# Psychological factors in long-term sickness absence: the role of shame and social support

Epidemiological studies based on the Health Assets Project

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## Scientific environment

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## Abstract

Long-term sickness absence (LTSA) is an important societal and public health challenge in many Western countries. To tackle the challenges, we need knowledge on risk factors for LTSA and what might prolong sickness absence. Transitions between work and sickness absence are influenced by a variety of factors and agents, including the sick-listed individual and his or her interaction in a social context. The individual's thoughts, emotions, behaviour and social experiences throughout the sickness absence process are therefore always relevant and will often play an important role. Despite this, there are considerable knowledge gaps in the epidemiological literature regarding social psychological aspects of LTSA. In particular, the role of individuals' emotions in sickness absence is hardly examined. Furthermore, little is known about associations between the individual's history of sickness absence and social inclusion and support at work. Thus, there is a need for novel research approaches and study designs to address these issues.

The overall aim of this thesis was to increase knowledge about how the social psychological aspects shame and social support relate to long-term sickness absence in the general population. Selective research participation presents an important threat for generalizability of epidemiological studies and more knowledge is needed on selective participation by sickness absence. An additional aim was therefore to examine if history of sickness absence is associated with survey participation.

This thesis is based upon three papers, all employing data from the baseline survey of the Swedish, general population-based Health Assets Project (HAP). This survey was conducted in 2008, and linked to official registries of sickness absence (LISA) from the period 2001 to 2009. HAP was specifically designed to gain knowledge about sickness absence, work and health. Three samples, aged 19-64 years, were included: a random general population sample (random-PS) and two samples including individuals with a recent episode of registered sickness absence (employer-reported >14 days and self-reported other insured>1 day). In paper I the employer-reported

sample was used, in paper II the random general population sample and in paper III all three samples were included. As sickness absence can be a process over time, correlates of both recent and more distant sickness absence was examined.

In paper I, the specific aim was to study relationships between shame concerning being sickness absent and LTSA among current sick-listed employees. Levels of shame were found to differ between subgroups of absentees. There was a particularly high level of shame reported among the younger, and those absent due to mental illnesses. Those reporting high levels of shame were more likely to have prolonged sickness absence the subsequent year.

The aim in paper II was to examine associations between history of LTSA across seven years and current perceived social support at work among employees. The results showed that those with previous LTSA, and in particular those with high levels of absence over several years, were more likely to report low social support at work and low immediate superior support.

The aim of paper III was to examine if history of sickness absence was associated with participation in the HAP survey. No substantial selection by sickness absence was found. Yet, overall participants had somewhat less registered sickness absence in the past than nonparticipants. Participants were also more likely than nonparticipants to be women, older, born in the Nordic countries, married and have higher incomes.

This thesis shows the complexity, but also also the importance, of expanding the scientific knowledge on social psychological factors in sickness absence. The examination of sickness absence over nearly a decade provided new and more detailed knowledge about patterns of sickness absence, and their associations with social psychological factors and survey participation. The findings show that LTSA can have negative social implications for the sick-listed individual, more specifically in terms of shame and low perceived social support at work, which may further become barriers towards return to work. Thus, the findings underscore that return to work interventions could benefit from taking into account social psychological aspects of LTSA to secure sustainable work retention.

## List of publications

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## Contents

SC	SCIENTIFIC ENVIRONMENT					
AC	CKNO	OWLE	EDGEMENTS	4		
AE	BSTR	RACT.		7		
LI	ST O	OF PUI	BLICATIONS	9		
CC	)NTI	ENTS.		10		
1.	В	BACK	GROUND	14		
	1.1	Psyc	CHOLOGY IN SICKNESS ABSENCE – FRAGMENTED KNOWLEDGE	14		
	1.2	The	SICKNESS ABSENCE RESEARCH FIELD	17		
	1.3	DESC	CRIPTIVE EPIDEMIOLOGY OF SICKNESS ABSENCE	18		
	1.	.3.1	Impact of long-term sickness absence for the individual	20		
	1.4 abse	Theo ence	ORETICAL AND CONCEPTUAL FRAMEWORKS RELEVANT FOR PSYCHOLOCIAL FACTOR	s in sickness 21		
	1.6	Appr	RAISAL OF THE LITERATURE	27		
	1.	.6.1	The lived experience of long-term sickness absence – knowledge from qualitative	e studies 28		
	1.	.6.2	Social emotions	30		
	1.	.6.3	Social support at work	30		
	1.7	AIMS	S AND RESEARCH QUESTIONS	33		
2.	N	ATE	RIALS AND METHODS	35		
	2.1	CON	TEXT: THE SICKNESS INSURANCE SYSTEM IN SWEDEN	35		
	2.2	The	HEALTH ASSETS PROJECT (HAP)	36		
	2.3	Stui	DY DESIGNS AND SAMPLES	38		
	2.	.3.1	Study samples	39		
	2.4	Mea	SURES	41		

	2.4.1	Demographic variables	41
	2.4.2	Level of shame concerning being sickness absent	42
	2.4.3	Cause of current sickness absence	42
	2.4.4	Symptoms of depression	43
	2.4.5	Perceived social support at work	43
	2.4.6	Operationalization of survey nonparticipation	44
	2.4.7	Measures of registered sickness absence	45
	2.5 STAT	ISTICAL PROCEDURES	47
	HANDLING N	MISSING DATA	47
	Statistica	al analyses	48
	2.6 Ethic	CAL CONSIDERATIONS	49
3.	RESUL	TS	50
	3.1 PAPE	R I	50
	3.2 PAPE	R II	51
	3.3 PAPE	R III	52
4. DISCUSSION		SSION	53
	4.1 Nove	EL CONTRIBUTIONS	53
	4.2 Meth	HODOLOGICAL CONSIDERATIONS	54
	4.2.1	Methodological strengths	54
	4.2.2	Methodological limitations	56
	4.2.3	Selection bias	56
	4.2.4	Information bias	56
	4.2.5	Confounding, mediation and causality	57
	4.2.6	Generalizability	58

so	URC	EOF	DATA	75
5.	С	ONCL	USION	74
	4.5	Sugg	ESTIONS FOR FURTHER RESEARCH ON PSYCHOLOGICAL FACTORS IN SICKNESS ABSENCE	e70
	4.4	Sugg	ESTIONS FOR PRACTICE	67
	4.	3.3	Long-term sickness absence – a marker for social exclusion?	66
	4.	3.2	Shame and low perceived social support at work as barriers in the RTW process	63
	4.	3.1	Shame among long-term sickness absentees	60
	4.3	INTER	RPRETATION AND DISCUSSION OF FINDINGS	60

#### Abbreviations for use in this thesis

CI – Confidence interval

CMDs - Common mental disorders

DP - Disability pension

Employer-RS - Employer-reported sick-listed sample

HAP – Health Assets Project

GPD - Global burden of disease studies

GDP - Gross Domestic Product

GP - General practitioner

LISA – Longitudinal integrated database for sickness insurance and labour market research

LTSA – Long-term sickness absence (>14 days)

OECD - Organization for Economic Co-operation and Development

OR – Odds Ratio

Random-PS - Random population sample

RTW - Return to work

SEK - Swedish Kronor

SES - Socioeconomic status

SIA – (Swedish) Social Insurance Agency

SCB - Statistics Sweden

Self-RS - self-reported sick-listed sample

## 1. Background

# 1.1 Psychology in sickness absence – fragmented knowledge

Psychology concerns how we perceive, experience, act, and react (1). What does this have to do with sickness absence? Simplified, sickness absence is a response to illness, that becomes relevant when capacity to work fall below the job's requirement (2). This plain explanation is contested on numerous grounds. For example, sickness absence varies substantially across individuals despite seemingly similar health (3). Recurrent and long-term sickness absence greatly increase the risk of future sickness absence (4, 5) and permanent work-life exclusion (6-11), but this association seem not to be explained by deterioration in health alone (8, 12). At a macro level, variations in sickness absence do not correspond with population health indicators observed in Western countries (13, 14).

In ecological models, such as Loisel's conceptual model (Figure 1), sickness absence and return to work (RTW) depend on actions and interactions of several stakeholders in the multiple systems surrounding the individual worker, including the workplace system, the health care system and the social insurance system (15), as well as the overall societal context (16-18). Not only the individual worker's health, but also cognitive and affective aspects, social relationships and interactions with others must be taken into account to understand and prevent work disability (16). Thus, sickness absence is a compound phenomenon, comprising both ill health and social behaviour (18, 19).



Figure 1. The social systems involved in sickness absence and return to work (adapted from Loisel et al. (15))

The complex and dynamic nature of sickness absence is increasingly acknowledged. Considerable research efforts have been carried out the recent years, in particular in the Nordic countries where the sickness and disability insurance rates have been high (20, 21). Owing to these contributions, several risk factors of sickness absence, both individual and contextual, are fairly well established (18, 22, 23) and has enabled stakeholders with a better empirical platform on which to design policy and manage sickness absence. But still, the empirical knowledge about psychological factors in sickness absence remains scanty. Research has mainly focussed on measures of mental illness and diagnoses, and left important knowledge gaps concerning the contributions of more general, non-clinical psychological factors, as well as about the interplay between individual and contextual factors (18, 24). Some aspects are as good as blind spots, such as how emotions influence sickness absence behaviour.

Long-term sickness absence (LTSA), specifically, often entails major changes in everyday life of the sick-listed individual, with abundant conceivable consequences (17, 25, 26). Interpersonally, LTSA may impact social role and relations, and, depending on culture and context, involve social stigma (27). Returning to work after LTSA is often a protracted process. It is suggested that long periods away from work as well as consequences of LTSA itself can create obstacles for RTW, regardless of disease-specific problem (4). Recent conceptualizations adopt a process perspective by stressing that sickness absence and RTW involves phases and transitions from onset, off work, re-entry, and retention (19, 28). Despite this, literature has to a large extent treated sickness absence as an event and focussed more on its causes than its possible consequences and factors related to RTW and reintegration at work (4, 26).

#### Overall aim and structure of the following presentation

The overall aim of this thesis was to contribute with new knowledge about social psychological factors in LTSA, with a primary focus on the role of shame and social support. An analytical, epidemiological approach was chosen to address these aspects in a general population perspective, employing data from a large population-based survey. Since sample representativeness is crucial for generalizability of epidemiological studies, and few have studied selective participation relating to sickness absence, and additional aim was to examine if history of sickness absence was associated with survey participation.

The introduction will start with a brief description of the sickness absence research field and the descriptive epidemiology of sickness absence, concentrating on the Swedish and Norwegian working population. Thereafter, theoretical frameworks and models that can serve to describe the role of psychological factors in sickness absence will be presented, including a clarification of central concepts employed in the thesis. The introduction will end with a description of how social emotions, such as shame, and social support are studied in the empirical sickness absence literature, including important findings and gaps of knowledge. The complexity of sickness absence invites the occasional repetition in the presentation, as well as some simplifications to ease readability.

## 1.2 The sickness absence research field

The complexity of sickness absence is reflected in the wide range of research approaches and scientific disciplines involved, in particular medicine, sociology, economy and psychology (29). Medical research often focuses on individuals, aiming to examine the course and prognosis of medical symptoms and diagnoses in relation to sickness absence (29). This focus resonates well with the medical professions' clinical and medicolegal roles. The field of psychology similarly focus on individual risk factors. The fields of sociology and economy are on the other hand often seen to focus on how societal structures affect health and sickness absence for individuals and groups (29). While the field of sociology emphasises how these structures affect groups, research within economy has traditionally been based on rational choice theories, where the individual's considerations of gains and losses are assumed to be key driving forces in sickness absence behaviour. These distinctions are notably simplifications. Social and occupational medicine, for instance, focus on populations and organizations, similar to sociology. In economic research, there is an emergent emphasis on formation and effects of group norms and social interaction effects on propensity for sickness absence. Finally, the distinctions between the disciplines are often less clear in the empirical than in the theoretical literature, and in the Scandinavian countries, research is heavily influenced by the access to administrative registry data. The multi-disciplinarity of the field is highly appropriate seen the multidimensionality of the phenomenon, and yield different pieces of knowledge approached from several angles. There has traditionally been relatively little contact between the disciplines, which may have detained an integrated picture (29, 30).

#### Psychology across research approaches

Though sickness absence is determined by many factors across temporal and structural dimensions, the individual remains a key figure (18, 19). As such, the

psychology of the individual always matters, and comprises one common link bridging research approaches and levels of analysis. For instance, the most common medico-legal causes of sickness absence are symptom-based diagnoses, for which the subjective experience is decisive in assessment (31). Self-perceived poor health is a strong predictor for work life exit (32) and individuals seem to predict ability to return better than health professionals (33, 34). In microsociology, psychological factors, such as coping resources, perceived social support, and health behaviour, are suggested to play important mediating roles to explain how social disadvantages translate into ill health and sickness absence (35, 36). In economic research, finally, motivational theories are, as mentioned, explicitly employed (37, 38).

## 1.3 Descriptive epidemiology of sickness absence

Reduced capacity to work due to ill health is a severe threat to an individual's ability to earn through paid work, and is one of the major causes of poverty worldwide (39). Epidemiology deals with the distribution and determinants of health-related states and events in populations (40), and epidemiological knowledge about sickness absence is crucial to implement appropriate prevention and rehabilitation measures.

#### The Nordic welfare system

Sickness absence rates vary greatly over time and by countries' welfare legislation and labour market. The Nordic countries are regarded as sufficiently similar to allow comparison (24, 41). Universal insurance schemes, including income replacement for those unable to work due to ill health, are girders in Nordic welfare systems (42, 43). "The Working strategy" ("Arbeidslinja") is a basic fundament across social policies, aiming to include as many as possible in working life. This strategy is based on the assumption that employment gains both the individual and the society (42). The ambition to include as many as possible in working life could imply relatively high absence rates, as groups that are vulnerable for reduced work capacity thus also are included. In line with the societal emphasis on work, and its importance for the state economy, there is an extensive interest in sickness absence, both in research, political agenda and public debate in the Nordic countries (20, 21).

#### Main levels of sickness absence across countries

Norway and Sweden had the highest levels of sickness absence within the Organization for Economic Co-operation and Development (OECD) countries until the beginning of the millennium (11), with public spending on disability and sickness insurance programs constituting 4-5% of GDP (44). The Nordic countries also has the highest general employment rates, particularly in subgroups of women with children and elderly women (11). Notably, unemployment rates and sickness absence rates have over time shown a countercyclical pattern both in Sweden (45) and to some extent in Norway (22, 46). Since 2003, the sickness absence rates have decreased in Sweden and in 2009 approached the average European level (47). In Norway, the rates have fluctuated, but are still among the highest in OECD (11).

Though sickness absence is common in the entire working population, it is not evenly distributed across social groups and gender. Long-term compared to short-term sickness absence, constitutes by far the biggest burden in the population in terms of volume of days (48) and thereby public expenditures. LTSA is found to be a good measure of overall health status (49) and is also associated with sustained morbidity (50) and excess mortality (51-54). Musculoskeletal disorders and mild to moderate mental disorders are the most common medico-legal causes of longer-term absences, and several countries experience growth in rates of sickness absence ascribed to mental disorders (11, 55-57). Sickness absence rates have remained higher among women than men ever since women fully entered the work force in the late 1970s (58). As for other health-related measures (59, 60), sickness absence increases with age and a strong social gradient is observed, such as indicated by education, occupational class and income (23, 61-63). These main patterns are observed across countries (11).

#### 1.3.1 Impact of long-term sickness absence for the individual

Employment is generally considered beneficial for health, and mental health in particular (64, 65). Besides financial security, employment can provide structure, activity, social contact and social identity, opportunities to increase skills, and to pursue meaningful life goals, purpose and sense of personal achievement (66, 67). Sickness absence, even though providing opportunities for rest and recovery from illness while having guarantied income replacement, consequently also means removing the individual from an, in most cases, important social and health-promoting arena. Thus, from a social psychological perspective, LTSA may represent a major life event, involving important changes in everyday life and social relations, which may impact on social role and identity (17, 26, 67).

There is extensive evidence that unemployment is not only associated with health problems, but influences health and wellbeing negatively (68-70). The empirical knowledge on health-related and social consequences of sickness absence is yet surprisingly scant, considering the major societal costs and potential wide-ranging impact for the individual and affected parties (26). To study this is however challenging, as it requires establishing the counterfactual; that is, how things would have been without exposure to sickness absence. Consequences of sickness absence may in many cases be similar to that which led to the sickness absence in the first place, and difficult to disentangle (71). Moreover, sickness absence is diverse as an exposure variable (26), and randomization designs are ethically challenging (72). To date, existing studies have focused more on negative than positive consequences on LTSA for the individual. In survey studies, long-term sick-listed commonly report negative impact on a range of aspects such as self-image and quality of life, sense of belonging to the work group, relationships at work and in domestics sphere, sleep and life-style, financial situation, and career possibilities (73, 74). Social isolation has been found to increase risk of disability pension, especially for mental diagnoses among young individuals (75, 76). Little is known about how sickness absence affects social life.

# 1.4 Theoretical and conceptual frameworks relevant for psycholocial factors in sickness absence

In 1991, Kristensen (77) proposed five recommendations for a theory on sickness absence. It should 1) acknowledge the complexity by incorporating factors at all levels, and preferably also clarify the relationships between these factors; 2) consider the individual as a product, but also as a conscious actor within his or her social context; 3) not regard sickness absence normatively, but rather as a coping behaviour, and seek to find the optimal level of absence from a health perspective; 4) acknowledge the importance of the individuals' subjective perception of his or her health and factors influencing it; and 5) incorporate the job strain model as this is found influential for health and also sickness absence. The two most striking aspects of these recommendations, in the light of the current thesis, are 1) the prominent emphasis put on the psychology of the individual in context, and 2) that such a unified theory is yet to be developed (29, 30, 78).

According to Krieger (2004), epidemiological research has traditionally devoted little attention toward explicit development of theoretical models, but a shift in attention has been observed the latter decades (79). Current theories within epidemiology can, in general, be grouped as "decontextualized" (including biomedical and lifestyle) and "contextualized" (i.e. various social epidemiological theories including psychosocial and ecosocial) (79, 80). Similar distinction can broadly be applied for sickness absence research as well, where explanatory models have tended to vary between scientific disciplines (29, 30). With regard to frameworks specifically relevant for psychological factors in sickness absence, some models describe the development of illness, whereof the Job Strain (81) and Effort-Reward imbalance (82) frameworks are of the most influential, and some describe factors influencing absenteeism in general (83, 84), such as Steers and Rhode's model (84). Of models more directly concerning sickness absence, some describe specific rehabilitation contexts (85) or medical conditions (19), which might be considered too narrow as for the aim of the current thesis.

One descriptive model, that may illustrate the aspects in focus for this thesis is the Illness flexibility model by Johansson (86). This model captures many of Kristensen's recommendations, adopts an ecological view of the individual as an actor inseparably tied to his/her context, and provides explicit suggestions on the role of psychological factors in transitions between work and sickness absence.

#### Illness flexibility model

The illness flexibility model (Figure 2) was developed to describe possible causes of sickness absence and RTW (86). In particular the model aim to describe the perceived flexibility or scope of action of a worker with reduced capacity concerning whether he/she can, ought to and want to attend work or not. According to the illness flexibility model, these evaluations are affected by contextual conditions, both in- and outside work. The model also incorporates a biomedical framework by including poor health as a prerequisite for sickness absence. More specifically, work ability (whether he/she can work) is decided by opportunities to adjust work assignments to health and capacity. Studies testing this model have found adjustment latitude strongly related to sickness absence and RTW (87, 88). Given the work ability, the worker's motivation to attend work will in turn depend on perceived *requirements* from the environment on the one hand (whether he/she ought to work) and internal incentives on the other (whether he/she wants to work). The requirements (such as norms, other's wishes and needs, and financial and legal constraints) describe negative consequences of either being absent from or attending work. The incentives, by contrast, describe positive consequences of attending versus being absent from work (like fulfilling needs for belonging, esteem, self-actualization etc.),

Applying the illness flexibility model, perceived social support at work and the feeling of belonging to the workplace can thus be examples of attendance incentives. Perceived lack of support or not feeling welcomed at work will conversely reduce incentives of attendance and can even be experienced as absence requirements.



Figure 2. The Illness flexibility model (86)

#### Key concepts

This thesis focuses on social psychological aspects of sickness absence. In a society where work participation is the norm, being off work on sickness absence represents a breach of normality (27). Studying sickness absence as a social phenomenon requires a clarification of key concepts, such as *norms, roles, social emotions* and *social support*. The need to belong, in particular to have frequent, non-aversive interactions in on-going relations, is a basic human need that motivates interpersonal behaviour (89). Identities are formed and defined in relation to social groups and categories. All individuals are influenced by *norms* of their groups; sets of implicit rules and expected behaviour within the group. Group members may furthermore hold different *roles* with additional sets of specific expectations related to their position. *Social emotions* can give us signals as to our standing in relation to important others/groups. Consequently, like in other social contexts, the worker's

emotions and behaviours is influenced by perceived norms and relationships in his or her social environment during the sickness absence process.

#### The sick role

In research on health and society, it is common to distinguish between "illness", "disease" and "sickness". The first refers broadly to the individuals' experience of not feeling well, the second to the formal condition or medical diagnosis defined by an expert, while the last denotes a social "sick role" given by the society to persons with a certain health condition. Theoretically, these concepts form layers where illness is required for disease, which again is a prerequisite for the sickness. The empirical relation between these concepts is far more complex (3).

The conception of a social model of illness, including the general term of a "sick role" is dated to Talcott Parsons' seminal book "The social system" from 1951 (90). Here, Parsons described illness as a disturbance of normal functioning and a deviance in society. He described "the sick role" as a way to channel this deviance and suggested aspects of institutionalized expectations with sentiments and sanctions for a "sick person". In short, the sick role allows one to be exempt from normal role demands and relieves the responsibility for one's current condition. On the other hand, one is expected to see the current condition as undesirable, with medical help seeking and recovery as expected behaviours (90). These social norms were regarded to discourage secondary gains of illness and consequently motivate the individual to reintegrate back into normal functioning as quickly as possible. Parsons' description of the sick role has been criticized, for instance for not being applicable to chronic illness and that he fails to address the impact of structural factors (91). However, the main idea remains useful as a general framework (91). From a social psychological perspective, sickness absence can be seen as a form of sick role, where its legitimacy varies across dimensions such as time and cultures (18).

Related theoretical frameworks underpin the emerging empirical studies on social interaction effects on social insurance dependency in the field of economy. By combining the traditional economic incentive model with theories on the influence of

social norms on decision making, it is posited that the propensity for claiming social insurances, like sickness absence insurance, will depend on absence patterns within social groups (27). An increasing body of studies provide empirical support for such social interaction effects (92, 93), of which transmission of work norms and changes in social stigma are of the suggested mechanisms (27, 92).

#### Social emotions: shame

Emotions involve a subjective experience, physiological arousal, a motivational component and a behaviour component (94). Furthermore, emotions are evolved so that the individual may adapt to fundamental life-tasks (95), they affect thoughts and behaviour, and guide decision-making processes (96-98). Social emotions, also denoted as self-conscious or moral emotions, include shame, guilt, embarrassment and pride (99). In our drive for social inclusion and acceptance, these emotions hold interpersonal functions that regulate our behaviour in forming and maintaining social bonds. As such, they may resemble "barometers", weighing our sense of self and our behaviour against perceived social standards (100, 101). Social emotions are possibly universal (102), but cognitively more complex than emotions like fear and anger as they require self-awareness and self-representation (95, 103).

Shame has been discussed theoretically and empirically in several disciplines, including philosophy (e.g. 104), sociology (e.g. 100) and psychology (e.g. 105). Shame has often been referred to interchangeably with guilt (99). Recent psychological research finds critical conceptual differences between shame and guilt, concerning what is "the object of negative evaluation" (the global self versus specific behaviour) (103, 105), behaviour tendencies (avoid and withdraw versus approach and repair) (106), and association to psychopathology (more strongly associated with shame than guilt) (107). Shame is commonly evoked by negative evaluations of our self "seen in the eyes of others", and linked to having deficits or failures exposed (103, 105). Shame is described as a strong barrier for patient and therapist communication (108).

#### Perceived social support (at work)

Social inclusion and belonging are basic human needs (89, 109). There are several theories, terms and measures to explain and examine the association between social relationships and health (110, 111). Berkman et al. (110) recently developed an overarching model, placing social support as one of the primary pathways between social networks and health and wellbeing. A much employed definition of social support is *"information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations*" (112, p.1). Social support is typically divided into "perceived" and "received", where the former is more commonly measured and linked to quality of life and health (113).

House (1981) was the first to describe social support in a workplace setting and described the following subtypes: emotional, instrumental, affirmative, and informational support (114). Inspired by the empirical studies on social network and mortality incidence, Johnson and Hall (115) further introduced workplace social support as a buffer for adverse health consequences when experiencing "job strain" (i.e. high demands and low decision latitude).

There is an increasing awareness in research of the possible reciprocal relationships between work stressors, including social support, and health (116, 117). This research draws on the dynamic perspective of the individual as "product and producer" of his or her environment (77), where the person, his/her behaviour and the environment affect each other bi-directionally or reciprocally over time (e.g. as described in Bandura's renowned and widely applied Social cognitive theory (118)). In the "reverse causation", health may influence work characteristics both through environmental change mechanisms and within-person perceptual mechanisms (119). Shortly, the former suggests that healthy workers are more likely to experience upward selection, while unhealthy workers may drift downward more adverse work environments or work tasks e.g. with poorer social climate or less social support. As for within-person mechanisms, changes for instance in health status can alter how one evaluates the environment (119).

#### Long-term sickness absence (LTSA)

In the scientific literature it is common to differentiate between short and long-term sickness absence, as these may have separate causes, consequences, and involve different populations at risk (120). There is, however, no scientifically established demarcation between short-term and long-term sickness absence (121), making comparison across studies difficult. The operationalization is often, more or less arbitrary, based on sickness absence legislation in the study context, or on availability of data.

#### 1.6 Appraisal of the literature

Psychological factors in sickness absence are approached through a wide variety of aspects and measures. For instance, stable behavioural dispositions are examined in form of cognitive abilities (122) and trait-related factors, such as childhood temperament (123), performance-based self-esteem (124) and personality disorders (125-127). Several coping-related aspects and measures are employed such as self-efficacy beliefs (128-130), RTW expectations (131), illness perception (131-133) and fear-avoidance beliefs (134, 135). Concerning motivational aspects, job satisfaction and monetary compensation are of the most commonly addressed (37, 136, 137), and studies on norms and attitudes include for instance work orientation or work attitude (128, 129), and effects of social interaction on absence propensity (37, 92, 93, 138). The wide variety of research approaches, concepts and measures employed, reflect the multi-causality of sickness absence, and also the lack of a unified theory.

Social psychological aspects of sickness absence have so far mostly been addressed in qualitative studies. Epidemiological studies with representative populations are needed to complement these studies, to gain knowledge about the general relevance of these phenomena and their predictive value (139). In epidemiological studies, in turn, self-reported survey data are highly advantageous to collect information on social psychological factors and can complement data available in administrative registries. The quality of survey data nevertheless rest on the participating sample and findings might be biased if the variables studied are differently distributed among participants and nonparticipants (140). Generally declining survey participation rates (141-143) thus call for studies that can provide a basis for how to approach potential participants in the future, and more knowledge is needed to evaluate whether surveys successfully renders representative samples. Selection mechanisms for survey participation are complex (143) and involve psychological factors (including internal and external motivations and perceived norms about participation) (144-147) in parallel with health-related factors (including ability to participate) (148-152). Few studies have examined whether the main variable of interest in the current thesis, sickness absence, predicts survey participation, and existing evidence is inconclusive. Some have found that those who participate have lower sickness absence rates (153-157), others have found such association among men only (158), or report weak (156) or no (159) association between prior sickness absence and study participation.

In the following literature review, studies on social emotions like shame and social support in LTSA will be presented by highlighting important findings and knowledge gaps. Studies addressing various stages of the sickness absence process will be presented, as factors leading up to sickness absence may differ from those facilitating or constituting barriers for RTW (10, 18). Population-based epidemiological designs will be emphasised, in accordance with the aim of the thesis. Initially, results from qualitative studies are described, as these can provide in-depth knowledge about people's experiences (160), and have provided important inspiration for the ideas in this thesis.

## 1.6.1 The lived experience of long-term sickness absence – knowledge from qualitative studies

Descriptions of the lived experience of LTSA overall lend support to a staged- or process-understanding of sickness absence, where both individual and structural factors and the interplay between them are important to take into account to understand prolonged sickness absence (161-165). In a large study among long-term sick-listed women, the establishment of LTSA was described as a process where the

onset was seen as a positive event, as an opportunity to rest, but where isolation and inactivity gradually created vicious circles and new problems increasing obstacles for RTW (161).

Systematic reviews of the qualitative literature on RTW after injury (166) and common mental disorders (167) similarly conclude that factors beyond health and functioning are important for successful RTW. Social support, good will and trust from the actors involved are described as important for health, self-esteem and successful RTW (166, 168-172). Social and communication barriers are nevertheless common, challenged by differing roles and insufficient coordination between stakeholders (166, 167). Contact with and support from the workplace supervisor is described as being of particular importance to facilitate the process of return to work (166, 173, 174), and supervisors themselves consider themselves as "key persons" (175).

Described social impacts of LTSA include altered relations and negative encounters (170, 176, 177). Experiences of distrust from others and the need to validate their illness and reduced capacity as something "real", is commonly described, in particular among absentees with symptom-based illnesses such as musculoskeletal conditions, CMDs and "burn-out" (164, 170, 178-180).

Negative encounters and relational difficulties may feed negative self-evaluation, reduced self-confidence and shame (168, 170, 176, 177, 181-184). Such internalized reactions are in turn suggested as driving forces in sickness absence-related behaviour, mostly in form of withdrawal from social contacts with friends and colleagues (169, 182, 185). By contrast, respectful interactions, desire and longing (181), as well as self-efficacy expectations (186) are suggested to be important driving forces behind successful RTW.

Impact of LTSA on social role and identity is addressed in only a few studies (169, 179). Findings suggest that some long-term absentees struggle to find an acceptable social role (169, 179), and experience the "sick role", including being a passive recipient, being labelled or regarded incapacitated by others, as stigmatizing. The

internalization of this role and to apply for disability pension can be a way to render dignity (169, 179), whereas others keep identifying themselves as "workers" (168, 169).

#### 1.6.2 Social emotions

As described above, several qualitative studies have suggested that being off sick can evoke negative emotions for the sick-listed, and that negative self-evaluations can be a barrier towards returning to work. Studies of the distribution and role of emotions as causes or consequences of sickness absence, or for return-to-work prognosis, are nonetheless rare in the epidemiological literature.

In a survey among long-term sickness-absentees, between a third and half, and the young in particular, reported guilt and alienation, such as having bad conscience for not being able to work and feeling outside of society when on sickness absence (74). Another survey on health-care encounters found one in five to report negative encounters; that experiencing nonchalant behaviour and being treated with disrespect were particularly associated with feeling wronged (187); and that feeling wronged in turn was closely related to shame (188). Negative encounters, in particular when feeling wronged, were related to impeded self-estimated ability for RTW, with the opposite result for positive encounters (189). Embarrassment avoidance cognitions are finally found associated with LTSA among patients with chronic fatigue syndrome (190). All these studies were cross-sectional, and to the very best of my knowledge there are no studies examining the prospective associations between emotions and sickness absence-related outcomes.

#### 1.6.3 Social support at work

Relations and sources of support relevant for sickness absence include workplace relations with supervisors and colleagues, private relations to family and friends, as well as relations and support from health professionals. Most studies have focussed on workplace social support.

#### Social support as risk factor for ill health

Several systematic reviews of prospective studies have found that adverse psychosocial work conditions, including low social support from co-workers and supervisors, contribute to mental distress and common mental disorders (117, 191-196). Measures of job control and demand, and imbalance between efforts and reward have dominated this literature. Emerging concepts in this field include more relational aspects, such as "organizational justice" (192, 197), "sense of community" (198), "interpersonal conflict" (199, 200) and "workplace bullying" (201, 202). A recent prospective study examining both the "traditional" and more recent concepts, found the latter to be most consistently related to mental distress, including "support from immediate superior" and "fair leadership" (201). Work and non-work stressors, including low social support, is furthermore found independently associated with common mental disorders (203).

#### Social support as risk factor for sickness absence

A range of studies has examined the associations between social relationships at work and *onset* of sickness absence. In several studies, both cross-sectional (198, 204) and prospective (205-214), low social support at work is found to elevate the risk and high support conversely to lower the risk of sickness absence. Other studies have found significant associations among men only (215, 216), women only (217), mixed results (218), or no such association (48, 219-222). Other relational aspects, such as organizational injustice (197, 223, 224), low sense of community (198), role conflicts (198, 221), high emotional demands at work (221), and bullying (198, 218, 225, 226) have also been found associated with sickness absence. One study also found lack of attentive leadership associated with sickness absence independent of the demandcontrol-support model (227). A few studies have even found perceived low social support at work (228, 229), low supervisor support (230) and poor colleague fellowship (231) related to a higher risk of permanent work life exclusion through disability recipiency, though these association might be explained by confounding factors (228). Some studies on social support in the private sphere have on the contrary found high level of emotional support, but also negative aspect of support, to predict higher rates of sickness absence (222, 232).

#### Social support as predictor for return to work (RTW)

An increasing body of studies have found social support to be important for RTW, measured both as *rate* and *time to return*. Associations between workplace social support and RTW are found in samples including all-cause sickness absentees, regarding both colleagues and supervisor as the source of support (128, 129, 233-235). A systematic review found strong evidence for social isolation and some evidence for low superior support and low colleague support on prolonged duration of sickness absence among patients with acute low back pain (236). Notably, not all studies report significant associations (237), and some have, on the contrary, found low perceived support and low interactional justice by supervisor related to higher RTW rate (235, 238).

#### *The impact of sickness absence on social support – the reverse causality*

The impact of sickness absence on social inclusion, relationships and support is to a little extent addressed in the literature (117). Based on self-report from long-term sick-listed, a few cross-sectional (73, 74, 239) and one longitudinal study (240) indicate that negative impacts are common, and outnumber positive ones, on relations with friends, family, co-workers and sense of belonging to the work group. The possible bi-directional or reciprocal relationship between workplace social support and health-related factors is as of yet only studied in regard to wellbeing and mental health (116, 117). A recent systematic review found no evidence for a "reverse effect" between wellbeing and social support at work (241), whereas a four wave study, by contrast, found evidence for a reverse effect of mental health on supervisory social support (119).

## 1.7 Aims and research questions

The overall aim of this thesis was to increase the knowledge about how the social psychological aspects shame and social support relate to long-term sickness absence in the general population. An additional aim was to examine if history of sickness absence is associated with survey participation.

Although long-term sickness absence may have major impact on the life of the individual, the sickness absence literature has in general focussed more on causes than on consequences of sickness absence. Qualitative studies suggest that negative emotional reactions, such as shame, are prominent among many sickness absentees. The distribution of shame among sickness absentees in general, however, remains unknown. Also, no study has as of yet tried to establish how shame relates to later sickness absence. Several studies have found perceived social support at work to predict onset of sickness absence and return to work. Long-term sickness absence is suggested to have a negative impact on social inclusion at work. Despite this, little is known about whether perceived social support at work differs between workers with and without a history of long-term sickness absence. Thus, novel approaches and study designs are required to expand the knowledge about social psychological processes in sickness absence. The survey method is highly advantageous to gain epidemiological information about psychological factors in sickness absence. Findings might nevertheless be biased if the variables studied are differently distributed among participants and nonparticipants. Few studies have examined whether the main variable of interest in the current thesis, sickness absence, predicts survey participation.

To meet these knowledge gaps, the above aims were addressed in three papers employing data from the general population-based survey the Health Assets Project (HAP), linked to official registries of sickness absence across nine years, and were specified in following research questions:

- Among current sick-listed employees, is shame concerning being sicknessabsent associated with factors related to the sickness absentee, hereunder demographic characteristics, medico-legal cause of absence and history of registered sickness absence (paper I)?
- 2) Does shame among current sick-listed employees predict registered sickness absence the subsequent year (paper I)?
- 3) Does history of registered sickness absence across seven years predict current low perceived social support at work (paper II)?
- 4) Is history of registered sickness absence associated with participation in a population-based survey that explicitly focused on sickness absence, work and health (paper III)?

## 2. MATERIALS AND METHODS

The present thesis is based on data from the first wave of the Swedish Health Assets Project (HAP), conducted in 2008. The data comprise a postal survey and registry data on demographic variables and sickness absence through 2001-2009, linked using personal identification numbers. The design allowed for studying temporal associations and assured independency between several of the exposures and outcome measures. In the following the materials and methods employed to examine the research aims will be presented. First, a short description of the Swedish sickness insurance system will be given to get a backdrop of the context needed to evaluate the validity and generalizability of the findings. An overview of the study design is also provided in Table 1 in the Appendix.

### 2.1 Context: the sickness insurance system in Sweden

The current sickness insurance legislation in Sweden includes all inhabitants in working age. Sickness benefit can be provided if disease, injury or symptoms reduce the work capacity with at least a quarter, and awarded 100%, 75%, 50% or 25%. Similar benefits can be awarded during medical treatment, rehabilitation or to prevent illness. Absence beyond seven days requires a physician issued medical certificate. The employer covers the first 14 days of a sickness absence episode (sick pay) for employees, excluding one qualifying day, and after that, the national Social insurance agency (SIA) covers the expenses. Unemployed, students and self-employed can apply for insurance covered by SIA from day two of a sickness absence episode. The insurance covers 80% of the income. In 2008, several new regulations were introduced, involving an increased focus on adaption for new work tasks to avoid long absences without active rehabilitation or other active measures: The maximum time for being sick-listed got limited to 364 days (within a frame period of 450 days), with the possibility to apply for 75% compensation for an extended 550 days. Work

capacity is assessed in relation to the worker's *ordinary* work tasks the first 90 days, in relation to *other* work tasks within the workplace thereafter, and in relation to *any* available work at the labour market after 180 days. Since 2003, workers with permanent reduced work capacity can be entitled to sickness compensation if aged 30-64, whereas those aged 19-29 can get time limited activity compensation for one till three years at a time (100%, 75%, 50% or 25%).

The key eligibility criterion for sickness allowance is to have a medically acknowledged condition that reduces work capacity. This criterion is however challenged by a poor definition of work capacity (242), and especially concerning the common cases of symptom-based disorders such as musculoskeletal disorders and common mental disorders (243, 244). These aspects often make it difficult for the parties involved to evaluate whether and when to prescribe or recommend sickness absence (167, 245-247), and the decision is often patient driven (31, 247). In 2008, The National Board of Health and Welfare in Sweden launched a decision support system for physicians with suggestions for absence lengths based on medical condition.

## 2.2 The Health Assets Project (HAP)

The Health Assets Project (HAP) is a general population-based epidemiological cohort study, developed to gain knowledge of individual, organizational and societal factors that promote RTW and facilitate work life inclusion among individuals with health problems (248). The study base was the working population (19-64 years old) in Västra Götaland in Sweden, a region comprising 1.6 million inhabitants in 2008 (17% of the Swedish population). A unique feature of HAP was the sampling of "incident" sickness absence cases, permitting analyses without on-going cases included, in addition to a random population sample. This sampling was done to enable comparisons between workers with sickness absence experiences to workers without such experiences from the same overall population. More specifically three
cohorts were included: 1) a recent sick-listed *employer-reported* sample (employer-RS), 2) a recent sick-listed *self-reported* sample (self-RS, including self-employed, unemployed, students and others), and 3) a *random population* sample (random-PS).

The employer-RS targeted all employed individuals with a sickness absence episode registered in SIA (i.e. >14 days) in the period 18.02-15.04.2008 (n=12543). The self-RS targeted other insured individuals with a sickness absence episode registered in SIA (i.e. > 1 day) during the period 18.02-01.04.2008 (n=5004). As it was important to distribute the survey as close as possible to the current sickness absence episode, only those registered in SIA within the time frame were eligible (n=6140 in employer-RS and n=4240 in self-RS). In general those with lagged registration in SIA are more likely to be men, have lower income, higher education, be self-employed, and to some extent to be immigrants and first time sick-listed (249). Specific analyses of the employer-RS found those registered within the time frame to be younger, but had equal gender distribution compared those registered within the time frame. There was however no difference in registered sickness absence between those invited in the first and second round in employer-RS, with lagged registrations presumably overrepresented in the latter. In self-RS, those with late registration were younger and more often women (data not shown).

The total frame population in employer-RS (n=6140) and a random sample of every forth case of the frame population in self-RS (n=990) was invited to participate. The random-PS was extracted from Statistics Sweden (SCB) (n=7984). A negative coordination was performed, thus the random-PS included no individuals registered in SIA with a new sickness absence episode during the inclusion period.

Baseline data were collected by Statistics Sweden during spring 2008, using a postal survey covering socio-demographics, sickness absence-related aspects, physical and mental health, work and family conditions, life events, leisure and lifestyle. Two reminders were given. For each participant, the following demographic variables were extracted from Statistics Sweden: Gender, age, country of birth, marital status, gross income and occupational class per 2008, and annual employment status from

2001 till 2009. Moreover, the following information was obtained from "the Longitudinal integrated database for sickness insurance and labour market research (LISA)", held by Statistic Sweden: Annual number of SIA-compensated sickness absence days and episodes from 2001 till 2009, and reimbursed sickness or activity compensation from 2003 till 2009 (see description of legislation in section 2.1).

To enable nonparticipation analyses (paper III), we obtained the following aggregatelevel registry data from Statistics Sweden: 1) Socio-demographics (age, income, country of birth, region and marital status), distributed by gender, for participants and invited nonparticipants in all three samples; and 2) annual number of SIAcompensated sickness absence days and episodes from 2001 till 2009, distributed by gender and age-groups (19-30, 31-50, 51-64) in the employer-RS and self-RS target populations. Additionally, from official accessible statistics annual number of SIAcompensated sickness absence and rehabilitation days per insured individual in Västra Götaland were retrieved for the period 2001-2008, distributed by gender and age group (20-29, 30-39, 40-49, 50-59) (retrieved October 2014).

## 2.3 Study designs and samples

The study designs in the current thesis sort under analytic and observational epidemiology. All three papers employ a cohort design, more specifically a combination of a cross-sectional and prospective cohort design in paper I, a historical cohort design in paper II and again a combination of a cross-sectional and an historical cohort design in paper III (Figure 3-5). In cohort studies participants are defined by their exposure status and followed over time. In population cohort studies, like HAP, participants are usually defined by being part of a defined population at a given time (250), data collected on a range of topics, and exposure status categorized in each specific study. Cohort studies are always prospective, as they look forward from exposure to outcome. In terms of time, however, they might be called retrospective or historical if they use historical data on exposure (251).



Figure 3. Schematic presentation of the study design in paper I



Figure 4. Schematic presentation of the study design in paper II



Figure 5. Schematic presentation of the study design in paper III

## 2.3.1 Study samples

Paper I was based on the employer-RS and included those reporting being currently sick-listed and who also responded to the main measure of interest, shame concerning being sickness absent. We excluded n=13 cases due to ambiguous LISA information

on sickness absence status 2008, giving a final sample of n=1567 individuals. In the prospective analysis (step 2) we excluded those registered with sickness compensation in 2009 (n=174) or *not* responding "working as an employee" at baseline (n=72), resulting in a sub-sample of n=1321 individuals.

Paper II was based on the random-PS to study groups with and without previous registered sickness absence. We handled problems with age-related left-censored data when going back in time till 2001 by excluding those younger than 23 years of age in 2008 (n=277). Moreover, we excluded those reporting not being currently employed (n=1090), those registered with sickness compensation and not answering any of the items on social support (n=14) as the outcome was assumed irrelevant for these groups. Those with missing sickness absence data during 2001-2007 (n=65) were excluded as they could be out of risk due to migration. The final sample consisted of n=2581 individuals.

Paper III was based on all three samples and comparison groups formed from available registry data. In step 1, we took advantage of the case-control sampling strategy in HAP, and compared response rate in the two samples with a recent, new episode of sickness absence (employer-RS and self-RS) to the control sample without a recent, new episode of sickness absence (random-PS). In step 2, we compared history of registered sickness absence (2001-2007) between participants and nonparticipants/target populations within each of the three samples, respectively. In employer-RS and self-RS, participants were compared to nonparticipant groups approximated from the target populations (employer-RS: *n*=12543; self-RS: *n*=5004). In random-PS, participants were compared to the overall target population in Västra Götaland. More details about the comparison groups can be found in section 2.4.6, 2.4.7 and paper III. When comparing differences in history of sickness absence (2001-2007) between participants and nonparticipants (step 2), we handled problems with left-censored data by excluding those younger than 31 years of age in 2008 in employer-RS and self-RS, and those younger than 20 years per calendar year in random-PS. The cut-offs were set to correspond to age-categorization in the available aggregate data. Participants with no registered sickness absence day in 2008 were

excluded to correspond to the comparison groups. In secondary analyses, demographic differences were compared between invited participants and nonparticipants (random-PS: *n*=7984; employer-RS: *n*=6140; self-RS: *n*=990).

## 2.4 Measures

Some measures are employed in all three papers, including measures of registered sickness absence and socio-demographics, whereas others are specific to particular papers, such as the measures on shame (paper I), social support at work (paper II) and survey participation (paper III). See table I for an overview of variables included per paper.

## 2.4.1 Demographic variables

*Gender (Paper I, II, and III).* Registry data extracted from Statistics Sweden; Woman, man.

Age (Paper I, II, and III). Registry data on age at year of baseline participation (2008) obtained from Statistics Sweden. Dichotomized around the median in paper I ( $\leq 50$ ,  $\geq$  51 years); employed as a continuous variable in paper II; and categorized according to the grouping of the aggregate data in paper III (for employer-RS and self-RS: 19-30, 31-50, 51-64 and for random-PS: 20-29, 30-39, 40-49, 50-59).

*Country of birth (Paper I and III)*. Registry data obtained from Statistic Sweden and grouped into the categories "Nordic" and "others" due to small numbers while attaining possibilities for crude examinations of cross-cultural differences.

*Marital status (Paper III)*. Registry data extracted from Statistics Sweden: "married", "not married".

*Level of education (Paper I and II).* Self-reported across six given categories and merged into the categories "elementary or less", "upper secondary" and "higher education" to obtain large enough groups for doing meaningful analyses.

*Occupational class (Paper I and II).* Registry data extracted from Statistics Sweden, and based on their classification of occupations (252), the categories were grouped into the three levels "unskilled to skilled manual", "low to intermediate non-manual", and "higher non-manual and entrepreneurs".

*Gross income (Paper I, II, and III).* Registry data extracted from Statistics Sweden and merged into the categories "SEK  $\leq$  49 000", "SEK 150 000–299 000" and "SEK  $\geq$  300 000", as suggested by Statistics Sweden.

## 2.4.2 Level of shame concerning being sickness absent

Level of shame was the main variable in paper I, and measured through the item "*To what extent do you feel shame concerning being sickness absent?*", rated across five ordinal categories ("very low", "low", "moderate", "high", and "very high" level of shame) in the HAP survey. Shame is commonly measured via self-report (94, 253), but no available measures focus specifically on sickness absence. To ensure sufficient observations per category whilst keeping the possibility for dose-response examinations, "very low" was kept as reference, while "low" and "moderate" were merged into "moderate", and "high" and "very high" into "high" level of shame.

## 2.4.3 Cause of current sickness absence

Participants reporting current sick-listing were asked what the physician assigned as cause of their sickness absence. The measure included 12 categories, multiple responses were allowed, and was included as a covariate in paper I. Due to stigma related to mental illnesses (254, 255) and to gain reasonable group sizes for the analyses, we chose to group the categories into "mental", "somatic" and "mixed". "Mental" included depression, stress, anxiety, schizophrenia or other psychotic disorders, and other mental disorder; "somatic" included infection, cardiovascular disorder, complaints due to pregnancy, injury/accident, back pain and pain in neck or shoulders; whereas the "mixed" category was operationalized as reporting at least one mental and one somatic cause.

## 2.4.4 Symptoms of depression

As depression is related to shame (107) and sickness absence (256, 257), the contribution of symptoms of depression at baseline were explored on the associations in paper I between shame and history of, cause of, and subsequent sickness absence, respectively. The World Health Organization (Ten) Wellbeing Index (258) was used as an indicator for symptoms of depression. The measure indicates depression (259) and psychiatric diagnoses (260), has been employed in several Swedish population-based studies (260-262), is tested for validity and reliability (258) and the Swedish translation is found psychometrically sound (263). The measure comprises ten items covering depressive mood, anxiety, energy level and well-being, with a reference period of one week, rated on a four-point Likert scale ("all of the time" till "never"). Sum scores were calculated and cut-off set at  $\leq 12$ , as previously employed (264, 265).

#### 2.4.5 Perceived social support at work

As described in the introduction, social support is assessed by a wide variety of measures. In paper II, we employed two measures of social support at work: The first focuses on the atmosphere at work, support and relations with colleagues and superiors, and is based on Johnson and Halls' model (115). The second is a measure of support by immediate superior, based on the theoretical literature on organizational fairness/justice/participation (266).

The workplace social support indicator was constructed from the support subscale in the Swedish Demand-Control-Support Questionnaire (DCSQ) (267). The scale is commonly employed in Scandinavian population-based studies and has satisfactory factor structure and internal consistency (268). A principal component analysis supported a one-factor solution in the current data (Cronbach's  $\alpha$ =0.86). The measure comprises the following six statements, rated on a four-point Likert scale (ranging from "agree" to "disagree"): "*There is a calm and pleasant atmosphere at my workplace*"; "*There is good collegiality at work*"; "*My colleagues are there for me*"; *People at work understand that I can have a bad day*"; *I get along well with my*  *superiors"; "I get along well with my colleagues"*. Sum scores were calculated and split by the median due to non-normal distribution and to identify high versus low level of social support. A sensitivity analysis treating the scale continuously in log-transformed regression analyses gave the overall same results.

As social support is multifaceted and paper II was the first study to my knowledge to examine temporal associations between previous sickness absence and current social support at work, the relevance of each item was explored as separate outcomes.

The second measure was a single item, "*Does your immediate superior consider your views*?", rated across the following categories: yes, frequently; yes, sometimes; no, rarely; no, never/almost never; no, I don't have a manager. Responses were dichotomized into "high" (yes, frequently; yes, sometimes) and "low" (no, rarely; no, never/almost never) support. Those responding, "no, I don't have a manager", were censored from the analysis regarding this outcome (*n*=6).

An exploratory factor analysis supported a one-factor solution then grouping the two measures as one scale, though the single item notably showed lower inter-correlations than the items in the established scale (data not shown). The two measures were nevertheless analysed separately, as they are based on different theoretical constructs, to explore various aspect of social support, and to not distort the quality of the scale.

## 2.4.6 Operationalization of survey nonparticipation

Participation rates can be calculated in various ways as sampling often takes place over several stages. Galea (269) has recommended to present a careful description of sampling procedures, including the total sample, who were contacted, who successfully recruited and what data that are partially or fully completed. A detailed flow diagram is presented in paper III and the appendix, showing successive selection from the target population, via the frame population and the invited sample, to the participating sample in each of the three cohorts in HAP. The examinations of selective participation in paper III employed somewhat different comparison groups, based on available registry data: *Step 1:* Participation rate in all three samples were operationalized as the number of individuals responding to the questionnaire divided by the number invited to participate.

*Step 2: random-PS.* Concerning history of sickness absence, levels among participants were compared to the corresponding levels in the whole target population via official accessible statistics of Västra Götaland.

*Step 2: employer-RS and self-RS.* Concerning history of sickness absence, levels among participants were compared to the corresponding levels in their specific target populations, using LISA data. To approximate nonparticipation groups, we subtracted participants to from the corresponding target populations.

*Secondary analyses:* For examination of demographic differences, participants were compared to invited nonparticipants.

## 2.4.7 Measures of registered sickness absence

The skewed distribution and complex nature of sickness absence challenge operationalization, and many measures are used in research (121). The operationalizations employed in the three papers are based on recommended measures (121), available data and adjusted according to the specific research aims.

## Paper I: History of sickness absence

Sum scores of registered sickness absence days during 2001-2007 were calculated and categorized into the groups "no registered sickness absence" and "lower", "middle" and "upper" tertiles. The split into tertiles was done separately for each 10year band since sickness absence increases with age and to partly come around agerelated left-censoring when going back in time.

#### Paper I: Sickness absence the subsequent year

The total number of registered absence days during 2009 was divided into the groups "no registered sickness absence", "sickness absence days below the median" and "sickness absence days above the median".

#### Paper II: History of sickness absence

In paper II, we were interested in examining various patterns of previous sickness absence in terms of both timing and extent. Based on annual number of registered sickness absence days during 2001-2007, subgroups were initially identified by performing a latent class analysis (LCA), a technique suitable for identifying subgroups without constrains regarding linearity (270). However, this approach was abandoned, as it was unfeasible to accommodate cases (n=86) that were granted sickness compensation for more than one year, and excluding them resulted in power constraints. Instead, sub-groups were constructed based on the widely applied median splits, informed by the preliminary results from the LCA. The follow-up was sectioned into a "distant" (2001-2004) and "recent" (2005-2007) period. In both periods, sum scores of registered sickness absence days were calculated and split by the median. Sickness benefit was recoded to 365 sickness absence days the calendar receiving such benefit, as this benefit is awarded for severe and lasting work disability. These calculations yielded five mutually exclusive categories: 1) "no absence": no registered sickness absence during follow-up, 2) "stable low": a total number of sickness absence days below the median in both periods, 3) "distant high": above median in the "distant" period, and below the median in the "recent"; 4) "recent high": below the median the "distant" period, and above the median in the "recent", and finally, 5) "stable high": above the median on number of sickness absence days in both periods.

#### Paper III: History of sickness absence

To examine selective participation in the HAP survey by history of sickness absence, the following three operationalizations of history of sickness absence was employed, based on available registry data on nonparticipants/target population:

*Recent new episode of registered sickness absence (step 1).* Firstly, as described, employer-RS and self-RS were both invited by having a new episode of registered sickness absence during inclusion, whereas the random-PS did not have a new episode of registered sickness absence during inclusion. Based on this case-control

approach, participation rates in the employer-RS and self-RS (cases) were compared to the participation rate in the random-PS (control).

*Days with registered sickness absence, annually (step 2)*. Secondly, in each of the three samples, respectively, mean number of registered sickness absence days annually, 2001-2008, were calculated and compared between participants and their respective comparison groups.

*Individuals with registered sickness absence, annually (step 2).* Finally, in the employer-RS and self-RS, respectively, proportion of individuals with previously registered sickness absence annually, 2001-2007, were calculated and compared between participants and nonparticipants.

## 2.5 Statistical procedures

## Handling missing data

Some of the HAP participants had missing responses for some of the variables of interest, commonly referred to as item nonresponse (271). In paper I, data were missing on the variables education, occupational class, history of sickness absence, cause of sickness absence and symptoms of depression, in paper II on the variables education, occupational class, form of employment and social support, and in paper III on history of sickness absence among participants.

Missing data in paper I and II were handled through multiple imputations to reduce risk of systematic bias and to come around reduction of power related to exclusion of cases (i.e. list-wise deletion) (272). The imputation procedures were guided by the user written Multiple Missing Imputation program in Stata (273), and by Allison's (274) recommendations for imputing on nominal variables. In paper I, 100 cycles of imputation were run, in paper II, 20 cycles. All analyses were repeated without the imputation procedure (list-wise deletion), giving approximately the same results and

estimates within the 95%CI of the imputation-based estimates, which indicated little impact of unit nonresponse on the results.

In paper III, missing data on participants was handled by list-wise deletion, as loss of cases was small and bias and loss of power, hence, most likely inconsequential (272), and due to unknown missing pattern in the aggregate comparison data.

#### Statistical analyses

All three papers included descriptive statistics of the study sample to outline the distributions and bivariate associations between demographic characteristics and main variables of interest (paper I: level of shame, paper II: history of sickness absence, paper III: survey participation), using chi-square tests.

In paper I, both the cross-sectional associations between level of shame and factors related to the sickness absentee, and the prospective association between level of shame and subsequent sickness absence were analysed using multivariate, multi-nominal regression models. In paper II, the associations between history of sickness absence and each of the two social support outcomes were examined using multivariate logistic regression models, where each of the sickness absence pattern groups were compared to the group without previous sickness absence. In both studies covariates were decided *a priori*, but only included in the regression models if found related to both exposure and outcome in the data (p < .05) to avoid unnecessary adjustment and reduction of power (275). In all models we first tested for crude associations before entering candidate confounders. In paper I, the covariate "symptoms of depression" was entered in the final models as an exploratory analysis.

Associations between history of sickness absence and survey participation in paper III were examined in three steps: Firstly, we compared participation rates (95% CIs) between the three samples and performed chi-squared tests for aggregate data. Secondly, we performed one-sample mean-comparison t-test to measure differences in annual mean number of sickness absence days from 2001 till 2008 between participants and their comparison groups within each of the three samples, respectively. Finally, we calculated proportions (95% CIs) of individuals with previous registered sickness absence, annually through 2001-2007 among participants and nonparticipants within employer-RS and self-RS, respectively. In this latter analysis, we used non-overlapping confidence intervals as marker of statistical differences between groups. To account for gender and age differences between the comparison groups in step two and three, we calculated means and proportions weighted for the gender and age distribution in the respective participant groups.

Analyses for all three papers were mainly performed in Stata 12.0 (276), but Mplus6 (277) was used for the LCA in paper II and Microsoft Excel 2010 for data preparation in paper III.

## 2.6 Ethical considerations

The HAP study was approved by the Regional Ethical Review Board in Gothenburg, Sweden (reg.no: 039-08) and conducted in accordance with the World Medical Association Declaration of Helsinki – Ethical Principles of Medical Research Involving Human Subjects (278). The principle of autonomy was met by giving potential participants written information along with the survey, describing the aim of the study, procedures, assurance that withdrawal was possible at any time, as well as contact details to the research group at Gothenburg University. Thus, participation was chosen after informed consent. The aggregated data on the target population, including nonparticipants, was based on official data records, which is available for researcher purposes. Only aggregated data were used for nonparticipants and individual information was not possible to identify. Statistics Sweden moreover stored the identification key to ensure confidentiality.

## 3. RESULTS

The following presentation will give an overview of the most important findings in the present thesis. More detailed descriptions are given in the respective papers.

## 3.1 Paper I

To examine correlates between shame and LTSA (research questions 1 and 2), participants from the employer-RS reporting being currently sickness absent were included (n=1567). Among these, 20% (95%CI 18-22) reported high level of shame concerning being sickness absent, 34% (95%CI 31-36) reported moderate level, and 46% (95%CI 44-49) low level of shame.

Reported level of shame was found related to some, but not all, of the sociodemographic characteristics examined: The young and those born outside the Nordic countries reported being more ashamed of their sickness absence than their comparison groups. By contrast, level of shame was not associated with gender or occupational class. Lower incomes and higher levels of education were also associated with higher levels of shame, but as these two associations were explained by age adjustment in additional analyses, they are considered spurious (data not shown). The odds for higher level of shame moreover increased incrementally with extent of registered sickness absence days one to seven years prior to the survey, adjusted for covariates. A strong association between shame and cause of sickness absence was found, where those reporting absence due to mental illness had an adjusted 3.8 (95%CI 2.8-5.3) and 4.4 (95%CI 3.1-6.4) times higher odds for reporting moderate and high level of shame, compared to those absent due to somatic illness. Comparing those reporting comorbid causes to those with somatic illness gave similar increased odds for higher levels of shame.

In the prospective analyses, an overall statistical significant association between level of shame and subsequent sickness absence was found (p=0.002, adjusted). Those reporting high level of shame were more likely to have registered sickness absence

the following year compared to those reporting low level of shame, adjusted for age and history of sickness absence. The relationship was stronger for longer periods of sickness absence (adjusted OR=1.5, 95% CI 1.0-2.2 and OR=2.1, 95% CI 1.5-3.1 for having sickness absence days below and above the median, respectively).

Symptoms of depression at baseline partly explained these associations.

## 3.2 Paper II

To examine associations between history of sickness absence and current perceived social support at work (research question 3), participants from the random-PS reporting working as an employee as their main occupation were included (n=2581). The registry data showed that these had various histories of sickness absence during the seven years preceeding the time of the survey (2001-2007): The majority had no previous sickness absence (59.9%). Of those with at least one sickness absence episode, 20.2% were categorized as having a "stable low" absence pattern, 7.7% as "distant high", 5.8% as "recent high", and finally 6.9% were categorised as having a "stable high" sickness absence pattern (see details on operationalization in the method section).

Overall, employees with previous registered sickness absence reported lower levels of perceived social support at work than employees with no previous registered sickness absence. Having a "recent high" and "stable high" pattern of sickness absence gave increased odds for both overall low social support at work (focusing on collegiality, understanding and relations) and low immediate superior support. The "stable low" pattern was borderline significant associated with the overall social support outcome but not immediate superior support. The "distant high" pattern was associated with the superior support outcome. Thus, having a high level of absence, irrespective of recency, was associated with low perceived immediate superior support.

Sub-analyses showed that the item in the social support scale with highest effect size across sickness absence patterns was "My colleagues are not these for me", which

were significant for all but the "distant high" group compared to those without previous registered sickness absence.

## 3.3 Paper III

In paper III, we examined whether history of sickness absence influenced survey participation across the three samples included in HAP (research question 4).

Overall, we found no substantial selection by history of sickness absence in the HAP survey. More specifically, the three measures of history of sickness absence showed the following relation to participation:

*1-Recent new episode of registered sickness absence.* The participation rate was slightly higher (absolute 3.5%) in the sample with a recent episode of employer-reported sickness absence (>14 days) than in the random population sample (53.9% vs 50.4%, chi<sup>2</sup>=16.75, df=1, p<0.001). The participation rate in in the sample with a recent episode of self-reported sickness absence (>1 days; students, self-employed, unemployed, others) was similar to the random population sample (50.3%).

*2-Days with registered sickness absence annually.* Participants in random-PS and employer-RS had statistically lower mean number of registered sickness absence days annually than nonparticipants and the target population for most, but not all of the follow-up years (2001-2008), when weighted for gender and age. In self-RS, there were no significant differences between participants and nonparticipant.

*3-Persons with registered sickness absence annually.* In employer-RS, the proportions with registered sickness absence annually during 2001-2007 were statistically lower among participants than nonparticipants, weighted for gender and age. In self-RS, there were no significant differences between participants and nonparticipants.

Finally, the secondary analyses showed that participants were more likely than nonparticipants to be women, older, born in the Nordic countries, be married and have higher incomes.

# **4. DISCUSSION**4.1 Novel contributions

In the present thesis the social psychological aspects shame and social support were examined in relation to long-term sickness absence, in study designs new to this context. Data from a large epidemiological survey (HAP) were employed, linked to registries on sickness absence spanning over nearly a decade. The main findings comprise the following novel contributions:

- Shame concerning being sickness absent was a prominent emotion among many currently sick-listed employees. The young, those born outside the Nordic countries, those absent due to mental illness and those with previous high levels of registered sickness absence reported higher levels of shame than their comparison groups.
- The findings suggest that shame predicts prolonged sickness absence, as those reporting high levels of shame were more likely to have sickness absence the subsequent year than those reporting low levels of shame.
- Previous sickness absence, and particularly high levels of absence over a period of seven years, was a risk factor for current low perceived social support at work and low perceived immediate superior support.
- By inviting individuals from the general working age population to a postal survey on sickness absence, work and health, participants did not differ markedly from nonparticipants and the target population concerning history of sickness absence. Yet, overall participants had somewhat less previous sickness absence than the comparison groups.

## 4.2 Methodological considerations

## 4.2.1 Methodological strengths

The main methodological strengths of this thesis was the use of general population representative data on social psychological aspects of sickness absence in large samples, samples specifically design to capture incident cases of sickness absentees, and the possibilities for studying temporal associations with complete follow-up through the linkage to registry data across nine years.

The HAP survey included measurements of topics around sickness absence that hardly at all have been addressed epidemiologically before, such as the role of shame (paper I) and organizational climate (hereunder the single-item outcome in paper II), and which are not available in routinely collected registry data. The comprehensive data collection and large sample size moreover enabled exploring several covariates and controlling for important confounders.

The HAP samples were drawn directly from a general working population, and were linked to objective and complete registry data on all-cause sickness absence. As sickness absence is common in the working population (257, 279) and non-medical factors relevant for LTSA are suggested to be relevant across disease-specific problem (4), these qualities of the sample greatly increase the ecologic validity and generalizability of the findings. By the use of independent measurements of exposures and outcomes for many of the associations, common method bias was avoided (280).

The general decline in survey participation rates (141, 142) is a source of concern in survey-based research, as selective participation can bias results and reduce generalizability (140). Yet, nonparticipation analyses and even reporting of participation rates have often been missing, both in epidemiological surveys in general (269) and in sickness absence research in particular (78). Thus, the analysis of nonparticipation in paper III constitutes a major strength. The focus on participation by history of sickness absence was of particular importance: Generally,

few studies have investigated what characterizes those who do and do not participate beyond general demographic characteristics (269). Furthermore, vulnerability for bias is highest when selection is related to key statistics (269, 281), which certainly was a relevant concern for the present thesis, and therefore addressed in paper III.

Few studies have specifically sampled from populations of incident sick-listed individuals (i.e. onset of a new sickness absence episode during inclusion). In paper I, this design secured a substantial sample of the population of interest, and enabled to single out exposure related to a current sickness absence episode. In paper III, the design allowed for comparing participation rate of recent sick-listed individuals to individuals without such experience during inclusion within the same overall population.

The longitudinal designs constituted additional strengths. One advantage is that it "offers a shortcut" in studies where one would expect long intervals between exposure and outcome. Additionally, bearing in mind important constraints discussed below, temporality, i.e. that a cause must precede an outcome, is the only Bradford Hill guideline for causation generally agreed upon (282). The link to registry data back in time allowed examination of sickness absences over time in a time- and resource efficient way. Registry data are also less riddled with missing data and loss to follow up, and problems with recall bias are avoided (283). These data enabled examining both distant and more recent sickness absence in relation to the outcomes in paper II and paper III. This elaboration is a particular advantage considering the dynamic nature of sickness absence, and that various pattern of sickness absence may have separate correlates.

Finally, strategic responses were likely reduced as participants explicitly were informed that the survey was administered by Statistics Sweden, with the University of Gothenburg as contact institutions, and not by the welfare services, as well as by assuring confidentiality. This approach was considered a particular advantage due to the intense public and political debates about sickness absence during the time of data collection.

#### 4.2.2 Methodological limitations

Random and systematic error threatens accuracy of estimates in epidemiological studies. Systematic errors reduce validity of results and can occur from information bias, confounding, selection bias, and generalizability issues (284). In the following these issues will be discussed related to the current dissertation.

#### 4.2.3 Selection bias

Nonparticipation includes unit nonresponse and item nonresponse, and both can bias results if they are non-random and related to key statistics (271). Paper III is in itself a thorough analysis of unit nonresponse. The handling of item nonresponse is discussed in the method section. The unit participation rate in HAP was around 50%, similar to what is obtained in many other recent European surveys (285). Though paper III showed selective participation across several demographic variables included in the three papers, this probably did not affect effect estimates of the associations studied in paper I and II (148, 281). Prevalence estimates are on the other hand more vulnerable for selection bias: The level of shame found in paper I could well be underestimated, as some of the groups reporting highest levels of shame (the younger; those born outside the Nordic countries) were underrepresented in the survey.

## 4.2.4 Information bias

Systematic measurement errors can bias data (284). Many of the included measures were ascertained from official registries, reducing risk of misclassification.

Two of the key variables were measured with single item self-report measures of unknown psychometric properties (level of shame in paper I and immediate superior support in paper II). Single items raise concerns regarding validity and reliability and will have implications for the following interpretation of the finding. The facevalidity of the measurement was nevertheless considered good, and it is assumed that the labels were familiar and understood by participants (94). The question about shame was also explicitly directed towards the situation of interest, namely the experience of being sickness absent. Interpretations of the experiences underlying the ratings of shame will be discussed in further detail in section 4.3.1.

Levels of shame may nevertheless be misclassified: Unrecognized shame cannot be ascertained via self-report measures (286, 287) and some participants might have been reluctant to report on such an emotion, e.g. by being ashamed of being shameful (288). In research settings and when directly asked, most people seem to be open about shame (101, 289), and the use of a self-administrative questionnaire yielded good opportunities for privacy and anonymity, which should reduce this concern. The use of fixed response-alternatives, and particularly not including a "no shame" option, might have "primed" the responses (94) and was a clear weakness. The presence of differential misclassification is uncertain, but cannot be ruled out, due to the collapsing of response-categories, and possible differential misclassification by age and education (284, 290). In sum, the extent and direction of the possible bias on the results are uncertain. Underestimations of the associations are regarded more likely than overestimations, however, estimates with confidence intervals close to 1 should be interpreted with caution.

## 4.2.5 Confounding, mediation and causality

Understanding the causation of diseases and health-related events is an ultimate goal of many epidemiological studies. Cohort studies are often used where the randomized control trials (RCTs) are not feasible. Often researchers use cohort studies to "mimic the RCT" through statistical procedures, but layers of selection effects and confounding can severely challenge causal inferences.

Many of the variables employed in this thesis were measured cross-sectionally. Theoretically, some of the relationships examined are possibly reciprocal, complicating interpretations regarding causality and the differentiation between confounders and mediators. The role of symptoms of depression in paper I was particularly challenging in this respect, since shame and depression are related, but separate constructs (94, 107) and complexly related to the other covariates examined. For example, depression could both be a *confounder* and a *mediator* on the association between shame and subsequent sickness absence. In the latter case, adjusting for depression would lead to an underestimation of the association of interest (291). To complicate the matter even further, shame could also mediate a depression – sickness absence association. Finally, depression and shame could be subject to common method bias, or a third common cause explaining their common association with sickness absence (280, 292). As a consequence, the regression models in paper I including symptoms of depression should be interpreted with caution until further replicated and explored.

As with most studies, and despite a comprehensive questionnaire and retrieval of key demographic information from registries, the possibility of residual confounding cannot be ruled out. The most critical residual confounder was perhaps the unknown contribution of socioeconomic status and severity of illness on the relationship between sickness absence and survey participation (paper III). In paper II, personality could confound the relationship between sickness absence and perceived social support at work (292). The difference found between distant and recent sickness absence in relation to social support could however suggest the association has more to do with a process/situation than stable/trait-like explanations. The possible reciprocal causal relation between social support at work and sickness absence was not possible to examine in detail as social support only was measured at one time point. As an attempt to test its impact, those reporting to be on sickness absence at time of responding to the survey were censored. This sensitivity analysis reduced the effect-sizes to some extent, but an association between previous sickness absence and current perceived social support remained (data not shown). A similar "reverse causality" can neither be ruled out for the association between level of shame and subsequent sickness absence, though this possibility was addressed by adjusting for history of sickness absence across seven years.

## 4.2.6 Generalizability

Generalizability relates to the external validity of study findings in both time and space. More specifically it concerns the applicability of results observed in the

samples to the target population and other populations similar to the target population. A common challenge in ecological research is to meet the complexity of interrelated factors affecting the study object.

In this thesis, the study aims concerned common tendencies in LTSA, covariates were adjusted for, and general population samples addressed, all of which set up for high generalizability. It may nevertheless be questioned whether one misses out on important nuances through such an approach. For instance, there are many and complex differences in exposures concerning gender and labour market situations related to sickness absence. Only 14% of women and 13% of men worked in workplaces with equal distribution of men and women (i.e. 40-60% of each gender) in Sweden in 1012 (293). Some gender- or occupation- specific processes relevant for the aspects studied in this thesis might thus have been overlooked by not running stratified analyses. Keeping that in mind, few gender differences were observed in this thesis. Yet, reflecting on the overall higher levels of sickness absence observed among women than men in the population, this will still imply that more women than men are affected, e.g. by shame concerning being sickness absent.

As described in paper III, participation rates were lower in some demographic groups, including men, younger individuals, those born outside the Nordic countries, the unmarried, and those with lower income. The findings may therefore be less representative for these groups, although the impact of selective participation on analytic studies is not likely to be substantial (148, 149, 269). The registry sickness absence data employed only cover sickness absence beyond 14 days for employees, and findings are not necessarily generalizable to shorter episodes of absence. Furthermore, the studies mostly focused on and included employees. The finding might neither be representative nor applicable to other insured (self-employed workers, unemployed and students).

The target population from which the sample was drawn was the working population in the Västra Götaland (VG) region in Sweden. This region can generally be considered to be representative of Sweden as a whole, holding a large proportion of the population (about 16%), containing both urban and rural areas, the whole spectre of demographic groups, and a wide range of industries. The population in VG has on average somewhat higher education and lower sickness absence rates than the national means. One empirical study of regional differences in attitudes and propensity for sickness absence in Sweden, suggest that the VG residents have about average propensities for sickness absence (294). Concerning generalizability to other countries, differences in legislation may to some extent reduce generalizability of the findings. The Nordic countries can be considered fairly comparable, both concerning legislation and overall culture. By contrast, labour market differences, such as differences in unemployment, may have affected the inflow, causes and consequences of sickness absence differently in Sweden than in other countries. Also, there are some evidence pointing towards stricter attitudes towards sickness absence in Sweden than in Norway (295).

## 4.3 Interpretation and discussion of findings

In the following, shame and social support in relation to long-term sickness absence, with emphasis on the novel contributions of the current thesis, will be discussed and related to theoretical frameworks and the empirical literature. Suggestions for practice and further research following the contributions of this thesis will thereafter be elaborated on.

#### 4.3.1 Shame among long-term sickness absentees

As described in the introduction, being on sickness absence implies a "sick role" (90). In paper I, we found that among long-term sick-listed employees, as many as one in five reported a high level and one in three a moderate level of shame related to this role. This finding adds to the literature by quantifying the relationship between shame and sickness absence, and aligns with another study which similarly found many sickness absentees to signal discomfort with their current status (74). Even though the prevalence of shame is likely to vary by the framing of the question and response

options, these findings clearly indicate that negative emotions are common responses to being on LTSA. Shame involves negative evaluations of our selves "seen in the eyes of others" (99), which may relate to many aspects of interactions with both professional and private relations during the sickness absence process (108, 169, 170, 177, 182, 188). The experiences underlying the shame reported in paper I was not ascertained, but the differences in level of shame found across sub-groups can be illustrative, seen in concert with related literature.

Having a mental illness as cause of sickness absence gave four to five times higher odds for reporting moderate and high level of shame, compared to being absent with somatic illnesses. This finding aligns well with a series of studies suggesting that mental illnesses are less legitimate grounds for the "sick role", and with higher degree of behavioural blame than somatic illnesses (170, 180, 255, 296, 297). Distrust of weakened work capacity is described both in encounters with health professionals (176), at work, and in the domestic sphere (169, 170), and could partly relate to the relative "invisibility" of symptoms (178-180). Such experiences are also described by absentees with common musculoskeletal disorders, such as low-back pain (298). In paper I, musculoskeletal conditions were merged into a general category of "somatic illness". Future studies could benefit from a more fine-tuned categorization to gain a deeper understanding of the social impacts of being sick-listed across medical causes. A related interpretation of the high shame among those absent due to mental illnesses is that it reflects the continuing stigma towards people with mental illness (255, 299). The major and detrimental effects of stigma were highlighted in a recent OECD report, where stigma was included among the four big issues standing in the way of employment for people with mental illness (300).

That the younger sickness absentees reported a higher level of shame than the older could seem surprising. In public debates of changing attitudes towards and even "over-usage" of sickness insurances, the younger generation have been highlighted (301). The assumption of less restrictive attitudes towards sickness absence utilization among younger than older workers has, however, mixed support in the scientific literature (295, 302). Another explanation of the finding is differences in

response styles by age or cohort, e.g. with generally higher openness towards sharing emotions among the younger. The finding may nevertheless also reflect legitimacy or stigma: Younger workers are in general expected to be healthy and LTSA is far less common among younger than older workers. Thus, being on LTSA breaches with social expectations for this group and can involve more severe social impacts (27). Alienation and guilt are similarly found to be reported more often among younger than older long-term sick-listed (74).

Shame has repeatedly been described as a reaction related to having a patient/ recipient/dependent role (108, 169, 170, 177, 182, 188). The finding of increasing levels of shame by extent of previous sickness absence could reflect that changes in relations and social identity are more relevant the longer the absence from work. Such interpretations also fit well with the lower perceived social support at work among employees with high levels of previous sickness absence found in paper II.

Overall societal norms and climate concerning sickness absence can influence the experience of being sick-listed (303). The jurisdictions and rehabilitation systems in the Nordic countries have undergone a focus-shift toward the individual the latter decennium, for instance by increased responsibility regarding work capacity and the RTW process (11, 47). In Sweden in particular, new regulations were under implementation during the HAP data collection (302). Also, political, economic and public debates about sickness absence in Sweden have been described as harsh in the years preceding and during HAP, establishing a discourse on cheating and overexploitation of sickness absence (304). Notably, social norms and sanctions is an important part of the basic underlying regulation mechanisms in the Nordic welfare systems, and are needed in a system based on a high degree of trust. The hypothetical alternative would perhaps be to have a welfare regime based heavily on bureaucratic control. Also, there can be important motivational, health promoting and empowering benefits by giving the individual responsibilities and in keeping the individual active. Thus, how to keep these qualities of the system, while avoiding "victim blaming" and undue suspicion towards some groups of sick-listed remain an important and complex issue.

## 4.3.2 Shame and low perceived social support at work as barriers in the RTW process

RTW, especially after longer sickness absences, commonly happens trough steps and phases (28). The results of this thesis adds evidence on how social psychological aspects can act as barriers for RTW and reintegration at work, and expands the sparse literature on perpetuating factors in sickness absence (4).

In paper I, high levels of shame concerning being sickness absent was associated with sickness absence the following year. One the surface, this finding seemingly contrasts the emerging theoretical and empirical literature on the influence of social norms about sickness absence on sickness absence behavior (27, 92, 93). With some variations, this literature propose that absence from work will be less likely the more deviant and socially sanctioned sickness absence is in the work group. Using the Illness flexibility model, workplace norms will affect the workers perceived attendance requirements (87). Since negatively valued social emotions like shame are more likely to occur when norms are breached, one could expect shame of being sicklisted to act as an *attendance requirement* and thus *promote* RTW. By contrast, the results of paper I indicated that high levels of shame *hindered* RTW. But, this finding is not necessarily in conflict with the above-mentioned literature: Firstly, studies of work commitment and social norms focus on attitudes, and attitudes are not the same as emotions, and involve other mechanisms (94). Secondly, there are important differences between social emotions, where shame in particular is related to exposing shortcoming as a *person*, more than negative evaluations about specific *behaviour* (103, 105).

The direction of the paper I finding aligns with, and can be explained in light of, theoretical understandings of shame and adjacent empirical literature: Shame could be related to not feeling welcomed at work, which also has previously been found to prolong sickness absence (4). As such, shame can be part of an *absence requirement*, again in the terms of the Illness flexibility model. The main finding in paper II, that previous LTSA was associated with low perceived social support at work, harmonize with this interpretation. Furthermore, shame is suggested to increase barriers for RTW through psychological disempowerment and weakened work ability and health (85). This notion has empirical support from studies where shame is associated with withdrawal behaviour (106), reduced self-esteem, maladaptive coping strategies (99), and psychopathology (99, 107, 305). Similar findings can be found in literature on stigma among mentally ill (306). RTW, especially after a longer period on sickness absence, requires contact with a range of persons including the GP and other sicklisting physicians, rehabilitation personnel, insurance officers, the employer, and colleagues. In these social contexts, being ashamed about one's situation or condition is likely to complicate communication (108, 177), where avoidance can be a coping strategy (307), with reluctance to seek help (308, 309) and less open communication (299) as results. And, these are all factors seen important to achieve successful work reintegration, socially and professionally (177, 307, 310). Additionally, shame-related behaviour may in turn impact the other actors' assessments of the workers functioning and possibilities for RTW (167). Support and understanding from the superior is important in the return to work process (166, 173, 174, 311, 312), and likely suffers with poor collaboration with the immediate superior.

The post-RTW sustainability phase has received little attention in both research and practice (28, 313). The findings of paper II show that those with previous LTSA absence, and in particular high levels of absence, are vulnerable for low perceived social support also after having returned to work. Several causal mechanisms underlying this observation are possible, but could not be examined in the current thesis. The low perceived support could have contributed to the sickness absence in the first place, and if deteriorated by sickness absence, both within-person (i.e. perceptual changes) and environmental (i.e. selection) changes are possible (119). Workers with LTSA are likely to change work tasks or jobs more often than others as part of the rehabilitation process (314). Accordingly, the finding could reflect that those with long absences have shifted to jobs with less inclusive and supportive work environments, *or* that the workers over time experience a reduced inclusion in the work group. The latter explanation aligns with results from a survey among long-term sick-listed about consequences of their absence (73). Regardless of cause, the finding

in paper II was compatible with a dose-response-relation as effect-sizes were higher for the groups with high level of previous sickness absence than for those with stable low levels. Furthermore, the finding might indicate that the risk of recurrent absence following LTSA (4, 5, 315, 316) partly goes through the low perceived social support at work. As of yet, predictors of recurrent sickness absence have received little attention in research. One study found conflict with the supervisor, but not social support, to predict recurrent sickness absence following RTW among workers initially on sickness absence due to CMDs (317). An emerging literature has also found social support, influence at work and fair organizational climate to be predictors for "remaining in work" (318, 319), to promote healthy work environments (320-322), and to be associated with increased work ability among sick-listed (323). This literature seen together, further studies on social inclusion and fair leadership toward workers with previous LTSA are warranted.

Reporting, "my colleagues are not there for me" was the single item with the overall highest effect size across patterns of previous sickness absence in paper II (with the notable exception of the former high absence pattern). This finding could suggest that sickness absence in particular can pose difficulties for collaborations at work. Considerations of colleagues are congruently a commonly reported reason for sickness presenteeism, i.e. going to work despite illness (324, 325). From an ecological, reciprocal understanding, social support will be interpreted differently depending on characteristics of the perceiver, the support provider and the relationship between them (326). Little is, however, known about how co-workers experience their colleagues' sickness absences. Interestingly, mental illnesses and long-term absences are described to pose more unease in the work group than shorter absences and musculoskeletal disorders during RTW (327). In paper I and II, mental illnesses and high levels of sickness absence and mental illness were similarly related to shame and low perceived support, respectively. It is also found that disabled workers are evaluated by their social abilities (328), which are of the capacities described to be reduced by workers with CMDs in particular (185, 329). As a whole, these findings suggest specific social challenges and double burdens for some groups of workers with health difficulties

#### 4.3.3 Long-term sickness absence – a marker for social exclusion?

The main findings in the thesis might also be interpreted in light of social exclusion theory. Social exclusion can be defined as not participating in the normal activities of citizens in a society (330). Consequently, LTSA itself implies social exclusion in "employment societies" such as the Nordic countries, where work life participation are among the major dimensions and arenas for societal inclusion in adult life (330). According to social exclusion theories, barriers following labour market exclusion may generate viscous circles and increased marginalization across several societal arenas, primarily through its impact on private economy and social isolation (331).

Stigma and economic problems contribute to deteriorate social ties and increase social isolation (331). Among unemployed, shame, low social support and economic problems increase likelihood of psychological distress (69, 332). The findings in paper I and paper II have identified that some workers with LTSA also are vulnerable for such exclusion processes. The possible prolonging effect of shame on sickness absence as discussed above (paper I) is also compatible with this perspective. One important way in which social isolation and lack of social support may reinforce labour market exclusion in turn, is by cutting off information about advancement (331). The finding in paper II can have identified LTSA as a vehicle for exclusion processes, with the finding of low immediate superior support among those with high levels of previous absence potentially particularly relevant in this matter. In line with this, a register-based study among managers found that absences, and in particular multiple absences, were associated with fewer subsequent promotions and smaller increase in salary (333).

Social exclusion theory suggests that labour market exclusion extends to less participation in society at large (330). Beyond the workplace arena, there are few studies on whether sickness absence is related to or have impact on participation in other activities, like leisure time activities (74), political activity (334) and voluntary societal participation – such as participation in research which was addressed in paper III. Overall, we did not find substantial differences between participants and

nonparticipants in history of sickness absence. Notably, nonparticipants tended to have somewhat more sickness absence in the past than participants, even though HAP addressed aspects of particular relevance for those with sickness absence experiences. But, this association could be confounded by differences in socioeconomic status (156, 158). Taken together, the findings in paper III did not provide strong indications for social exclusion in the form of survey participation among recent or previous sickness absence.

The bulk of studies on social marginalization following sickness absence are limited by the use of cross-sectional data (17), but also the general challenge of disentangling consequences of the sickness absence from problems leading to sickness absence, such as severity of illness (71). The sickness absence patterns identified in paper II reminds us that a minority remain absent over many years (335, 336). It should be noted that paper II was not designed to examine this specifically, and inherently include a "healthy worker effect" by only including those currently employed. More studies following workers' various experiences of sickness absence over time are needed to more precisely identify patterns as well as outcomes of sickness absence, including the role of social psychological processes for work life and social exclusion. This knowledge can in turn be highly valuable to identify groups at risk for long-term disability and for directing more tailored and adequate preventive measures (335).

## 4.4 Suggestions for practice

In contemporary disability policies and practice, there is an increasing focus on mental health and how health is formed through societal participation and inclusion (337, 338). Common mental disorders are leading causes of disability worldwide (339-341), with severe impact on occupational functioning (300, 342), sickness absence and incapacity benefits (55-57). Early return-to-work policies, graded sickness absence and work-focussed preventive and treatment approaches, such as

"Individual placement and support (IPS)", have become common across most welfare states (11, 300, 337). Central assumptions underlying these approaches include that work life participation has a health promoting potential, and that upheld contact with the workplace can prevent long-term exclusion. The current thesis offers relevant results for this development. Based on the novelty of the main aspects studied in this thesis, with few possibilities for direct comparisons in previous literature, practice suggestions need nonetheless to be done with caution.

The social or relational dimension of sickness absence and return to work can be complex and challenging, but important to address to prevent exclusion processes. This challenge is perhaps best addressed through universal health promoting and preventive workplace-based interventions. Firstly, the majority of the adult population participate in work life and spend considerable time there. This makes the workplace a suitable arena for health promotion and preventive interventions. Secondly, such interventions may prevent incidence of ill health and sickness absence in the first place. For instance, there is some emerging evidence that boosting the overall workplace social capital, both vertical and horizontal (343), promotes mental health for all workers, and is found particularly beneficial for workers experiencing stress (344, 345). Thirdly, good workplaces are likely to become arenas that workers more easily can return to after sickness absence. And finally, it can be easier to avoid labelling and stigma in universal interventions. It could also be argued that such interventions could contribute to a more universal ownership of the problem. Rehabilitation interventions have mostly aimed at changing and improving the individual's prerequisite for RTW (346). However, treatment alone often is insufficient for sustained return to work, especially after LTSA (167), and the beneficial effect of employment depends on the quality of the psychosocial work environment (347, 348). Thus, by only directing interventions toward the individual, one runs the risk of "blaming the victim" (349), with experiences of personal failure and shame for the individual as possible results. In interventions to secure psychosocial work environment risks, the demand-control model has dominated. The

current thesis highlights the need for also addressing relational aspects of work environments.

Many workplace-based interventions aimed at promoting mental health (350), reducing sickness absence (351, 352) and promoting RTW (313) exist, yet few are properly evaluated, and few interventions are found successful in reducing sickness absence (351, 352), or to promote RTW (313). There is moderate evidence in support of an effect of early contact between the worker and the workplace on time to RTW (353, 354). The findings in this thesis concord with this literature, and might indicate that keeping contact with the workplace during sickness absence can be beneficial to secure social inclusion at work. Despite this, role and impact of social relations at work (355, 356) and employee centred outcomes (313, 353), as well interventions targeting the post return/sustainability phases have been relatively neglected in workplace-based interventions and evaluations (313, 353). Disregarding the impact of such aspects of RTW process may jeopardize sustained work retention. The thesis supports the call for interventions and evaluations of sustained work retention (313), as employees were found vulnerable for low workplace social support even years after their sickness absence.

The findings relating to shame and low perceived social support further emphasize the importance of addressing the individual worker's experiences in rehabilitation contexts (108). Increasing relevant agents' communication competencies, awareness and knowledge about common psychological processes and reactions in LTSA might be one venue of improvement in rehabilitation services (357). The responsibility for creating safe and supportive environment for dialogue needs to be put on other stakeholders than the sick-listed (108, 358). According to the Work Environment Act in the both Norway and Sweden (359, 360), the employer and employee shall cooperate to establish a good work environment, but the employer has a specific responsibility for preserving the employee's integrity and dignity, inclusion in the psychosocial work environment and as far as possible provide opportunities for selfdetermination and influence. As discussed, the supervisor might play a key role for employees' RTW, but studies suggest that they often struggle in handling this process (175).

## 4.5 Suggestions for further research on psychological factors in sickness absence

Mechanisms leading to prolonged sickness absence and how to circumvent it, as well as the consequences of sickness absence are still poorly understood. Given how common sickness absence is, the high disability rates, and considerable cost for individuals and their families, companies and society, more research addressing these issues is rightfully called for. The current thesis could inspire further research, both pertaining to theoretical and methodological approaches.

#### Thematically

First and foremost, the studies included in the thesis include novel aspects, both thematically and methodologically, that invite replication and further development.

Collecting data on shame including more comprehensive measures, such as full-scale instrument including measures of eliciting situations and "no shame" options could be useful to gain a better understanding of the mechanisms underlying the observed differences in level of shame found in this thesis (287). The impact of shame could be compared to that of other social emotions, such as "guilt" and "pride", as well as work attitudes. Relatedly, more knowledge is needed on associations between workplace social relations, norms and cultural values regarding illnesses and sickness absence, and on emotional reactions and sickness absence behaviour.

Like most studies in the field, the current thesis has only taken on the perspective of the individual worker, despite addressing relational aspects (16, 28, 30, 165). This approach will by design overlook the reciprocity of relations, the dynamics in the process both before and during RTW, as well as the perspective and possible social impact of the absence for colleagues, the employer and the family (17, 165). As such, potentials for interventions on a system level can go amiss (346). Workplace,

domestic and other social relations should be examined both as separate and intertwined factors (17, 203), and seen from the perspective of different actors (165, 327). There is also a need for more knowledge on the impact of overall social climate and inclusion in workplace contexts to promote health and wellbeing among workers, prevent work disability and promote RTW.

Better descriptions of sickness absence trajectories and their correlates are needed to more precisely identify marginalization processes (335). Regarding the different phases of sickness absence and RTW, more knowledge is particular needed on the post-RTW phase, including factors promoting social inclusion and sustainability of work participation (313, 353).

As a first step, a systematic review of research on psychological and social psychological factors in sickness absence, beyond clinical factors, could identify the major research gaps and critically appraise the quality of the existing evidence.

#### Methodologically

To approach the knowledge gaps described above, there is a need for better descriptive research and also more rigorous designs to test causal models.

Many of the psychological and social aspects of sickness absence, revealed in qualitative interview studies, are yet to be examined in representative samples. The findings of paper III suggest that it is possible to reach fairly representative samples regarding history of sickness absence trough surveys, and thus support the continuing use of surveys in epidemiological research on sickness absence.

More studies should aim for designs that can reflect sickness absence as a dynamic process. Multi-wave studies with repeated measurements could circumvent some of the methodological constraints met in the current thesis. Before carrying out such studies, careful considerations of the processes of interest are recommended, e.g. regarding expected time lags and reciprocity of variables (117, 361). The operationalizations of history of sickness absence employed in this thesis could provide suggestions for further research on sickness absence trajectories, and the

findings highlight the value of differentiating between both extent and recency of sickness absence. Though the latent class analysis approach was abandoned in paper II due to data constraints, the technique should be considered to describe patterns of sickness absence and their correlates. Linking survey data to appropriate registries can furthermore be of immense value, by expanding possibilities for following individuals across long time spans, while countering resource and methodological challenges such as attrition, and independency between exposures and outcomes.

Alternative modes of data collection, in addition to self-reported survey data and registries, are needed to ascertain more fine-tuned social mechanisms, and include the perspective of different actors in sickness absence management. As for shame, for instance, self-report requires verbal understanding and conscious awareness, and overlook others apprehensions and reactions towards shame-related behaviour.

Finally, the vantage point chosen for this thesis was the adult life work context. Factors influencing social emotions and social support may nevertheless have long roots back to childhood adversities. Childhood adversities show persistent associations with psychopathology (362), and the small literature taking on a lifecourse perspective relating to sickness absence and work disability, have for instance found childhood temperament (123) and high school dropout (363) to increase the risk of LTSA in adulthood, and educational attainment and childhood IQ to explain the association between decision latitude and LTSA (122). Future studies addressing more distal factors can thus be useful to gain a better understanding of how individual vulnerabilities and social disadvantages may accumulate and increase risk of social and work life exclusion (35, 122).

#### Theoretically

The need for theoretical development in the sickness absence research field remains. Theoretical models have tended to draw an artificial line between the individual and the social, where psychological research has focussed on the former and sociological research the latter (79, 364, 365). This thesis lends support to emerging theoretical models with a more dynamic focus of the return to work process and the interaction
between the individual and the multiple social relations and systems surrounding the individual (15, 30).

It has been argued that the complexity of factors involved in sickness absence defies one unified theory (29), and that the reciprocity and complexity of social impacts of disability will render any analysis fragmented (17). This remains a challenge in the sickness absence field: on the one hand the relation and interaction between the factors can be important for scientific and clinical advancement in the field. On the other hand, too complex models reduce applicability for guiding research and possibilities for testing their validity. Parsimonious multi-variable models could increase our understanding of and ultimately enable prevention of work disability. To this end, true transdisciplinary approaches are warranted, that acknowledge the temporality of sickness absence (29, 30).

## 5. CONCLUSION

In this thesis, social psychological aspects of long-term sickness absence was examined through three papers, employing a link between the population-based survey "the Health Assets Project" and official registries of sickness absence across nine years. The studies performed and literature addressed throughout the thesis show both the complexity, but also the importance and value of enhancing the scientific knowledge about social psychological factors in sickness absence.

Social sanctions and social emotions are embedded regulating mechanisms in welfare systems based on a high degree of trust. However, if these mechanisms are not well calibrated, they may pose unintended obstacles for individuals. The findings of the present thesis show that shame predicts subsequent sickness absence and that previous sickness absence, indicated by both extent and recency, is associated with low perceived social support at work and low immediate superior support. Thus, the findings underscore the need to account for social psychological aspects of sickness absence, which in particular may constitute barriers for return to work and sustainable work retention. The high levels of shame reported among those absent due to mental illness point to the importance of increasing the knowledge about mental illnesses in the population to reduce the stigma relating to these illnesses. Seen in concert with the literature on social support as a risk factor for sickness absence, the result contributes to the literature by indicating a bi-directional causal relationship. Negative spirals creating a gradual social exclusion from work life are possible, but the paths of such processes need further investigation and require more rigorous study designs. The operationalisations of history of sickness absence employed in the current thesis could provide suggestions for further research on sickness absence trajectories and their correlates. Finally, the results showed that in a survey that specifically addressed sickness absence, participants were fairly representative of their target population regarding history of sickness absence. Thus, this finding supports the continuing use of surveys to gain epidemiological knowledge on sickness absence

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