinically relevant effects on participants' self-rated eating disorder morbidity or BMI. Somewhat surprisingly, mixed results regarding participants' self-rated HRQoL were found: on the EQ VAS measure, a 25% improvement was observed, whereas the general EQ-5D and SF-36 scores were largely unaffected at 12-month follow-up. Notably, participants' baseline HRQoL scores on these measures were fairly high and a substantial improvement would therefore have reflected a very good-to-excellent range HRQoL at follow-up. A beneficial tendency was seen for participants in terms of number of days on sick leave, with a reduction during the year after baseline; this finding, however, did not reach statistical significance.

Regarding the reallocation of healthcare resources associated with the self-admission model, this thesis project shows that by establishing a program of self-admission to inpatient treatment for patients with AN, a “win-win situation” in terms of resource allocation was achieved. In the program, participants were able to reduce their utilization of regular inpatient treatment at SCÄ specifically by 67%. In doing so, hospital beds were made available for non-participants due to the removal of a yearly average of 13.2 high-utilizers of inpatient treatment from the regular waiting list. A sensitivity analysis showed that this “win-win situation” occurred across the entire 95% CI of the inpatient treatment utilization reduction.

In interviews with participants in the self-admission program, increased levels of agency and motivation were clearly described. Oftentimes, the level of patient involvement and responsibility in the program was seen as a new and somewhat unfamiliar experience, albeit a mostly positive one that could promote motivation to strive towards recovery. However, participants also described how the self-admission model requires a certain level of maturity as well as a supportive environment in order to overcome barriers such as ambivalence and difficulties in self-monitoring of health status. Participants said that they used self-admission for multiple reasons: to prevent deterioration of their mental health and prevent longer periods of hospital

treatment, to boost healthy eating behaviors, and to get rest and relief in times of stress and crisis. Even those participants that never made use of the opportunity to self-admit thought that the mere availability of swift access to brief admissions provided them with a valuable safety net in their everyday lives. Moreover, participants described that their relatives felt more at ease knowing that they could access inpatient treatment at will.

In sum, the findings from this thesis project point to self-admission as a useful tool in preventing deterioration and forestalling the need for long periods of inpatient treatment. In contrast, self-admission did not help participants to reduce their eating disorder morbidity and achieve symptom remission. Even though it was initially hypothesized that the introduction of a self-admission program may have at least some positive impact in promoting healthier eating behaviors and normalizing BMI, it is understandable that brief admission episodes did not allow participants to address long-term treatment goals. Instead, these admission episodes should primarily be seen as booster opportunities or short periods of relief in situations where the risk of relapse is heightened. Participants' own ideas of what self-admission may actually help them with reflect a focus on symptom and crisis management rather than on remission and recovery. Considering that participants had on average been suffering from AN for 13.4 years, it is unlikely that self-admission (or any other single intervention) would somehow provide a “quick fix” or a catch-all solution. This can be illustrated by the changes in GAF scores in the study. Participants displayed a 33% improvement on the GAF scale. However, a closer look reveals that these changes corresponded to moving from “major impairment in several areas” (i.e., range 30-40) to “serious impairment in social, occupational, or school functioning” (i.e., range 40-50) (American Psychiatric Association, 1994), indicating that seriously impaired everyday functioning remains. Similar tendencies have been observed in the treatment of patients with borderline personality disorder (Bateman & Fonagy, 2016), where an improved overall functioning may still result in low GAF scores due to intermittent suicidal impulses that may remain even though they occur more seldom and the patients have strategies to cope with them.

#### **4.1.2 Dismantling ambivalence towards inpatient treatment**

In previous Norwegian qualitative studies of participants in self-admission programs suffering from schizophrenia or bipolar disorder, mostly positive effects of the model were reported, including the development of a broader repertoire of coping strategies and diminished feelings of resignation (Olsø et al., 2016; Rise et al., 2014). In contrast, as described above, the present study revealed a number of obstacles and barriers that could reduce the likelihood of AN patients making constructive use of self-admission. One such major barrier was participants' ambivalence towards active help-seeking. Ambivalence is certainly not a unique feature of AN—however, it is a core element of the clinical AN picture that can often make effective long-term treatment engagement difficult. As described in the Introduction section, models for enhancing motivation in AN are, unfortunately, generally not supported by available evidence (Waller, 2012). In light of these challenges, it is interesting to note that the present findings indicate that self-admission may actually aid in altering how participants grapple with their AN illness on a more fundamental level. A central component of self-admission is promoting



patient agency and highlighting participants' own choice to engage in inpatient treatment, thereby avoiding the “tug of war” with staff that may arise in more coercive settings. As one participant stated: “Even if I don’t do everything with joy when I’m [at the ward], I know that I’m doing it because I’ve chosen it myself.” Findings from other studies on individuals with AN echo this sentiment (Tan et al., 2003, p. 635):

“When I haven’t got anyone forcing me to do anything, then I fight against my own thoughts, what my mind is telling me. Whereas when someone is forcing me to do something, then it makes it a hell of a lot easier to fight against them, and then in the end you’re fighting the wrong enemy.”

For at least some participants, self-admission can highlight the individual’s own choice in engaging with treatment and foster useful reflection on personal motives behind not seeking help even though it is readily available. Of course, self-admission did not simply eliminate participants’ ambivalence—however, it provided a framework in which participants could begin to ponder upon their own responsibilities in treatment and on how they could put their energy to use in ways that actually benefited them.

These findings mirror the results from previous research on patient experiences of specialist inpatient treatment for eating disorders (i.e., “regular” inpatient treatment), where topics such as sense of control and processes of self-discovery have been raised (Smith et al., 2016). For individuals with AN, the inpatient ward has been described as “an alternative reality” characterized by feelings of disconnection and restriction (Haynes, Eivors, & Crossley, 2011). Inpatients often report having to navigate a highly ambiguous terrain, where they may need to recognize the seriousness of their illness and actively relate to others on the ward while also asserting their non-disordered identity and distancing themselves from “excessive” belonging (Eli, 2014). An individual’s relationship to AN is typically ambivalent. Not seldom, “the AN” is experienced as almost separate from oneself; as an external voice that can be both comforting and critical (Fox & Diab, 2013). Even so, many patients also simultaneously experience AN as a central part of their identity that helps keep negative emotion at bay and offers a sense of mastery. Importantly, a perceived main barrier to admission to inpatient treatment in AN is the challenge of daring to allow others to help, a task that implies that the sense of control that is often at the core of AN is taken away and that established daily routines are given up (Elran-Barak, Barak, Cohen-Ashkenazi, & Schifter, 2018). In this context, experiencing agency and being an active collaborator in treatment rather than a passive recipient becomes important (Sly et al., 2014).

It has been shown that in spite of the ambivalent stance towards therapeutic change inherent to many eating disorders, patients with AN are indeed able to request inpatient treatment once the initial phase of reinforcement inherent to the disorder has passed (Gorse et al., 2013). When patients gradually come to realize that their AN symptoms are in strict control of them and not the other way around, they may also become less reluctant to ask for treatment. From that perspective, it is not necessarily certain that the assumption on which our evaluation of self-admission is based—that a reduction in the time spent in inpatient treatment is a positive out-

come—holds true in all contexts. On the contrary, for some patients, an increase in the time spent in hospital could reflect improvement in terms of increasing awareness and overcoming ambivalence. As seen in Figure 6, some participants did indeed increase their total utilization of inpatient treatment in the program.

#### **4.1.3 Inconsistencies in findings on health-related quality of life**

Findings from interviews with participants revealed that they highly appreciated the safety net function that self-admission provided, which they clearly experienced as supportive in helping them expand their scope of everyday activities. Against this backdrop, the very modest findings concerning self-reported quantitative HRQoL measures are unexpected. In terms of EQ VAS, a substantial 26% improvement was observed. In contrast, no significant changes in the EQ-5D single-index value or the SF-36 standard gamble health state variation value were found. As already noted, baseline scores for these items were relatively high. This points to a hypothetical failure of the main five-item portion of the EQ-5D instrument to accurately capture the difficulties in everyday life encountered by individuals with AN. To reiterate, participants tended to score relatively high on those particular items that refer to mobility and self-care (see Table 6), which may at least partly reflect a preserved capacity in AN patients to engage in physical activities—indeed, trying to burn calories by excessive physical exercise is often an integral part of AN and it may therefore not be surprising that participants considered themselves highly mobile. Moreover, a closer look at the SF-36 item-level data provided by the participants shows that a high proportion of those who did indeed score low on items related to their own well-being at baseline simultaneously said that their health status was no worse than that of other people around them, which inflated the total scores. This observation may reflect a relatively limited social network; interestingly, some participants described that after prolonged prior episodes of hospitalization, most of their friends and acquaintances were others with severe AN. Another noteworthy observation regarding item-level SF-36 data is that it was quite common among those who answered that their subjective well-being had improved at follow-up to simultaneously score *higher* on items describing specific everyday obstacles, resulting in a contradictory picture that may have reduced total scores at follow-up. Answers such as these could in fact be due to an increased level of awareness over time regarding the actual difficulties associated with living with severe AN (Gorse et al., 2013), whereas the baseline answers may have represented a somewhat more “glossy” picture influenced by AN-related self-perception. As patients change, their grounds for self-assessment in terms of HRQoL may also evolve, a phenomenon that is known as *response shift* and that may pose problems for the interpretation of self-reported HRQoL (Schwartz, Andresen, Nosek, & Krahn, 2007). In this context, the relative directness of the EQ VAS—on which respondents indicate on a straight line representing a scale from 0 to 100 how they experience their overall well-being—may actually prove to be a more reliable indicator of change, even though VAS scales can also be associated with issues such as end-of-scale and context bias (Drummond et al., 2015d). Moreover, in analogy to the GAF findings discussed above, an EQ VAS score of 56.1 on average among participants at follow-up still points to a severe remaining impairment in terms of HRQoL.

For similar reasons, the value of using generic HRQoL measures such as EQ-5D or SF-36 in mental health in general has been questioned. For example, several of the EQ-5D items focus on physical health domains that may or may not be relevant to the overall level of functioning in a psychiatric disorder (Papaioannou, Brazier, & Parry, 2011). It has been shown that whereas generic HRQoL instruments can be used to describe the impact of common mental health issues such as mild to moderate depression and anxiety, they do not accurately reflect the level of functioning in schizophrenia (Brazier, 2010). The same holds true for certain somatic conditions, such as in relation to visual impairment and hearing loss, where generic measures may not fully capture the impact on HRQoL (Papaioannou et al., 2011). Instead, HRQoL instruments such as the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0) developed specifically with mental, neurological, and addictive disorders in mind may be more appropriate (Federici, Bracalenti, Meloni, & Luciano, 2017). Alternatively, for the present study, instruments developed specifically to be used with patients with eating disorders, such as Eating Disorders Quality of Life (EDQoL) or the Eating Disorders Well Being Questionnaire (EDwell), could have been better options (Ackard, Richter, Egan, Engel, & Cronmeyer, 2014; Castellini et al., 2013)—however, this approach would of course not allow for comparisons across different healthcare sectors, which is one of the strengths of generic measures.

As described in the Methods section, a mixed methods approach is ideal for revealing inconsistencies between quantitative and qualitative data and highlight important areas of discovery that need to be further examined (Curry & Nunez-Smith, 2015). In the present case, the findings from the qualitative part of the study show that participants did indeed experience an increased HRQoL that was not adequately captured by the quantitative part of the study, calling into question the external validity of generic HRQoL measures in the assessment of eating disorders. Of course, these discrepancies may also reflect a poor insight among the participants into the real difficulties they face in their everyday lives or a will to please the researcher conducting the interview. However, evidence from studies on other disabling psychiatric disorders points to shortcomings of EQ-5D and SF-36 in accurately capturing all aspects of HRQoL in serious mental illness as a main reason behind these observations (Brazier, 2010; Papaioannou et al., 2011).

## **4.2 CLINICAL IMPLICATIONS: THE RECOVERY MODEL AND HARM REDUCTION**

### **4.2.1 Different views of recovery**

In sum, the outcomes of this thesis show that self-admission can aid individuals with severe AN in preventing relapse and reducing their overall subsequent utilization of inpatient treatment, even though it was not helpful in achieving symptom remission such as a normalized BMI or reduced eating disorder cognitions. Drawing on these findings, self-admission is probably best applied within a *recovery model* framework. As mentioned briefly in the Introduction section, in this model a distinction is made between recovery *from* and recovery *in* a disorder (Davidson & Roe, 2007). To reiterate, the notion of recovery *from* a disorder focuses on a tradi-

tional biomedical concepts of cure and a “return to normal”. In contrast, the notion of recovery *in* a disorder acknowledges that although patients may still fulfill diagnostic criteria, they can gain access to and learn how use everyday tools that support them in managing symptoms and achieving a higher level of functioning despite not being formally cured: “Unlike in most physical illnesses, people may consider themselves to be ‘in’ this form of recovery while continuing to have, and be affected by, mental illness.” (Davidson & Roe, 2007, p. 462). The recovery model originated in the consumer-advocacy movement that rose to prominence during the 1980s, emphasizing lived experience of recovery and an optimistic view on the chances of improving HRQoL in severe mental illness (Dawson et al., 2014; Watson, 2012). It has been described as “a process that involves gaining or regaining many aspects of life that are usually taken for granted and may have been lost or severely compromised by mental illness” (Roberts & Wolfson, 2004, p. 40). A number of other terminologies that closely resemble the recovery model exist in the literature. For example, a distinction between *clinical* and *personal* recovery has been suggested (Trachsel, Irwin, Biller-Andorno, Hoff, & Riese, 2016). Another similar model contrasts *provider-directed* recovery—i.e., achieving goals that have been defined by healthcare professionals, such as complete or almost complete remission of symptoms—with *consumer-centered* recovery, conceptualized as a process focusing on personhood and empowerment rather than as an outcome (Watson, 2012).

In line with the recovery model, it has been highlighted that recovery from AN should not necessarily be seen as a “final point”, but rather as an ongoing process that typically involves non-clinically oriented components such as creating and nurturing important relationships, acknowledging spirituality as a positive force, etc. (Garrett, 1997; Hay & Cho, 2013; Mitchison et al., 2016). In interviews, AN patients mention the development of new and improved personal relationships towards friends, family, partners, pets, and/or spiritual beings as an important factor in initiating and strengthening the recovery process (Hay & Cho, 2013). Moreover, influential life events—such as entering a new school or starting a new job, becoming a parent, or experiencing medical problems—can also play a pivotal role in inducing change (Venturo-Conerly et al., 2020). Patients typically identify a “turning point” or a “tipping point” at which their path towards recovery begun; however, many factors may interact in creating this tipping point (Hay & Cho, 2013) and it may also involve an “emotional low point” (Venturo-Conerly et al., 2020, p. 1249) that somehow motivates change. Often, patients describe how a cascade of important factors set the recovery process in motion; for example, a new interest or a new hobby may help distance a patient from the illness and build confidence that in turn encourages them to socialize more with friends, etc., so that an upward spiral is created (Hay & Cho, 2013; Venturo-Conerly et al., 2020). Sudden epiphanies *and* gradual changes are often mentioned in the same patient interviews (Venturo-Conerly et al., 2020). In AN, psychological components of recovery (such as increased self-acceptance) tend to lag behind physical and behavioral markers (such as a normalized BMI) and a strict focus on body weight and eating behaviors therefore risks promoting a state of pseudo-recovery (Richmond et al., 2020). Importantly, recovery *in* AN and recovery *from* AN need not be mutually exclusive: since HRQoL may have a greater influence on eating disorder symptoms than vice versa, interventions that primarily

enhance HRQoL may by extension also aid in promoting clinical recovery (Mitchison et al., 2016).

In the field of AN research, two main bodies of literature on recovery can be identified: one that focuses on outcomes in terms of symptom remission and one that focuses on personal narratives, psychological insights, and turning points. Both of these perspectives, however, analyze data primarily at the level of the individual. It has been suggested that an additional socio-cultural focus may be fruitful, emphasizing societal barriers to recovery such as a focus on diet and healthism and a cultural fixation with self-surveillance and self-monitoring (Hardin, 2003; Musolino, Warin, Wade, & Gilchrist, 2015). In this view, recovery from AN becomes an almost unattainable goal:

“Individuals who no longer refuse food and gain weight are also positioned in opposition to a culture in which dieting, food restriction, and exercise are considered normal [...]. When an individual takes steps to discontinue the work of self-starvation, another set of subject positions are generated concerning women, the body, food intake, food refusal, exercise, and weight management. Hence, women who are trying not to diet and trying not to lose weight find it difficult, if not impossible, to step out of this culture.” (Hardin, 2003, pp. 12-13)

Indeed, it is easy to get the impression that AN patients are almost required to develop a healthier and more wholesome relationship to food, fitness, and their own bodies than what is seen in society at large. Some patients manage to find strength in and make use of spiritual and political aspects of recovery, such as developing a feminist view on body ideals (Borowsky, Eisenberg, Bucchianeri, Piran, & Neumark-Sztainer, 2016; Matussek & Knudson, 2009; Venturo-Conerly et al., 2020). However, patients may also occasionally be hindered in the recovery process by feeling as “bad feminists” at times when they did not manage to live up to their own expectations of being able to neglect societally enforced ideals. It is worth remembering that “recovery does not mean getting rid of the fears, instead it means moving forward in spite of them” (Goldkopf-Woodtke, 2001, p. 169). Here, tools such as self-admission can prove useful in preventing relapse in times of limited motivation and low self-esteem.

#### **4.2.2 Principles of harm reduction**

A concept similar to and at times overlapping that of the recovery model is *harm reduction*, i.e., interventions whose primary aim is to diminish the negative impact of problematic behaviors without necessarily fully extinguishing the underlying behaviors themselves (Hawk et al., 2017). Harm reduction approaches such as needle exchange programs have proven successful in diminishing the risk of human immunodeficiency virus or hepatitis C infection in people who inject drugs (Karlsson, 2020). Similarly, providing training in condom-negotiating skills and other safety tips for women in street-based prostitution may reduce harm while not explicitly addressing the broader societal problem (Rekart, 2005). In psychiatry, it has been suggested that principles of harm reduction could be useful for patients who engage in self-injurious behaviors. In this context, harm reduction interventions could include educating patients in first

aid skills and basic anatomy so that they can at least avoid permanent tissue damage or sepsis (Sullivan, 2017), or promoting safer methods of self-injury (e.g., not engaging in the use of ligatures or overdoses) (James, Samuels, Moran, & Stewart, 2017). The overall aim behind these principles is to reduce the impact of self-injury on patients' lives (Gutridge, 2010), while also acknowledging the fact that insisting on a “zero tolerance” policy regarding non-suicidal self-injury may heighten the risk of an actual suicide attempt (Edwards & Hewitt, 2011; Sullivan, 2017). However, the idea of “assisting” patients in their disordered eating, substance use, or self-injurious behaviors stands in opposition to what many healthcare professionals fundamentally believe that mental healthcare should strive towards (James et al., 2017). It is worth noting that harm reduction interventions have typically met with large initial skepticism, not least from policy makers and politicians (Des Jarlais, 2017; Karlsson, 2020).

#### **4.2.3 Pragmatism in the treatment of severe anorexia nervosa**

A number of examples of approaches to treatment and health services provision incorporate elements of the recovery model or harm reduction principles for patients with AN. For example, it has been suggested that established interventions such as FBT, where the therapist avoids taking an “expert” stance and instead encourages the family to take ownership and responsibility for recovery, incorporate basic elements compatible with the recovery model (Dawson et al., 2014). In severe AN, harm minimization may include regular monitoring of body temperature, hydration, and electrolyte balance by a primary care physician, providing symptomatic treatment when necessary:

“Symptomatic relief is important, and we may need to encourage anorexic patients to accept this given their habituation to self-punishment. Maximizing function and quality-of-life, mobilizing support, holding the hope, and trying to find and coax out the person behind the illness are all part of the therapeutic brief.” (Russell, Mulvey, Bennett, Donnelly, & Frig, 2019, p. 400)

Unfortunately, due to the medical risks associated with severe AN, healthcare services may be overly reluctant to provide community-based programs for these patients. Here, self-admission can serve as a tool in reducing the dependence on recurrent hospitalization episodes, breaking the revolving door pattern (Wonderlich et al., 2020). Another example of a similar model aimed at increasing the HRQoL for SE-ED patients is the current treatment program at SCÄ, targeting patients with a severe eating disorder who have been subjected to several previous unsuccessful treatment attempts. At this outpatient service, participants are assigned a clinician whose role is to plan various interventions tailored to the individuals' unique situations—these may include systematic and tailored psychological treatment, somatic controls with a physician, laboratory tests, vocational rehabilitation, family support, etc. A main focus is on supporting patients to increase their everyday level of functioning, to improve their HRQoL, and to avoid medical complications *in spite of* severe mental illness. Symptom remission or a normalized BMI may very well be explicit treatment goals; however, some participants focus more on HRQoL elements and may maintain a low BMI continuously. Treatment in the program is eval-

uated every 6 months to ensure that treatment goals accurately reflect the patient's current situation.

Similar models of healthcare services provision, based on assertive community treatment, for patients with SE-AN who have opted out of traditional curative treatment have been described in Vancouver (Williams, Dobney, & Geller, 2010) and Toronto (Kaplan & Miles, 2016). Here too, “the success of [the program] is not measured by how much weight an individual has gained or whether they cease binge eating and purging, but rather on an improved quality of life while still having an eating disorder and an ability to be maintained in the community” (Kaplan & Miles, 2016, p. 225). As illustrated by a case vignette from a British Columbia community outreach program, an improved nutritional status may very well be a treatment goal—here, however, these goals become meaningful only in relation to subjective patient priorities, such as being able to attend art class, rather than from a traditional notion of striving towards clinical recovery (Williams et al., 2010). Similarly, patients may choose to make use of the self-admission opportunity for whatever reasons they see as important.

### **4.3 POLICY IMPLICATIONS**

#### **4.3.1 A healthcare utilization equilibrium**

By establishing a program of self-admission to inpatient treatment for patients with AN, a “win-win situation” in terms of resource allocation was achieved. Program participants were able to reduce their utilization of regular inpatient treatment at SCÄ by 67%. In doing so, hospital beds were made available for non-participants due to the removal of a yearly average of 13.2 high utilizers of inpatient treatment from the regular waiting list. A sensitivity analysis showed that this “win-win situation” occurred across the entire 95% CI of the inpatient treatment utilization reduction. Thus, at SCÄ, no crowding out effects with a negative impact on non-participants were seen.

The two hospital beds earmarked for the self-admission program were on average utilized 49.5% of the time. Here, it should be remembered that perceived—and real—availability of free hospital beds is a prerequisite for the program to function. Moreover, since a reduced need for inpatient treatment is a core aim of the intervention, a low hospital bed utilization within the program is in itself a positive outcome. As outlined in Study II, the discussion about health services efficiency with regards to self-admission is fundamentally *not* about whether the designated hospital beds should primarily be offered to regular patients or solely to those who participate in the program, but rather about whether they should be offered to regular patients or largely remain empty and ready for use by participants once they need them. The present utilization rate is actually comparatively high considering previous studies, where the hospital beds reserved for self-admission have been occupied for 24-31% of the time (Strand & von Hausswolff-Juhlin, 2015). Even so, noting that the SCÄ hospital beds were “only” utilized just under half of the time available, it may be tempting for healthcare policy makers to simply re-assign one of the two beds to the pool of regular patients and thereby seemingly increase the “win-win” efficiency of the program even further. Considering that the perceived availability

of beds may hypothetically alter the overall equilibrium of the program (e.g., making participants more eager to self-admit if they have the impression that the designated beds are too scarce), such a reallocation of resources may not have the intended result. Interestingly, in the present study, only one participant saw the brevity of the self-admission episodes as a negative aspect, and most participants did not experience poor availability of the designated self-admission beds. In future self-admission programs, the optimal proportion of hospital beds assigned to self-admission at a ward should be carefully followed.

On a similar note, even though threshold values for number of participants and reduction of the number of inpatient days were calculated for the purpose of sensitivity analysis, the number of participants in the program or the proportion of hospital beds earmarked for them are intimately related to the outcomes in terms of reduced healthcare utilization in a complex, reciprocal manner that makes a straightforward analysis difficult. Clearly, the findings presented here do not imply that one can simply increase the number of earmarked beds or program participants and achieve a corresponding increase in inpatient days made available for non-participants—at a certain point, an equilibrium is reached.

#### **4.3.2 Implementation of self-admission**

The participants in the self-admission program at SCÄ displayed an overall high level of satisfaction with the model. Even so, they identified several practical issues that should preferably be taken into account when similar programs are introduced and implemented (Strand et al., 2017). For example, a number of participants described that whereas they saw self-admission as a valuable tool in increasing their own influence over the treatment, they also felt that they could not always live up to their own expectations of being able to handle this newfound agency. Interestingly, the improvements that were suggested by participants typically aligned with more traditional models of healthcare services provision. Hence, while they emphasized the novel elements of self-admission, such as a focus on autonomy and flexibility, they also tended to ask for modifications that may actually neutralize or even counteract these core concepts. These suggestions include increased staff continuity and individual designated contact staff members during the admission episodes, more time with a consultant psychiatrist at the ward, less flexible rules for meals outside the ward or for discharge, etc. This reflects the ambivalent stance among participants towards being endowed with real influence over treatment choices. Moreover, and perhaps more importantly, it may point to the fact that empowerment cannot be provided *for* someone by healthcare policy makers—rather, empowerment must be arrived at by the individuals themselves and be based on their own perceived needs and goals (Tambuyzer et al., 2014). Nevertheless, when future self-admission programs are implemented, it is advisable to apply a pragmatic view towards patient involvement and accountability and to acknowledge that autonomy can be at once liberating and frightening. Healthcare providers should be aware of the potential conflict between positive and negative aspects of these concepts and be prepared to address these issues should they arise.

Bearing in mind that some participants felt that they did not fully grasp the novelty of the self-admission model before they decided to enroll in the program, healthcare providers should



make an effort to inform potential participants in detail about what to expect and not to expect in the program. The rationale behind the model must be carefully explained and the focus on patient agency and accountability should be underscored before any potential candidate decides to join. Moreover, in order to avoid disappointment among participants, healthcare providers should be clear about the fact that it is unrealistic that enrollment in a self-admission program will help them achieve long-term treatment goals during any one stay.

Furthermore, in order to prevent confusion and frustration among participants and staff, an explicit waiting list procedure should be put in place for occasions when all earmarked self-admission beds are occupied. Active outreach by staff informing patients on this waiting list when a bed can be expected to be available is likely to be highly appreciated, so that participants do not have to make repeated calls to the ward. Also, even though it may be difficult to achieve full staff continuity during brief self-admission episodes, healthcare providers should try to meet participant requests for an individual designated contact staff member as far as possible so that a fragmented overall experience is avoided.

#### **4.4 LIMITATIONS**

The findings reported here need to be considered in light of several limitations. In terms of generalizability and transferability, it may not be feasible to introduce a service delivery model characterized by patient choice and high levels of flexibility in all settings, since there is a large variance between countries in how healthcare systems operate (Strand et al., 2015; Wonderlich et al., 2020). The self-admission model described here was implemented in a healthcare system that relies on rationing by waiting list. In contrast, the model may not be fully compatible with healthcare systems that ration resources by ability to pay. Moreover, in systems that rely largely on private healthcare insurance and where most interventions need to be vetted against an insurance company, the potential “spontaneity” of self-admission may be difficult to uphold.

Notably, even though the self-admission program at SCÄ does not formally exclude patients with other eating disorder diagnoses, all participants in the program had an AN diagnosis at inclusion (although for some of them it was in partial remission). Thus, the findings reported here may not be readily transferable to patients with BN, BED, OSFED or other eating disorder presentations. Moreover, some of the findings observed in the participant interviews can be seen as relevant to AN and specialized inpatient treatment *in general* rather than to the self-admission concept specifically. For example, the issues that were raised regarding ambivalence towards help-seeking have broader implications, even if it also affects participants’ chances to make use of self-admission in a constructive manner. Previous research has shown that self-admission can be helpful in psychiatric disorders such as schizophrenia, bipolar disorder, and borderline personality disorder (Strand & von Hausswolff-Juhlin, 2015). However, it is uncertain for which specific patient groups and subgroups that self-admission is most suitable and what factors that influence this. For example, differences in terms of cognitive deficits, executive functions, activity level, and self-awareness may affect patients’ ability to make use of the model. The occurrence of paranoid delusions or full-fledged manic symptoms would certainly seem to be incompatible with the basic self-admission concepts of constructive self-monitoring

and taking action in times of need. More research into which patient groups that stand to benefit the most (and the least) from self-admission could aid in further refining the model. This holds true for AN and other eating disorders as well, where there might be within-group differences that affect viability of the model.

Statistical power was limited by the small number of participants in absolute numbers. This made it difficult to identify effects of a small magnitude. When the study was designed, statistical power was predicted based on the assumption that changes in healthcare utilization and other outcome variables of a relatively large magnitude—comparable to those seen in the Norwegian pilot studies—would need to be observed in order for the reallocation of resources associated with self-admission to be justifiable. Nevertheless, there may have been smaller unidentifiable changes that still influenced participants' well-being in a clinically meaningful way. The naturalistic study setting meant that a large share of eligible patients—i.e., individuals with severe AN in the Metropolitan Stockholm area who are known to healthcare services—were invited to participate in the self-admission program at some point. With around 2 000 active treatment contacts and 1 200 new patients yearly, SCÄ is a very large specialist eating disorder service by international standards. Still, the number of eligible participants were ultimately limited. Because of the fact that many healthcare services only have a limited number of SE-AN patients in their catchment area, it has been suggested that collaborative, multicenter initiatives may be needed in order to achieve sufficient statistical power in research on severe AN (Wonderlich et al., 2020).

The limited number of eligible patients with severe AN also had a negative impact on the closeness of match between participants and comparison groups. For age, illness duration, and BMI, a sufficient match at baseline was achieved. Further matching using previous healthcare utilization and days on sick leave as matching variables was, however, not possible, due to difficulties in involving multiple government agencies in cross-database queries. After matching had been performed and data for the comparison groups had been extracted and analyzed, it was found that the participants displayed a clear tendency to have utilized healthcare more than the individuals in the comparison groups. This may have been expected—after all, the participants were offered enrollment in the self-admission program based, in part, on their previously high utilization of inpatient treatment. Still, the comparability of outcomes is limited because of the less-than-optimal baseline match regarding previous healthcare utilization. The data concerning the comparison groups can be regarded as a reference illustration of tendencies in patients with severe eating disorders and low-to-moderate utilization of inpatient treatment. Given that patients in the moderate-utilization comparison groups had been hospitalized 71 days on average in the past year, it can be argued that they too spent a considerable part of their time at an inpatient ward, albeit not quite as much as the participants. Even so, the data generated in the present thesis project may not fully allow for an analysis of whether the reduced utilization of inpatient treatment observed among participants represents a “real” difference or a regression towards the mean.

A number of reasons behind these discrepancies may exist. The higher utilization of inpatient treatment seen in the moderate-utilization group compared to the low-utilization group could be associated with the fact that a personality disorder diagnosis was substantially more common in the former—thus, they may have been hospitalized primarily because of difficulties related to their personality disorder rather than because of their eating disorder. Individuals in the participant group, on the other hand, were more likely to be diagnosed with ADHD/ADD or an autism spectrum disorder and more often suffered from restricting subtype AN. It has been noted that these features may often coincide and that they predict a poorer prognosis (Westwood & Tchanturia, 2017). Furthermore, the mean BMI was not in the extreme range (as defined in DSM-5) for any of the three groups at baseline. Rather, ranging from 15.8 to 16.5 kg/m<sup>2</sup> across groups, baseline BMIs were moderately to severely low. However, since the participants had been subjected to more than 4 months of inpatient treatment on average in the year prior to inclusion, they may initially very well have displayed even lower BMIs that prompted hospitalization. Thus, participants' baseline mean BMI—at 15.8 kg/m<sup>2</sup>—may actually have represented a high point that had been reached after months of inpatient treatment. The low-utilization comparison group, on the other hand, may have displayed a more stable BMI in the year prior to baseline, judging from the fact that their low weight had obviously not prompted inpatient treatment to the same degree.

It must also be remembered that, as outlined in the Methods section, while self-admission can at this stage indeed be characterized as an experimental approach per se, it was not feasible to carry out a formal experimental study (such as an RCT) of the self-admission program at SCÄ. Early on, the Stockholm County Council decided that self-admission should be made widely available and rolled out on a broader scale, although there was not yet sufficient evidence to suggest that the model was effective. This decision meant that it would not have been possible to randomly allocate eligible patients to different study arms—i.e., active participation in the self-admission program or a control condition such as TAU—since this would have involved offering patients treatment on unequal terms, which is not usually seen as acceptable once a treatment intervention has been established and confirmed by government agencies as the treatment of choice and a standard option. Of course, an alternative approach could have been to ask eligible participants if they agreed to *opt out* of self-admission for a set period of time and instead be assigned to the control condition; however, this would have introduced bias into the randomization procedure and was not seen as a feasible option. All things considered, the self-admission program at SCÄ thus had to be evaluated using a cohort study design.

This also has implications from the perspective of health economics. Ideally, an economic evaluation of a novel healthcare intervention should be based on data from a RCT. Even so, data from observational studies can provide robust evidence on cost-effectiveness:

“The value of such studies is particularly high when RCTs are simply impractical. For example, policy initiatives are rarely introduced in such a way that experimental designs are feasible. In such situations the use of routine observational data can provide a vehicle for evaluation.” (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015f, p. 281)

Unfortunately, once an intervention is formally approved and established, the likelihood of further experimental research being conducted is reduced, which means that decision makers should also take account of the value of the evidence that is forgone when a policy is hastily introduced (Claxton, 2008).

Furthermore, it should be noted that by applying a strict healthcare service provider perspective, the present analysis does not take patient opportunity costs (e.g., lost income during admission or travel costs) or broader non-health sector benefits (e.g., being able to return to work or school faster because of a reduced need of inpatient treatment) into account. Study data indicate that there may indeed be additional benefits in terms of reduced days in sick leave for participants, although this tendency was statistically non-significant. Moreover, as a basis for healthcare sector decision making, broader aspects related to patient satisfaction (as outlined in Study I) and equity (as outlined in Study II) need to be carefully considered. For example, it may be argued that self-admission prioritizes the worse off patients with longstanding illness; on the other hand, all patients with AN that require inpatient treatment are by definition suffering from a severe life-threatening disorder (Arcelus et al., 2011; Keshaviah et al., 2014).

The present resource reallocation analysis only takes eating disorder specialist treatment at SCÄ into account. In Stockholm County, an individual can in practice only maintain one active eating disorder specialist treatment contact at once. Therefore, it is certain that participants did not partake in parallel eating disorder specialist treatment at another clinic during follow-up. However, many of them had active treatment contacts in general psychiatry, as well as in primary care and somatic medicine. As shown in Study III, participants reduced their overall need for inpatient treatment (including other healthcare services) by 51.1%, even though the reduction of regular inpatient days at SCÄ specifically observed in Study IV, at 66.6%, was even greater. Thus, the resource reallocation at SCÄ led to positive ripple effects freeing up resources in other branches of the healthcare sector too, which have not been accounted for here.

At SCÄ, self-admission is available within the Stockholm County Council framework of publicly funded healthcare. Still, this does not mean that the healthcare offered is entirely free. For self-admission as well as for regular admission to the SCÄ adult inpatient ward, standard patient fees are applied as described in the Methods section. Arguable, these patient fees are fairly small; however, this is of course a relative matter and it is not unthinkable that the per diem cost associated with admission had a negative impact on some participants' opportunity to make use of the intervention, even though none of them mentioned this as a barrier in the interviews.

Finally, regarding sick leave, it cannot be known for certain whether the beneficial pattern observed among participants relative to the comparison groups was a result of an overall improved well-being or if it was merely due to the reduction of the number of days spent in inpatient treatment. Moreover, sick leave episodes shorter than 14 days are not registered in the LISA database, which means that some of the observed improvement could simply reflect that sick leave days incurred during self-admission episodes (which, by definition, last for a maximum 7 days) were not captured.

## 4.5 RECOMMENDATIONS FOR FUTURE RESEARCH

### 4.5.1 A stepped wedge approach

In light of the present findings and the limitations detailed above, a number of recommendations for future research can be made. A major problem is the difficulties in randomizing participants, due to the highly naturalistic nature of the study and the decision of policy makers to introduce the self-admission model on a broader scale without prior trialing. In studies of similar programs in the future, a feasible alternative option could be to use a so-called *stepped wedge cluster randomized trial* design. This approach is increasingly being used in research on complex healthcare service delivery interventions where traditional randomization designs may not be possible (Hemming, Haines, Chilton, Girling, & Lilford, 2015). In a stepped wedge trial, the entity that is being studied is healthcare services rather than individual patients. For example, if several different hospital wards are about to implement a novel treatment, they can be randomized to do this sequentially, one ward at a time in a scheduled fashion, until patients at all wards have been subjected to the treatment. Hence, all study sites eventually switch from control status to intervention status, but at different points in time. It has been suggested that a stepped wedge approach may be particularly useful in contexts involving logistical and/or political constraints. In parallel to the way self-admission was introduced in Stockholm County Council healthcare facilities, stakeholders such as managers or politicians may want to implement a novel treatment approach broadly without prior trialing, perhaps due to attentiveness to their constituents, to patient requests, or to current trends in healthcare. As described above, when a treatment intervention is introduced as a standard option, patients may not readily accept that they as citizens are randomly assigned to treatment within government-run or government-sponsored healthcare services (Hemming et al., 2015). If researchers nevertheless believe that the intervention should be further studied, a stepped wedge design may be a feasible option while still being mindful of broader considerations in implementation. Since most policies are rolled out over a period of time, the stepped wedge cluster randomized trial design offers an alternative that is at once fair *and* randomized.

For the present study of patients with AN in Stockholm County, a stepped wedge approach probably would not have been possible since the number of specialized inpatient services is limited. If, however, self-admission would be introduced in the treatment of eating disorders nationwide, a stepped wedge cluster randomization trial may be a viable approach. Also, for self-admission programs targeted to patients with other psychiatric disorders, such as schizophrenia or borderline personality disorder, a stepped wedge approach may be more realistic.

### 4.5.2 Pragmatic trials

In circumstances where a formal trial of self-admission—RCT or otherwise—is possible, a *pragmatic trial* approach is advisable. The concept of pragmatic trials arose due to concerns that standard explanatory RCTs optimized to determine efficacy can be insufficient in predicting real-world effectiveness and informing practice (Ford & Norrie, 2016). Many trials are conducted under ideal conditions with highly select participant groups where, for example, poten-

tial participants with comorbid conditions are often excluded. These procedures are often seen as prerequisites in ensuring generalizability, but may in fact compromise the applicability of the study findings in real-world clinical settings where patients present with all types of issues which would make them ineligible for a trial. In order to better reflect this clinical reality, a pragmatic attitude to trials has been suggested whereby interventions are delivered the way they would be in normal practice. Notably, a number of similar or overlapping approaches exist, such as *effectiveness trials*, *practical clinical trials*, or *large simple trials* (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015).

Whereas a traditional explanatory trial seeks to explore whether an intervention *can* work in a well-resourced, ideal setting in which it is strictly enforced and adherence is monitored closely, a pragmatic trial explores if the intervention *does* work when used in normal clinical practice (Treweek & Zwarenstein, 2009). Therefore, a pragmatic trial involves little or no participant selection beyond the clinical indication of interest—that, for example, the participant suffers from severe AN. Moreover, outcome measures in a pragmatic trial should be directly relevant to participants and healthcare professionals, in contrast to explanatory trials that often uses short-term surrogates or process measures as outcome measures. A pragmatic trial should ideally not involve blinded interventions, since this is not how real-world clinical interventions are applied. Instead, in order to avoid bias, pragmatic trials often focus on major outcomes such as emergency hospital admissions or death rather than minor outcomes of less clinical relevance (Ford & Norrie, 2016).

Although the quantitative part of the present thesis is an observational study and not a trial, many aspects of pragmatic trials apply. The setting is strictly “real-world”, the intervention is offered the way it would be in usual care—it is, indeed, usual care after it has now been rolled out on a broader scale as described above—and participants are not excluded based on comorbidity in any higher degree than what would happen for regular patients at the SCÄ inpatient ward. Furthermore, although participants have a support network at SCÄ that they can use as a discussion partner in deciding whether they should self-admit, this is not beyond what is offered to any patient and adherence to a study protocol has not been strictly enforced on individual level. Nevertheless, the observational nature of the study does not yield as high-quality evidence as a trial could. In future trials of self-admission, it is recommended that a pragmatic attitude is applied in order to fully reflect the real-world complexity of the intervention and the targeted patient groups.

#### **4.5.3 N-of-1 trials**

Another way of introducing a prospective and experimental approach to the study of a complex intervention such as self-admission is to employ a so-called *N-of-1 trial* methodology or similar single-subject designs. In a *N-of-1 trial*—also known as a single-patient trial—an hypothesis is tested within an individual participant based on repeated measurement over time, acknowledging that the intraindividual effects observed may differ from those seen in traditional between-participant studies (McDonald et al., 2017). In contrast to trials involving parallel groups of participants, such as RCTs, *N-of-1 trials* use crossover between treatments for a single partici-

pant in order to control for treatment-by-time interaction, i.e., the possibility that the relative effects of two interventions or control conditions vary over time (Kravitz & Duan, 2014). *N*-of-1 trials typically involve multiple crossovers between baseline and intervention states (such as A-B-A-B or A-B-A-B-A designs, where initial baseline and intervention phases are followed by return to baseline, a subsequent second intervention phase, etc.). Moreover, they are usually randomized and often blinded (Kravitz & Duan, 2014; Schork, 2015). However, *N*-of-1 observational studies have also been reported (McDonald et al., 2017).

*N*-of-1 trials are commonly heralded as an integral component of patient-centered care and so-called personalized or precision medicine (Schork, 2015). Another rationale behind employing an *N*-of-1 approach is that a substantial uncertainty often exists regarding the comparative effectiveness of treatments that are being considered for an individual patient, due to an overall lack of evidence or when available evidence is not fully relevant to the particular patient at hand (Kravitz & Duan, 2014). Here, a purpose of *N*-of-1 trials may be to generate hypotheses for further evaluation in larger trials. However, it has also been argued that much psychological research is overly focused on variation between cases, whereas time-dependent variation within a single participant is often neglected, even though results obtained from research on group level do not necessarily lend themselves to valid application on an individual level (Molenaar, 2004). By design, single-subject approaches such as *N*-of-1 trials are sensitive to individual differences, whereas group approaches are sensitive to group averages. Here, findings from *N*-of-1 trials can offer unique insights, not least in areas where traditional between-group trials are difficult to perform. Even so, meta-analysis of similar *N*-of-1 trials also offers the opportunity to aggregate group mean effects across individuals and studies.

One might argue that physicians have long used this approach ad hoc in clinical practice (Schork, 2015): a doctor may, for example, prescribe an antidepressant medication to a patient and then closely monitor the effect before altering the dose or switching to another medication. In the past, however, this method has rarely been translated into well-designed trials. There has been a surge in the number of published *N*-of-1 trials in the last two decades, as the methodology has been employed in the assessment of a variety of interventions for a broad spectrum of medical conditions (Punja et al., 2016). It has been suggested that three conditions should be fulfilled in order for an *N*-of-1 trial to be meaningful (Kravitz & Duan, 2014; Punja et al., 2016). First, the condition under study should be relatively stable; this is certainly the case for longstanding AN. In contrast, a condition that is more likely to improve spontaneously may not be suitable for an *N*-of-1 approach, since it will be difficult to attribute any change to the trialed treatment. Second, the intervention being studied should have a distinct onset and a distinct point of termination, to allow for swift intraindividual crossover between intervention and control conditions; this holds true for self-admission. Third, similarly to a pragmatic trial, the outcomes of interest should be clinically relevant to both patient and provider; again, this holds true for self-admission in severe AN. In sum, an *N*-of-1 trial approach could prove useful in studying self-admission targeted to patients with longstanding AN as well as with other enduring psychiatric conditions. In fact, the original Norwegian pilot studies on self-admission where

patients served as their own controls could be seen as multiple parallel single-subject design studies.

#### 4.5.4 Implementation science

Establishing the efficacy or effectiveness of a novel treatment intervention does not guarantee its uptake and implementation in routine practice; “regardless of how valuable clinical interventions may be, they scarcely implement themselves” (Eldh et al., 2017, p. 1). It has been estimated that fewer than 50% of healthcare innovations are actually implemented in clinical practice; for those that are, the average time from establishment of effectiveness until implementation is between 17 and 20 years (Bauer & Kirchner, 2020). This is at least partly due to a research-to-practice gap, whereby research findings generated in academia are not always readily translated into public health impact (Bauer et al., 2015). In the field of eating disorders, an urgent need for closing the gap between what is known about effective psychosocial interventions and what is actually provided to patients has been identified (Kazdin, Fitzsimmons-Craft, & Wilfley, 2017). Even if a pragmatic attitude to trialing is employed, it is not certain that evidence of real-world effectiveness will guarantee implementation, since pragmatic trials often depend on resources which are separate from the routine practice infrastructure (Bauer et al., 2015).

Therefore, implementation science is increasingly recognized as a vital part of mental health services research (Proctor et al., 2009). An efficacy-effectiveness-implementation spectrum is sometimes envisaged—here, “implementation science seeks to ‘continue the job’ of biomedical research, taking evidence-based clinical innovations and testing strategies to move them into wider practice” (Bauer & Kirchner, 2020, p. 5). Clinical research assesses health effects of an intervention; in contrast, implementation science is focused on the rates and quality of the actual use of an intervention rather than its effects (Bauer et al., 2015). In practice, however, it is often difficult to draw a sharp line between clinical research and implementation science (Eldh et al., 2017) and an increasing number of studies use a hybrid design where both effectiveness and implementation outcomes are examined (Landes, McBain, & Curran, 2019).

In the present study, assessment of effectiveness and implementation goes hand in hand, which is reflected in the publication of a separate paper outlining the “dos and don’ts” of implementing a self-admission program (Strand et al., 2017). This approach was further necessitated by the decision of Stockholm County Council policy makers to introduce the self-admission model on a broader scale without first having established its effectiveness. In future evaluations of similar programs, a hybrid effectiveness-implementation design should be considered from the outset. Interestingly, it has been suggested that implementation research exploring the effects of real-world policy change could benefit from employing a so-called *interrupted time series design* whereby outcomes of interest are measured at multiple time points before and after implementation (Bauer et al., 2015)—this largely resembles an *N-of-1* trial, although the single subject is a healthcare service rather than an individual patient. Moreover, an economic evaluation could easily be integrated into the implementation science framework (Eisman, Kilbourne, Dopp, Saldana, & Eisenberg, 2020).



Another integral part of evaluating the implementation of self-admission in psychiatry is ensuring that staff experiences are explored and that there is room for continuous modification of the intervention based on these findings. In future evaluations of the implementation of similar programs, it would be of significant interest to formally collect data on staff experiences; this has been done for self-admission programs targeted to patients with self-injurious behaviors in Stockholm (Eckerström et al., 2019) and in Denmark (Ellegaard, Mehlsen, et al., 2017).

## 4.6 CONCLUSIONS

In sum, this thesis shows that self-admission to inpatient treatment for patients with severe AN is a viable and effective treatment tool in terms of strengthening autonomy and reducing the total number of days spent hospitalized. The introduction of a self-admission program at SCÄ resulted in a more than 50% decrease in the total number of days that participants spent in inpatient treatment during 12 months in the program. In comparison, only smaller and statistically non-significant changes over time were observed in low- and moderate utilization comparison groups. However, no significant effects were seen in terms of the number of days spent in involuntary inpatient treatment or the number of visits to the outpatient clinic. Moreover, the introduction of self-admission did not have any significant or clinically relevant effects on participants' self-rated eating disorder morbidity or BMI. Somewhat surprisingly, mixed results regarding participants' HRQoL were found. Whereas participant interviews pointed to marked improvements in agency, motivation, and autonomy that made a real difference in patients' everyday lives, these changes were not mirrored by unequivocal improvements on HRQoL as measured by standard quantitative self-rating instruments. A beneficial tendency was seen for participants in terms of number of days on sick leave; this finding, however, did not reach statistical significance. Importantly, the reallocation of hospital beds earmarked for self-admission was offset by an overall reduced need for inpatient treatment among participants, resulting in a net increase in available hospital beds for non-participants.

These findings imply that self-admission in AN may be most useful as a tool within a recovery model framework—an approach where the primary goal is not necessarily achieving full symptom remission and recovery in a traditional sense, but instead improving symptom management, strengthening the overall levels of functioning and social inclusion, and maintaining a community-based treatment focus. Interestingly, brief episodes of inpatient treatment at times of heightened risk of relapse appears to facilitate further community-based efforts; thus, hospitalization can be a complement to community treatment rather than a substitute.

Unfortunately, for various reasons related to the real-world nature of the study, it was not possible to conduct an RCT of the self-admission program at SCÄ. Overall, there is a dearth of randomized and/or controlled studies of self-admission—in future program evaluations, incorporating a randomized controlled design should be a priority. Moreover, further evaluation of resource allocation and health economics in other settings is much needed, as well as research on how the self-admission model can be implemented in an optimal way. The self-admission model is meant to remove barriers and increase access to healthcare for patients with severe mental illness. However, as shown in the qualitative part of this thesis, making optimal use of

self-admission also requires motivation, support, and a certain amount of insight into the severity of one's illness. Therefore, it may not be suitable for all categories of patients in psychiatry; for example, the occurrence of paranoid delusions or full-fledged manic symptoms would seem to be incompatible with the basic self-admission concepts of constructive self-monitoring and taking action in times of need. More research into which patient groups and subgroups that stand to benefit the most (and the least) from self-admission could aid in further refining the model.

Although the participants in the self-admission program at SCÄ reduced their need for inpatient treatment by more than 50%, in real numbers this translates to a change from 140 to 68 days spent in hospital per year on average. Thus, participants still spent more than 2 months per year on average in inpatient treatment after the introduction of self-admission, reflecting a continuously severe illness with recurrent need for hospitalization. Even so, for patients with long-standing illness and pervasive difficulties in maintaining community-based treatment contacts, this represents a major improvement. Naturally, the brief nature of the self-admission episodes does not allow for full-scale weight restoration or achievement of other long-term treatment goals. Instead, self-admission offers "booster" opportunities or short periods of rest and relief in situations where the risk of relapse is heightened. In this way, brief admission to inpatient treatment may support individuals with an eating disorder in turning a destructive trajectory around so that community-based treatment can be resumed. The self-admission approach may also help promote an understanding of the hospital ward as a safe and helpful sanctuary in times of need rather than a place implicitly associated with crisis and coercion. This is mirrored in Norwegian reports of how self-admission allows for new experiences for the hospital staff too. Being able to invite patients to make constructive use of the ward rather than either forcefully admit them or, at times of high demand and little resources, fend them off may offer a novel perspective on one's own professional role. In its proper context, the self-admission model holds the potential to transform mental healthcare from crisis-driven to pre-emptive, and to promote autonomy for severely ill patients.

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