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Abbreviations

ICD 10	International Statistical Classification of Diseases and Related Health Problems, 10th revision, by WHO

F0	Mental disorders due to known physiological conditions
F1 other	Mental and behavioral disorders due to psychoactive substance use
F10	Alcohol-related disorders
F11	Opioid-related disorders
F19	Other psychoactive substance-related disorders
F2	Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders
F3 other	Mood (affective) disorders
F32	Major depressive disorder, single episode
F4 other	Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders
F41	Other anxiety disorders
F43	Reaction to severe stress, and adjustment disorders
F5	Behavioral syndromes associated with physiological disturbances and physical factors
F6	Disorders of adult personality and behavior
F7	Intellectual disabilities
F8	Pervasive and specific developmental disorders
F9	Behavioral and emotional disorders with onset usually occurring in childhood and adolescence
F99	Unspecified mental disorder
Z	Factors influencing health status and contact

PER	Psychiatric emergency room (a psychiatric care unit, open 24 hours a day, seven days a week)
WHO	World Health Organization

Definitions

Holistic perspective:	The person is seen as a subject and as a whole, and his/her whole life situation (encompassing the biological, psychological, social, cultural, and spiritual dimensions) is taken into account (cf. Arvidsson and Skärsäter, 2006, PRF & SSF, 2014, Brenner et al., 2016). The holistic perspective is part of the humanistic approach.
Mental illness:	An umbrella term covering a broad range of mental health problems that restrict the individual's ability to function well in and cope with everyday life. It includes both severe psychiatric illness such as schizophrenia as well a minor and moderate conditions such as depression (Bremberg and Dalman, 2015, Public Health Agency of Sweden (Folkhälsomyndigheten), 2016).
Need:	A subjectively experienced problem of the person-in-care that may be communicated/expressed or self-assessed and may be met by means of a conscious and deliberate intervention.
Person who frequently visits PERs:	A person making five or more PER visits during a period of 12 months (Aagaard et al., 2014, Schmidt et al., 2018).
Psychiatric healthcare:	Is provided by Sweden's county councils/regions and includes specialized psychiatric care, primary healthcare, and emergency care focusing on persons with mental illness.
Social care services:	Are provided by Sweden's municipalities. These include various support functions, for example, social rehabilitation, child care, home care, mental health care, and family counselling for all municipal inhabitants, including the elderly, families, and persons with psychiatric disabilities.

Triage:	A systematic and standardized interview/examination conducted by triage nurses on patients visiting an emergency room to prioritize and risk-assess patients according to the severity of their illness. In Sweden, the Rapid Emergency Triage and Treatment System (RETTS) is used in most emergency rooms (SBU 2010). In PERs, RETTS-psy is often used.
Triage nurses:	Triage is conducted by triage nurses. In the context of this thesis, triage nurses refer to registered and assistant nurses working in triage in PERs.

Original papers

This licentiate thesis is based on the following papers:

I: Schmidt, M., Ekstrand, J., & Bengtsson-Tops, A. (2018). Clinical profiles and temporal patterns of psychiatric emergency room visitors in Sweden. *Nordic Journal of Psychiatry, 72*(3), 197–204.

II: Schmidt, M., Ekstrand, J., & Bengtsson-Tops, A. Self-expressed and self-assessed needs in persons who frequently visit psychiatric emergency rooms in Sweden. *Submitted*.

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Abstract

Persons who frequently visit psychiatric emergency rooms (PERs) account for a disproportionately high number of total visits to PERs. They have needs just as any other human beings do. Yet in addition, they also have specific daily function needs, service needs, and needs for professional healthcare.

The overall aim of this thesis was to investigate who persons frequently visiting PERs in Sweden are and what needs they have. Both studies I and II were conducted in southern Sweden. Study I is a quantitative mapping study describing who persons who frequently visit PERs are, what characterizes them, and what characterizes their visits, while study II investigates their self-expressed and self-assessed needs using a mixed-methods design.

For data collection, a large-scale registry was used in study I, while in study II an interviewer-administered manual was applied consisting of open-ended questions and validated instruments covering the person-in-care's needs assessment, alcohol and drug use, exposure to violence, and social network. Quantitative data were analysed using descriptive statistics and non-parametric tests (I, II) and qualitative data were analysed using qualitative content analysis (II).

The results indicate that persons who frequently visit PERs represented 8.1% of the total number of PER visitors but accounted for 38.3% of the total number of PER visits (I). They differed significantly from the rest of the PER visitors in terms of gender, diagnoses, hospital admissions, and temporal patterns of visits. Differences were also found in the distance between the PERs and the home municipalities of the visitors (I). In addition, they reported problems in many need areas in life, involving physical and psychiatric health problems as well as financial, emotional, and social problems (II). Results also indicate that they are often subject to violence and have limited social networks (II).

The results may be used for planning, developing, and evaluating interventions targeting the needs of persons who frequently visit PERs, which is in line with a person-centred approach. Such an approach might eventually address their needs better, reduce their suffering, and consequently result in fewer PER visits.

Introduction

Persons who frequently visit psychiatric emergency rooms (PERs) are a vulnerable group of individuals (Aday, 2001, WHO, 2010). Many of them struggle in expressing their needs, which in turn leads to difficulties in mastering their lives in general and in interacting with psychiatric healthcare and social care services in particular (Saarento et al., 1998b). They not only have healthcare needs, but also social care needs. Like many persons suffering from mental illness, persons frequently visiting PERs struggle with stigmatization, discrimination, exposure to violence, and emotional suffering and are at high risk of comorbidity and premature mortality (Goodman et al., 2001, Keyes, 2002, Rüsch et al., 2005, WHO, 2013, Khalifeh et al., 2015). Although they have numerous contacts with psychiatric healthcare and social care services, they appear not to receive the help they need to meet their needs, but incorporate those contacts with PERs into their otherwise limited social networks (Nordström et al., 2009, Aagaard et al., 2014). In addition, it has been argued that persons who frequently visit PERs account for a disproportionately high number of total visits to PERs, claiming a considerable proportion of their already limited resources (Ellison et al., 1986, Ledoux and Minner, 2006, Chaput and Lebel, 2007a).

Due to the growing number of persons suffering from mental illness and their demand for interventions, healthcare providers such as psychiatric care, including PERs, have not yet adequately adjusted to the growing demand. Consequently, the gap between the need for treatment and its provision is wide (WHO, 2017).

To improve healthcare delivery to as well as the life situation and quality of life of persons who frequently visit PERs, two steps are proposed here: first, related issues of defining and characterizing these persons ought to be addressed so that they can consistently be identified; second, their needs ought to be identified. Since their visits are recurring over time, persons frequently visiting PERs appear to have continuous unmet needs that prolong their suffering and drain healthcare services' resources.

This thesis applies a person-centred approach and aims to determine: who persons frequently visiting PERs are, what characterizes them, and what characterizes their visits (I); what their needs are and to what extent they are met (II). Needs cannot be objectively defined (Brewin et al., 1987, Slade, 1994) but should be understood in terms of the person possessing them. By applying a person-centred approach, the subjective experience of persons frequently visiting PERs is emphasized.

From an international perspective, the phenomenon of persons frequently visiting PERs is well studied, with a particular focus on North America and Europe. From a Nordic perspective, research is scarce, comprising only one comparative study of Denmark and Finland (Saarento et al., 1998b) and a few studies conducted in Denmark (Buus, 2011, Aagaard et al., 2014) and Finland (Saarento et al., 1998a). A recent literature review found that no studies have explored persons who frequently visit PERs in Sweden (Schmidt, 2018). Furthermore, there is a lack of studies investigating the temporal patterns of these visits, or the needs of persons who frequently visit PERs. The results of studies I and II may lay the groundwork for adjusting interventions in both psychiatric healthcare and social care services to improve the life situations and quality of life of persons frequently visiting PERs by meeting their needs more efficiently and effectively.

Background

Mental health and mental illness

The prevalence of mental illness worldwide and in Sweden is increasing, and its global burden is underestimated (Vigo et al., 2016). Its disease burden is among the highest. Despite this, treatment rates of mental illness are low in low-, middle-, as well as high-income countries (WHO, 2017). Mental illness and its treatment are often related to stigma and personal failure, which makes those with mental illness suffer not only invisibly but also in silence and loneliness.

Mental health is a complex phenomenon that is hard to define, as is mental illness, and universal definitions have yet to be found (Townsend, 2015, Videbeck, 2017). Within the psychiatric care context, attention has long concentrated entirely on treating illness, ignoring health-promoting interventions (Jormfeldt et al., 2008) and recovery approaches (Barker and Buchanan-Barker, 2010).

There are many different perspectives on health and illness, two of which are the most prominent in the literature. *The biomedical perspective*, particularly dominant in the Western world (Bentall, 2014, Bowling, 2014), is based on the assumption that health is the absence of disease. Health and illness form opposites along a one-dimensional continuum. This model is limited in applicability to mental illness since it fails to adequately address the multidimensional complexity of the illness, i.e., only the objective, measurable, psychical, and chemical dimensions of the disease can be addressed. Illness, i.e., the person's own perception of the experience of symptoms or feelings, is ignored, as are the social, cultural, and, to a great extent, psychological causes of a disease. The second is the *holistic perspective*, i.e., the humanistic perspective, which emphasizes that health means wholeness, implying that 'health cannot exist unless all aspects of the person and the person's world are invoked' (Barker, 1999, p. 26).

Theorists attempting to define or operationalize mental health agree that mental health should consist not merely of the absence of mental illness, i.e., the absence of something negative, but also the presence of something positive (WHO, 1948, Jahoda, 1958, Ryff and Singer, 1998). Research also usually emphasises various dimensions of individuals' functioning. Keyes (2005, p. 539), for example, conceives mental health "as a complete state in which individuals are free of psychopathology and flourishing with high levels of emotional, psychological and social well-being" and views mental health as an integrated and essential part of health (WHO, 1948).

Despite being highly interrelated, mental health and mental illness are viewed here as belonging to separate continua (Keyes, 2002, 2005), i.e., mental health can be present (flourishing) or absent (languishing), and so can mental illness; for example, depression can be present or absent.

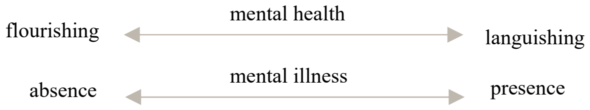

Figure 1. The mental health and mental illness continua.

This is in line with several health models and theories proposing that health and illness coexist in varying degrees throughout life, forming a multidimensional continuum (Eriksson, 1984, Antonovsky, 1996, Moch, 1998). Even nearly unbearable suffering and experiences of health can coexist (Eriksson and Herberts, 1995) and health is an ever-changing process and a process of becoming (Eriksson, 1984).

In this thesis, mental illness is used as an umbrella term covering a broad range of mental health problems that restrict the individual's ability to function well in and cope with everyday life. It includes both severe psychiatric problems such as schizophrenia as well as minor and moderate conditions such as anxiety (Bremberg and Dalman, 2015, Public Health Agency of Sweden (Folkhälsomyndigheten), 2016).

Mental illness in Sweden

Mental illness is considered one of Sweden's major public health problems. The prevalence of mental illness in Sweden is like that in many other countries in Europe (The National Board of Health and Welfare (Socialstyrelsen), 2009), and has increased in recent decades, as has the number of persons seeking care. According to Sweden's Public Health Agency (2016), which includes in their definition of mental illness both severe psychiatric problems (such as schizophrenia or major depression) as well as mild and moderate symptoms of mental conditions (such as sleeping problems or anxiety), 20-40% of the Swedish population suffer from mental illness (The National Board of Health and Welfare (Socialstyrelsen), 2005, Persson et al., 2006, Public Health Agency of Sweden (Folkhälsomyndigheten), 2016). Another source claims that more than half of the population suffer from mental illness at some time during their lives (Brenner et al., 2016).

The most prevalent psychiatric diagnoses in Sweden are neuroses/anxiety (F40–F49) (8–10% of the total population), substance abuse (F10–F19) (5–7%), and depression (F32) (3–5%) (The National Board of Health and Welfare (Socialstyrelsen), 2009). In 2016, 951,849 visits were made by 331,322 persons to specialized outpatient care units in Sweden, receiving psychiatric diagnoses (ICD F00–F99), an increase of 51% in visits and 41% in number of patients compared with 2010. Mental illness is also the main reason for sick leave in Sweden, with severe stress (F43) being the most common psychiatric sick leave diagnosis (Brenner et al., 2016, Insurance Agency (Försäkringskassan), 2017).

Persons suffering from mental illness are considered to have worse life circumstances than does the general population in Sweden and worldwide (Nordström et al., 2009). Their lives are often characterized by lack of support from society, social marginalization, and poor health (Green et al., 2003, Nordström et al., 2009), leading to lower quality of life and well-being (Slade et al., 2005, Wiersma, 2006). Mental illness is also associated with feelings of guilt and shame (Vuokila-Oikkonen, 2002), which can even prevent the person from seeking care (Wiklander et al., 2003). Furthermore, persons suffering from mental illness experience violence to a significantly higher degree than does the general population (Goodman et al., 2001, Khalifeh et al., 2015). Certain groups in society are at significantly higher risk of experiencing mental illness, such as persons living in poverty, suffering from chronic health conditions, minority groups, persons imprisoned, exposed to conflict, and young unemployed persons (WHO, 2013). Consequently, mental illness itself can lead to poverty (WHO, 2010), stigmatization and discrimination (Rüsch et al., 2005, Thornicroft et al., 2007), conflict, and unemployment (Insurance Agency (Försäkringskassan), 2017). Furthermore, persons suffering from mental illness are at increased risk of premature mortality (WHO, 2013, Aagaard et al., 2016) and comorbidity (Keyes, 2004, Smith et al., 2014).

Healthcare and social care services in Sweden

Healthcare and social care services in Sweden are based on a socialized welfare system that addresses both somatic and mental illness and is primarily financed by taxes. The provision of psychiatric healthcare and social care services is regulated by law and policies, and is based on the principle that everyone is of equal value and has equal rights and that autonomy and integrity of the patients need to be respected (SFS, 2017:30). Furthermore, the responsibility for psychiatric healthcare and social care services is shared between national government, municipalities (N = 290), and county councils (N = 21) as a result of the implementation of the Mental Health Care Reform in 1995, which imposed a new care structure on psychiatric care (SOU, 1992, Stefansson and Hansson, 2001). The objective of the reform was to improve the conditions in society and the quality of life for persons with mental illness (The Swedish Government, 1994). While the national government is responsible for promoting research, auditing processes, and providing subventions and incentives within specific areas, the municipalities are obliged to provide social care services such as housing, social support, and activities for persons with psychiatric disabilities. This legislation emphasizes participation, countering discrimination, and self-determination and is embedded in the Social Services Act (SOL) (SFS, 2001:453) and the Act Concerning Support and Service to Persons with Certain Functional Impairments (LSS) (SFS, 1993:387). However, the design of goals and priorities can differ among municipalities because they self-govern their own budgets, which can result in large variation in or lack of support functions provided by the municipalities to persons suffering from mental illness or psychiatric disabilities. Health and medical care is provided by the county councils. This includes primary healthcare, specialized psychiatric care, emergency care, and in- and outpatient care and is regulated by the Health and Medical Services Act (HSL) (SFS, 2017:30). Meanwhile it can be a challenge to provide good continuous healthcare and social care services and to collaborate across the boundaries of organizations applying different perspectives and various legislations (Brenner et al., 2016, Janlöv et al., 2016), yet collaboration between all parts of the system is stipulated by those laws.

Developments within the field of psychiatry

Psychiatry is a very dynamic yet complicated discipline and, not least, a demanding occupational field (Hem et al., 2008, Morse et al., 2012). It is a medical speciality and a relatively young discipline. In Sweden, psychiatric healthcare was established around 1850 with a focus on care administered in mental hospitals (The National Board of Health and Welfare (Socialstyrelsen), 1997) applying a biomedical perspective.

Since the 1960s, the humanistic approach within psychiatry has become more prevalent, resulting in the deinstitutionalization process on a global scale. One of the purposes was to increase the quality of life for persons with severe mental illnesses by moving away from institutions to the community setting, which was well in line with the ‘antipsychiatric’ approach that criticized the authoritarian hegemony of the mental hospitals and sought a more humane and democratic approach based on patient experiences. Sweden participated in this movement as well and closed its larger mental hospitals. By the 1990s, all mental hospitals had been closed in Sweden. Though with good intentions, economic and political forces within the healthcare environment soon led to fewer and shorter in-patient beds, fewer out-patient services, more admissions, service gaps, as well as inadequate housing and community support services; mental health patients were in and out of treatment faster (Brown, 2005).

In retrospect, the relatively fast process of deinstitutionalization may also have contributed to an increase in the number of persons being homeless, an increase in violence in a societal context to and by persons suffering from mental illness (Monahan et al., 2017), and increase of prisoners in forensic institutions in Sweden (Åsberg and Agerberg, 2016). It also contributed to a greater need for PER, introducing the phenomena of recidivism and revolving doors (Kastrup, 1987, Botha et al., 2010, Aagaard et al., 2014).

Psychiatric emergency rooms in Sweden

In Sweden, the initiation of deinstitutionalization (Dencker and Gottfries, 1991, Reitan, 2016) as well as the Mental Health Care Reform (SOU, 1992, Stefansson and Hansson, 2001, Arvidsson and Ericson, 2005) had a paramount effect on the development of PERs and the staff working in them.

The main task of PERs is to function as gatekeepers assessing and prioritizing, by means of triage, visitors' mental health problems and needs according to their urgency and severity in order to initiate immediate intervention and treatment (Buus, 2011). The triage system has been shown to play a significant role in emergency room resource distribution in general, as it prioritizes resource use according to clinical urgency (Smart et al., 1999). In Sweden, the Rapid Emergency Triage and Treatment System – psychiatry (RETTS-psy) has been used in most PERs (SBU 2010) since 2011; it is executed by triage nurses, who often are also the first ones to meet the visitors.

Nowadays in Sweden, PERs are usually hospital based and operate 24 hours a day, serving either smaller or larger urban areas. Provision may differ from that in other countries, where psychiatric emergency care can be administered by ambulance or mobile assessment teams (Brown, 2005, Alves et al., 2013).

At PERs, staff usually works in teams, which can comprise psychiatric nurses, psychiatric assistant nurses, attending physicians and psychiatrists, and physicians on call (Currier and Allen, 2003, Ottosson et al., 2010). What is considered an "appropriate" psychiatric emergency varies (Chaput et al., 2008). In its most elementary form, it can be characterized as an interaction between a healthcare professional and a patient within the context of a crisis (Chaput et al., 2008). In a psychiatric emergency, the condition is often intrinsically subjective (Swartz, 1987), which complicates assessment of the urgency and severity of the condition.

Increase in psychiatric emergency room visits

In recent decades, a significant increase in the number of PER visits has been noted worldwide (Brown, 2005). In Denmark, the number of PER visits has increased with 151.3% from 1995 to 2004 (Aagaard et al., 2014), while other sources report increases of up to 400–500% (Videbeck, 2017). Reasons for the increase are manifold: an increasing number of persons suffering from mental illness (WHO, 2013, Whiteford et al., 2013, Vos et al., 2015), the long-term effects of deinstitutionalization and downsizing of hospital beds, increasing rates of substance abuse, service gaps, and increasing community social problems (Schmidt, 2018). Another possible reason for the increase in PER visits may be that persons suffering from mental illness are using PERs as a primary care source (Eppling, 2008), when in fact they represent a medical specialty. Furthermore, for many who lack socioeconomic resources or access to care, PERs also represent a safety net (Young et al., 2005, Nicks and Manthey, 2012), refuge, and part of their social network (Aagaard et al., 2014). Although persons who visit PERs have several points of contact with psychiatric healthcare and social care services (Nordström et al., 2009, Aagaard et al., 2014), PERs are a preferred place to go, not least due to their availability 24 hours a day, seven days a week. These findings are supported by several studies finding that 43–64% of PER visits were not urgent (Vigiser et al., 1984, Chaput et al., 2008, Adeosun et al., 2014), recalling similar findings regarding somatic emergency rooms (Uscher-Pines et al., 2013).

Principally, the first-line care for persons suffering from mental illness in Sweden is primary care (Skårderud et al., 2010), including both the treatment and rehabilitation of those with mild and moderate symptoms, while specialized open psychiatric care treats more severe forms of mental illness.

Persons who frequently visit psychiatric emergency rooms

It has been argued that persons frequently visiting PERs are a relatively small group, but one that accounts for a disproportionately high number of total visits to PERs and claims a considerable amount of their limited resources (Ellison et al., 1986, Saarento et al., 1998a, Pasic et al., 2005, Ledoux and Minner, 2006, Chaput and Lebel, 2007a, Chaput and Lebel, 2007b).

Judging from the literature, it is challenging to define persons who frequently visit PERs, with the defining usage ranging from three or more visits per year (Surles and McGurrin, 1987, Richard-Lepouriel et al., 2015) to six or more visits per year (Arfken et al., 2004). Another way used for defining these persons is in terms of patients belonging to the upper tenth percentile of contacts (Saarento et al., 1998b). This variety of definitions makes it difficult to compare or summarize results from this field of study. In addition, differences in healthcare systems, social welfare systems, and demographic varieties further explain difficulties in identifying characteristics of persons who frequently visit PERs (Aagaard et al., 2014). Also complicating matters is the diverse terminology used when referring to persons frequently visiting PERs, for example, frequent visitors, recurrent visitors, frequent repeaters, recurrent utilizers, repeat users, and heavy users. In line with Aagaard (2014), empirically derived observations, and, the classification used by the PER initiating this research, a definition of five visits or more within a period of 12 months, was applied here.

Previous studies focusing on North America and Europe have identified a number of characteristics of persons who frequently visit PERs; they tend, for example, to be: male (Ledoux and Minner, 2006), young (Chaput and Lebel, 2007a), single (Boyer et al., 2011), living alone (Saarento et al., 1998a, Pasic et al., 2005), homeless (Arfken et al., 2004), unemployed (Pasic et al., 2005), economically impaired (Bruffaerts et al., 2005), without reliable social support (Pasic et al., 2005), and socially disabled (Ledoux and Minner, 2006). In relation to those socioeconomic factors, the cause-and-effect relationship is often unclear, and it is questionable whether persons who frequently visit PERs are homeless, single, or socially disabled due to their mental illness or whether these factors can be seen as the main contributors to or causes of their mental illness (Gayer-Anderson and Morgan, 2013). Furthermore, it has also been found that persons who frequently visit PERs suffer from mental illness such as personality disorders (Saarento et al., 1998b, Pasic et al., 2005), pharmaceutical drug abuse (Bruffaerts et al., 2005, Ledoux and Minner, 2006), and severe mental illness such as schizophrenia (Chaput and Lebel, 2007b, Chaput and Lebel, 2007a) and have experienced prior psychiatric hospitalization (Ellison et al., 1989, Arfken et al., 2004).

In the Nordic countries, research on persons frequently visiting PERs is scarce. The most recent study was conducted in Denmark in 2014 (Aagaard et al., 2014). Two earlier studies from 1998 focused on persons who frequently visit PERs in Finland (Saarento et al., 1998a) and a comparison of PERs' visitors in Denmark and Finland (Saarento et al., 1998b). Studies in a Swedish context on persons who frequently visit PERs are lacking. There is a need for mapping studies examining the characteristics of persons who visit PERs in general and who frequently visit PERs in particular. Furthermore, the temporal patterns of PER visits have rarely been investigated. Such information may be of use when tailoring interventions for this specific group.

This substantial variation in characteristics indicates a rather heterogeneous profile of this group, which adds to the complexity of providing good care for each of those persons in care. Consequently, this complexity indicates a need for a more person-centred approach of caring for these people (Barker, 2001, Jormfeldt et al., 2013) that aims at facilitating recovery and empowerment. According to Barker's person-centred approach (Barker and Buchanan-Barker, 2005) and in line with the above, these characteristics indicate that persons who frequently visit PERs experience problems carrying out tasks in important areas of life over an extended period due to their mental illness (National Psychiatrc Coordination (Nationell Psykiatrisamordning), 2006). Not only do they have needs like any other human being, but they also have specific needs for professional healthcare (Bengtsson-Tops, 2014).

Needs

In a healthcare context, a need can be defined as a lack of health or welfare, or a lack of access to care (Brewin, 1992). Health needs incorporate wider social and environmental aspects of health, such as housing and diet (Wright et al., 1998). It is an important concept not only for the planning and management of health services but also for the use of resources. According to Brewin et al. (1987), a need for care exists when the level of functioning falls below a minimum specified level due to certain remediable causes. Economists, sociologists, philosophers, and healthcare staff have different views of how to define needs (Culyer, 1976, Bradshaw, 1972) and of who should define them. The most influential view of needs remains Bradshaw's sociological perspective (1972), which distinguishes between normative needs (i.e., defined by a professional based on a desirable standard), felt needs, expressed needs, and comparative needs (e.g., people receiving care while others with similar characteristics do not).

In a psychiatric context, persons-in-care experience multiple need areas in life, such as basic, health, social, psychological, daily function, and service needs (Phelan et al., 1995, Slade et al., 1998). In line with a person-centred approach emphasizing the person-in-care's autonomy, this thesis understands need as a subjectively experienced problem of the person-in-care that may be communicated/expressed or self-assessed and may be met by means of a conscious and deliberate intervention. Within a psychiatric healthcare context, previous studies' ratings of patient needs are often staff based (e.g., Ruggeri et al., 2004, Power et al., 2013, Sirotich et al., 2016), since patients in psychiatric care have been considered too ill to actively assess their own needs (Arvidsson, 2001). Using self-assessment of persons' need areas may, however, be more applicable in a person-centred approach.

Self-assessment of needs within psychiatric healthcare

Individual needs assessment refers to a systematic method of identifying health needs at the individual level and planning services and interventions to meet these needs (Wright et al., 1998, Wing et al., 2001). A health need is met when an intervention has been effective.

Needs can be assessed in various ways. In psychiatric healthcare, needs are commonly assessed by healthcare professionals such as nurses or even by significant others (e.g. Ruggeri et al., 2004, Power et al., 2013, Sirotich et al., 2016). The most commonly used instruments for assessing needs are the *Camberwell Assessment of Need* (CAN) and the *Camberwell Assessment of Need Short Appraisal Schedule* (CANSAS) (Hansson et al., 1995, Phelan et al., 1995, Wennström et al., 2004, Ericson, 2013). These are based on a quick assessment of 22 problem or need areas in life, covering basic, health, social, daily function, and service needs (Slade et al., 1998). This instrument also allows patients to self-assess their needs and was used in study II.

Studies of the needs of persons frequently visiting PERs are scarce (Sirotich et al., 2016). However, in the literature, the needs of persons with severe mental illness (primarily schizophrenia) have been investigated, both internationally (Slade et al., 1998, Lasalvia et al., 2000, Power et al., 2013, Stefanatou et al., 2014) and in a Swedish context (Bengtsson-Tops and Hansson, 1999, Arvidsson, 2001, Wennström et al., 2004, Wennström and Wiesel, 2006). Yet previous research has concentrated on just one particular diagnosis (i.e., schizophrenia) and on settings other than PERs.

Several studies have found high agreement between self-assessed patient needs and staff-assessed patient needs, implying that CAN and CANSAS are good screening tools to be used in clinical settings by patients suffering from mental illness (Slade et al., 1996, Arvidsson, 2001, Ponizovsky et al., 2014, Stefanatou et al., 2014). Furthermore, in line with a person-centred approach, this thesis focuses solely on patients' self-assessment of their needs to learn about the subjective experience of the need areas of persons who frequently visit PERs. In a Nordic context, there is a lack of studies investigating the needs in general and the self-assessed needs in particular of persons frequently visiting PERs.

Aim

Overall aim of the thesis

The overall aim of the thesis was to investigate who persons frequently visiting psychiatric emergency rooms in Sweden are and what needs they have.

Specific aims

I: The aims of the study were: (1) to describe persons visiting Swedish PERs and (2) to compare persons who frequently and infrequently visit PERs in terms of group size, age, gender, PER location (inside versus outside the home municipality), diagnosis (ICD 10), temporal patterns of visits, and hospital admissions.

II: The aim of the study was to investigate in which need areas in life, persons who frequently visit psychiatric emergency rooms self-express and self-assess problems.

Theoretical framework

Persons who frequently visit PERs are at the centre of this research. The context in which healthcare is delivered is the PER, though the broader environment, i.e., the life situation of persons frequently visiting PERs, is also taken into account. This thesis is situated in the context of health science and nursing as it is concerned with the delivery of healthcare by health professionals and with the improvement of health of humans. Health science in general and nursing in particular apply a humanistic and holistic view of the person, so her subjective experiences of her life situation are of importance. The patient is thus seen as the expert (Dahlberg and Segesten, 2010). In the discipline of nursing, models and theories apply a metaparadigm consisting of four main concepts: person, environment, health, and nursing (Fawcett, 1995, Basford and Slevin, 2003).

The person is regarded as active, equal and unique and should be treated and met according to her prerequisites. A person is viewed holistically as consisting of biological, psychological, social, cultural, and spiritual dimensions that are acknowledged (cf. Arvidsson and Skärsäter, 2006, PRF & SSF, 2014, Brenner et al., 2016). The person-centred approach (McCormack and McCance, 2006, McCormack and McCance, 2017) incorporates these values, and is in line with the holistic perspective and nursing's outlook on the person. Thus person-centredness is the basis of the thesis' theoretical framework. Within the psychiatric care context, such holistic, person-centred theory was developed by Barker and Buchanan-Barker in the late 1990s, in what is called the 'Tidal model' (2005, 2010). This mid-range nursing theory can be applied as both a philosophy and/or a practical guide. Central concepts of the Tidal model are the empowerment and autonomy of the person in care. As implied by humanism and person-centredness, the person's positive qualities and life experiences are emphasized. Furthermore, the Tidal model also serves as a recovery model, as the person is believed to have the capacity to change, i.e., to possess resources on its own for recovery. It is a pragmatic and respectful approach to identifying problems of living.

Methods

Design

The philosophical view proposed here is pragmatism, which opens the door for multiple methods, viewpoints, and assumptions, as well as multiple forms of data collection techniques, analysis, and procedures (Creswell, 2014). Pragmatism stresses free choice in designing studies in order to fit the specific purpose of the research. This implies that the objective of the study is more important than the specific methods to be used to address it (Richards and Hallberg, 2015). Pragmatism, as the word suggests, is practical, i.e., the approach that best fits the actual research problem should be applied. It also goes hand in hand with the practice relevance of this thesis, since the project was initiated by professionals within a psychiatric care unit that also participated in the data collection (II).

The thesis incorporates both quantitative (I) and mixed-methods (II) research designs. By combining the methods and exploiting their specific strengths, more insight can be gained, facilitating a better and deeper understanding of the phenomena under investigation. An overview of the methods and designs used is given in Table 1.

Table 1. Overview of the thesis.

Studies	Design	Sample	Data collection	Analysis
Study I	Cross-sectional, descriptive, and quantitative	All visitors to PERs in one county in southern Sweden (*N* = 27,282)	Register study of archival data	Descriptive statistics and chi-square tests
Study II	Cross-sectional and mixed methods[1]	Visitors (5 + visits) to a selected PER in Sweden (*n* = 81)	A - Individual interviews B - CANSAS B - AUDIT B - DUDIT C - brief ISSI D - Interpersonal violence	Qualitative content analysis[2] Descriptive statistics, chi-square tests, and Mann-Whitney U tests

In accordance with [1]Creswell (2014) and [2]Graneheim and Lundman (2004).

The thesis is part of a more comprehensive research project with the aim of developing, implementing, and pilot testing a care model based on the needs of persons who frequently visit PERs. The main project was initiated by the management of a PER in a southern Swedish county, which motivated the decision to conduct study II at that particular PER.

Research context

PERs serve as the context of this thesis. The two studies included in this thesis were conducted in one county in southern Sweden. That county has roughly 1.3 million inhabitants (Statistics Sweden, 2015), representing 13.2% of Sweden's population and consisting of both urban and rural areas.

In study I, all PERs (*N* = 4) in the county were included while in study II, data were collected in one PER in the county, i.e., the PER initiating the research project, whose triage nurses were involved in the data collection. This PER is part of the hospital of a larger town and serves a catchment area of around 200,000 inhabitants (Statistics Sweden, 2015). It has open access 24 hours a day, seven days a week and is connected to a psychiatric intensive care unit with several beds for short-term stays of up to two days.

Persons presenting at that PER undergo triage, i.e., meet a triage nurse, based on their turn. During the waiting time, which may be long, some patients might need to be reassessed and sometimes triage nurses may change shifts. After triage and following payment of the patient fee to the medical secretary, most of the patients meet a medical intern (who is stationed at the PER for a few months for educational purposes). After meeting the patient, the medical intern consults with a specialized senior physician or on-call physician, who on case to case bases also meets the patient. Patients not meeting with a medical intern usually present at the PER for counselling or medicine retrieval. After seeing the medical intern (and specialized physician or on-call physician), the patient meets with the triage nurse once more for intervention purposes, for example, hospital admission or medication distribution. Teamwork and collaboration between nurses and physicians are close.

The RETTS-psy triage system is used in the selected PER (II), as it is in most PERs in Sweden (SBU 2010). It is an assessment tool that helps the triage nurse sort and prioritize the patients according to their medical needs, i.e., the severity of their illness. It is based on five levels of priority and involves both the measurement of vital variables and a specific algorithm, i.e., Emergency Signs and Symptoms (ESS) (Magnusson et al., 2016). Triage assessment also helps to minimize the risk of subjective evaluations. The work experience level of the involved triage nurses (*n* = 16) was not investigated; they consisted of registered general nurses, registered psychiatric nurses, (psychiatric) assistant nurses, and mental care assistants who had substantially varying levels of education and experience within triage. In Sweden, as in the other Nordic countries, Classification of Mental and Behavioural Disorders, version 10 (ICD-10) is mainly used (WHO, 1992). It is a diagnostic manual that provides a common language for reporting and monitoring psychiatric diseases, which allows for comparison and standardization (WHO, 2018) from the outside perspective, i.e., biomedical perspective. Yet according to Stein et al. and others (cf. Andrews et al., 1999, Stein et al., 2010), some criticism remains against clinical manuals such as ICD and the Diagnostic and Statistical Manual of Mental Disorders (DSM), not least regarding their definitions of the term ‘mental disorder’ and their inclusion of various concepts such as stress and disability. In this thesis, it is acknowledged that mental illness includes severe psychiatric problems with clinical diagnoses, i.e., diagnostic categories, as well as minor or moderate mental conditions falling short of diagnostic criteria, though negatively affecting the person’s everyday life (Bremberg and Dalman, 2015, Public Health Agency of Sweden (Folkhälsomyndigheten), 2016).

Data collection

Study I

Study I was a large-scale register study; register data were drawn retrospectively for the years 2013–2015 from the support database for care recipients from the county’s central management division in June 2016. Applied inclusion criteria (i.e., providing 24-hour service, a triage system, open referral system, telephone helplines, and beds for acute short-term stays in a specialized inpatient psychiatric intensive care unit) identified four PERs in the chosen county. A dependency centre was excluded since it did not fulfil all the inclusion criteria.

The variables collected were age, gender, PER location inside versus outside the home municipality, diagnosis (ICD 10), temporal patterns of visits, and hospital admissions. One diagnosis was registered per visit in the register. Temporal patterns included day of the month (1–31), day of the week (Monday–Sunday), and time of day (morning shift 07:00–14:59, afternoon shift 15:00–22:59, and night shift 23:00–06:59).

Study II

For study II, data were collected at one PER located in southern Sweden. Data were collected from December 2015 to May 2016 by triage nurses by means of face-to-face interviews using a structured interview manual, developed in collaboration with researchers, service user organizations, and PER professionals. The choice to collect data by triage nurses was motivated by the fact that the research project was initiated by the management and staff of this PER and because resources could be supplied to allow for this participatory approach. The data-collection approach also helped protect the integrity of the patients and make them feel more comfortable with the interview situation. All triage nurses received one day of training in how to perform an interview according to the interview manual. One triage nurse was given the main responsibility for the data collection; in total, 16 triage nurses were involved in the data collection due to the stressful workplace situation. Each interview lasted around 30–45 minutes and was interviewer administered, i.e., all questions were read out loud and answers were written down by the interviewer with the agreement of the participants.

The first part of the interview manual covered background characteristics such as gender, age, and home municipality. In the next part (A), four qualitative open-ended questions about self-expressed needs were asked, concerning the motives for their visits and what kind of help they receive at the PER. Open-ended questions were used to give the participants the opportunity to freely discuss their problems, relating to the PER, their everyday life, or their health. Since needs assessment tools consist of pre-defined need domains, it was felt important to investigate whether other problem areas could be identified by using open-ended questions. The answers were written down by the interviewer, mainly verbatim or sometimes in paragraph form. In the third part of the interview manual, instruments commonly used for assessing needs in persons with mental health problems were used. This part collected quantitative data and included (B) the *Camberwell Assessment of Need Short Appraisal Schedule* (CANSAS). To capture a more comprehensive and detailed picture of needs concerning alcohol/drug abuse and social network, the *Alcohol Use Disorders Identification Test* (AUDIT), *Drug Use Disorders Identification Test* (DUDIT) and (C) part of the *Interview Schedule for Social Interaction* (ISSI) were used as well. Since CANSAS does not cover needs related to interpersonal violence, which previous studies have noted that persons with mental health problems are often subjected to (Howard et al., 2010, Bengtsson-Tops and Ehliasson, 2012, Oram et al., 2013), three dichotomous questions (D) concerning *interpersonal violence* covering experiences of threats, physical violence, and sexual abuse within the last year were added.

CANSAS

CANSAS (Phelan et al., 1995, Ericson, 2013) is an instrument for assessing persons' needs within a psychiatric context. It consists of 22 pre-defined domains of needs, each represented by one question, experienced within the last month: accommodation, food, household skills, self-care, daytime activities, physical health, psychotic symptoms, information about condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, public transport, money, and social benefits. CANSAS provides the ability to add additional domains that fit the context of the study, so the domain 'dental care' was added (Bengtsson-Tops and Hansson, 1999).

In the first section of the instrument, which was used in this study, the prevalence and severity of the needs experienced by persons who frequently visit PERs were self-assessed using a three-point-scale: 0 = no need, 1 = met need, and 2 = unmet need. A rating of 9 = not known was used when the patient did not know or did not want to answer questions within specific domains. The instrument produces three scores: *total needs*, *total met needs*, and *total unmet needs*. CANSAS is a validated instrument (e.g. Phelan et al., 1995) and has been used in different psychiatric care contexts (e.g., Kulhara et al., 2010, Zahid and Ohaeri, 2013).

AUDIT and *DUDIT*

The Swedish versions of the *Alcohol Use Disorders Identification Test* (AUDIT) (Babor et al., 2001, Bergman and Källmén, 2002) and the *Drug Use Disorders Identification Test* (DUDIT) (Berman et al., 2003) were used for the visitors' self-assessment of frequencies and amounts of intake of alcohol and drugs. The scales consist of 10 and 11 questions, respectively, and result in scores of 0–40 and 0–44. AUDIT scores of 8 in men and 6 in women indicate hazardous and harmful alcohol use or alcohol dependency (Källmén et al., 2007). For DUDIT, scores of 6 in men and 2 in women were used (Berman et al., 2005). Both AUDIT and DUDIT are widely used screening instruments that have good psychometric standards in various psychiatric care contexts (Hildebrand, 2015, Lundin et al., 2015).

ISSI

Parts of the *Interview Schedule for Social Interaction* (ISSI) (Undén and Orth-Gomér, 1989, Eklund et al., 2007) from the sub-scale 'Availability of social interaction' were used consisting of four questions, to investigate the social networks of persons who frequently visit PERs. Answers categorically ranking six options ranging from 'No-one' to 'More than 15 people' were provided.

Participants

As stated earlier, five visits or more within a period of 12 months was used to define persons who frequently visit PERs.

Study I

A total of 27,282 patients participated in study I based on their visits made to PERs during the 2013–2015 period, resulting in 67,031 visits. There was a relatively even gender distribution (50.9% women, 49.1% men) and the mean age of the participants was 42.6 years (SD ± 17.8).

Study II

A total of 81 persons participated in study II, which corresponds to a response rate of 62.3%. Persons suffering from acute psychosis or severe aggression were excluded, as were persons coming with police assistance or who were intoxicated ($n = 47$). An additional 11 persons declined participation and 38 persons were not asked to participate due to the high workload of the staff. Participants were persons frequently visiting the PER. Of the participants, 56.8% ($n = 46$) were men and the mean age was 39.74 years (SD ± 15.6).

Analysis

Statistics

All statistical analyses were performed using SPSS software by IBM, version 23.0© (I, II) by MS and JE.

In study I, descriptive statistics (i.e., numbers, percentages, and means) were used to present the participants' background information (e.g., sociodemographic characteristics) as well as results (e.g., diagnosis frequency). Furthermore, Chi-square tests in combination with Bonferroni correction (Field, 2013) were used in comparing differences between categorical variables for persons with one to four visits or five and more visits with regards to age groups, most common diagnoses, temporal patterns of visits, and temporal patterns of hospital admissions. Confidence intervals (95%) (Field, 2013) were calculated when estimating the size of differences in proportions and significant differences in age groups, diagnoses, and temporal patterns of visits.

In study II, descriptive statistics (i.e., numbers, percentages, means, and medians) were used to present the participants' background information. Medians were used to dichotomize the continuous variables age (20–36 and 37–82 years) and number of visits (5–7 and 8–112 PER visits). Chi-square tests in combination with Bonferroni correction (Field, 2013) were used in comparing differences between categorical variables, for example, gender differences or number of visits, with regards to specific CANSAS need domains (i.e., interpersonal violence and social interactions) and to explore the relationship, if any, with alcohol and drug problems. Mann-Whitney U tests (Field, 2013) were performed to test for differences between categorical variables (i.e., gender, dichotomized number of needs, and dichotomized age) and continuous measures (i.e., total need, unmet need, and met need scores).

A drop-out analysis was performed comparing participants with the total number of excluded patients, those not asked to participate, and those who declined by using a Chi-square test with regard to gender and a Mann-Whitney U test with regard to age (II).

P values of .05 or less were considered to be statistically significant (I, II).

Qualitative content analysis

When analysing the four open-ended qualitative questions of part A of the interview manual, a content analysis was performed (II) inspired by Graneheim and Lundman (2004). Content analyses are used to analyse written or verbal communication in a systematic way (Krippendorff, 2013). As any text can have multiple meanings, there is always a certain degree of interpretation when analysing them (Graneheim and Lundman, 2004). Furthermore, an interpretation can have varying levels of depth and abstraction. Graneheim and Lundman's (2004) analysis process includes selecting meaning units, condensing, clustering (i.e., forming content areas), and abstracting (i.e., coding and forming categories and themes). This method emphasizes differences and similarities within categories and includes manifest (what does the text say) and latent (what is the text talking about) analysis of the text.

In study II, analysis of the manifest content of the text was performed due to the level of richness and amount of data collected by MS and ABT. This started with repeatedly reading the text, comprising 16 A4 pages in total, to obtain a sense of the whole. Verbatim text was formed to meaning units, and condensed. The content was then sorted into clusters (Barroso et al., 1997), also called content areas (Graneheim and Lundman, 2004). Thereafter, the data were labelled into subcategories and categories that are the core features of qualitative content analysis (Graneheim and Lundman, 2004), i.e., an inductive analytical approach was used (Elo and Kyngäs, 2008). This process continued until MS and ABT reached agreement on the manifest content of the data.

Ethical considerations

Persons frequently visiting PERs represent a vulnerable group of society. Special care accordingly needs to be taken when interacting with this group of persons which requires good research planning and study design. The participants' involvement in the studies should by no means add to their already complex life situation, but rather should make them feel seen and heard.

The Helsinki Declaration's Ethical Principles (World Medical Association, 2013) as well as the four principles that lie at the core of moral reasoning in healthcare, i.e., respect for autonomy, non-maleficence, beneficence, and justice (Beauchamp and Childress, 2013), were considered and upheld in both studies to protect participants, gain the trust of the participants and the involved organization, and demonstrate integrity.

Respect for autonomy

The principle of autonomy is concerned with the participants' right to make their own decisions based on knowledge and understanding of all the risks and benefits of the study. It is the basis of the principle of informed consent. In study I, prospective participants were informed about the study through an advertisement in three local newspapers. The advertisement included information about the right to decline participation. Furthermore, the prospective participants were informed about the data to be included in the study and of the contact persons from both the research group and the involved clinical organization.

In study II, prospective participants were informed about the study by means of posters at the chosen PER. The patients were invited to participate by triage nurses after they had received triage assessment, i.e., while waiting. The letter of consent was read out loud for the participants and signed before the interview started. Based on this principle, triage nurses excluded persons who, for example, suffered from acute psychosis, severe aggression, or temporary intoxication that may affect their capacity to make competent, reasonable decisions. Though limited in the choice of location, the participants were asked where in the waiting room they would be most comfortable being interviewed, and the interviewer took care that the interview would not be disturbed or overheard.

Beneficence and non-maleficence

These principles refer to the value of research, doing good and to the risks of harming the participants or others in society. In studies I and II, data were collected in an anonymous manner for the researchers, and results were presented at the group level in study I. In study II, triage nurses were chosen to conduct the interviews, to make the participants feel comfortable and to protect their integrity. An additional reason for involving these nurses was to engage them in their work and involve them in research. However, the person-in-care may also have felt some degree of dependency on the triage nurses due to the high possibility of previously established contacts. Therefore, the patients were only asked for participation after the triage process, and of the invited patients, 11 declined participation. However, it was believed that the chance of being more comfortable during the interview with a known and familiar healthcare professional outweighed the possible risk of dependency. Certain questions in the interview manual used in study II may have caused psychological discomfort, for example, questions about physical or sexual abuse. However, contact information for support groups was provided by the interviewer in case abuse had occurred and if the participant wanted it. In the case of self-harm (i.e., suicidal or other self-destructive behavioural tendencies) or harm of others, the involved physician would have been notified (which participants were informed of in the letter of consent). Triage nurse with main responsibility had vast experience in meeting the persons-in-care, and therefore had good expertise and knowledge regarding how to encounter persons frequently visiting the PER. The involved triage nurses received education from ABT in how interview-based questionnaires were to be used in study II. They also received education in research ethics.

The answers to the four qualitative open-ended questions were written down by the interviewer (mainly verbatim or sometimes paragraph form) instead of being audio recorded, to make the participant feel more comfortable. Part A of the interview manual intentionally contained a limited number of open-ended questions with no distressing content, so as not to cause discomfort for the participants. The manual-guided interview used in study II lasted around 30–45 minutes.

Questions were formulated to be easy to understand, and since the manual was interviewer administered, all questions were read to the participants. This strengthened the interaction with the person-in-care and helped engage them in meaningful dialogue and discussion, which seemed to be appreciated by the participants during the sometimes long waiting times. The research may be considered highly beneficial with regard to clinical/practical relevance. Since the idea of this research project originated from the studied PER, i.e., its management and staff, and the research is intended to develop and implement a need-based care model, the present results may contribute new knowledge that could improve not only awareness of this patient group among healthcare providers but, most importantly, improve the care this group receives in PERs and elsewhere, depending on how and where the model is implemented, and potentially meet their needs more efficiently. The development and implementation of the model, however, is beyond the scope of this thesis.

Justice

This principle refers to the participants' right to be treated fairly during the recruitment process. In study II, several patients were not invited to participate due to the high workload at the PER, which implies that this principle may not have been fully realized. However, when choosing to work with organizations, jointly collecting data with them, researchers have to accept the existing work conditions and contexts. Furthermore, study II was conducted at one PER in the county, whereas four were identified in study I. The decision to conduct study II at only one location was based on the fact that this PER had initiated the research project, so its staff could be involved in the research process.

Ethical approval was sought for both studies from the Ethics Board in Lund (Dnr. 2015/645, Dnr. 2016/181) (I, II) and the county's deputy medical director (I).

Results

Study I

Persons frequently visiting PERs represented 8.1% (*n* = 2201) of the total number of visitors but accounted for 38.3% (*n* = 25,695) of the total number of PER visits.

To investigate whether this group differed in any way from other persons visiting PERs, persons making frequent visits were compared with persons making infrequent visits. The study found differences between those two groups in gender, diagnostic profile, hospital admissions, and temporal patterns of visits. Differences were also found in the distance between the PERs and the home municipalities of the visitors. However, the results section of this thesis concentrates on reporting results mainly concerning persons who frequently visit PERs.

Age

Persons making frequent PER visits were on average 42.4 years old (SD ± 15.8) and did not differ in age from persons making infrequent visits (average age 42.6 years, SD ± 18.0). However, when investigating the age distribution in detail using age groups (i.e., 18–30, 31–50, 51–65, and 65 or more years), significant differences were found between the groups ($p < .0001$). Notably, the proportion of persons making frequent PER visits was higher among middle-aged persons aged 31–65 years.

Gender

Gender differences were found between persons making frequent and infrequent PER visits ($p = .001$), i.e., the proportion of persons making frequent PER visits was higher among men. However, by adding an additional variable layer of age group (i.e., 18–30, 31–50, 51–65, and 65 or more years), those gender differences only remained significant for the age group 31–50 years ($p = .033$).

Distance between PERs and home municipalities of the visitors

The proportion of persons making frequent PER visits was higher among persons living in a municipality with a PER ($p < .0001$). However, adding an additional variable layer of age (i.e., 18–30, 31–50, 51–65, and 65 or more years) revealed that the above only remained significant for those aged 51–65 years ($p = .001$) and 65+ years ($p = .041$).

Diagnostic profile

Anxiety (F41), alcohol-related disorders (F10), and schizophrenia (F2) were the most common diagnoses among persons making frequent PER visits. Furthermore, when adding the additional variable layer of age (i.e., 18–30, 31–50, 51–65, and 65 or more years), findings indicate strong variation in the most common diagnoses for persons making frequent PER visits, as follows: 18–30 years, disorders of adult personality and behaviour (F6); 31–50 years, schizophrenia (F2); 51–65 years, alcohol-related disorders (F10); and 65+ years, anxiety (F41). Furthermore, with regards to all diagnoses from all visits made, n = 448 (20.4%) received the same diagnoses throughout the three investigated years, n = 621 (28.2%) received two diagnoses, n = 542 (24.6%) three, n = 311 (14.1%) four and n = 279 (12.7%) received five to ten different diagnoses.

Temporal patterns of visits

The temporal patterns of visits were investigated with regard to which day of the month (1–31), which day of the week (Monday–Sunday), and what time of day (morning, afternoon, and night shift) the visits occurred.

The visits of persons making frequent PER visits were equally distributed throughout the month, as were those of persons making infrequent visits.

With regard to weekdays, the proportion of visits was highest at the beginning of the week, declining towards the end of the week for both groups. Comparing both groups revealed that persons who frequently visited PERs were more likely to visit on weekends ($p < .0001$, 26.5% vs. 21.2%).

With regard to time of day, the proportion of visits was highest during morning shift, somewhat lower during afternoon shift, and much lower during night shift for both groups. Comparing the visits between the two groups, significant differences ($p < .0001$) were found between the afternoon and night shifts. Visits made during the night shift were more likely to be made by persons making frequent visits.

Hospital admissions

The proportion of hospital admissions was lower among persons making frequent visits than among those making infrequent visits ($p < .0001$, 28.9% vs. 31.6%). However, when adding the additional variable layer of age (i.e., 18–30, 31–50, 51–65, and 65 or more years), the proportion of persons making frequent visits admitted to hospital was found to be higher than that of persons making infrequent visits (40.5% vs. 32.4%) in the age group 18–30 years. In the other age groups, the proportion of hospital admissions was higher among persons making infrequent visits.

Temporal patterns of hospital admissions

With regard to day of the month, all hospital admissions were evenly distributed throughout the month for both groups.

With regard to weekdays, most hospital admissions occurred early in the week, i.e., Mondays and Tuesdays, dropping toward the end of the week, which was the case for both groups as well.

With regard to time of day, significant differences were found between the shifts ($p < .0001$), i.e., the proportion of hospital admissions was highest during the night shift (39.2%), when fewest visits were made. When comparing persons making frequent versus infrequent visits, a significant difference ($p < .0001$) was found, with significantly more admissions among persons making infrequent visits during each shift.

Study II

Self-expressed needs

Qualitative data revealed that persons frequently visiting PERs have self-expressed needs to 1) reduce acute suffering, 2) feel secure, and 3) have caring encounters with staff. All categories and subcategories are shown in Table 2.

Table 2. Categories and subcategories of the content analysis.

Categories	Subcategories
Need to reduce acute suffering	Need to talk to someone Need for medication Need for hospital admission
Need to feel secure	Need for a professional approach Need for PERs to be accessible
Need to have caring encounters with staff	

‘Need to reduce acute suffering’ concerned finding relief from troublesome psychiatric symptoms, primarily anxiety/panic attacks, suicidal thoughts, and substance abuse, that strongly affected the participants’ current living situation and activities of everyday life. Two participants described their situation by stating ‘[I] panic and [have] pain in my chest, I did not have time to sleep or eat or care for my everyday life' (woman, 34 years old, 13th visit) and '[I am] thinking to come here instead of killing myself' (man, 35 years old, 32nd visit). This category comprised three subcategories: 1) 'need to talk to someone', which generated a sense of relief and was expressed in terms of: 'unburdening my heart' (man, 48 years old, 5th visit); 2) 'need for medication', including obtaining prescriptions or adjusting prescribed medication regimens; and 3) 'need for hospital admission', which was expressed by the participants.

'Need to feel secure' concerned PERs as a type of place. One participant expressed this need by stating: 'There are not that many knives here that you could hurt yourself with' (man, 23 years old, 19th visit). This category also concerned staff working in the PER: '[I] feel safe with the staff here' (man, 10, 41 years old, 6th visit), and the PER as providing a safe environment: 'I can come here instead of sitting alone and brooding; it's reassuring to know you can land here when your thoughts are at their worst' (man, 32 years old, 5th visit). The category comprised two subcategories: 1) 'Need for a professional approach', which involved being guaranteed privacy and secrecy when talking to staff, being taken seriously by non-stressed staff, correct prioritizing, competent assessment, and a fair triage process. The lack of this approach was described in terms of 'being unfairly treated by the doctors – feeling like an experiment' (woman, 49 years old, 11th visit) or 'the staff are substandard, not all are well suited for working in psychiatry' (man, 27 years old, 6th visit). The second subcategory was 'need for PERs to be accessible', which touched on PERs' close proximity and knowing 'that you can come round the clock' (woman, 21 years old, 5th visit).

The third category, 'need for caring encounters with staff', was described in terms of being taken care of, feeling welcomed, and being treated well, and involved being met with kindness and humanity. Participants expressed this by stating: 'Getting a smile makes me feel better' (man, 37 years old, 7th visit); and 'they listen and understand, don't give you the cold shoulder' (woman, 24 years old, 5th visit). This could also be expressed in terms of 'feeling like a burden sometimes, "here he comes again", so I avoid coming here', (man, 32 years old, 5th visit).

Self-assessed needs

According to CANSAS (23 need domains), persons frequently visiting PERs reported on average 9.52 total needs (SD ± 3.85, range 2–18), 2.89 met needs (SD ± 2.00, range 0–8), and 6.63 unmet needs (SD ± 4.09, range 0–16). No gender or age differences were found with regard to the need scores.

The most frequent assessed CANSAS need domains were: 'psychological distress', 'psychotic symptoms', 'daytime activities', 'intimate relationships', 'company', 'safety of self' , 'money', and 'physical health'.

There was a significant difference with the total need score and the number of visits (*p* = .043), i.e., persons with more needs consequently made more PER visits. All the women participants self-assessed having problems in the need domain ‘psychological distress’ (*p* = 0.044, 89.1% of men vs. 100% of women). Self-assessed problems in the domains ‘accommodation’ (*p* = 0.018, 17.5% with up to 7 visits vs. 41.5% with 8 or more visits) and ‘money’ (*p* = 0.020, 42.5% with up to 7 visits vs. 68.3% with 8 or more visits) consequently resulted in more visits. Conversely, self-assessed needs in the domain ‘physical health’ resulted in fewer visits (*p* = 0.035, 62.5% with up to 7 visits vs. 39.0% with 8 or more visits). Finally, problems in the domain ‘safety of self’ were more often reported by younger persons (*p* = 0.018, 70.0% of participants aged 37 and younger vs. 43.9% of participants aged 38 and older), whereas needs in the domain ‘dental health’ were reported more often by older participants (*p* = 0.019, 32.5% of participants aged 37 and younger vs. 58.5% of participants aged 38 and older).

In total, any kind of interpersonal violence was experienced and reported by 41.8% (*n* = 33) of participants. More specifically, one third of participants (*n* = 29, 36.7%) reported being exposed to verbal threats, of which 22.8% (*n* = 18) were death threats, one fifth reported being exposed to physical violence (*n* = 17, 21.5%), and 11.4% (*n* = 9) reported being sexually abused. Gender differences were found among persons being sexually abused, with women experiencing more of such abuse, and death threats were significantly more often received by persons making more visits (*p* = 0.037, 12.8% with up to 7 visits vs. 32.5% with 8 or more visits).

In addition, the results indicate that the majority of the participants had limited social interactions. Almost two thirds (65.1%, *n* = 52) of the participants either knew no-one or up to two persons who could visit them and feel at home, and more than half (58.2%, *n* = 46) reported having no-one or up to two people with whom they could speak openly. Furthermore, nearly half of the participants (46.3%, *n* = 37) knew no-one or up to two people who had the same interests, and more than a third (35.1%, *n* = 28) reported meeting no-one or up to two persons to talk with during a week. With regard to common interests and speaking openly with someone, age differences were found, i.e., older participants reported having fewer contacts than did younger ones (*p* = .033; 7.7% vs. 34.1% and *p* = .029; 17.9% vs. 40.0% respectively).

Around one fifth of the participants self-assessed having problems in the CANSAS need domains ‘alcohol’ and ‘drugs’; AUDIT and DUDIT scores, respectively, confirm those results by indicating associated dependency problems, but found slightly higher rates of 29.5% and 28.8%, respectively. There was a significant relationship between alcohol and drug dependency (*p* = .007): of 23 participants with alcohol-dependency problems, 11 (47.8%) also suffered from drug-dependency problems.

Discussion

Methodological considerations

This thesis consists of one quantitative (I) and one mixed-methods study (II). The use of different methods is recommended when deeper knowledge of a subject is sought (Polit and Beck, 2016). To investigate into persons who frequently visit PERs, register data (I), interviewer-administered questionnaires (II), and open-ended interview questions (II) were used and analysed statistically (I, II) and by means of qualitative content analysis (II). However, the methods and instruments chosen for these studies have both strengths and weaknesses that affect the studies' results, influencing their generalizability and quality (Olsson and Sörensen, 2011).

In quantitative research, internal validity (i.e., validity of the conclusions) and external validity (i.e., generalizability of results) are often used as quality indicators (Polit and Beck, 2016). The use of national registries for research is well established in Sweden and is considered a standard method permitting outstanding result quality (Swedish National Data Service (SND), 2017). However, it posed certain challenges for the study design. The variables chosen in study I were limited by the register, which is used purely for administrative purposes. Since the register contains only one diagnosis per visit, investigation into possible comorbidity was limited. Excluding a regional dependency centre located within the studied county affected the prevalence of substance abuse diagnoses; this affected the internal validity and therefore should be considered when interpreting the results of this study. Furthermore, by choosing a cross-sectional design, the visitors were defined as persons who frequently or infrequently visit PERs which was based solely on their visits from 2013 to 2015, entailing a risk of wrongly defining persons based on those visits only. For example, a person making four PER visits in January 2013 may be classified as a person infrequently visiting PERs, even though previous visits may have occurred in 2012 (which was unavailable information), posing a threat to internal validity. However, due to the high proportion of participation in study I, external validity can be considered very high. How far the results may be generalizable to other groups within healthcare or to other regions inside or outside Sweden, however, may be questioned. This is because the number of PER visits may be influenced by the availability of other facilities, by PER services being delivered differently (e.g., by psychiatric emergency ambulance or mobile assessment), or by the extent to which processes involve case managers or assertive community treatments (i.e., ACT and flexible ACT).

Overall, study II has a retrospective design; most questionnaires used in it refer to time periods of the last month (i.e., CANSAS) or the last year (i.e., AUDIT, DUDIT, interpersonal violence), which may pose a risk of recall bias, i.e., the correct answer may have been forgotten or was hard for participants to recall. Recruitment for study II proved to be a challenge. The staff workload at the studied PER was high, which led to a generous extension of the data collection period. Despite the extension, several persons who frequently visited the PER were not invited to participate ($n = 38$). An additional number of eligible patients ($n = 47$) were excluded due to their condition, although they represented the target group, which could in turn raise questions about the participants' and the study's representativeness. Yet a drop-out analysis identified no differences with regard to age and gender when comparing who was included and who was excluded. Despite the number of participants who were not invited to participate, the response rate was considered high, which strengthens the validity of the study, as does the use of data triangulation. Regarding data collection, the possibility that the participants may know the triage nurses, i.e., the interviewers, was high, creating a risk of dependency and thus affecting the credibility as well as confirmability of the study. Yet, that the interviewer and interviewee knew each other might also increase familiarity and hence interviewee openness in revealing sensitive information, which could be important for the participants, particularly in this study. Although participants self-assessed AUDIT, DUDIT, and ISSI, they might not necessarily view their alcohol use, drug use, or lack of interaction as a problem. Therefore, some level of interpretation with regard to these instruments may have been added by the researchers. Given that the data were collected in one PER, the generalizability of the results of study II should be viewed with caution and considered in light of the applied context, which may vary from the studied context. To enhance the trustworthiness of the qualitative part of the study, MS and ABT analysed the qualitative data first independently and thereafter jointly until consensus was reached. Quotations were used to validate the findings.

General discussion of the results

The overall aim of this thesis was to investigate who persons who frequently visit PERs are and what needs they have. The present results contribute to a better definition and description of persons who frequently visit PERs, which is the first step in attempting to meet their needs better, reducing both their suffering and number of PER visits (Vandyk et al., 2013). In a Swedish context, this is the first thesis to examine this group scientifically. Persons who frequently visit PERs formed a relatively small group representing 8.1% of all visitors, yet they accounted for nearly two fifths of PER visits, in line with results of previous research (Pasic et al., 2005, Ledoux and Minner, 2006, Chaput and Lebel, 2007a). Furthermore, persons frequently visiting PERs differ significantly from other PER visitors with regard to sociodemographic characteristics, diagnostic profile, and temporal patterns of visits. Study I provides a detailed description of this group, how they utilize PERs, and when they are admitted, which, for example, differs based on gender or diagnosis, a finding well aligned with a recent study of persons suffering from mental illness and who are frequently visiting an emergency room (Vandyk et al., 2018). Study II complements study I by providing a detailed profile of this group's self-assessed and self-expressed needs, which occur in the physical, psychiatric, financial, emotional, and social need areas in life. The results indicate that persons who frequently visit PERs have complex, intertwined need patterns and suffer from psychological distress and psychotic symptoms that can be described as fundamentally disempowering, especially when PER visits recur (Barker and Stevenson, 2000).

Diagnostic profile of persons who frequently visit PERs

Persons who frequently visit PERs have a heterogeneous diagnostic profile. Not only does this profile differ from that of other PER visitors, but it appears to encompass a broad spectrum of diagnosis categories, with anxiety (F41) and alcohol-related disorders (F10) being the most common diagnoses, followed by schizophrenia (F2) (I). These results were strengthened by results of study II indicating that the vast majority of persons who frequently visit PERs also suffer from 'psychological stress' and 'psychotic symptoms'. These findings are in line with previous research stressing the high prevalence of psychotic and affective disorders among this group (Vandyk et al., 2013, Schmidt, 2018).

More detailed investigation of the most common diagnoses of persons frequently visiting PERs according to age groups revealed strong variation in the diagnostic profile, with each of the four age groups having a different most common diagnosis, i.e., disorders of adult personality and behaviour (F6) in the age group 18–30 years, schizophrenia (F2) in the age group 31–50 years, alcohol-related disorders (F10) in the age group 51–65 years, and anxiety (F41) in the age group 65+ years. In addition, study I confirmed that persons who frequently visit PERs receive several different psychiatric diagnoses at the same time or within a short period, implying a high degree of suffering. Study II contributed to that picture by revealing that the majority of persons who frequently visit PERs also have problems with somatic diseases. These results are confirmed by other studies

(WHO, 2013, Phelan et al., 2001, Blanner Kristiansen et al., 2015). This complex diagnostic profile of persons who frequently visit PERs may complicate correct diagnosing and thus the choice of adequate treatments. One way forward is to apply a person-centred approach, as proposed by Barker and Buchanan-Barker (2010), in which the person as a whole is taken into account, which resonates well with a holistic approach. By applying a holistic assessment, needs as well as personal and interpersonal resources can be identified (Barker, 2001). Furthermore, and in line with the above, viewing the person as a whole and as embedded in her context allows, those identified resources to be used when tailoring person-centred interventions in order to strengthen the person-in-care's autonomy, i.e., empower the person.

Temporal patterns of PER visits

PER visits made by persons who frequently visit PERs can to a certain degree be predicted. Investigation of the temporal patterns of PER visits in study I showed that more visits were made on Mondays than on other days. Few studies have examined the temporal patterns of PER visits. However, Arfken et al. (2002) confirmed that persons who frequently visit PERs make significantly more visits on Mondays than other days. They also found that visits are more often made by this group in the first and last weeks of the month; this could not be confirmed by study I, which reports an even distribution of PER visits by this group throughout the month.

Persons who frequently visit PERs have also been found to visit PERs on weekends more often than do other visitors. This stresses that persons making frequent PER visits need PER accessibility at any time, which can be confirmed by study II and previous research (Aagaard et al., 2014). In addition, Vandyk et al. (2018) confirmed that each PER visit by persons making frequent visits was experienced as necessary and unavoidable by these patients, regardless of the time and day.

Furthermore, study I demonstrated that it is somewhat possible to associate persons with certain diagnoses with certain work shifts. Persons suffering from anxiety (F41), for example, which was the most common diagnosis among persons who frequently visit PERs, are strongly associated with visits during morning and day shifts. These results are supported by a qualitative study noting differences in utilization patterns according to psychiatric diagnosis (Vandyk et al., 2018). Findings of diagnostic profiles and temporal patterns of visits may be used in planning and organizing PER services. Human resource planning and development in PERs could be aligned with the proportion of expected visits per shift to provide more flexible care based on patient needs, in line with a person-centred approach. According to the diagnostic profile prevalence and the number of visits, day shifts could be staffed with more personnel, including nurses specializing in depression

(F32) and anxiety (F41), while night shifts could be staffed with fewer personnel, but include nurses specializing in alcohol-related disorders (F10) and schizophrenia (F2). Regarding dual diagnoses, it may be a challenge to identify the primary diagnosis and underlying mechanisms, which might complicate decision-making on effective interventions, i.e., personnel might need extensive and broad knowledge of various kinds of diagnoses.

Need patterns of persons who frequently visit PERs

No previous studies have investigated the need patterns of persons who frequently visit PERs in Sweden, and very few have done so in an international context (e.g. Sirotich et al., 2016). The *Camberwell Assessment of Need* was previously used in a Swedish context to investigate the needs of persons suffering from severe mental illness who are in contact with psychiatric outpatient facilities; study II differs from these studies (Bengtsson-Tops and Hansson, 1999, Arvidsson, 2001, Wennström et al., 2004, Wennström and Wiesel, 2006) by instead investigating the needs of persons who frequently visit PERs. Given that persons suffering from severe mental illness comprise a subgroup of persons who frequently visit PERs, as diagnosis patterns in study I show, one could draw some parallels between the studies. Previous studies report a total need score of 6.2–6.4, both staff-assessed and patient-assessed, with the most common needs found in the ‘psychotic symptoms’, ‘psychological distress’, ‘company’, and ‘daytime activities’ domains (Bengtsson-Tops and Hansson, 1999, Arvidsson, 2001, Wennström et al., 2004, Wennström and Wiesel, 2006). It was further concluded that the number of needs did not change over a period of six years (Wennström and Wiesel, 2006).

Comparing those results with the results of study II revealed the same most common self-assessed needs: ‘psychological distress’, ‘psychotic symptoms’, ‘daytime activities’, ‘intimate relationships’, and ‘company’. The total number of needs reported in study II by persons frequently visiting PERs is comparatively high at 9.52. The number of specific unmet needs, i.e., 6.63, among frequent PER visitors appears much higher than that among patients with severe mental illness, i.e., 1.53, 1.7, and 1.5 according to Wennström et al. (2004, 2006) and Arvidsson (2001), respectively. Study II found that 72.8% and 60.5% of needs in the domains ‘psychological distress’ and ‘daytime activities’, respectively, remained unmet, possibly reflecting the high degree of mental suffering that persons with frequent PER visits wish to be relieved of.

Persons who frequently visit PERs both self-expressed and self-assessed unmet needs concerning their own safety, including feelings of security, implying that not only emotional security (e.g., feelings of trust, support, and care) but also physical security (e.g., reducing suicidal thoughts and attempts at self-harm) is important in a crisis. In addition to the personal, internal dimensions of safety, the results indicate that feelings of safety in terms of external, environmental security are equally important for persons who frequently visit PERs, which offer a ‘safety zone' for them. Those results are in line with the Swedish law that care should meet patient needs for safety and security (SFS, 2017:30) as well as with Barker's Tidal model, which suggests that the primary aim of acute psychiatric care is to provide a safe haven (Barker and Buchanan-Barker, 2010). Such care addresses immediate (i.e., critical) care needs to feel emotionally secure (Barker, 2001). Thereafter, transitional and developmental care needs involving both hospital and community services ought to create a care continuum (Barker and Buchanan-Barker, 2010). This continuum as well as good collaboration between patient and nurse in psychiatric and social care service settings are requirements for achieving the best short- and long-term outcomes for the person-in-care (Allen et al., 2003).

Furthermore, the results of this thesis emphasize that persons who frequently visit PERs self-expressed being subject to interpersonal violence, in verbal, physical, or sexual terms. Previous studies have demonstrated that violence against persons suffering from mental illness threatens their senses of self, self-esteem, and self-efficacy as well as their existence in general (Khalifeh et al., 2016), as would be the case in any person exposed to violence or suffering from mental illness (cf. Barker, 2001, Matheson et al., 2015, Evans and Feder, 2016), re-emphasizing the vulnerable disempowering position of these people. Triage assessment in PERs could better identify those persons and better collaborate with other organizations that offer relevant interventions (e.g., trauma-informed treatment or housing; e.g., Monahan et al. (2017)) by including a screening tool concerning exposure to violence. Barker's Tidal model is intended to re-empower the person and help her to recover (Barker, 2001). A empowerment approach to diagnosis and recovery processes could be part of a solution helping persons who frequently visit PERs, since it is intended to improve self-confidence and optimism (Arvidsson and Skärsäter, 2006). By creating a care continuum, as proposed by Barker and Buchanan-Barker (2010), persons identified as exposed to violence could be offered better long-term care based on establishing collaboration between hospital and community care. However, in a Swedish context, this collaboration has proven to be challenging due to division of responsibility and legislations (Brenner et al., 2016, Janlöv et al., 2016).

Persons who frequently visit PERs both self-expressed and self-assessed unmet needs concerning their social interactions. They self-assessed problems in the CANSAS domains 'intimate relationships' and 'company'. Furthermore, the present results indicated that the social networks of persons frequently visiting PERs were limited in terms of interactions (e.g., the number of talks during a week or rarely inviting friends home). Furthermore, these persons also expressed that talking to someone and caring encounters in PERs are valuable for them, since they constitute rare opportunities to start dialogue with someone. By talking to others about their problems, sharing their experiences and worries, they feel somewhat acknowledged as a person and human being. A study of PER visitors' self-expressed needs revealed similar results, identifying important needs such as being treated with respect and as a human being, talked to, listened to, and asked about one's needs (Allen et al., 2003). These talks may function as a coping mechanism (Ellison et al., 1989), which a functioning social network and social support would otherwise supply (Ozbay et al., 2007, Carver and Connor-Smith, 2010).

It can be concluded that persons frequently visiting PERs have many needs in various need areas in life that remain largely unmet. These areas are somewhat overlapping and primarily concern relief from suffering, safety (i.e., both internal and external safety), and social life (e.g., lack of interaction, exposure to violence, and lack of activities). These results reflect the high degree of psychiatric disability and vulnerability from which this group is suffering (National Psychiatrc Coordination (Nationell Psykiatrisamordning), 2006). Furthermore, other studies have associated higher levels of unmet needs with lower subjective quality of life (Slade et al., 2005, Wiersma, 2006), suggesting that it is not the symptomology, disability, or functioning that is the cause of lower quality of life, but rather the level of unmet needs (Slade et al., 2004), which was found to be comparatively high in study II.

The results of studies I and II confirm that persons who frequently visit PERs have insufficient physical, psychiatric, emotional, financial, and social health based on their reported needs and unmet needs and consequently a possibly lower quality of life. Thus, not only are these persons languishing due to a lack of mental health, but also floundering due to a combined lack of mental health and presence of mental illness (Slade, 2010).

To improve the health of persons who frequently visit PERs, a positive approach to and outlook on health, including recovery, ought to be applied, focusing on the person-in-care's needs. According to Arvidsson and Skärsäter (2006), three internal as well as external conditions may be necessary to help the person once again participate in important life areas: (1) increase in autonomy, (2) being active in a social context, and (3) meaningful activities. This reasoning is in line with a person-centred approach (Barker and Buchanan-Barker, 2005). Based on the results of study II, persons who frequently visit PERs are expected to experience deficiencies in all three conditions. By regaining autonomy, both self-esteem and sense of self are strengthened, providing a foundation for recovery. Recovery is understood here as 'working towards better mental health, regardless of the presence of mental illness' (Slade, 2009, p. 126), emphasizing well-being rather than treatment of illness when regaining one's life, and finding meaning by reclaiming a valued identity and social roles (Slade, 2010).

However, it is acknowledged that the literature is somewhat inconsistent on how the assessed needs of persons who frequently visit PERs could be reduced by tailored interventions, on whether these needs decrease over time at all (Wiersma, 2006), and on whether certain needs are simply unmeetable. Often, the frequency of visits indicates chronicity and comorbidity, which are related to more unmet needs (Wiersma, 2006), further stressing the need for both short- and long-term solutions. A study conducted in Sweden by Wennström and Wiesel (2006) confirmed that no decrease in the number of needs was found over a period of six years; rather, there was some variation in these needs, which may make it difficult to fully predict need patterns in persons suffering from severe mental illness. Other studies either confirmed this stability in needs over time or found either a slight increase or decrease in the total number of (unmet or unmeetable) needs over time (Wiersma et al., 1998, Salize et al., 1999, Kallert et al., 2004, Hansson and Björkman, 2007, Arvidsson, 2008, Drukker et al., 2008, Arvidsson, 2010). Overall, it can be concluded that needs as well as unmet needs are prevalent in a broad variation in persons suffering from severe mental illness, vary over time, and are somewhat predictable in a certain region (Wiersma, 2006). These findings could be used as the basis of a person-centred care approach by facilitating tailored interventions that improve the delivery of psychiatric healthcare.

Person-in-care's perceptions of triage nurses and other healthcare and social care services

When the person-in-care is in acute crisis, as persons visiting PERs are, only short-term solutions can be offered, as well as providing internal and external safety (Barker and Buchanan-Barker, 2005, 2010). As study II demonstrated, staff working in PERs play a pivotal role in the visitors' experiences. Not only do persons-in-care need their caring encounters, but they also need staff with a professional approach and who talk to them. These results resonate well with a study by Allen et al. (2003) stressing the importance of staff having a positive outlook and reassuring attitude as to the possible recovery of the person-in-care. Slade (2010) proposed that hope-supporting relationships are necessary in order to help floundering people to recover (cf. Arvidsson and Skärsäter, 2006).

Triage nurses are of great importance as they often are the first to encounter the person-in-care, setting the tone for the patient's feeling of being understood and cared for (Sjöstedt et al., 2001). Staff within a psychiatric healthcare context also represent significant others in the patient's life who are fundamental to the patient's self-perception and confidence (Hedelin and Jonsson, 2003). Several participants in study II, however, said that triage nurses could be experienced as stressed and nonchalant, participated in non-caring encounters, and had negative attitudes towards the person-in-care, results that could be confirmed by other studies (Nyström et al., 2003, Vandyk et al., 2018). Such negative experiences may add to the feeling of loneliness originating in their illness, causing suffering from care (Nyström et al., 2003). Stress among nurses in (acute) psychiatric care settings is well known (Currid, 2009, Wang et al., 2015), while others have highlighted the feeling of powerlessness among nurses (Plant and White, 2013).

Yet it is fundamental for the person-in-care's recovery to have caring encounters and a good nurse–patient relationship to feel empowered, regain hope, and build self-esteem.

Previous studies as well as study II have confirmed that persons who frequently visit PERs already have numerous other contacts with psychiatric healthcare and/or social care services (Nordström et al., 2009, Aagaard et al., 2014). Nevertheless, they still use PERs because it is assumed that they are in too much crisis to use their other contacts, poorly understand network procedures, or, due to their complex service needs, have difficulties navigating the ever-changing, decentralised healthcare system (Arfken et al., 2002, Vandyk et al., 2013). Another possible reason for their reliance on PERs is that they are dissatisfied with the service provided by those other facilities, as was expressed during the interviews in study II. However, none of the participants reported having contact with case managers, who use a person-centred approach and strives for recovery, which may be of help in addressing the complex needs of that persons who frequently visit PERs (Janlöv et al., 2015). Case management have also been demonstrated to reduce both costs and emergency room visits among both the general population (Althaus et al., 2011, Soril et al., 2015) and those using psychiatric services (Björkman and Hansson, 2007).

Good alignment between psychiatric healthcare and social care services is of profound importance in establishing continuity of care, which is also stipulated by Swedish law (SFS, 2017:30). According to Barker (2000), the primary focus ought to be on the person's needs rather than the healthcare setting. This was strengthened by the findings of two review studies within the area (Vandyk et al., 2013, Schmidt, 2018) that singled out continuity of care as a key factor in improving care, meeting patient needs, and reducing PER visits. However, if persons who frequently visit PERs are seen as 'hard to treat', 'lost causes', and not benefiting from social care services or psychiatric treatment (Koekkoek et al., 2006, Buus, 2011, Vandyk et al., 2013, Vandyk et al., 2018), continuity of care may be hard to achieve unless organizational prerequisites are established, staff views are changed, and/or staff are educated better.

Conclusions

Implications for practice

In line with a person-centred approach, it is suggested that persons who frequently visit PERs may require different PER triage processes, focusing particularly on reducing their mental suffering, identifying exposure to interpersonal violence, and improving social integration, which could facilitate care flexibility and interventions tailored to fit this group's needs. Furthermore, there is a need for enhanced collaboration with public and community-based resources and facilities (Fleury et al., 2011) to achieve better continuity of care and follow-up, which could consequently lead to improved care for the patients and fewer visits to PERs.

This thesis contributes to the development of more detailed knowledge of the persons who frequently visit PERs, helping care providers tailor interventions and care accordingly, i.e., improve the organization of psychiatric services, both inside and outside of PERs (I), according to these patients' specific needs (II). In addition, the findings could help in the early identification of those at risk of becoming frequent PER visitors, which could reduce prolonged suffering and number of visits in the future. The present results could also be used for educational purposes for nursing students and specialized triage staff. Finally, the finding of a surprising lack of contact with case managers could be of practical relevance in providing these patients with information about case managers when visiting PERs and in locating available case managers near their places of residence.

Future research

It would be desirable to learn more about how to organise or/and structure the psychiatric healthcare context to more effectively meet the needs of, improve healthcare delivery to, and enhance the life situation of persons who frequently visit PERs.

One way forward would be to explore the resources and competences perceived to be required by staff working in PERs. For example, what type of learning, caring, and competence needs are expressed by PER nurses? When conducting study II, it was found that, during triage, the patients met with various professionals, who possessed different levels of education and experience. Study II also found that there was a certain degree of suffering caused by deficient care (also referred to as 'non-caring encounters' in the literature), which was expressed in terms of dissatisfaction with staff or not being taken seriously or understood. The cause of suffering from deficient care is mostly found in the relationship between the patient and the staff (Dahlberg, 2002), who instead should aim at reducing suffering and enhance health processes. Therefore, besides technical competence, staff may need to acquire specific competences for encountering persons who frequently visit PERs, so as to better meet their needs.

Another way forward could be to consider organizational and structural aspects that form the context of which persons who frequently visit PERs are part. For example, a better understanding of the role of PER structure and hierarchies could inform PER management practices, potentially meeting the needs of both frequent and infrequent PER visitors more effectively. Within this domain, one could further explore leadership practices and how these form the context in which PER nurses attend to patient care.

Finally, one more possibility would be to gain a better understanding of those persons delivering care to patients at PERs, i.e., staff working at PERs. Investigating their perspectives on work environment, and experiences of encountering and caring for persons who frequently visit PERs, could potentially contribute to improved work satisfaction for staff, which consequently could benefit the patients.

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