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## Daily occupations among asylum seekers- Experience, performance and perception

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# Daily occupations among asylum seekers – Experience, performance and perception

Anne-Le Morville



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## DOCTORAL DISSERTATION

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To be defended at Hörsal 1, Health Sciences Centre, Baravägen 3, Lund,  
Friday March 21<sup>st</sup>, 2014, 13.00.

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<p>Asylum seekers often find themselves in a situation where the structure and content of daily occupations have been disrupted and they might have limited access to paid work and education. Studies have shown that asylum seekers experience occupational deprivation and a change in daily occupations which might even influence their identity. Such deprivation can eventually lead to dissatisfaction with everyday life and to occupational dysfunction, i.e. a decline in ADL ability. Asylum seekers are a group who are more likely to suffer from health problems than the background population. Especially torture survivors suffer from ill health. Pain and psychological symptoms are among the most frequent health issues for both asylum seekers and torture survivors and may cause occupation-related problems.</p> <p>The overarching aim of this thesis was to investigate how staying in an asylum centre influenced occupations on three levels – the experience of occupational deprivation, satisfaction with daily occupations and performance of ADL tasks – and whether occupational satisfaction and performance changed over a ten-month period. As there are often torture survivors among asylum seekers, another aim was to assess whether torture had an influence on the occupational satisfaction and performance, and whether this had changed after ten-months.</p> <p>Forty-three asylum seekers from Afghanistan, Iran and Syria participated at baseline and ten months later 17 were available for inclusion in follow-up studies. Study I showed that the asylum seekers experienced occupational deprivation during detention, and had trouble maintaining former occupations due to limited access to activities. The results in Studies II-IV showed a high prevalence of torture survivors, high ratings of distress and low ratings of general well-being and health, all of which had associations to occupational satisfaction, activity level and occupational performance. Torture did not appear to have an influence on satisfaction with daily occupations, but physical torture could be a predictor of decline in ADL motor skills (Study III). On arrival the participants had difficulties performing ADL tasks and expressed low satisfaction with daily occupations. Ten months later there was a statistically and clinically significant decline in ADL performance, although not in satisfaction with daily occupations and activity level. A significant decline was also seen regarding self-rated health measures. However, there was no difference between tortured and non-tortured asylum seekers regarding ADL ability and self-rated health at baseline. Due to dropout at follow-up and a prevalence of torture survivors, this analysis could not be performed at the follow-up.</p> <p>This thesis points at a need for developing adequate occupation-focused rehabilitation programmes for asylum seekers and torture survivors, in order to enable occupation and prevent development of ill health for this specific group.</p>		
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Date 17-02-2014

# Daily occupations among asylum seekers

– Experience, performance and perception

Anne-Le Morville



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Citation from a participant, a 26-year-old Afghan farmer



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# Definitions

Asylum seeker	An asylum seeker is a person who has exercised his or her right to seek protection under the 1951 UN Geneva Convention (United Nations High Commissioner for Refugees, 1951). The term asylum seeker in the current thesis refers to a person currently seeking asylum in a host country, but has not yet been granted refugee status.
Occupation	<p>Occupations are engagement and participation in activities that are part of one's socio-cultural context and that are desired and/or necessary to one's health, well-being and sense of identity (Kielhofner, 2007; Wilcock, 1999)</p> <p>An occupation is a specific persons subjective perception of an event and is</p> <p>‘the experience of a person, who is the sole author of an occupation's meaning,’ which originates from the person (Pierce, 2001). An occupation is observable, but the person can only interpret the meaning and content of the occupation.</p>
Activities	An activity is the culturally shared idea of a certain set of actions, i.e. cooking or going to work, which implies a certain set of actions. It is not experienced by a specific person and is non-observable (Pierce, 2001).
Task	A task is a defined piece of work, such as making a sandwich, cleaning the car, and refers to the occupation that a person will do or has done (Fisher, 2009).
Activities of Daily Living	<p>Activities of Daily Living (ADL) tasks are tasks that either pertains to personal care (PADL) or domestic or instrumental tasks (IADL) (Trombly, 2008).</p> <p>PADL covers self-care tasks, which most people perform regardless of gender, culture and conditions. This includes bathing, grooming, eating etc. IADL are tasks such tasks as shopping, cooking and housework.</p>

Occupational disruption	Occupational disruption is described as the act of delaying or interrupting continuity in everyday life, or in other words, something which creates disorder. Occupational disruption occurs when a person suddenly loses the opportunity to maintain and pursue their goals and the daily well-known roles and related occupations are lost (Whiteford, 2000). People experience occupational disruption at some point in their lives, and most regain the disrupted occupations or develop and adapt to new ones (Whiteford, 2000).
Occupational deprivation	Occupational deprivation is the disadvantage which comes from losing something, and Whiteford (2000) has defined the concept as follows: ‘Occupational deprivation is, in essence, a state in which a person or group of people are unable to do what is necessary and meaningful in their lives due to external restrictions. It is a state in which the opportunity to perform those occupations that have social, cultural and personal relevance is rendered difficult if not impossible.’ (Whiteford, 2000).
Occupational dysfunction	Occupational dysfunction implies that people subjected to circumstances which cause occupational deprivation over a longer period of time, decrease their ability to perform everyday tasks and eventually develop dysfunction. However it is important to see the development from disruption to dysfunction in a temporal perspective, as people being subjected to circumstances that cause occupational deprivation over a longer period of time do not necessarily develop dysfunction (Whiteford, 2000).
Torture	In this thesis the definition for torture used is the ‘WMA Declaration of Tokyo – Guidelines for physicians concerning torture and other cruel, inhuman or degrading treatment or punishment in relation to detention and imprisonment’ (1975).  ‘For the purpose of this Declaration, torture is defined as the deliberate, systematic or wanton infliction of physical or mental suffering by one or more persons acting alone or on the orders of any authority, to force another person to yield information, to make a confession, or for any other reason.’ Adopted by the 29th World Medical Assembly, Tokyo, Japan, October 1975.
Rehabilitation	In this thesis the definition for rehabilitation is:  ‘A goal-oriented, cooperative process involving a member of the public, his/her relatives, and professionals over a certain period of time. The aim of this process is to ensure that the person in question, who has, or is at risk of having, seriously diminished physical, mental and social functions, can achieve independence and a meaningful life. Rehabilitation takes account of the person’s situation as a whole and the decisions he or she must make, and comprises co-ordinated, coherent, and knowledge-based measures.’ (Rehabiliteringsforum Danmark, 2004).

# Abbreviations

ADL	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
DIS	Danish Immigration Service
MDI	Major Depression Inventory questionnaire
PDQ	Pain Detect Questionnaire
SDO	Satisfaction with Daily Occupations questionnaire
UNCAT	United Nations Convention Against Torture
WHO-5	WHO-5 Well-being questionnaire
WMA	World Medical Association



# Abstract

Asylum seekers often find themselves in a situation where the structure and content of daily occupations have been disrupted and they might have limited access to paid work and education. Studies have shown that asylum seekers experience occupational deprivation and a change in daily occupations which might even influence their identity. Such deprivation can eventually lead to dissatisfaction with everyday life and to occupational dysfunction, i.e. a decline in ADL ability. Asylum seekers are a group who are more likely to suffer from health problems than the background population. Especially torture survivors suffer from ill health. Pain and psychological symptoms are among the most frequent health issues for both asylum seekers and torture survivors and may cause occupation-related problems.

The overarching aim of this thesis was to investigate how staying in an asylum centre influenced occupations on three levels – the experience of occupational deprivation, satisfaction with daily occupations and performance of ADL tasks – and whether occupational satisfaction and performance changed over a ten-month period. As there are often torture survivors among asylum seekers, another aim was to assess whether torture had an influence on the occupational satisfaction and performance, and whether this had changed after ten-months.

Forty-three asylum seekers from Afghanistan, Iran and Syria participated at baseline and ten months later 17 were available for inclusion in follow-up studies. Study I showed that the asylum seekers experienced occupational deprivation during detention, and had trouble maintaining former occupations due to limited access to activities. The results in Studies II-IV showed a high prevalence of torture survivors, high ratings of distress and low ratings of general well-being and health, all of which had associations to occupational satisfaction, activity level and occupational performance. Torture did not appear to have an influence on satisfaction with daily occupations, but physical torture could be a predictor of decline in ADL motor skills (Study III). On arrival the participants had difficulties performing ADL tasks and expressed low satisfaction with daily occupations. Ten months later there was a statistically and clinically significant decline in ADL performance, although not in satisfaction with daily occupations and activity level. A significant decline was also seen regarding self-rated health measures. However, there was no difference between tortured and non-tortured asylum seekers regarding ADL ability and self-rated health at baseline. Due to dropout at follow-up and a prevalence of torture survivors, this analysis could not be performed at the follow-up.

This thesis points at a need for developing adequate occupation-focused rehabilitation programmes for asylum seekers and torture survivors, in order to enable occupation and prevent development of ill health for this specific group.

# Original papers

This thesis for the degree of Doctorate is based on the following papers referred to in the text by their Roman numerals:

- I Morville, A-L., Erlandsson, L-K. (2013). Occupational deprivation in an asylum centre: The narratives of three men. *Journal of Occupational Science*, 20,3 212-223
- II Morville, A-L., Erlandsson, L-K., Eklund, M., Danneskiold-Samsøe, B., Christensen, R., Amris, K. (2013). *Activity of daily living performance amongst Danish asylum seekers: A cross-sectional study*. Re-submitted to Torture, 2013
- III Morville, A-L., Amris, K., Eklund, M., Danneskiold-Samsøe, B., Erlandsson, L-K. (In press). A longitudinal study of change in asylum seekers Activities of Daily Living ability while in asylum centre. *Accepted for publication in Journal of Immigration and Minority Health*, 2014
- IV Morville, A-L., Erlandsson, L-K., Amris, K., Danneskiold-Samsøe, B., Eklund, M., (2013) *Satisfaction with Daily Occupations amongst asylum seekers in Denmark*. Submitted to Scandinavian Journal of Occupational Therapy, 2013

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Study I is available from <http://www.tandfonline.com>





# Introduction/rationale

Forced migrants, and among those asylum seekers, experience a major change in their daily life by fleeing their homeland. This disruption, and often deprivation, of daily routines and the consequences for resident asylum seekers, is the focus of this thesis. More specifically, this thesis focuses on how a 10-month detention in an asylum centre influences the experience of occupations, the performance of occupations and perception of satisfaction with occupations.

Within occupational therapy and occupational science there is a lack of research regarding forced migration and most of the research available focuses on those with refugee status, and not those in camps or centres, seeking asylum in other countries. However, many occupational therapists encounter forced migrants in their clinical practice, and there is a need for knowledge in this area in order to develop intervention programmes aimed at enabling occupation in this specific group.

On a global level, the number of people forcibly displaced by war, civil unrest or danger of persecution is rising. The United Nations Refugee Agency (2013) estimated that in 2012, 45.2 million people were forcibly displaced due to conflict and persecution, 7.6 million people were newly displaced and another 6.5 million people were displaced within their own country. Most of those seeking asylum in 2012 originated from Afghanistan, Somalia, Iraq, Syria and Sudan (United Nations Refugee Agency, 2013).

The increased number of asylum seekers in Denmark reflects the trend. Per 31<sup>st</sup> 2013, 7,540 had applied for asylum in 2013, whereas in 2011 3,806 applied for asylum. At the time of the data collection (2011) 4,289 adults were living in asylum centres (DIS, 2013a).

Subsequently, asylum, immigration and the debate surrounding refugees and asylum seekers have become highly emotive issues, where focus is often on how forced migrants influence their host societies, with relatively little consideration of how these societies influence forced migrants.



# Background

## Using the occupational lens

Occupations are the core domain of concern for occupational therapy and the study of human occupation. The perspective used in this thesis is based on the basic assumption that people are occupational beings and health and well-being in everyday life is achieved by 'doing' (Townsend & Polatajko, 2007, p. 21; Wilcock, 2006, p. 78). Here health is meant as more than the absence of disease and is the ability to act and engage in society on a daily basis (Townsend & Polatajko, 2007, p. 17; Wilcock, 2007) and to care for family, friends and others, and being able to choose one's occupations and take control over one's life situation.

## Different levels of occupations

Occupations can include everything that people do to occupy themselves, including such activities as looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (work/productivity) (Townsend et al., 1999, p. 42). As a person belongs and participates in a family, network and societal context, with different traditions and values, the value, meaning and even purpose of the occupation will be perceived differently and possibly changes over time (Huot & Rudman, 2010; Iwama, 2007; Kielhofner et al., 2008). The key in this is the subjectivity and therefore even though an activity is the same across cultures, it might have a different meaning and purpose in different cultures, and may change the individual's perception of the occupation accordingly (Iwama, 2007; Kielhofner et al., 2008; Persson, Erlandsson, Eklund, & Iwarsson, 2001; Townsend & Polatajko, 2007, p. 74).

### *Three levels of occupations*

People choose their occupations based on earlier experiences and perception of an occupation (Kielhofner, 2007, p. 60). Their choices are based on what are needed and wanted in the specific time and context, and provide meaning and purpose. The occupations a person chooses and engage in reflects their social and personal identity; both how

they see themselves and are perceived by others (Kielhofner, 2007, p. 16). A person's choice of occupations should be seen on different levels; the life course level, the daily level and the level pertaining to the performance of a task. The life course perspective is where it is the deliberate commitment to undertake a personal project, enter a new role or acquire new regular occupations (Kielhofner, 2007, p. 14; Persson et al., 2001). Different occupational roles, such as worker, parent, spouse, student etc., implies that a certain set of regular occupations are to be undertaken in order to fulfil the obligations of each of such roles (Kielhofner, 2007, p. 60). Inherent in the life perspective of occupations is the daily occupations where the choices of occupations are based on these roles and habits and the capacity to perform the occupations (Kielhofner, 2007, p. 51; Persson et al., 2001). Daily occupations are needed in order to organise time and structure daily life, and is necessary in order to be able to participate and integrate into society. This can be daily occupations and tasks, that are needed and wanted, e.g. doing the home chores, going to work, reading a book, etc. (Kielhofner, 2007, p. 16; Persson et al., 2001). How the roles are fulfilled and which tasks and occupations are acted out, are based on the norms of the surrounding society at the specific time and place, as well as what the person finds valuable and meaningful (Fisher, 2009, p. 10; Persson et al., 2001; Pierce, 2001).

### *Meaning and value in occupations*

The choice of a specific occupation is motivated by whether the occupations give purpose and meaning in the specific cultural and personal context (Kielhofner, 2007, p. 112; Townsend & Polatajko, 2007, p. 146; Wilcock, 1999). This pertains not only to the individual, as groups of people also engage in specific activities that have meaning and value for the specific group. However, contexts and persons change over time, and thus the same person or persons might perceive the meaning and value of an occupation differently at different stages of life.

Meaning in life comes through the enactment of valued occupations (Hammell, 2004; Persson et al., 2001). Occupation is deeply rooted in a person's existence, so much that people identify themselves by what they do (Townsend & Polatajko, 2007, p. 21). The concrete value of a person's occupation is often the external marker of competence, capabilities and skills, reflecting the individual and a cultural appraisal of the occupation. According to Persson et al. (2001), value in occupation is both person and culture bound, as the same activity communicates different things to different persons, it contributes to cultural identity and this is described as the intrinsic, symbolic value. The very personal and individual value of an occupation is usually bound to the performance of an occupation, as when a person engages in an occupation simply because he or she enjoys being absorbed in the occupational performance. In its most pure form this has been described as an experience of flow, where the doer melts together with the doing. People with occupations that incorporate all three types of values have been found to experience a higher level of meaning in life, as well as more well-being and subjective health (Erlandsson, Eklund, & Persson, 2011).

In short people seek not only to cover daily needs, but also to create meaning and positive identity in life, by seeking engagement, challenge and development through occupations (Wilcock, 1999; Wilcock, 2006, p. 107).

## Forced migration's influence on occupation

When being forced to leave one's homeland the change in environment touches many aspects of daily occupations. By not belonging to a network and culture, the ability to do and feel capable and valuable through occupations might be lost as the opportunities to keep busy and have something valuable and meaningful to wake up to, are missing (Hammell, 2004; Townsend & Polatajko, 2007, p. 79). Asylum seekers find themselves in a new country, and maybe even in a new part of the world and without the means and/or opportunity to continue a daily life with valued occupations. It is on a basic level such as the opportunity to perform a familiar task e.g., cooking a meal might not be present, because one is obliged to eat in a canteen or the environment do not support the habitual way of cooking (Martins & Reid, 2007; McElroy, Muyinda, Atim, Spittal, & Backman, 2012). Also expressing oneself in one's own language, amount of clothes to put on (Whiteford, 2004) and different ways of structuring daily life are influenced by this change in environment (McElroy et al., 2012). Some may adapt to the new environment if it supports the opportunity to regain old occupations or develop new ones. However, most asylum seekers are in an environment that does not support the opportunity to engage and participate in occupations which reduces their choice and range of occupations available, and subsequently reduces health and well-being (Whiteford, 2000).

## The importance of being occupied

### *Occupational disruption*

Asylum seekers often leave their homeland due to traumatic incidences of persecution, war or armed conflict. They experience serious and demanding occupational disruptions lasting for longer periods, influencing their opportunity to make choices regarding occupations (Bennett, Scornaiencki, Brzozowski, Denis, & Magalhaes, 2012; McElroy et al., 2012). They are, due to both legal and local regulations and/or limitations of war or civil unrest, excluded from participating in and contributing to the society in which they live, which makes it hard if not impossible to regain or replace valued occupations and a structured daily life (McElroy et al., 2012; Whiteford, 2005). Whether they are able to regain their occupations or adapt is dependent on whether the surrounding environment supports or limits the opportunity to adapt or create new occupations (Huot & Rudman, 2010).

### *Occupational deprivation*

When the environment does not support the opportunity to engage in occupations, new or old, the risk of developing a state of occupational deprivation is high. Asylum seekers are in danger of experiencing occupational deprivation by losing the opportunity to maintain and pursue well-known and valued occupations, due to the move from a known environment, and/or subject to legal restrictions.

Occupational disruption and deprivation occur for most asylum seekers as their life suddenly changes due to fleeing their homeland (Bennett et al., 2012; Burchett & Matheson, 2010; Steindl, Winding, & Runge, 2008) and may influence all levels of occupation. The exposure to such a major occupational disruption as fleeing, and possibly even before leaving the homeland, may lead to a loss of the sense of belonging in a well-known environment, including cultural norms, customs and social support systems (Bennett et al., 2012; Bhugra & Becker, 2005; McElroy et al., 2012). Leaving behind the opportunity to belong and participate in work, family relations and network and the occupations connected to this, are some of the primary consequences of forced migration (Bennett et al., 2012; McElroy et al., 2012; Townsend & Polatajko, 2007, p. 225). Studies have shown that these rather profound changes in environment, life roles and daily occupations influence the meaning and purpose of familiar occupations to such an extent that it influences the identity of the asylum seeker (Bennett et al., 2012; Bhugra & Becker, 2005; Huot & Rudman, 2010; McElroy et al., 2012). Former and current occupations may change meaning and purpose due to new geographic and cultural contexts and basic needs have to be taken care of in new surroundings (McElroy et al., 2012; Steindl et al., 2008). Asylum seekers often spend months, if not years, in the centres without the opportunity to pursue former occupations or develop new ones and often describe their lives as interrupted, on hold, or blown off course (Bhugra & Becker, 2005; Burchett & Matheson, 2010; McElroy et al., 2012). Whether the asylum seekers experience occupational deprivation may differ between different countries, as there are different rules and legislations regarding the rights and obligations of being an asylum seeker. Most of the research on asylum seekers experience of occupational deprivation has been done in North America and Australia (Bennett et al., 2012; Burchett & Matheson, 2010; Huot & Rudman, 2010; Martins & Reid, 2007; Steindl et al., 2008; Whiteford, 2004, 2005) and so far only one study was done in a Northern European context (Horghagen & Josephsson, 2010).

### *Occupational dysfunction*

The subjection to a state of occupational deprivation over a longer period of time may not only reduce an asylum seeker's opportunity to maintain occupations on a daily basis, but also decrease the ability to perform occupations. The capacity to perform occupations is based on whether the person possesses the skills to act (Kielhofner, 2007, p. 68.). None the less, though the person possesses those skills, the lack of occupations over a longer period of time might reduce the person's skills and their experience of health and well-being, i.e. they might develop occupational dysfunction (Whiteford,

2000). The types of problems that people may encounter after a longer period of deprivation, could be difficulties retaining a job, loss of ability to engage in leisure activities and a decrease in ADL ability, and eventually changes in roles and the habits of daily life (Kielhofner, 2007, p. 62), which might be the case for asylum seekers. It is well described that being in an asylum centre for an extended period of time reduces the asylum seeker's health and well-being (Coffey, Kaplan, Tucci, & Sampson, 2010; Hallas, Hansen, Stæhr, Munk-Andersen, & Jorgensen, 2007; Mueller, Schmidt, Staeheli, & Maier, 2011; Ryan, Benson, & Dooley, 2008; Steel, Momartin, Silove, Coello, Aroche & Tay, 2011). There is, none the less no research on whether the asylum seekers' reduced health and well-being influences occupations and if it eventually leads to occupational dysfunction, as there is very little literature within occupational therapy and science that pertains to asylum seekers.

### *ADL ability and occupational performance*

The experience and perception of occupations are crucial to health and well-being, but in order to discuss meaning and purpose with occupations in relation to asylum seekers well-being and health, it is important to include the ability to perform occupations. A person's ability to perform an occupation is dependent on whether she or he possesses the skills needed in order to execute the occupation, such as the ability to push a trolley or lift a pan, i.e. performance skills (Fisher & Jones, 2010, p. 1-3).

Studies have described that the experience of well-being is dependent on the ability to perform ADL tasks (Law, Steinwender, & Leclair, 1998; Menec, 2003). Illness and disease often compromise the ability to perform ADL tasks (Borg, Runge, & Tjørnov, 2003, p. 15; Fisher & Jones, 2010, p. 15-31), and there are several studies describing the ill health (Bhugra, 2003; Masmas et al., 2008; Silove, Sinnerbrink, Field, Manicavasagar, & Steel, 1997; Steel, Chey, Silove, Marnane, Bryant, & van Ommeren, 2009) and decline in health of asylum seekers (Coffey et al. 2010; Hallas et al., 2007; Mueller et al., 2011; Ryan et al., 2008; Steel et al., 2011). Prip and colleagues (2011) included items regarding physical functioning in a study of torture survivors based on a few self-rated questions, but otherwise studies including specific measures of ADL have not been found. Low ADL ability may have consequences such as low well-being and dissatisfaction with daily life and may even make resettlement more difficult. It is surprising that research on ADL ability amongst asylum seekers is so rare, especially as this group often suffer from or develop ill health and may experience a decline in ADL ability.

### *Satisfaction with daily occupations and level of activity*

Asylum seekers are at risk of experiencing occupational deprivation (Bennett et al., 2012; Burchett & Matheson, 2010; Huot & Rudman, 2010; Martins & Reid, 2007; Steindl et al., 2008; Whiteford, 2004, 2005), even though a limited numbers of activities are available in the asylum centre. The activities may have purpose, but not meaning for the asylum seeker and therefore not necessarily experienced as satisfactory. Whether an occupation is meaningful is dependent on the individual's perception of



the occupation and not just its purpose (Hammell, 2004). The perception of satisfaction with occupations can be both on the daily level, describing satisfaction with a daily occupation, but also on a level, where the satisfaction links with the occupational performance in itself. Though the perception of an occupation includes many aspects, the satisfaction derived from the occupation is important (Christiansen et al., 2005, p. 528; Townsend & Polatajko, 2007, p. 26), as it has shown to be closely linked to health and well-being (Eklund & Leufstadius, 2007). Having the opportunity to include and perform an occupation of one's own free will and without an obvious external reward creates meaning and satisfaction as it is driven by intrinsic motivation, and not necessarily a specific goal or purpose (Hammell, 2004; Ryan & Deci, 2000). This also implies that the self-reward value of the occupation is perceived as high and thus increases health and well-being (Erlandsson et al., 2011).

The number or level of activities during the day are not an indicator for satisfaction *per se*, but more to do in general has shown to be associated with value for the individual (Eklund, Erlandsson, & Leufstadius, 2010), leaving the asylum seekers at risk for low occupational satisfaction. This might be the case if their occupations are used to fill time and space, and not perceived as something meaningful. A study by Argentzell and colleagues (2012) including mental health patients showed that in order to bring meaning into occupations, a sense of control and daily structure is crucial and this could be hindered by the limited accessibility to activities in an asylum centre. Studies of satisfaction with occupations have primarily been performed within mental health settings and have shown that mental health patients often spend more time on rest and sleep than well persons. This type of daily structure is associated with a low level of satisfaction with occupations (Eklund, et al., 2010). With the limited possibilities for activities in an asylum centre a lower level of satisfaction would not be surprising. Even though there might be possibilities for creating a structured day, the lack of control over one's life situation and exposure to occupational deprivation probably influences the opportunity to create meaning and thus influence the satisfaction with occupations.

## Seeking asylum in Denmark

The major part of asylum seekers in Denmark lives in asylum centres spread throughout the country. The Danish Red Cross is responsible for the registration of all newly arrived asylum seekers in Denmark, except for unaccompanied children under the age of 18 years. The Danish Red Cross is responsible for running of most the centres. Local municipalities run a few centres.

Upon arrival all asylum seekers are interned in a receiver centre and after primary evaluation by the Danish Immigration Service (DIS), they are moved to other centres around the country, where they stay until they either are granted asylum or are expelled from the country. The average stay in an asylum centre at the time of the data collection (2011) was 600 days (DRC, 2012), but might range from 3 months to more than

10 years. Danish Red Cross or the municipalities are responsible for the administration of daily necessities, clothes and the allowance that all asylum seekers receive. The centres range in size from 120 to 600 inhabitants (DRC, 2012). During their stay in the centres asylum seekers are free to come and go as they please, though if they do not show up at appointed times, they are not eligible for their allowance of 2,300.00 DKK (Euro 310.00) per month for food and other necessities for a single living person (DIS, 2013b). When participating in practical chores within the centre the allowance increases. Most of the asylum seekers receive financial support for food and do their own cooking, but others receive less financial support and are obliged to eat in the centres' canteens. At the time of the data collection all food in some centres was prepared by a canteen and in other centres the asylum seekers bought and prepared their own food.

## The application process

In Denmark, the process of seeking asylum is divided into three phases (DIS, 2013b).

### *Phase one:*

The initial phase of seeking asylum is based on whether DIS decides that an asylum application may be processed in Denmark. In the case of having sought asylum in another EU country before coming to Denmark, the applicant will have to go back to country of entrance (DIS, 2013b; European Union, 2003).

### *Phase 2:*

In a normal procedure DIS will interview the applicant and during the course of the interview the asylum seeker will have the opportunity to clarify why he/she is applying for asylum in Denmark. Following the interview, DIS will rule in the case based on a 'factual and individual assessment of all relevant information' pertaining to the case (DIS, 2013b). If the Danish Refugee Council disagrees with a decision to reject the application, DIS will generally maintain the rejection and refer the case to the Refugee Appeals Board for a final ruling (DIS, 2013b).

### *Phase 3:*

A final rejection means that the applicant has no other avenues available to appeal the ruling. Rejections delivered by the Refugee Appeals Board, or by DIS in the case of 'manifestly unfounded' cases, are regarded as final (DIS, 2013b). If substantial humanitarian considerations are present, the Ministry of Justice can grant a temporary residence permit. Rejected applicants cannot be expelled unless the home country is willing to accept the applicant. If the home country does not want to receive the applicant, a final date for departure cannot be set, in which case the asylum seeker stays in Denmark (DIS, 2013b).

During all phases the asylum seeker has a right to accommodation and receives an allowance for food and other necessities (DIS, 2013b).

## **Access to activities**

Each phase has its own regulations regarding what sorts of activities are possible inside and outside the centres. During all three phases the asylum seekers have access to activities provided by Danish Red Cross or the municipalities, although there can be restrictions depending on the status of the application (DIS, 2013b; DRC, 2012). At the time of the data collection, asylum seekers were not allowed to study or earn money and work in normal settings and were only allowed to participate in courses and work-like placements provided by Danish Red Cross or the municipalities. After the data collection for this thesis, new legislation allowed asylum seekers to apply for and work in paid employment after 6 months in a centre, though only when cooperating with the DIS regarding deportation to the homeland (DIS, 2013b).

During the initial phase it is compulsory to take part in a weeklong course (30 hours) about rights and obligations as an asylum seeker in Denmark. The asylum seeker must also sign a contract obliging him or her to participate in the general up-keep, as cleaning their own rooms and common areas, such as kitchens and bathrooms (DRC, 2012). In addition he/she may help with other tasks at the centre ("in-house activities"), such as helping staff with routine office work and the upkeep and repair of buildings and furnishings of the asylum centre etc. While the asylum seeker waits for decision about whether his/her application will be processed in Denmark, he/she may only help with in-house activities. The same applies if the application has been rejected (phase 3) and the asylum seeker is refusing to assist with the deportation process.

When the initial phase is completed and it has been decided that the asylum seeker's application is to be processed in Denmark (phase 2), the asylum seeker is required to participate in courses, which provide the asylum seeker with skills that might improve integration prospects in Denmark, if residency is granted, and which can at the same time prepare the asylum seeker for life in his/her country of origin if the application for asylum is rejected. An average of 10 hours per week is used for courses and the courses run for 3 months at a time. A limited number of asylum seekers are allowed to take part in courses outside of the Red Cross educational programmes (DRC, 2012).

If the asylum seeker's application is to be processed in Denmark, he/she may participate in both in-house activities as well as unpaid job training programmes at a company not affiliated with the asylum centre ("out of house activities"), in average 10 hours a week although in very few cases it may amount to more. The asylum seeker can also participate in unpaid humanitarian work or any other form of voluntary work.

# Asylum seekers, health and well-being

Experiencing occupational deprivation and its relation to asylum seekers' health has not been explicitly studied. However lack of occupations and control over one's life is not specific to asylum seekers. Studies concerning others with limited access to occupations, e.g. long-time unemployed or underemployed and prisoners, show that these persons often suffer from the same health problems as asylum seekers (Farnworth, Fossey, & Nikitin, 2004; Fazel & Baillargeon, 2011; Rosenthal, Carroll-Scott, Earnshaw, Santilli, & Ickovics, 2012). Asylum seekers are in an uncertain situation, without the structure that life in prisons gives and without knowledge of when detention in an asylum centre will end. Longitudinal studies, have found statically significant differences, in distress between those who were still asylum seekers at follow-up and those that were granted asylum, the latter showing less psychological symptoms (Ryan et al., 2008; Steel et al., 2011). Others have shown that ill health and psychological symptoms among asylum seekers are associated with delays in the processing of asylum applications, employment obstacles as well as loneliness and boredom (Carswell, Blackburn, & Barker, 2011; Silove et al., 1997; Steel et al., 2011). The distress of pending cases, no access to work or education and lack of control of one's life situation are factors that seems to influence the health of asylum seekers, whereas refugees who have access to work, social services and the knowledge that they will not be expelled seem to be less at risk for ill health.

## *Health problems*

In relation to engagement in occupation, many stressors such as refugee's trauma and loss of social roles and networks (Bhugra & Becker, 2005; McElroy et al., 2012) could influence asylum seekers and refugees' occupations and health in general. Pre-migration conditions such as poor living conditions, subjection to armed conflict or persecution in the homeland and during flight are well-known factors contributing to post-migration stress (Lindencrona, Ekblad, & Hauff, 2008; Silove et al., 1997). Also loneliness, family separation, uncertainty about the family and a sense of guilt in cases of separation from small children or elderly parents, are problems which influences post-migration stress (Ryan et al., 2008; Williams & Volkmann, 2011).

Previous studies show that general health problems in the asylum seeker and refugee population are greater than in the background population, including high ratings of psychological symptoms and pain problems (Masmas et al., 2008; Norredam, Krasnik, Garcia-Lopez, & Keiding, 2009). The study by Masmas and colleagues (2008) showed that asylum seekers already on entrance to Denmark suffer from both mental health problems and physical symptoms. The long-term mental health consequences in the asylum seeker population are mostly described in terms of major depression, generalized anxiety and post-traumatic stress, sleeplessness and lack of concentration (Coffey et al., 2010; Laban, Komproe, Gernaat, & de Jong, 2008; Ryan et al., 2008; Williams & van der Merwe, 2013), which all are conditions that influence occupations and occupational performance negatively (Fisher & Jones, 2010, p. 15-30). Posttraumatic

stress symptoms have been found to be strongly associated with the report of pain and pain-related disability in traumatised populations (Egloff, Hirschi, & Känel, 2013) and persistent pain related to the musculoskeletal system are reported to be among the dominant physical complaints in the asylum seeker population (Masmas et al., 2008). Though many asylum seekers experience post-migration stress and have been subjected to traumatic incidents that influence their health and well-being, Masmas and colleagues (2008) found that the asylum seekers who were subjected to torture had greater health problems compared to asylum seekers who had not been subjected to torture.

The term torture survivor in this thesis denotes the primary torture victim, and not the family or network, even though they often suffer from secondary traumatisa-tion, which might afflict families and networks through generations (Quiroga, 2005). Torture is one of the most serious violations of human dignity. It is not directed only against the individual, but also their societies, with the goal of destroying the community (Quiroga, 2005), and by making examples of individuals and their families it terrorises the entire community into silence and submission. Methods of torture are unfortunately legion, and some connected to specific cultures, whereas others are more common. Torture can be both physical torture (Amris, Danneskiold-Samsøe, Torp-Pedersen, Genefke, & Danneskiold-Samsøe, 2007), such as beatings, which can be either unsystematic beating or systematic, sometimes targeting specific areas of the body, such as *falanga* (beating of the soles). Other frequently used methods are forced positions, suspension from limbs or sexual abuse (Amris et al., 2007; Amris & Williams, 2007). Waterboarding and other methods of inducing strangulation/drowning as well as isolation over longer periods of time and deprivation of basic needs, such as lack of sleep, or no access to food or water are probably some of the most common ways of torture (Amris et al., 2007). Witnessing of, or being forced to ‘help’ torture others are also common, as well as mock executions (Amris et al., 2007). However, classifying torture as either physical or psychological are problematic (Williams & Volkmann, 2011), as physical torture are psychologically damaging and exposure to psychological torture and traumas often are related to physical symptoms such as pain (Egloff et al., 2013; Williams & Volkmann, 2011). It is common to diagnose torture survivors as suffering from post-traumatic stress, which includes symptoms such as lack of concentration, irritability, sleep disturbance and re-experiencing or memory loss regarding the traumatic incident (Carlsson, Olsen, Kastrup, & Mortensen, 2010; Taylor, Carswell, & Williams, 2013; Williams & Volkmann, 2011).

Persistent pain is a prevailing long-term consequence of torture, often related to the loci of torture (Amris & Williams, 2007; Egloff et al., 2013; Olsen, Montgomery, Bojholm, & Foldspang, 2007; Prip, Persson, & Sjolund, 2011; Thomsen, Eriksen, & Smidt-Nielsen, 2000; Williams, Peña, & Rice, 2010). Studies of torture survivors have documented connections between some specific forms of torture such as nerve lesions caused by blows, strangulation, traction and other forces. It has been described that severe traumatic brain injury caused by blows or jolt to the head, results in fracture and/or internal brain damage and also that suspension from arms or tight handcuffing causes peripheral neuropathies has been described (Amris & Williams, 2007; Moreno &

Grodin, 2002; Thomsen et al., 2000). None the less, in the clinical practice, pain in torture survivors is often seen as regional or widespread pain (Amris & Williams, 2007; Prip & Persson, 2008), and studies have shown associations between specific methods of torture and pain e.g. falanga and pain in the feet and lower leg (Amris & Williams, 2007; Prip & Persson, 2008). However pain in torture survivors are not necessarily related to a local physical trauma, but might be due to a central sensitisation (Amris & Williams, 2007; Egloff et al., 2013; Thomsen et al., 2000).

Both national and international studies show differing rates of torture and other traumas in asylum seeker populations; some up to 40-45% (Masmas et al., 2008; Quiroga, 2005), whereas a review by Steel and colleagues (2009), concluded that the rates were closer to 20%. The latest study from a Danish asylum seeker population, showed a prevalence of 45%, though there were variations between countries (Masmas et al., 2008). It should be noted that an important topic regarding the prevalence of torture is the assessment of torture, which is usually done using self-report, based on a single question, leaving the possibility of personal and culturally understandings of the term open (Başoğlu, 2009; Gurr & Quiroga, 2001). This might lead to an under-reporting of torture.

#### *Access to health care and rehabilitation for asylum seekers*

Asylum seekers have restricted access to health care in Denmark. All asylum centres have health-care staff, usually nurses, who take care of minor injuries, administration of medicine etc. (DRC, 2012). Most centres have part-time medical doctors and psychologists and psychiatrists who are available as consultants. Asylum seekers in Denmark are not covered by the national health insurance system. Instead, expenses for their health care are covered by DIS (DIS, 2013b). Health care expenses concerning adult asylum seekers are covered by DIS provided that the health care is necessary, urgent (treatment cannot be postponed) and/or pain relief and if there is a risk that postponing will result in permanent injury, in the condition worsening or in the condition becoming chronic (DIS, 2013b). Furthermore, the asylum seeker may be referred for several types of treatment by the health staff such as consultations with midwives and medical specialists, such as ear-nose-throat doctors, dentists etc.

Many victims of torture, combat and armed conflicts are in need of rehabilitation as studies have documented that torture and other related human rights violations produce long-term health related consequences, such as described above (Amris & Williams, 2007; Carlsson et al., 2006; Carlsson et al., 2010; Coffey et al., 2010; Egloff et al., 2013; Laban et al., 2008; Olsen et al., 2007; Prip et al., 2011; Ryan et al., 2008; Taylor et al., 2013; Thomsen et al., 2000; Williams & van der Merwe, 2013; Williams et al, 2010). As opposed to Danish citizens and persons with residents permit, rehabilitation services are not available for asylum seekers until granted asylum (DIS, 2013b). One of the consequences of restrictions on access to health care and rehabilitation is that asylum seekers living in centres over time could develop a persistence of both physical and psychological symptoms, which might contribute to, among other factors, a decrease of the ADL ability. Considering the amount of forced migration from areas

of war, armed combat and repressive systems, plus the accumulation in numbers of asylum seekers seen over the last decade has made traumatised asylum seekers, refugees and torture survivors a common sight in clinical settings, not only in Denmark, but all over the world. It is a group with special needs and often in need of rehabilitation. Denmark along with several other countries has ratified the UN convention on torture (UNCAT, 2012) and by doing so committed to provide rehabilitation to torture survivors and other traumatised groups. However this is not followed as asylum seekers in Denmark have a very limited access to rehabilitation as long as the asylum case is not yet decided.

## Implications for research

Currently there is increasing interest from the occupational therapy and occupational science communities in the field of immigration and health. However, most research has focused on legal immigrants and/or those who have already gained refugee status e.g. Huot & Rudman (2010), Mondaca & Josephsson (2013), Mpofu & Hocking (2013), and Whiteford (2004). A few have begun to shed some light on the issues of forced migrants through investigating the experiences of asylum seekers and displaced people living in asylum centres or refugee camps (Horghagen & Josephsson, 2010; McElroy et al., 2012; Steindl et al., 2008; Whiteford, 2005), but none includes torture survivors.

Previous research has predominantly been investigations using qualitative methods, and for the most part with the aim of describing the experience of occupational deprivation and the research, so far, confirms that asylum seekers do experience occupational deprivation. However, available opportunities for activities, legal conditions and living standards for asylum seekers differ from country to country, making it necessary to continue this line of investigation. Furthermore research with larger populations is needed in order to describe the population more thoroughly and find factors, which influence the asylum seekers occupations in both daily and lifetime perspectives.

As stated above satisfaction and performance are important parts of the phenomenon of occupation. But so far there has been very little research in regard to these issues within an asylum seeker population. According to the literature the asylum seeker population in general experiences occupational deprivation and suffers from more health problems than the background populations, and there is reason to believe that this influences their occupational performance and satisfaction with occupations. Although occupation-based research is sparse, the general health problems experienced in this population indicate that there might be occupation-related problems.

Including the occupational perspective in health related research regarding asylum seekers and torture survivors is thus needed. In order to develop targeted rehabilitation programmes aimed at enabling occupation, inclusion and participation, it is necessary to start filling the knowledge gap.



# Aims

The overarching aim of this thesis was to describe the influence that detention in an asylum centre has on asylum seekers and their occupations. A longitudinal perspective was taken as the literature indicates that longer periods of deprivation might lead to occupational dysfunction.

Therefore the focus is on the experience of occupational deprivation and change in occupational performance and in satisfaction with occupations while residing in an asylum centre over a ten-month period. Furthermore as asylum seekers are at risk for being exposed to torture and are more likely to experience health problems than the background population, another aim was to describe torture and physical and psychological symptoms, and to uncover if they were associated with occupational performance and satisfaction with occupations.

The specific aims of the four studies were:

Study I: To explore whether adult asylum-seeking men in a Danish asylum centre experienced occupational deprivation and how prior life experience formed and shaped their choice and the value of current occupations.

Study II: To assess the ADL ability in newly arrived adult asylum seekers in Denmark, including any group differences between tortured and non-tortured persons, and to assess whether self-reported health and exposure to torture were related to ADL ability

Study III: To assess if there were any changes in adult asylum seekers ADL ability from arrival to a ten-month follow-up and to assess if changes in self-reported health and exposure to torture were related to changes in ADL ability.

Study IV: To describe adult asylum seekers' satisfaction with daily occupations and activity level upon arrival in the asylum centre and at a ten-month follow-up. Furthermore, the aim was to investigate whether measures of ADL ability, exposure to torture and general health variables were associated with satisfaction with occupations and activity level.





# Materials and methods

## Study design

This thesis is based on four studies, described in four papers. Study I was based on field notes and narrative interviews. The narrative approach was used to uncover whether the participants could use former occupations during their time in detention and if they experienced occupational deprivation.

Study II was conducted within the first four weeks after the participants' arrival and had a cross-sectional design. The study addressed the participants' ADL ability in order to assess any differences amongst those exposed to torture and those not exposed to torture. The study also assessed whether there were any associations between torture, self-rated health measures and ADL ability.

Study III had a baseline–follow-up correlational design and addressed changes in ADL ability from arrival (baseline) to follow-up ten months later, and if there were any associations between torture, changes in self-rated health measures and ADL ability.

Study IV had a baseline–follow-up correlational design and addressed satisfaction with daily occupations within the first four weeks after arrival (baseline) and whether there were any changes in activity level and satisfaction with daily occupations after ten months in a centre, and if there were any associations to torture, self-rated health measures and ADL ability.

Table 1 presents an overview of design, selection procedures and methods.

# Overview of studies

Table 1  
*Overview of design and methodology in this thesis*

	Paper I	Paper II	Paper III	Paper IV
Research design	Qualitative	Cross-sectional descriptive design	Baseline—follow-up correlational design	Baseline—follow-up correlational design
Selection procedure	Purposeful selection	Consecutive selection	Inclusion of available participants from Study II	Inclusion of available participants from Study II
Participants	3 males	43 participants	Baseline: 43 participants  Follow-up: 17 participants	Baseline: 43 participants  Follow-up: 17 participants
Inclusion criteria	Male 20-50 Able to speak English at college level	Age 20-50 From Afghanistan, Iran or Syria Max. 4 weeks in Denmark	Took part in Study II Lived in an asylum centre	Took part in Study II Lived in an asylum centre
Data	Narrative interviews (and field-notes) based on informal observations and conversations	<i>Observation:</i> Assessment of Motor and Process Skills  <i>Questionnaires:</i> WHO-5 Well-being Major Depression Inventory Pain Detect Questionnaire Self-rated Health (1-item) Socio-demographic questionnaire and torture item checklist	<i>Observation:</i> Assessment of Motor and Process Skills  <i>Questionnaires</i> WHO-5 Well-being Major Depression Inventory Pain Detect Questionnaire Self-rated Health (1-item)	<i>Observation:</i> Assessment of Motor and Process Skills  <i>Questionnaires:</i> Satisfaction with Daily Occupations WHO-5 Well-being Major Depression Inventory Pain Detect Questionnaire Self-rated Health (1-item)
Analysis	Thematic Analysis (a)	Two-sided t-test Wilcoxon ranked sum test Spearman's rank order correlations test	Wilcoxon signed Rank test Wilcoxon ranked sum test Spearman's rank order correlations test Chi <sub>2</sub> test	Wilcoxon signed Rank test Mann-Whitney U-test Spearman's rank order correlations test Chi <sub>2</sub> test

(a) Accordance with Creswell (2009) and Polkinghorne (1995).

## Study context

The studies took place in Danish asylum centres, and all data was collected within the centres. In order to enrol and observe daily life in a centre, the author spent two to three days per week in the larger receiver centres during a period of five months. For the col-

lection of follow-up data the author visited centres around the country, both large and small, in order to meet the participants in their own environment.

The centres are usually placed in rural areas where transportation options to local townships are limited. Transit to larger cities is costly and time-consuming. Asylum centre rooms hold two to four beds, some with a private kitchenette and a bathroom. Others have communal kitchens, toilets and bathing facilities located on each floor. Families are entitled to a two-room apartment, enabling parents and children to have separate rooms (DRC, 2012).

## Participants and inclusion

Afghanistan, Iran and Syria were the three countries from which participants were selected for inclusion. At the time of the data collection (2011-2012) these were three of the countries from which Denmark received the largest number of asylum seekers (DIS, 2013a). Persons from the Middle East differ ethnically in their ethnic characteristics from country to country, but they do share some cultural similarities in thought systems, values, customs, norms and behaviours (Lipson & Meleis, 1983). The cultural similarities are also reflected linguistically. Dari, one of the two main Afghan languages is close to Farsi, which is spoken in Iran. The official Syrian language is Arabic, but one of the larger dialects is Kurdish Kumanji, which is also spoken in Iran. To avoid large cultural difference amongst the participants, it was decided to include participants from said countries. This also kept the number of interpreters who needed introduction and instructions at a minimum and advanced positive collaboration between interpreters and the author.

The participants for all four studies were recruited with the aid of Danish Red Cross. Inclusion criteria for all participants in the studies were being an asylum seeker from Afghanistan, Iran or Syria, and newly arrived (< 4 weeks) in Denmark. It was decided to include participants between 18 and 50 years of age, as the asylum seekers mostly are within this age range, but also in order to have a more homogeneous group by excluding the risk of age related illness that might influence the results. Exclusion criteria were a diagnosis of severe mental illnesses, severe handicaps and pregnancy in the last trimester. The latter, though a natural condition, might influence the occupational performance and satisfaction.

A specific inclusion criteria for Study I was that the participants were able to conduct fluent college level English conversation without the assistance of an interpreter.

### Participants Study I

The choice of participants was based on knowledge gained from previous informal conversations and observations of their activities in the centre. At the time of the data collection most papers concerning occupational deprivation in asylum centres focused on

the female perspective. It was therefore decided to examine the male perspective. Two pilot interviews were performed, one with an interpreter and one without. Although a trained interpreter was used, the data lacked substance in comparison with the interview performed in English. This was decisive for selecting participants with proficiency in English. The pilot interviews were not part of Study I.

Six participants gave informed consent, but before the interviews could take place one received refugee status and two had been moved to other centres.

## Participants for Studies II to IV

In regards to Studies II to IV, (Figure 1) 176 asylum seekers, who fitted the inclusion criteria, were referred to the Red Cross Centre during the study period. For reasons unknown eighty-nine of these declined to participate, leaving 87 eligible for inclusion. Out of these, 67 gave written informed consent, but as illustrated in the flowchart in Figure 1, an additional 17 study participants were excluded from the study for various reasons, such as moving to another centre or not showing up at appointed times. Moreover, for four of the participants the interview and observation of ADL task performance had to be terminated prematurely due to emotional reactions. This resulted in a total study sample of 43 participants in the baseline sample (i.e. available case scenario).

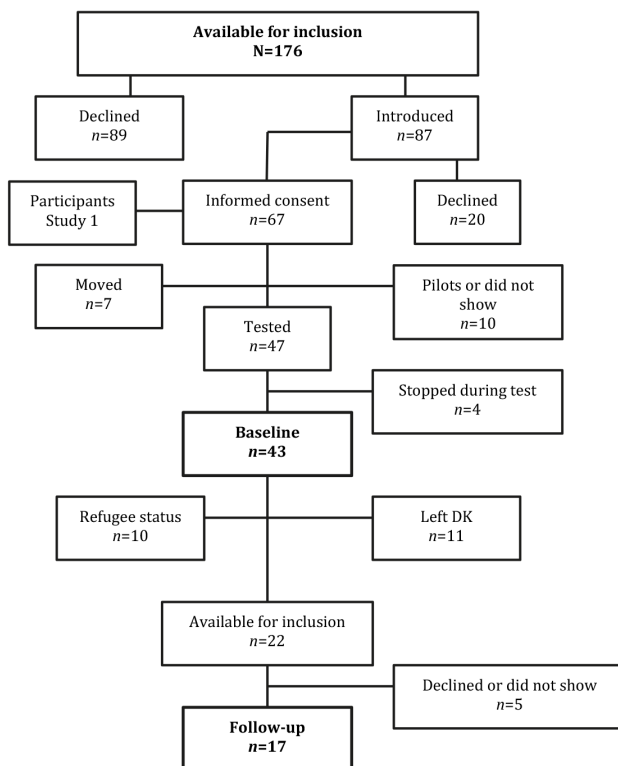


Figure 1. Flowchart of inclusion of participants for Studies I-IV.

At follow-up ten months later, ten from the original sample had gained refugee status, five had disappeared, five had left the country and one was imprisoned. This left 22 to participate, but 2 refused and 3 did not turn up at appointed time, leaving a total of 17 individuals included in the follow-up sample.

## **Procedure**

During initial medical screening the newly arrived asylum seekers were invited to participate in the studies, and if interested referred to the author. The author provided interested asylum seekers with general information about the project, including information about voluntary participation, anonymity of identity, and confidentiality of the data collected. Written information about the project had been prepared in Dari, Arabic and Farsi, to enable the asylum seekers to read the information in their native language. Written informed consent ensured final inclusion in the studies. The Danish Red Cross's trained telephone interpreters were employed during all communication with the participants in Studies II-IV, including introduction and information about the project. All interpretation was from the participant's own language to Danish and vice versa.

All of the instruments described below were applied at both baseline and follow-up (see Table 1), except for socio-demographic information and questions of torture.

## **Interpretation during data collection**

In order to ensure that language barriers were kept at a minimum, the telephone interpreters were maintained on stand-by even if the asylum seeker and the author were able to communicate in the same language.

Except for data in Study I, all data was collected with the aid of an interpreter.

Both the Satisfaction with Daily Occupations (SDO) (Eklund, 2004; Eklund & Morville, 2013) questionnaire and the Assessment of Motor and Process Skills (AMPS) (Fisher & Jones, 2010) were pilot tested before data collection, and the pilots are not part of this thesis. The rating scale of the SDO needed further elaboration in order to function well with the sample used for Studies II-IV. The numeric scale in the SDO posed some problems, as some pilots did not understand the principle of numeric rating, which led to a rating scale using a combination of smileys and numbers. In order to diminish language bias by using the available questionnaires in the participants' own language, all questionnaires were in the Danish version and an interpreter was used. This method proved to be an advantage, as some of the participants were illiterate and would not have been able to read the questionnaires.

Translators of written material and interpreters were recruited from the Danish Red Cross interpretation bureau. They were instructed to interpret only what the author and participants said during the interviews, and not add any of their own explanations or comments. Before commencing the introductions and the data collection the author

was present at several initial medical screenings with Red Cross nurses. The experience gained during those interviews, and during initial introductions to future participants, revealed that a live interpreter disturbed the interaction between interviewer and interviewee. Thus it was decided that all data would be collected using a telephone interpreter and before data collection was initiated, cooperation with five interpreters was established and further used during all data collection.

After each interview and observation had taken place, the author checked with the interpreter if any problems or misunderstandings had occurred during the interview, in order to ensure that as few language errors as possible were made.

## Characteristics of the participants

### *Study I*

The participants in Study I were three men aged 25, 28 and 30 respectively. Two came from Iran and one from Afghanistan. The two had finished their university education at MSc level and one was still a university student before fleeing. None of the participants were married or had a partner.

### *Studies II to IV*

#### *Baseline characteristics*

The sample of 43 participants came from Syria ( $n=8$ ; 19%), Iran ( $n=18$ ; 42%) and Afghanistan ( $n=17$ ; 39%). Thirty-six were male and seven female. Their mean age was 30 years (range 20-50), the mean level of education was 10 years (range 0-19) and 19 (44%) of the asylum seekers had arrived in Denmark unaccompanied by family members or spouses.

#### *Follow-up characteristics*

The sample of 17 participants came from Syria ( $n=3$ ), Iran ( $n=8$ ) and Afghanistan ( $n=6$ ). The mean age was 27 years (range 20-49), the mean level of education was 10 years (range 0-18) and nine of the asylum seekers had arrived in Denmark unaccompanied by family members or spouses.

#### *Differences between non-participants, participants and drop-outs*

At baseline 43 persons participated (Table II). There were no differences between the study sample of 43 participants and the 133 non-participants regarding marriage ( $p=0.092$ ), age ( $p=0.393$ ), gender ( $p=0.160$ ) or education ( $p=0.687$ ).

Table 2  
*Differences in demographics between non-participants and participants in Studies II to IV*

	Non-participants (n=133)	Participants (n=43)	Participants (n=17)
Age (mean/SD)	31.32 (9.11)	30.05 (7.68)	27.24 (6.84)
Education (years) (mean/SD)	10 (5.0)	10.5 (5.35)	10.5 (5.02)
Marriage yes (%)	54 %	63 %	70 %
Gender male (%)	73 %	83 %	82 %

Ten months later, 17 of the original 43 participants were available for follow-up. The differences between baseline and follow-up are shown in Table 3.

Table 3  
*Difference in demographics between dropouts (n=26) and participants (n=17) in Studies III and IV*

	Median (IQR)	Median (IQR)	Difference	p-value
Variables	Drop-outs	Participants		
Age	29.5 (27.5–36)	25 (23.5–29)	4.5 (0.9 to 8.1)	0.013*
Education, years	12 (6–13)	12 (6.5–14)	0	0.919
Marriage/yes	15 (58%)	12 (70%)		0.093
Gender /male	22 (86%)	14 (82%)		0.844

## Data collection

The author performed all collection of data for this thesis.

### Interviews and observations for Study I

Data collection took place during a three-month period, with two to three visits to the centres each week. The data based on observations and field notes was collected while, e.g. greeting participants and engaging in conversation at different locations, or being invited for tea or coffee in the participants' rooms. During this phase of the data collection, the author did not ask for any personal information, but followed the issues that the participants themselves presented. In general, the participants were reluctant to discuss the experience of fleeing during the interview, although during the more informal conversations bits and pieces were revealed and noted.

The narrative interviews were held in an undisturbed office in the centres' medical clinics. Qualitative interviewing techniques were followed, including an open-ended outline with no specific questions formulated for the interviews (Cresswell, 2007; Kvale & Brinkmann, 2009). However the interviews were based on certain themes, broadly formulated, and the questions then gradually became more focused and specific during the process, as the author followed up on the participant's answers.



Each interview lasted about two hours and were recorded and transcribed verbatim by the author.

## Occupation focused instruments for Studies II to IV

In order to assess occupational performance and satisfaction with everyday activities, two tests were chosen: the observation-based test AMPS (Fisher & Jones, 2010), and the Danish version of the interview questionnaire SDO (Eklund, 2004; Eklund & Morville, 2013). Both tests are developed by occupational therapists and have been tested on various diagnosis groups, as well as healthy samples, which could be used as reference groups for the asylum seekers occupational performance and satisfaction.

### *Assessment of Motor and Process Skills (Studies II and III)*

In order to assess ADL task performance the AMPS was used. Performance skills in relation to occupation are the smallest units of goal-directed observable actions that are linked together, one after another, during the process of executing an ADL task (Figure 2) (Fisher & Jones, 2010, p. 1-3). Both motor and process skills are needed in order to perform an ADL task safely and independently (Fisher & Jones, 2010, p. 1-2; Kielhofner, 2007, p. 68).

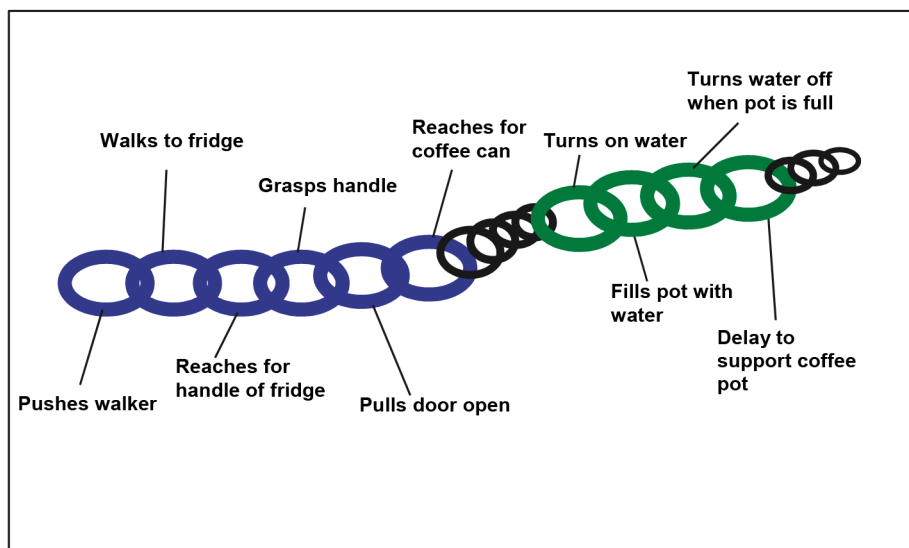


Figure 2. Observable performance skills during making a pot of coffee (Center for Innovative OT Solutions, 2014).

In general, motor skills are such actions as to reach for, grip and lift a coffee cup, or the ability to move oneself and objects during the execution of the task in a safe manner, without any exertion. Process skills are the ability to plan and perform the task in an orderly manner, such as sequencing the task in a logical and appropriate manner or

keep a steady pace during the performance, so that the task is done using the right tools at the right time (Fisher & Jones, 2010, p. 1-2).

The person administering the AMPS must be an occupational therapist who is specifically trained to use the AMPS and calibrated for rater severity (Fisher & Jones, 2010, p. 1-10). The author is a trained AMPS observer and was calibrated in 1996 and recalibrated in 2010. The author has used the AMPS in clinical work and research settings for the last 17 years.

The AMPS test focuses on the quality of the skills used during task performance, and it does not assess underlying body functions (Fisher & Jones, 2010, p. 15-72). The AMPS allows for a culture relevant evaluation, while remaining free from cultural bias, as the ADL standardised tasks included in the AMPS allows for cross-cultural variations (Fisher & Jones, 2010, p. 1-7). The AMPS is standardized and validated on more than 100,000 individuals globally and cross-culturally, and several studies support good test-retest and rater reliability as well as validity across diagnostic groups (Fisher & Jones, 2010, p. 14-24).

The AMPS has mainly been applied in studies of ADL ability in psychiatric, neurologic, geriatric and healthy populations, but has also been introduced in studies of rheumatologic patients and patients with chronic widespread pain (Fisher & Jones, 2010, p. 15-24; Girard et al., 1999; Waehrens, Amris, & Fisher, 2010). The AMPS has also been shown to be a sensitive outcome measure in rehabilitation studies (Fisher & Jones, 2010, p. 1-6).

The test is based on an occupational therapist's observation of a person performing at least two ADL tasks. Before the observation, the participant is interviewed about daily activities, to ensure that the ADL tasks are well known and relevant for the person. During the observation, the person performs at least 2 of 111 standardized ADL tasks. The chosen tasks should be of appropriate challenge and at the same time meaningful and relevant to that person's daily life (Fisher & Jones, 2010, p. 1-6). The standardized ADL tasks are divided into groups according to challenge as seen in Table 4 (Fisher & Jones, 2010, p. 1-3).

Table 4  
*Examples of AMPS tasks according to task challenge*

Very easy	Much easier than average	Easier than average	Average	Harder than average	Much harder than average
Eating a snack with a utensil	Eating a meal	Folding a basket of laundry	Changing standard sheets	Vacuuming two rooms on different levels	Pasta with sauce, green salad and beverage
Putting on socks and shoes	Beverage from the refrigerator for 1 person	Making a bed against a wall, duvet folded under	Setting a table	Fresh fruit salad for two	Cake, muffins or brownies

Following the observation, 16 ADL motor and 20 ADL process skills items are used to rate the quality of the performance of each of the ADL tasks according to ease, efficiency, safety and independence. A four-point ordinal scale is used (1 = markedly defi-

cient, 2 = ineffective, 3 = questionable, 4 = competent). The AMPS incorporates the use of Rasch analysis, and therefore provides equal-interval linear measures of the quality of ADL task performances. Computer-scoring software is used to convert the person's raw scores into two overall linear ADL ability measures, one for ADL motor ability and one for ADL process ability. These two overall ADL measures are adjusted for ADL task difficulty and rater severity (i.e. how strict the rater scores the observed performance) and are expressed in logistically transformed probability units (logits) (Fisher & Jones, 2010, p. 1-6). As seen in Figure 3, two separate measures are reported, one for ADL motor ability and one for ADL process ability.

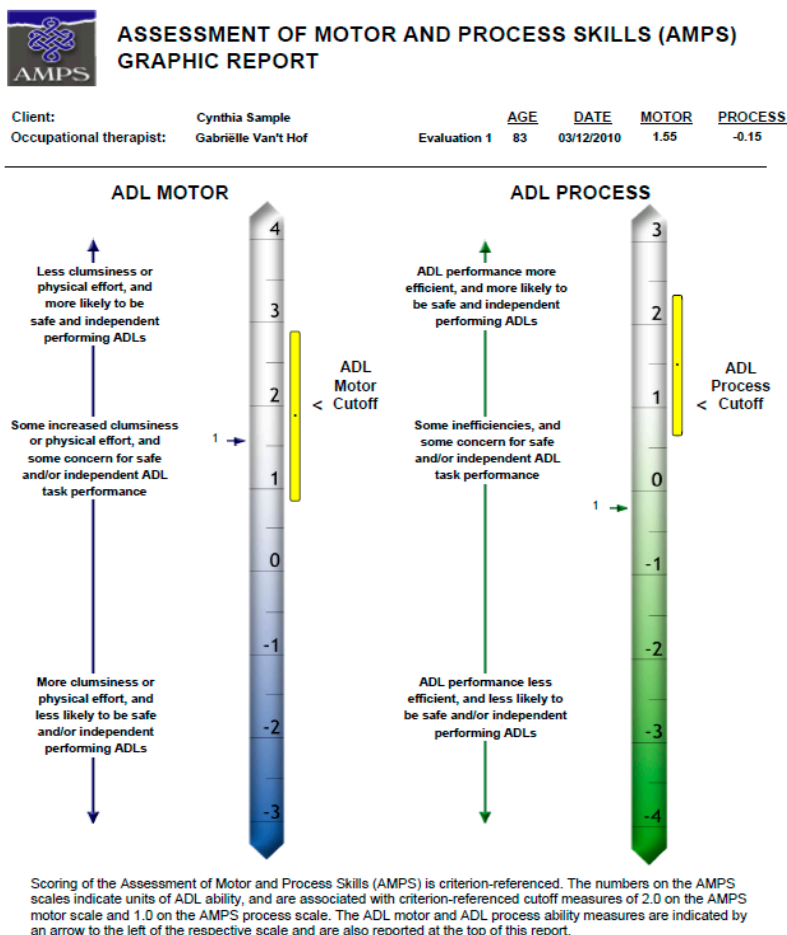


Figure 3. Example of an AMPS graphic report showing ADL ability in reference to criterion-based cut-off measures and the normative range for healthy, well people of the same age (Center for Innovative OT Solutions, 2014). The yellow line indicates the normal range of ADL ability.

The results of the AMPS include the expected range of ADL measures for healthy, age-matched peers, based on more than 12,000 individuals, and indicates whether the per-



The second part asks the person to rate his or her satisfaction with the presence or absence of the activity in question, e.g. is working or unemployed, and he or she rates the satisfaction with that condition. The person is instructed not to think of how he or she performs the occupation, unless the performance influences the satisfaction score. Sample questions are shown in Figure 4, along with the seven-point satisfaction response scale of the original questionnaire. The satisfaction score may range between 13 and 91, whereas the activity score may vary between 0 and 13. The scores are used as separated scales of satisfaction and numbers of activities, and higher scores indicate more satisfaction and activity respectively.

The testing of the SDO indicates that it has good psychometric properties in terms of internal consistency, construct validity, test-retest reliability and sensitivity to change (Eklund, 2004; Eklund & Gunnarsson, 2007, 2008). It has also been shown to function adequately with people with physical disabilities and healthy individuals (Eklund & Sandqvist, 2006). Unpublished data based on the Swedish 13-item version indicates the satisfaction scale has good internal consistency ( $\alpha=0.79$ ) and logical associations with other constructs, in terms of general occupational satisfaction ( $r_s=0.46$ ) and self-rated health ( $r_s=0.20$ ). The Danish version of the SDO has shown satisfactory internal consistency and criterion and concurrent validity (Eklund & Morville, 2013).

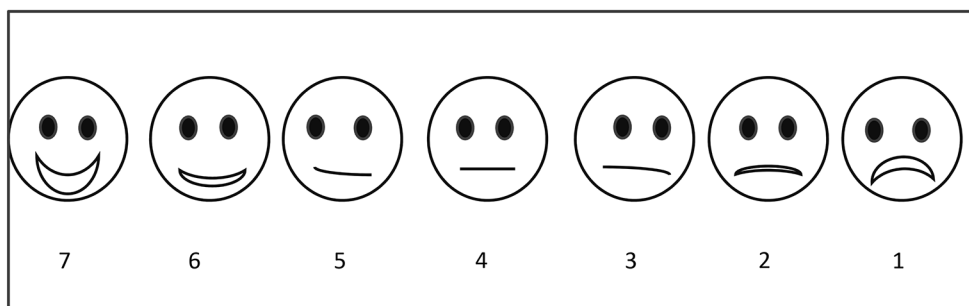


Figure 5. SDO response scale used during data collection.

For this study the rating scale was reversed, so that the numbers read from right to left, as Arabic, Farsi and Dari are read and written from right to left. For the illiterate participants smileys were added to the scale (Figure 5). The reversal of scales has been used in other translations of questionnaires, such as the Arabic and Farsi translations of WHO-5. The pilot testing showed that the reversal of scales and the use of smileys on the rating scale made it easier for those who were not acquainted with numerical scales.

## Questionnaires and participant-reported outcomes (Studies II to IV)

As described above, research has shown that asylum seekers and torture survivors are often suffering from psychological and physical symptoms, which might interfere with their ability to perform ADL tasks and their experience of satisfaction with daily occupations. As this might be important variables regarding occupational performance and

satisfaction with daily occupations, the following questionnaires were chosen in order to describe if health-related problems were present.

### *Baseline interview*

The baseline interview included a questionnaire used to retrieve the following information: Date of arrival in Denmark, age, gender, country of origin, civil status and education.

The participants were also asked about whether they had been imprisoned or arrested, and whether they had been exposed to torture. A torture item checklist was developed, based on literature on torture methods in the Middle East (Amris et al., 2007; Masmaz et al., 2008). During the development of the questionnaire health personnel from the Danish Red Cross were consulted, in order to ensure that the most common torture methods were included. Based on their profound experience with interviewing asylum seekers, they were also asked to review the questionnaires and give feedback on whether the questions might provoke flashbacks. Based on the literature and the input from the health personnel the following questions regarding torture were included.

The items formed a checklist, as seen in Table 5, consisting of eight physical items and eight psychological items and a question of whether the torturer was acting in an official capacity or other. The questions were formulated as yes/no questions, although the opportunity to elaborate was present during the question of whether other methods were applied.

Table 5  
*Checklist of torture methods*

Physical methods	Psychological methods
Beatings	Deprivation of basic needs (sleep >24 hours, food, etc.)
Suspension from limbs	Isolation > 48 hours
Falanga (beating of the soles)	Sensory deprivation or over-stimulation
Forced positions	Severe humiliation
Rape or other sexual assault	Witnessing torture of others
Strangulation	Witnessing sexual assaults on others
Electricity	Mock executions
Other methods	Other methods

After the data collection another researcher, experienced in research on torture, decided whether the incidents could be defined as torture according to the WMA (1975).

### **Self-rated health questionnaires**

The following standardized questionnaires were applied to all participants at baseline and follow-up.

### *WHO-5 Well-being Index*

WHO-5 is a 5-item questionnaire used to calculate the risk for stress and depression (Bech, 2004). The questionnaire is psychometrically valid in a mental health context (Blom, Bech, Högberg, Larsson, & Serlachius, 2012). The questions covers positive mood, vitality and general interest in daily life and are rated on a 6-point scale from 0 (= not present) to 5 (= constantly present). The theoretical raw score ranges from 0 to 25 and is transformed into scales from 0 (worst thinkable well-being) to 100 (best thinkable well-being). A change of more than 10% is considered clinically relevant. A raw score below 13 indicates poor well-being (Bech, 2004; Bech, Olsen, Kjoller, & Rasmussen, 2003). A change of more than 10% is considered clinically relevant. A raw score below 13 indicates poor well-being (Bech et al., 2003).

### *The Major Depression Inventory (MDI)*

The MDI is a validated 10-item self-report instrument for depression that can be scored both according to the DSM-IV and the ICD-10 algorithms for depression and according to severity scales by the simple total sum of the items, the total score ranging from 0-50 (Bech, Rasmussen, Olsen, Noerholm, & Abildgaard, 2001). A MDI sum score above 30 indicates major depression, between 26 and 30 moderate depression, between 21 and 25 mild depression, and below 21 no depression. In this study the ICD-10 algorithm for depression was used.

Even though WHO-5 and the MDI are self-report questionnaires, they were used as interview questionnaires.

### *Internal consistency*

Internal consistency was calculated for the WHO-5 and the MDI on the baseline data. The alpha values in the group of 43 participants were 0.88 for WHO-5 and 0.85 for MDI. An alpha value of 0.70 to 0.80 is considered satisfactory (Field, 2009) and therefore the reliability of the instruments were considered adequate.

### *Self-Rated Health*

The first item of the Medical Outcomes Scale (MOS) 36-item, short-form health survey (SF-36) was used as an overall self-estimate of health (Ware & Sherbourne, 1992). It is considered a reliable and valid one-item estimate of self-rated health (Bowling, 2005). The person rates his or her health on a five-point scale from 1 = excellent to 5 = poor.

### *Pain Detect Questionnaire (PDQ)*

The PDQ is a screening questionnaire developed and validated to predict the likelihood of a neuropathic pain component being present in the patient (Freyenhagen, Baron, Gockel, & Tolle, 2006). It consists of questions about pain intensity (VAS intensity values for current, average, and worst pain), course of pain (selection between 4 pain

course patterns), subjective experience of a radiating quality of the pain (yes/no), and the presence and perceived severity of seven somatosensory symptoms of neuropathic pain rated on a 0-5 verbal rating scale (never, hardly noticed, slight, moderate, strong, and very strong). For diagnostic purposes, a validated algorithm is used to calculate a total score ranging from 0 to 38 based on the respondent's answers. A total score above 18 indicates that a predominantly neuropathic pain component is likely, whereas a total score below 12 indicates that this is unlikely (Freynhagen et al., 2006).

Pain location was assessed by asking the participant to report the number of pre-defined body regions in pain and identifying locations on a body chart. Pain duration was recorded as time with pain (0-3 months, 4-6 months, 7-12 months and 12 months or more).

## Data analysis

### Qualitative analysis (Study I)

Data from narrative interviews can be analysed with the purpose of constructing a storyline or using a phenomenological approach to find hidden meanings and themes in the data-set (Cresswell, 2007, pp. 78; Riessman, 2005). The purpose of Study I was to describe if the 'occupational' story influenced the present occupations, but not necessarily to create a story line for each participant. Therefore a thematic analysis of the data from interviews and field notes was applied. This method is useful for finding common thematic elements across the participant's stories, focusing on meanings (Cresswell, 2007, pp. 78; Riessman, 2005).

Before analysis, the language in the transcripts was structured in order to make them more readable, but kept true to the original wording in the transcript. To enhance the readability in quotes, the actual wording was edited to reduce length, improve grammar, and in a few quotes, link sections for continuity, while maintaining the original meaning.

No theoretical framework guided the analysis. The analysis started by reading the transcripts and similar statements were grouped under the same common categories. In the continuing analysis, phenomena that shared common characteristics were assembled in the same meaning units. If a statement or field note expressed more than one aspect, it was placed in all the relevant units. Based on the aim of Study I, the statements about the participants' former occupations were identified and categorised. In order to uncover if the participants experienced occupational deprivation, all statements pertaining to deprivation were selected in order to assemble the data into meaning units and place it in the relevant category, while still using the statements in the context in which they originated. Afterwards the categories were structured into themes in order to uncover links between occupations over time and the experience of occupational deprivation.



## Statistical analysis (Studies II-IV)

Depending on the type of variables, as well as on the distribution of data, parametric or non-parametric methods were chosen. Two-sided statistical significance tests were used;  $p$ -values  $< .05$  were considered statistically significant.

Regarding Studies II and III it was estimated that including 50 participants in total with 25 individuals in each group (torture/non-torture) would correspond to a power of 0.934 (93%) to detect a statistically significant difference of 0.5 logit-points on the AMPS process ability measure. The ADL process ability measure was chosen as the main outcome as it has proved to be a better indicator than the ADL motor ability measure with respect to need of assistance when living in the community (Fisher & Jones, 2010, p. 15-45).

### *Descriptive statistics*

In order to describe the characteristics of the participants, descriptive statistics were used to present frequencies and means or medians of different variables.

### *Group differences*

The two-sample  $t$ -test, assuming unequal variances was used to compare the mean scores between participants and non-participants, and between tortured and non-tortured regarding the parametric data in Study II. The 'Wilcoxon rank sum' test was used on non-parametric data in Studies II and III and in Study IV the Mann-Whitney test was used for group comparisons. The  $\chi^2$  test was used for nominal variables. In Studies III and IV the 'Wilcoxon signed rank' test was used to test for change in variables between baseline and follow-up.

### *Relationships between variables*

In order to describe correlations between variables the Spearman correlation coefficient ( $r_s$ ) was used in Studies II to IV.

The analysis for Study II was done using the Statistical Analysis Software (SAS); for Study III Statistical Package for Social Sciences (SPSS) version 19.0 was used and for Study IV SPSS version 20.0 was used.

## Ethical considerations

The data collection for this thesis followed the principles and guidelines for medical research involving human subjects from the World Medical Association's Helsinki Declaration (1964). In article 17 of the Helsinki declaration it is stated that:

'Medical research involving a disadvantaged or vulnerable population or community is only justified if the research is responsive to the health needs and priorities of this population or community and if there is a reasonable likelihood that this population or community stands to benefit from the results of the research' (WMA, 1964).

Asylum seekers are humans who are a disadvantaged and vulnerable population, due to their legal situation and exposure to traumatic incidents. They are also vulnerable as an economically and medically disadvantaged group as they do not have the same access to work and health care as the resident population.

Therefore both written and thorough oral introduction and information was given to all, especially regarding voluntary participation, anonymity of identity, and confidentiality of the data. Asylum seekers were informed that both the Danish Red Cross and the researcher are politically independent and that participation in the project would and could not have any influence on their asylum case. Also lack of participation or withdrawal from the project would not influence the asylum seeker's case. This was repeated at the start of every individual interview. Before each interview the participant was informed that flashbacks to traumatising situations could occur, and that they could stop the interview at any time<sup>1</sup>.

The interviews and observations had no curative purpose. If the asylum seeker displayed a need for medical treatment, the author would, after having received oral consent, contact Danish Red Cross health personnel in order to initiate appropriate diagnosis and treatment.

The project was registered with and approved by the local Committee on Health Research Ethics in 2010 (KF 01-045/03). The project was also reported to the Danish Data Protection Agency.

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1 Flash-backs are when a person suddenly re-experiences the torture or other traumatic incident, triggered by something that reminds the person of the trauma.



# Results

Regarding the overarching aim of the thesis the results showed that the asylum seekers experienced occupational deprivation during detention, and that the sample at arrival had difficulties performing ADL tasks and perceived a low satisfaction with daily occupations. Ten months later there was a statistically and clinically significant decline in ADL performance, although not in satisfaction with daily occupations and activity level.

In the following the descriptive data of health and exposure to torture in the sample are presented first, and followed by the results regarding occupations in a lifetime perspective and daily occupations and tasks.

## Health and exposure to torture

### Torture prevalence (Studies II-IV)

Thirty-three (77 %) of the participants included at baseline reported exposure to torture (Table 6). There was a significantly higher ( $p=.011$ ) prevalence of torture amongst the participants (77%), than amongst the non-participants (54%). The data available for the non-participants were based on a single yes/no question; 'Have you been exposed to torture?'

*At baseline* 6 asylum seekers from Syria, 14 from Iran and 13 from Afghanistan reported exposure to torture either in their homeland or during the flight to Denmark. All the participants had been exposed to such traumatic incidents as armed conflict and threats to themselves or their family. The most commonly applied physical torture methods were unsystematic beatings or blows, suspension by the extremities and forced positions (Table 6). Frequent psychological torture methods were isolation, deprivation of basic needs and witnessing the torture of others.

Table 6  
*Participants' exposure to torture methods at baseline (n=43) and follow-up (n=17)*

Torture methods	Baseline n (%)	Follow-up n (%)
Exposure to torture	33 (77)	14 (82)
Beatings	31 (72)	10 (59)
Suspension from limbs	7 (16)	2 (12)
Falanga	4 (9)	1 (6)
Forced position	6 (14)	2 (12)
Sexual abuse	2 (5)	0 (0)
Strangulation	2 (5)	1 (6)
Electricity	2 (5)	1 (6)
Other physical methods	6 (14)	1 (6)
Deprivation of basic needs	20 (47)	7 (41)
Isolation	14 (33)	4 (24)
Sensory over/under stimulation	3 (7)	1 (6)
Humiliation	21 (48)	6 (35)
Witnessing torture of others	13 (30)	4 (24)
Witnessing sexual assaults on others	0 (0)	0 (0)
Mock executions	1 (2)	0 (0)
Other	5 (12)	1 (6)

*At follow-up* three of those who participated had been exposed to psychological torture, two to physical torture and nine to both, before arriving in Denmark. The most frequent torture methods were un-systematic beatings and deprivation of basic needs. There were no difference between drop-outs and participants at follow-up regarding number of physical torture methods ( $p=.119$ ), number of psychological torture methods ( $p=.288$ ) and of the total number of torture methods ( $p=.142$ ) the participants had been exposed to.

It should be noted that during the interviews none of the participants experienced flashbacks to traumatic incidents, but four had to be terminated due to emotional reactions.

### Self-rated health (Studies II-IV)

Depression and low well-being was present in most of the 43 participants. The self-rated health variables for baseline and follow-up are presented in Table 7.

Table 7  
Self-rated health variables at baseline (n=43) and follow-up (n=17)

	n=43 Mean (SD)	n=17 Mean (SD)
WHO-5 Well-being	30.79 (20.70)	22.35 (20.73)
MDI	30.25 (11.38)	35.82 (9.98)
Self-rated health	3.10 (1.28)	4.13 (0.88)
Pain, region-distribution	1.55 (1.38)	1.82 (1.33)
PDQ	7.32 (7.61)	9.59 (7.89)
Current pain	2.07 (2.93)	3.71 (3.40)
Average pain	3.74 (2.92)	4.81 (3.27)
Worst pain	5.74 (4.01)	6.38 (4.03)
Time w. pain	2.76 (1.79)	3.06 (1.74)

### Baseline

Of the 43 participants at baseline, 36 (84 %) scored below 50 on the WHO-5 indicating that the sample as a whole suffered from stress and low well-being. The same was reflected in MDI, using the ICD-10 algorithm for depression (Bech et al., 2001). According to the ICD criteria, 16 (37%) showed signs of severe depression, seven (16%) showed signs of moderate depression and five (12%) had signs of distress and milder depression. Thirteen participants (35%) rated their health as excellent or very good, 11 (30%) as good and 15 (35%) rated their health as fair or poor.

Regarding pain, 12 (28%) participants reported that they had no pain at all, 13 (30%) reported pain in one body region, and five (12%) in two body regions. Widespread pain, defined as pain in three or more body regions, was reported by 13 (30%) and duration of the pain problem of more than six months was reported by 28 (65%). The most prevalent pain complaints were headaches and stomach aches. Musculoskeletal pain in lower extremities was reported by 12 (28%), in the upper extremities by ten (23%), in lower back by nine (21%), in the neck region was reported by seven (16%) participants and in the feet by five (12%). Based on the cut-off algorithm of the PDQ (Freynhagen et al., 2006) a predominantly neuropathic pain component was likely in four (9%) of the participants, three of which were tortured and one not tortured. A neuropathic pain component could not be refuted in eight (19%), and was unlikely in the remaining 31 (72%).

There was no difference between tortured and non-tortured regarding self-rated health variables at baseline.

### Follow-up

At follow-up, 15 scored below 50 on the WHO-5, indicating that the larger proportion of the sample suffered from stress and low well-being. Using the ICD-10 algorithm, 11 participants suffered from severe depression, three from moderate depression and three

showed no sign of depression (Bech et al., 2001). One participant rated his health as excellent or very good, three as good and 13 rated their health as fair or poor.

Regarding pain problems at follow-up, the 13 participants who reported pain problems, had experienced pain for more than six months. The most prevalent pain complaints were headaches ( $n=8$ ) and stomach aches ( $n=7$ ). Musculoskeletal pain in the lower extremities were experienced by three, pain in upper extremities by two, pain in the lower back by four, pain in the neck region was reported by five participants and in the pelvic region by one. Five persons reported widespread pain, defined as pain in three or more body regions. Based on the cut-off algorithm of the PDQ (Freyenhagen et al., 2006), a predominantly neuropathic pain component was likely in two of the participants, one of whom had been tortured and one not tortured. A neuropathic pain component could not be refuted in five, and was unlikely in the remaining six.

The change in the self-rated variables from baseline to follow-up was statistically significant in the negative direction as shown in Table 8, except for worst pain and time with pain, which did not show statistical significance.

Table 8

*Differences in self-reported health variables from baseline ( $n=43$ ) to follow-up ( $n=17$ )*

	Median (IQR)	Median (IQR)	Difference (95% CI)	p-value
Variables	Baseline	Follow-up		
WHO-5 Well-being (Score 0-100)	36 (18 -42)	16 (6-40)	-20 [- 37.8 to -2.2]	.025*
Major Depression Inventory (Score 0-50)	29 (22.5-34.5)	40 (31.5-42.5)	11 [2.7 to 19.3]	.008*
Self-Rated Health 1 (excellent) to 5 (poor)	2 (1-3.5)	4 (4-5)	2 [-0.8 to 4.8]	.003*
Region distribution (0-4+)	1 (0 - 1.5)	2 (2 - 3)	1 [ 0.1 to 1.9]	.047*
Pain Detect Questionnaire (0-38)	0 (0 - 11)	9 (0 - 9)	9 [3 to 15]	.001*
Current pain (0-10)	0 (0 - 1)	4 (0 - 6.5)	4 [1.1 to 6.9]	.004*
Average pain (0-10)	2 (0 - 5)	4 (0.50 -7)	2 [0.2 to 3.8]	.026*
Worst pain (0-10)	6 (0 - 8.5)	8 (1.25 - 9.75)	2 [-1.4 to 5.4]	.276
Time w. pain 1= 0-3 months 2= 4-6 months 3= 7-12 months 4= 12+ months	3 (0-4)	4 (2-4)	1 [-0.2 to 2.2]	.141

Due to the small sample size and particularly the number of torture survivors, differences between tortured and non-tortured were not calculated.

# Occupational experience, performance and perception

## A lifetime perspective

### *Familiar occupations and the need to stay active*

Study I explored the lifetime perspective and showed whether adult asylum-seeking men experienced occupational deprivation and how their life experience and former occupations formed and shaped their choice and value of current occupations.

The unfolding categories, found during analysis, were structured into six themes covering past, present and future: Playing and going to school; university years; fleeing your homeland: the distress and motives; daily activities in a centre; “I want to...” wishes for the future.

Each of the three participants’ narratives were imprinted by experiences of fear and retribution caused by suppressive regimes or groups. Mean and degrading treatment and torture were widespread, and they had to flee their homeland, which made them feel caught in a very difficult and transitory ‘present’ with no way of shaping a future. Many of their childhood occupations were more or less restricted, due to limited possibilities to play, lack of a supporting physical environment and restrictions from oppressive governments. Their childhood and youth were experienced as being in a more or less constant state of being on guard, and not being able to speak freely for fear of retribution from the government or Taliban. One of the participants was imprisoned and tortured by the government, whereas the others escaped before being arrested or killed by the Taliban.

Before fleeing they all had occupations within the areas of education and work, which they to a certain extent managed to use as a base for adapting to life in the asylum centre, by using their acquired skills and competencies. In general the participants expressed satisfaction about coming to Denmark, since it provided a safe place and no danger of persecution or arrest, but they were still unable to feel sure about their future. Waiting for months for an answer from the DIS was experienced as demanding and they stated that the long application process compromised their well-being. They experienced their need to cope as a strong motive for building a structured daily life in order to keep busy and not think about their pending cases. The participants mentioned the lack of family and friends and one was very explicit about missing his family. Although he was able to chat with his brother on the Internet, he was afraid that his family would be hurt.

### *Daily occupations in a centre*

The results in Study I showed that the participants’ motives for participating in available activities were related to the experience of distress and effect of insufficient occupations. They used their occupations as diversions, in order to keep busy to avoid depression, which to a certain extent enabled the participants to experience meaning. The participants shared an interest in being helpful to others, but complained about the lack of



“real work” and opportunities for education. The participant who had been exposed to torture seemed to have suffered the greatest loss of occupations and had trouble maintaining former occupations. He suffered from pain during physical exercise and had lost one of his favourite leisure occupations due to the pain. Though he had access to Persian literature through the local library, he acted, as he ironically expressed it, as ‘boss in the hairdresser salon’. He took on the task of taking care of a room with barber chairs and getting supplies. He even started cutting the hair of other residents at the centre. The lack of occupations was evident, and they stated that to cope with this they tried to build a structured routine in order to keep distress at bay. The participants tried to keep themselves busy and valued their occupations, but primarily as diversions. Although they had different stories and differed in number and type of occupations, all talked about the experience of a profound occupational deprivation and though they had access to a range of activities, they were mostly experienced not as adding meaning to life, but only enabling an everyday life. The participants’ former occupations reflected their desires for the future; however they were aware that the post-migration life might not be easy. This showed that the participants not only told about their former and present selves, as planned for by the author, but through their narratives also negotiated and constructed a future possible self, incorporating earlier occupations.

## **ADL ability and the influence of torture**

Study II assessed the newly arrived adult asylum seekers’ ADL ability, including any group differences between tortured and non-tortured persons. Study III investigated if there were any changes in the ADL ability soon after their arrival to the ten months follow-up and if self-reported health and exposure to torture might be associated factors.

### *Baseline*

The results regarding ADL ability showed that none of the participants had both ADL motor and ADL process ability measures above the expected age mean for healthy subjects. All 43 (100%) participants had ADL motor ability measures and 35 (81%) ADL process ability measures below the age mean of healthy subjects of the same age (Figure 6).

The ADL motor skills measures were less diverse (1.20 to 2.90 logits), whereas process skills measures were more diverse (-0.02 to 2.49 logits) in their range on the AMPS scale.

Twelve (28%), including 10 who had been subjected to torture, were below the expected ADL motor ability age range. Fifteen (35 %), including 11 who had been subjected to torture, were below the expected ADL process ability age range. Fifteen (35%) were below the 2.00 logits ADL motor ability competence cut-off indicating increased effort during ADL task performance. Eleven (26%) of the participants were below the 1.00 logit ADL process ability competence cut-off, indicating inefficiency during task performance as well as a potential need of assistance in community living.

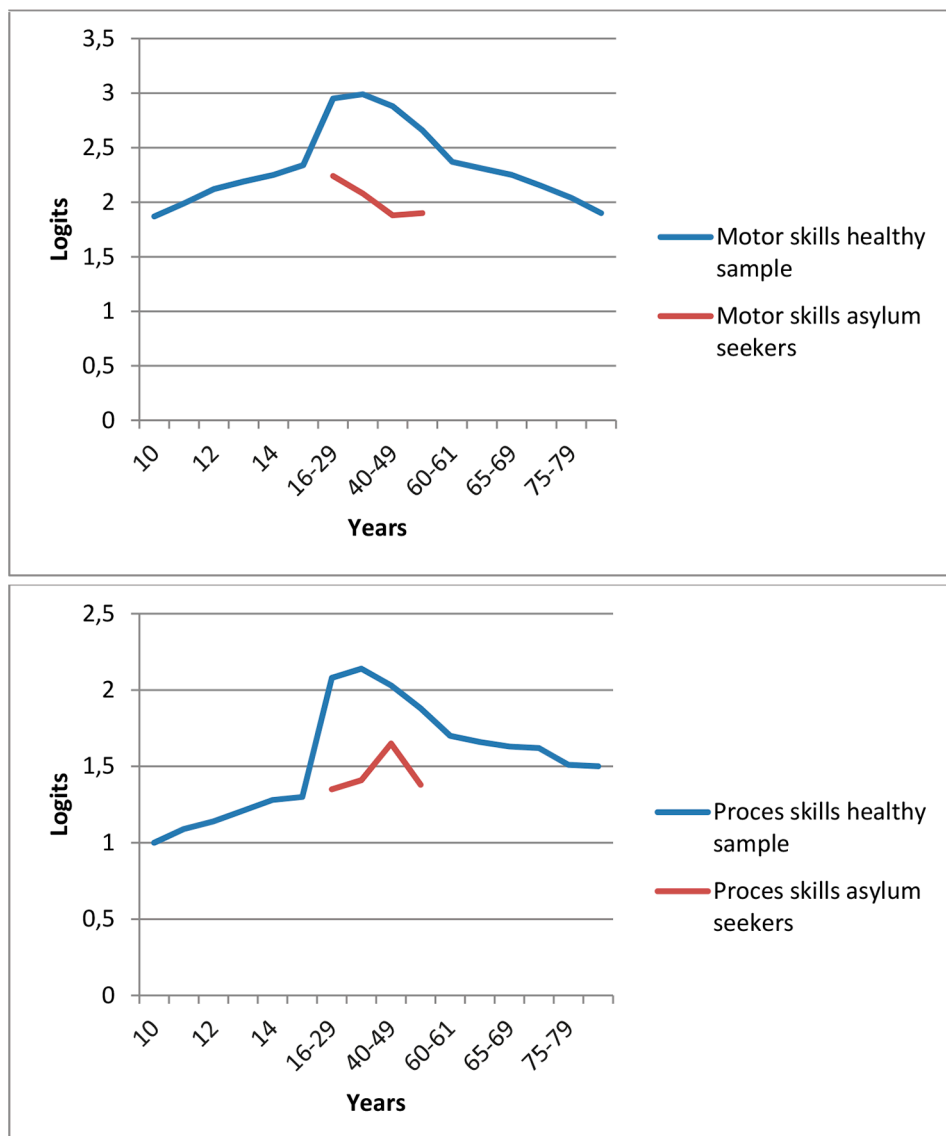


Figure 6. Asylum seekers' ADL motor and process ability compared to a healthy sample according to age-groups (yrs).

Further, two participants, both subjected to torture, were below both the 1.50 logits ADL motor ability cut-off and the 0.70 logit ADL process ability cut-off indicating a definite need of assistance in community living and self-care.

The most used observation tasks were within the average and harder than average domestic tasks (see Table 4), such as preparing coffee and biscuits and serving at a table, making a sandwich or a meal, cleaning the room/bathroom and doing the dishes.

There was no statistically significant group difference between tortured and non-tortured present in the mean ADL motor or process ability measures.

## Follow-up

Due to the small sample size and preponderance of torture survivors, no analysis of difference between tortured and non-tortured was performed.

As seen in Table 9 the participants had a statistically significant decline in both ADL motor ( $p=.017$ ) and process ability measure ( $p<.001$ ), and that the decline in the medians of ADL motor and process ability measure dropped by 0.44 logits and 0.71 logits respectively, which both exceed the clinically significant change at 0.3 logits or more (Fisher & Jones, 2010, p. 15-60).

Table 9  
*Changes in ADL ability from baseline (n=43) to follow-up (n=17)*

	Median (IQR)	Median (IQR)	Difference [95% CI]	p-value
Variables	Baseline	Follow-up		
AMPS motor	2.35 (2.04 – 2.56)	1.91 (1.36 – 2.50)	- 0.44 [-0.8 to- 0.1]	.017*
AMPS process	1.53 (1.25 – 1.94)	0.82 (0.64 – 1.08)	-0.71 [-1.1 to -0.3 ]	<.001**

Regarding ADL motor ability measures at follow-up all participants scored below the expected age mean and nine scored below the expected age range; five were below the 1.50 logits cut-off, indicating a potential need for minimal assistance for community living. Regarding ADL process ability measures, all participants were below the expected age mean, and fifteen of the seventeen were below the expected age range. Eleven were below the 1.00 process logits cut-off. Five participants were below the ADL motor ability measures of 1.50 logits and the ADL process ability measures of 1.00 logits, which is the best prediction of need for assistance to live in the community, including ADL tasks such as shopping, heavy housework and home maintenance tasks (Fisher & Jones, 2010, pp). Furthermore one participant was below the ADL motor ability measure of 1.50 logits and ADL process ability measure of 0.70 logits indicating a need for moderate to maximal assistance for community living in relation to domestic tasks and self-care.

Eleven of the 17 participants had a clinically significant decrease (-0.37 to -1.38 logits) of ADL motor ability measures at  $\geq 0.3$  logits and 14 a decrease (-0.36 to -1.75 logits) in ADL process ability measures at  $\geq 0.3$  logits between baseline and follow-up. Eight participants fell from above to below the ADL motor ability measures cut-off at 2.0 logits and ten participants fell from above to below the ADL process ability measures cut-off at 1.0 logits.

There was an increase in ADL motor ability measures for five participants, and two of these had a clinically significant change of  $>0.3$  logits (0.51 and 0.79 logits respectively). The same was seen regarding ADL process ability measures, where two participants showed an increase, and one of these had a clinically significant increase at  $> 0.3$  logits (0.73 logits). One participant had an increase in both ADL motor and process ability measures, though both  $< 0.3$  logits.

### *Associations between torture, self-rated health variables and AMPS measures*

*At baseline* the analyses revealed statistically significant correlations ( $p < 0.05$ ) between self-reported psychological distress measured with the WHO-5 and MDI and observed ADL motor measure (WHO-5:  $r_s = 0.434$ ; MDI:  $r_s = -0.325$ ) and ADL process ability measure (WHO-5:  $r_s = 0.459$ ; MDI:  $r_s = -0.341$ ). Furthermore a statistically significant correlation between observed ADL motor ability measure and the average VAS pain score ( $r_s = 0.30$ ) and region distribution ( $r_s = 0.42$ ) was found. However, the analysis did not reveal any associations between torture and AMPS measures.

*At follow-up* analysis revealed a statistically significant correlation ( $p < .05$ ), between exposure to an accumulation of physical torture methods and change in ADL motor ability measures ( $r_s = 0.525$ ). Also a statistically significant correlation between current pain and change in ADL process ability measure was found ( $r_s = 0.525$ ).

### **Satisfaction with daily occupations among asylum seekers**

Study IV described adult asylum seekers' satisfaction with daily occupations upon arrival in the asylum centre and at a ten-month follow-up. Furthermore it investigated if measures of ADL ability, exposure to torture and general health variables were associated with satisfaction with daily occupations and activity level.

#### *Satisfaction with daily occupations and activity level at baseline and follow-up*

At baseline the mean ratings (SD) were 38.9 (10.6) for the satisfaction scale and 7.9 (2.08) for activity level. At follow-up the corresponding values were 37.25 (9.26) for the satisfaction scale and 8.56 (2.13) for activity level. There was no statistically significant difference between baseline and follow-up regarding satisfaction ( $p = .909$ ) or activity level ( $p = .056$ ).

#### *Correlations between ADL ability, self-rated health and SDO variables*

*At baseline* statistically significant baseline correlations were found between ADL process ability and activity level ( $r_s = 0.356$ ;  $p = .019$ ) and the satisfaction score ( $r_s = 0.351$ ;  $p = .021$ ). A statistically significant correlation was also found between intensity of worst pain and activity level ( $r_s = -0.321$ ;  $p = .038$ ). Furthermore a correlation between education and activity level ( $r_s = 0.319$ ;  $p = .037$ ) was found.

*At follow-up* statistically significant correlations were found between WHO-5 and satisfaction ( $r_s = 0.732$ ;  $p = .002$ ) and activity level ( $r_s = 0.770$ ;  $p = .001$ ). Statistically significant correlations were also observed between MDI and activity level ( $r_s = -0.566$ ;  $p = .028$ ).



# Discussion

The overarching aim of this thesis was to investigate how staying in an asylum centre influenced occupations on three levels, by looking at the experience of occupational deprivation in a lifetime perspective, satisfaction with daily occupations and performance of ADL tasks. The results point at several problematic issues regarding asylum seekers and occupation on all three levels. The lack of occupations, low satisfaction with daily occupations and reduced ADL ability showed that the sample in this thesis had occupation-related problems at the time of their arrival. The development of further reduction in occupational performance skills and self-rated health measures after ten months shows that the asylum seekers' condition worsened over time.

The lack of meaning and search for occupations with the purpose of keeping depression and low well-being at bay found in Study I, was the basis of a closer examination of satisfaction with daily occupations in a larger sample in Study IV, as the participants in Study I had trouble finding value in their occupations. They also expressed fear of depression and felt their well-being was compromised, which guided the aims in Studies II and III of investigating occupational performance and determining whether it was compromised by torture and health related factors in a larger sample.

## A lifetime narrative

The findings in Study I described the life stories of three men who arrived in Denmark with different backgrounds and different stories of why and how they fled their homeland. The participants' stories were based on their former experience, and their, at times chaotic, experiences were constructed into narratives about their life course. Based on their earlier occupations and life stories, two participants constructed their identities as the doctor and the journalist, and the third constructed an identity as 'boss of the hairdresser salon', this in his case, was not based on earlier occupations from his life story.

Losing or limiting their former roles indicated that their status and identity might have changed, due to the lack of former occupations connected to those roles. Though Study I did not focus on torture, the finding suggested that it might have an influence on the ability to maintain or find valued occupations. The participant who had experienced torture had more trouble with maintaining an identity through occupations, and Taylor and colleagues (2013) also described this in their study, which found that torture survivors had trouble maintaining their identity and a hope for the future due

to the limitations imposed by pain from torture and the subsequent loss of activities. However, the participants in Study I showed the will to pursue a structure in everyday life, to build a network and maintain an identity through their occupations, trying to avoid isolation and de-humanisation.

Constructing a story about past events is a universal human activity, learnt as early as during childhood (Riessman, 2005). Narratives are a way of making sense of what has happened, by constructing a storyline about specific times or particular incidences, and develop stories over time as new experiences give new perspectives to the life story and the person's identity (Riessman, 2005). This is an on-going process or work, where people produce new narratives as part of a transformation (Mattingly, 2010, p. 74). Trying to make sense of the traumatic circumstances that led to fleeing might not be easy, and may explain the participants' reluctance to discuss the flight, as it might be difficult to construct a narrative that makes sense. During the interviews they did not only produce narratives about their pre-migration past, but tried to create future possible identities by constructing narratives about which occupations they would like have when they received their residence permit. Even though the author did not have the aim of including future plans in the Study I, the topic emerged during the interviews and informal conversations, and so became a part of the results. Mattingly (2010, p. 51) writes about 'healing dramas' which allow participants to create 'as if' stories that have transformative implications for becoming. Though the participants in Mattingly's (2010, p. 51) research were patients, the same could be said for the participants in Study I. It might be seen as their way of keeping up hope and keeping despair at bay during the void between pre-migration and post-migration, and the uncertainty about what life will be. For the participants, separation from family and network and the conditions in the asylum centres meant a complete change of previous daily life. They went from actively pursuing the goal of being in a safe place to the experience of nothing to do but passively wait to be granted asylum. The participants may have been able to cope with being in a passive situation by holding on to the hope of receiving asylum and maintaining a daily structure. Even so, their feelings of distress and worry about their cases and the lack of occupations made them wonder if this could have a detrimental effect on their health and well-being.

### *Meaning and value in occupations*

The results from Study I showed that the participants, through their occupations, produced results, but lacked the opportunity to achieve the results they had potential for. This lack of challenge through occupation could be seen as a diminished opportunity to experience self-reward value, as they had few opportunities to be absorbed by the doing itself, or experience occupational satisfaction. The participants found a certain meaning and purpose with their present tasks, but the symbolic value was debatable as the perceived status of the occupations was lower. Even though the participants experienced a certain self-reward value when being able to forget their pending cases, the occupations were not what they personally found meaningful and the symbolic value might even be negative according to Persson et al. (2001). The participants experienced low self-

reward and maybe even negative symbolic value in their activities, which could imply lack of meaning, and this may in the long run be a risk factor for ill health (Erlandsson et al., 2011). The three value dimensions, concrete, self-reward and symbolic, cover different kinds of values that may be found in occupations and contribute to the discovery of meaning in life (Persson et al., 2001) and a life worth living (Hammell, 2004). The results from Study I showed that the participants had trouble with identifying meaningful roles or routines that could help to organise their daily lives.

The participants' experience of lack of meaningful time use is consistent with studies concerning internees, refugees and asylum seekers living under conditions that do not support occupations (Farnworth, 1998; Farnworth et al., 2004; Nelson & Wilson, 2012; Whiteford, 2005). Even though conditions in Danish asylum centres cannot be compared to a Nazi concentration camp, the participants used some of the same 'survival' techniques, using occupations as a means to stay sane (Nelson & Wilson, 2011). Their wish to help and their contribution to others' well-being has been described as one of the ways of holding on to a sense of being valuable and capable (Nelson & Wilson, 2012; Whiteford, 2005). Antonovsky (1987) found that people who survived the concentration camps and stayed healthy and strong had an experience of inner meaning, no matter how terrible the conditions were. The ability to help others and hang on to some former occupations and identities might have helped the participants interpret the events as comprehensible, manageable and meaningful, which gives rise to a sense of coherence (Antonovsky, 1987). This experience of meaning in life and the ability to construct a meaningful narrative, where the event is not seen as isolated but as something that makes sense in a longer perspective could support the participants in developing resilience and eventually even a feeling of control. The feeling of control, along with education, is one of the most important features when discussing determinants of health (Marmot, 2006) and plays a major part in coping with being an asylum seeker (Quiroga, 2005). Studies (Quiroga, 2005) have shown that those who cope with exposure to torture and/or persecution are the ones who, like the participants, have consciously entered into illegal or otherwise dangerous activities. Whether the participants had a feeling of control and sense of coherence was not studied, but they had occupations that helped them organise and build a daily structure, based on their wants and needs. However it remains to be investigated whether a limited access to valuable occupations over a longer period of time presents a challenge, as it might reduce the ability to maintain or build resilience.

## **Occupational performance**

The substantial decrease in ADL ability found in the sample supports the notion that occupational deprivation eventually leads to occupational dysfunction. As with the satisfaction scores found at baseline in Study IV, the results of Studies II showed significantly lower mean ADL ability measures, compared to the ADL ability measure found in the AMPS reference group of healthy adults as seen in Figure 6 (Fisher & Jones,



2010, pp. 15-17). Opposed to the satisfaction scores in Study IV the results of Study III showed that the asylum seekers not only had low ADL ability measures at arrival but also a substantial decrease after ten months in an asylum centre. The low ADL motor and process ability measures indicating increased effort, fatigability and inefficiency during ADL-task performance might be a reason behind the link found between ADL process ability and the low satisfaction score found at baseline.

The sample in Study II showed decreased ADL ability already at arrival, which might be due to the conditions during flight or the conditions in the homeland that led to fleeing. The extent to which reduced occupational performance skills were found in the study sample is illustrated by two of the participants, whose ADL ability measures were below the level of assistance cut-offs on both AMPS scales (Fisher & Jones, 2010, p. 15-54) already at baseline. This level of assistance indicates a need of assistance with ADL tasks such as shopping, housework, home maintenance tasks and self-care. The whole sample in Study II were below the age-matched means on both ADL motor and process ability measures, indicating that the participants were at risk for experiencing increased effort and fatigability during occupational performance (Fisher & Jones, 2010, p. 15-54; Merritt, 2011). That the sample had a potential need for assistance in community living was especially mirrored in the low mean of ADL process ability measures in Study II, which showed a difference to a healthy sample of more than the 0.3 logits (Figure 6); the marker for a clinically relevant difference (Fisher & Jones, 2010, p. 15-60). The fact that some of the participants fell below the expected age range of ADL ability measures suggests that some, even though they might not be under the competence cut-off, are below what can be expected from a person at that age.

Study III showed that a majority of the participants developed a decrease in ADL ability from baseline to follow-up. However, two participants increased their ADL motor ability measures clinically significant, but this could be due to their low general physical health status at inclusion. One individual increased clinically significantly in ADL process ability measures at follow-up, but this could not be explained by self-rated health factors at baseline.

Several of the participants fell from above to below the competence cut-off on the AMPS scale and this decline was more severe regarding the ADL process ability measures. Whereas both the ADL motor and ADL process measures can reflect independence in ADL performance, the ADL process measure seems to be a better indicator of need for assistance when living in the community, as the ability to adapt and change the environment is related to planning and executing a given task, i.e. ADL process skills (Fisher & Jones, 2010, p. 15-50).

The substantial decrease of 0.71 logits in ADL process measures and 0.44 in ADL motor measures is worrying, as it exceeds the  $\pm 0.3$  logits, the marker for a clinically significant change. This occurred after 10 months, which was less than the mean stay of a year and a half in an asylum centre at the time of the data collection (DRC, 2012). Persons who use increased effort and experience fatigue during ADL task performance are more likely to decrease their social participation and participation in society in gen-

eral (Crooks, 2007; Fisher & Jones, 2010, p. ), and this may over time limit the asylum seekers' chances of integration into their host society.

Study II revealed associations between psychological distress and ADL ability. These associations are not surprising as the relation between psychological symptoms, low well-being and ADL ability are well described (Fisher & Jones, 2010, p. 15-29). The results also showed associations between region distribution and VAS average pain and ADL motor ability. Regarding the prevalence of torture survivors in this sample, this is not surprising as chronic pain is often found in torture survivors and others suffering from trauma-related psychological problems (Amris & Williams, 2007; Egloff et al., 2013; Olsen et al., 2007). Chronic pain is known to be associated with a decrease in activity level (Crooks, 2007) and ADL ability (Amris et al., 2011; Waehrens et al., 2010), and the participants in Studies II-IV showed a higher prevalence of pain problems (72%) at baseline than the Danish background population (21%), which might to a certain extent explain the low ADL motor ability.

Regarding the associations between psychological symptoms, well-being and ADL process ability in Study II, the psychological stress might not be the sole factor as it is possible that the decreased ADL process ability reflects cognitive deficits which are important for efficient ADL task performance (Waehrens & Fisher, 2007). Cognitive dysfunction affects ADL ability (Waehrens & Fisher, 2007) and is often seen in populations with trauma-induced stress as well as chronic pain (Egloff et al, 2013), such as torture survivors (Moreno & Grodin, 2002). This could relate to the low ADL process measure in Study II and the further decrease found in Study III, but remains to be investigated.

Even though there were associations to both psychological and physical symptoms, which is often seen in torture survivors, Study II did not reveal any association between exposure to torture and ADL ability. This might be due to the preponderance of torture survivors, but such factors as the severity of torture, secondary victimisation, and the stress and strain of fleeing and often living under poor conditions, may in itself have a negative impact on ADL ability. Study III, however, showed an association between exposure to multiple physical torture methods and the change in ADL motor ability measures. It is an important finding, though not unexpected, that physical torture could be a prognostic factor for a decline in ADL motor ability. Study III showed an association between change in current pain and change in ADL process ability which supports that stress and psychological symptoms are strongly associated with pain and pain-related disability (Asmundson, Coons, Taylor, & Katz, 2002; Bryant, Marosszeky, Crooks, Baguley, & Gurka, 1999; Egloff et al., 2013). As opposed to the results in Study II, the results in Study III did not show any relationships between psychological symptoms and AMPS measures. This is puzzling, as previous studies show clear associations between well-being, health and ADL ability (Law, Steinwender, & Leclair, 1998; Menec, 2003), but considering the small sample size in Study III this finding might be due to lack of statistical power. It is also possible that other factors could affect the ADL ability, such as the long-time detention, refugees' traumas, lack of occupations and loss of social roles and networks as found in Study I. Psychological symptoms among

asylum seekers are often also associated with delays in the processing of asylum applications, employment obstacles as well as loneliness and boredom (Carswell et al., 2011; Ryan et al., 2008). These factors and the prolonged exposure to uncertainty about the future might explain the more severe decrease in ADL process ability than in the ADL motor ability, as psychological symptoms and stress symptoms often affect the ability to plan and perform an ADL task (Fisher & Jones, 2010, p. 15-29).

The low ADL ability measures, which indicated a potential need for assistance at the level of doing heavy housework and shopping, and for some participants even assistance with light housework, home maintenance tasks and self-care should be taken into consideration in order to protect the asylum seekers from further deterioration of the ADL ability and isolation.

## **Satisfaction with daily occupations**

Contemplating the experience of lack of occupations, as the participants in Study I described, the study of satisfaction with daily occupations in Study IV complemented the lifetime perspective of occupation. Also the low ADL ability described in Studies II and III might be reflected in the satisfaction with daily occupations. The results from Study IV showed a low level of satisfaction with daily occupations among the asylum seekers. Considering the limited number of activities in the centres, and the lack of activities related to the participant's earlier occupations, this was not surprising. Previous research has generally indicated that there are association between health-related factors and a person's perception of activities (Eklund & Leufstadius, 2007), but this was not the case in Study IV.

### *Access to activities*

The results from Study I indicate that when a large proportion of one's time is spent doing nothing, or when merely filling time with activities that are not engaging, there is a risk of decline in satisfaction with daily occupations, and, as Study III showed, also general well-being. It is likely that the occupational deprivation that the participants from Study I experienced is reflected in the dissatisfaction of the larger sample, as they also were subjected to few opportunities for feeling engaged, challenged and competent through being engaged in occupations.

The limited activities available could explain the low level of satisfaction, even though looking at the numbers of activities is not in itself an indication of whether a person perceives general satisfaction with daily occupations, self-rated health and well-being. It seems to depend on the area of activity, e.g. work/study, leisure, home chores and self-care, which all influence the satisfaction in different ways (Eklund & Leufstadius, 2007). Especially time spent in work has shown to be an important aspect of the actual doings that are of importance to self-rated health and well-being (Eklund & Leufstadius, 2007). Specifically fulltime work, as opposed to part-time and no work, has shown to be positively related to health and well-being among adults (Rosenthal et

al., 2012). Therefore the lack of time spent on work and/or studies could possibly play a large role in the low satisfaction score and eventually influence health in the sample, but this area needs further research. Also too much time spent on self-care activities and sleep has shown to be associated with a low satisfaction score (Eklund et al., 2010). As the participants did not have work or studies to attend to, they were at risk of such a situation.

### *Satisfaction with daily occupations*

The satisfaction score in this sample showed a lower level of satisfaction when compared to people with severe mental illness, as shown in a Swedish study (Argentzell et al., 2012); and healthy Danes (Eklund & Morville, 2013) whose ratings were 40% higher.

Many factors might play a role regarding the low satisfaction score in Study IV. The findings may be due to restrictions on particularly work and education. The results from Study I showed that the activities available had very little or no symbolic value to the participants and could point at the lack of symbolic value and meaning as factors which might reduce satisfaction. That the sample had such a low level of satisfaction with daily occupations is similar to the findings in Farnworth's (2004) study of young offenders. These described that a lack of engaging and challenging occupations and a preponderance of passive activities led to low satisfaction with time use and a state of boredom (Farnworth et al., 2004). Not only the lack of activities, but also the lack of a structure in daily life, has shown to be related to low satisfaction (Eklund et al., 2010), negative stress and boredom, which might as well come from doing nothing as doing too much (Eklund et al., 2010; Farnworth, 1998; Zuzanek, 1998). For asylum seekers, forced migration means separation from their family and a complete change of their daily occupations and routines, compared to those that previously structured their day (Bhugra & Becker, 2005). The imbalance that arises when a daily structure is interrupted might be a factor in the low satisfaction score, especially as the possibility to fill time with activities is as limited as it is in an asylum centre.

The association between education and activity level ( $r_s=0.319$ ;  $p=.037$ ) found at baseline in Study IV suggests that persons with a higher education are aware of the importance of staying busy, as was shown by the well-educated participants from Study I. The association, however, was not found at follow-up and nor was there an association between satisfaction and education at baseline or follow-up. The results could suggest that educational level to a certain extent can help support the activity level, but might not enable satisfaction. The statistically significant correlation between ADL process measures and activity level ( $r_s=0.356$ ;  $p=.019$ ) found at baseline in Study IV, suggests that those with higher ADL process skills might be able to change and adapt the environment to their advantage. Both education and ADL process measures at baseline had a relation to the activity level and seemed to have helped maintain the activity level, possibly through the knowledge of the importance of staying busy and the skills to adapt and change the environment. However, the associations between ADL process measures, education and activity level was not present at follow-up. It seems reasonable to assume that the moderate to strong associations between psychological well-being

and activity level at follow-up could possibly be related to the participants' ability to stay busy from baseline to the follow-up, but this needs to be further investigated.

An association between ADL process measures and the satisfaction score ( $r_s=0.35$ ;  $p=.021$ ) was also found at baseline in Study IV, and as with the activity level the association was not present at follow-up. As with the activity level, the associations between ADL process measures and the SDO variables may indicate that those with high process skills were able to maintain a range of activities and might thus be able to perceive a higher satisfaction. At follow-up, however, the association between AMPS process measures and the SDO variables were lacking, but this might be due to the number of dropouts from the sample, and this is an area that needs further investigation.

The baseline results in Study IV showed that there were no statistically significant associations between WHO-5, MDI and satisfaction with daily occupations, as opposed to earlier research, which has shown clear associations between health-related factors and satisfaction with daily occupations (Eklund et al., 2010; Leufstadius, Erlandsson, & Eklund, 2006; Sandqvist, Akesson, & Eklund, 2005). This association was, however, found at follow-up confirming the studies of associations between occupational factors and well-being. Staying busy, even though the activities might not be satisfying (Study IV) or meaningful (Study I), seems to have been very important to general well-being as the association between WHO-5 and activity level ( $r_s=0.770$ ;  $p=.001$ ) was strong at follow-up. This was also seen regarding the association between MDI and activity level ( $r_s=-0.566$ ;  $p=.028$ ), which suggests that any activity may have helped prevent ill health and maintain well-being in the asylum seekers' at follow-up. Strong statistically significant correlation between WHO-5 and the satisfaction score ( $r_s=0.732$ ;  $p=.002$ ) at follow-up also indicated that the participants might have tried to cope by filling their days the best they could and to create satisfaction from the activities at hand. This is aligned with the results from Study I, where the participants tried to stay busy and structure a day, using the activities at hand.

As mentioned earlier pain is one of the predominant physical complaints in the asylum seeker population (Masmas et al., 2008) and specifically the torture survivors suffer from pain (Amris & Williams, 2007; Masmas et al., 2008), which is often associated with a limited range of activities (Crooks, 2007; Taylor et al., 2013). Considering that 77% of the participants at baseline had been subjected to torture it was not surprising that an association between worst pain and activity level ( $r_s=-0.321$ ;  $p=.038$ ) was found at baseline. Though not statistically significant, a moderate association between current pain and activity level ( $r_s=-0.395$ ), were seen at follow-up. It seems plausible that such an association could influence activity level, but further research is needed. Regarding the lack of association between torture and the SDO variables, an association between physical torture and satisfaction ( $r_s=0.398$ ) was in fact seen at follow-up, though not statistically significant. In order to further understand the role of torture in relation to occupational satisfaction, this should be studied in larger populations.

To sum up, the findings suggest that anything one could occupy oneself with might positively influence psychological well-being, though not necessarily be perceived as satisfactory. The relations between ADL process ability, education and the SDO vari-

ables are findings that need further research in larger populations, as it might help target those in need of support to experience well-being through occupations and maybe help prevent illness during their stay in an asylum centre. Also further research regarding the role of torture in relation to activity level and satisfaction is needed.

## **Torture, health and occupation**

The results in Studies III and IV showed a significant increase in psychological symptoms and pain and a decrease in self-rated health after time spent in an asylum centre, all which are well described in other studies (Hallas et al., 2007; Ryan et al., 2008; Steel et al., 2011). The high ratings of distress as well as low ratings of general well-being and health, all had associations to occupational satisfaction, activity level and occupational performance. Torture, on the other hand did not seem to have a substantial influence on satisfaction with daily occupations, but regarding occupational performance, Study III showed that exposure to physical torture could be a predictor of decline in ADL motor ability.

Torture is known to be associated with both psychological and physical symptoms, but the results in Study II did not reveal any difference between tortured and non-tortured. This was opposed to earlier studies (Masmas et al., 2008) and the sample in Studies III and IV was too small to do such an analysis, since most participants were torture survivors. The large number of torture survivors was not expected, as earlier research has indicated the proportion of torture survivors in an asylum seeker population to be between 20-45% (Masmas et al., 2008; Steel et al., 2009). The Studies II to IV may thus not be sufficiently powered to show such differences in self-rated health variables, and further methodological issues regarding this will be discussed below.

Torture might not be the only factor contributing to the development of psychological distress. The symptoms may be caused by pre-migration conditions such as experience of armed conflict, civil unrest, separation from and uncertainty about the family and the flight itself. Also secondary traumatisation that many relatives to torture survivors experience and the possible lack of daily structure, as expressed in study I, may have a negative impact on psychological health. The results from Studies I and IV also point at occupations as an important factor in maintaining psychological health and well-being in the asylum seeker sample.

The prevalence of pain was high in the sample and thirty-one (72 %) of the participants in Study II reported that they suffered from a pain problem. This was not necessarily constant pain, which was reflected by a low mean score on VAS current pain in the sample. Twenty-eight (65%) of the participants reported that the pain problem had been present for more than six months, indicating that there could be persistent pain. The likelihood of a neuropathic pain component based on the cut-off algorithm of the Pain Detect Questionnaire (Freyenhagen et al., 2006) was found in four (9 %) of the participants in Study II. Also the participants at follow-up in Studies III and IV had a high prevalence of pain, as 13 out of 17 (76%) suffered from pain problems. The



sample showed a statistically significant increase over time in both current and average pain. Just as other studies of asylum seekers and torture survivors have shown (Masmas et al., 2008; Amris & Williams, 2007), common characteristics of the constellation of symptoms found in this thesis were regional or generalized musculoskeletal pain. Widespread pain, defined as pain in three or more body regions, were reported by 30 % in Studies II to IV and the duration of pain also indicated a possibility of the presence of persistent pain in the sample. The increase in pain and constellation of symptoms found at follow-up are also seen in other populations, such as persons suffering from chronic widespread pain and/or fibromyalgia (Amris et al., 2011). The study by Amris and colleagues (2011) showed that their sample suffering from fibromyalgia had a low level of ADL ability as was seen in the sample in this thesis. The low ADL ability found at baseline and the decline after 10 months could both be due to the accumulated exposure to physical torture, but the increase in pain seen from baseline to 10 months later could also be part of the explanation.

That torture and pain are related are well-described, but the relation to daily occupations and ADL ability has yet to be well researched.

## Methodological considerations

In the following some of the methodological and ethical issues associated with asylum seekers and torture survivors will be discussed.

Studying a population of asylum seekers called for a range of reflections on how to assess the variables described in this thesis and to act ethically in the process. The fact that the participants had the possibility to develop trust in the author made the data collection easier as the participants were open, interested and willing to participate at follow-up. Another advantage of this was that the participants were not subjected to several persons doing tests. That the same interviewer (the author) performed all the data collection at both baseline and follow-up may have inferred some bias regarding the interviewer-rated variables. Precautions were taken during the data collection, as the author at follow-up did not examine the baseline results before commencing on the interviews and observations. The final decision of whether the participant had been exposed to torture was taken after the data collection at baseline and was not made by the author herself.

### Assessing occupation

#### *Using a narrative approach in a lifetime perspective*

Narratives are useful in research precisely because storytellers interpret the past rather than reproduce it as it was. The 'truths' of narrative accounts are not in their faithful

representations of a past world, but in the shifting connections they forge among past, present, and future (Mattingly, 2010, p. 217).

A narrative is usually the story of an individual (Riessman, 2005), and as such might collide with a different cultural perspective, where the focus is not upon the individual, but on the extended family. Narrative descriptions exhibit human activity as purposeful engagement in the world, which is not just on an individual level, but also includes a collective level, as the stories incorporate the social interaction (Mattingly, 2010, p. 48). The narrative approach in this thesis was used as a way of capturing the occupational deprivation in an asylum centre, across backgrounds and, to a certain extent, culture. The strategy of collecting data over time as well as the narrative approach has possibly led to more substantial data, as the author was able to get to know the participants and their way of expressing themselves linguistically and vice versa. Analysing data in the thematic way as used here, is a way of moving from stories to common elements, which is also known as a paradigmatic analysis of narratives (Polkinghorne, 1995). Another way of analysing narrative material is to do a narrative analysis, which is where the events and happenings are synchronised into a story (Polkinghorne, 1995). The narrative analysis could have been applied to the data, but the results would not have given the same thematic knowledge as the one sought for in Study I.

### *Assessing daily occupations*

A range of different assessments may be utilised when assessing occupations (Christiansen et al., 2005, p. 340). The instruments do not need to be restricted or developed to specific diagnostic groups, as daily occupations are a part of daily life for everyone. However, an instrument might not be appropriate or possible to administer to all groups. The instruments below were chosen as both had been tested on different diagnostic groups, as well as healthy populations. Furthermore, the instruments supplemented each other as they measured different dimensions of occupation, i.e. performance (Fisher & Jones, 2010) and satisfaction (Eklund, 2004; Eklund & Gunnarsson, 2008).

### *AMPS*

AMPS is one of the best known and most widely used instruments for assessing ADL ability. It has robust psychometric properties and its reliability and validity have been proven in numerous studies. The studies in this thesis seem to be the first studies to apply AMPS on an asylum seeker population. None the less, using the AMPS proved easy to administer, both regarding the choice of ADL tasks and the participants' understanding of the aim of performing the tasks. Though the range of ADL tasks that were possible to perform was limited due to the physical environment, AMPS proved to be both feasible and sensitive enough to detect differences between participants and between baseline and follow-up measures.

It could be discussed whether applying AMPS only once at baseline and once at follow-up might reduce the validity of the measures obtained, due to fluctuations in ADL ability at each measurement. A previous study by Wachrens et al., (2010) showed



that AMPS measures remains stable in groups similar to the present sample regarding physical complaints, such as persons suffering from chronic widespread pain.

### *SDO*

The SDO was developed as a tool for measuring satisfaction with daily occupations. In order to assure that the questionnaire could be used in a Danish version, its psychometric properties were tested, showing a satisfactory internal consistency and criterion and concurrent validity (Eklund & Morville, 2013). The SDO includes a question regarding work, and as some asylum seekers work illegally, there may be some underreporting, even though the author reminded the participant that the data was confidential before asking questions. Dividing activities into specific categories is not universal, but culturally specific (Hammell, 2004), and such concepts as leisure are not known in all cultures, which might have led to errors in the data collection. The use of trained interpreters has hopefully reduced the risk of error.

In order to prevent the problem of numerical rating (discussed below) used in the SDO, a score sheet using both numbers and smileys was developed. This was understood by both illiterates and participants with a knowledge of the Arabic numerals.

## **Assessing torture and health of asylum seekers**

### *Defining torture*

The results of the study incorporating torture may be dependent on the definition of torture. According to Green and colleagues (2010), a majority use either the UN definition (1984) or the definition by WMA (1975) as in this thesis, but many do not state which definition they use. This poses a problem regarding comparisons of research, as much of the literature referenced in this thesis does not include a definition of torture. This should be noted when comparing the results in this thesis to other works, whose findings might have proved different where an alternate or no definition was used.

Taliban is not a public official body, and as the Taliban executed some of the torture described in this thesis, it would not have been torture according to the UN definition (1984). This would have diminished the prevalence of torture survivors in this thesis. Regarding the high prevalence of torture in this sample, Masmak and colleagues (2008), who also used the WMA definition (1975), found that the prevalence of torture from the selected countries tended to be higher (55%) than in other nationalities. The selection of nationalities in this thesis may therefore have influenced the frequency of exposure to torture in the study sample. It should be noted that the data collection took place in the spring of 2011, around the same time as the civil war in Syria started, which may also have influenced the large prevalence of torture survivors.

### *Assessing torture*

One of the problems with measuring torture is that the concept of torture is very dependent on cultural understandings of what constitutes torture. What is defined as torture in this thesis would in another cultural context be a normal part of being arrested or imprisoned. The significant difference ( $p=.011$ ) found between the non-participants and participants in this thesis, might be due to the fact that the participants were asked about exposure to specific methods of torture, where the non-participants were asked a single yes/no question about whether they had been exposed to torture.

Cultural differences are not only found in the understanding of torture, but also in the torture methods used in different countries and cultures (Quiroga, 2005). Culture specific assessments of torture are thus needed. For this thesis a specific questionnaire was developed, based on what has been described as the most common torture methods in the countries chosen. The use of a checklist was aimed at the specific incident and questions preceding the torture checklist regarding arrest and imprisonment might have strengthened the report of torture, as the author asked if anything occurred during arrest or imprisonment before commencing on the torture checklist. By using the checklist, an image emerged of whether the participant had been exposed to torture as defined by WMA (1975).

### *WHO-5 and MDI*

Danish versions of the WHO-5 (Bech et al., 2003) and the MDI have been validated (Bech et al., 2001). Both are based verbal rating scales which proved easier to administer in the present studies than the use of visual scales.

Most instruments used to screen for psychological and physical health have been developed and validated in a western context. Numerical rating scales are well-known and routinely used in the Western world and using instruments developed and validated in a European context might pose problems in studies with other populations. Therefore both the WHO-5 and the MDI were checked for internal consistency, using the data from baseline, and both instruments proved satisfactory. Using verbal statements during the data collection proved to be easier than putting a number to a certain experience of pain or self-rated health.

### *Pain measures*

As the expression of pain is culturally diverse, measuring pain is also a challenge (Williams & Volkmann, 2010). The use of PDQ, was based on its ability to detect the presence of neuropathic pain (Freynhagen et al., 2006), which is often seen in torture survivors (Amris & Williams, 2007; Thomsen, Eriksen, & Smidt-Nielsen, 2000). The PDQ, just as the SDO, posed some problems regarding the use of a visual scale. However the drawing of pain locations, which is part of the PDQ, was easy to administer, as well as questions based on verbal ratings relating to somato-sensory symptoms. Also questions of pain duration and pain location were easy to administer.

## Working with an interpreter

The choice of using only instruments in Danish during the data collection for this thesis was based on the notion that having yet another chain of language would further increase the possibility of errors in Studies II-IV. Investigating health, torture and trauma is a delicate matter and using an interpreter added an additional variable, which is important to discuss in relation to the trustworthiness of the data.

In order to include a representative sample using an interpreter was deemed unavoidable. It may also have minimised selection bias, as non-respondents often have poorer language skills and lower socioeconomic status, and socially vulnerable groups are less likely to participate in surveys (Harpelund, Nielsen, & Krasnik, 2012). It is assumed that the use of an interpreter with all participants to some extent has prevented systematic influence on the findings, as the results did not show any statistically significant difference between the participants and non-participants regarding age, education, marriage or gender.

A correct interpretation is not necessarily verbatim; it is about finding 'conceptual equivalence' (Ingvarsdotter, Johnsdotter, & Östman, 2012). The interviewer found it necessary to establish contact with and cooperate with as few interpreters as possible in order to ensure the quality of the interpretation. During the initial introduction to the participants, interpreters who clearly elaborated on a simple sentence were asked if they said more than the interviewer or participant had said. Most admitted doing so, and declared they wanted to explain what the participant or interviewer had said. The interpreters used during data collection were asked to keep to the sentences uttered, and to ask the interviewer to clarify if the participant did not understand the question. After each session, problems and cultural differences were discussed between interviewer and interpreters in order to further qualify the data collection. This also served as a debriefing for both author and interpreter, when the content of the interviews had been particularly disturbing.

None the less, regardless of how many precautions is taken, the use of an interpreter adds the possibility of errors during data collection (Ingvarsdotter, Johnsdotter, & Östman, 2012) and this should be taken into account when interpreting the results from this thesis.

## Statistics

Conducting longitudinal studies of asylum seekers is not without problems, as illustrated by the present studies, as asylum seekers, due to their legal status, either gain refugee status or are expelled from the country. The population as a whole and even within the small sample in this thesis was very heterogenic, particularly in regard to the level of education. This points to the need for including more asylum seekers in future studies, though the participants in Studies II-IV made up 24% of the available population at the time.

The follow-up data were based on only 17 participants, which in some regards limited the statistical power of Studies III and IV. Due to the dropout and a high prevalence of torture survivors in the sample, a somewhat different sample than intended was obtained. Given the relatively small sample size and a predominance of torture survivors in the overall study sample the studies may have been underpowered to detect a group difference between tortured and non-tortured regarding self-reported measures. Thus the studies II to IV are at risk for type-II errors.

Studies II and III were sufficiently powered to detect any change in the AMPS measures, and differences between participants, but may not have been sufficient to detect changes in the SDO variables.

In study IV some of the non-significant correlations between self-rated variables and the SDO variables at follow-up were above the  $r_s=0.350$ , which usually is interpreted as a moderate correlation (Field, 2009), but without statistical significance. Relationships of that size could be of importance and further research is needed in order to investigate whether such associations can be replicated in larger samples.

## **Ethical considerations**

Danish legislation did not require any approval from an ethical committee regarding this study (Retsinformation, 2011). Nevertheless ethical permission was applied for, in order to ensure that the study did not violate any legislation or ethical principles. The studies in this thesis might not have been feasible under stricter legislations, but it could be argued that avoiding research on asylum seekers and torture survivors would be even more questionable from an ethical viewpoint, as they are one of the groups in society with the greatest need for adequate intervention.

### *Ethics in relation to research on asylum seekers*

During the planning of the Studies II-IV using the Harvard Trauma Questionnaire (Mollica, Caspi-Yavin, Bollini, Truong, Tor, & Lavelle, 1992) was discussed as an option and whether any physical assessment of pain should be part of the instruments used. It was decided not to include any of the assessments, as they might trigger pain and/or flashbacks and compromise the person's welfare. It was found unethical, as the participants did not have access to any treatment following the participation in the studies (DIS, 2013b). By consulting with experienced researchers and the Red Cross health-care personnel, the author tried to take precautions against provoking any pain or suffering.

By applying both written and thorough oral introduction and information to all, the person could accept or refuse participation and the persons' rights and autonomy was respected. During the initial introductions many were wary of participating for fear of retribution, as they were afraid that either the author or the interpreter would reveal information to the authorities. After further information regarding voluntary participation, anonymity of identity, and confidentiality of the data, most felt secure in their

decision, and those who wavered were informed that they could come back at any time if they wanted further information.

Working with such a vulnerable population requires ethical considerations, regardless of legislation. As cited earlier in this thesis the Helsinki Declaration (WMA, 1964) specifies that research with vulnerable groups should be done based on the principles of beneficence and non-maleficence and only if there is a reasonable likelihood that this population stands to benefit from the results of the research.

The research within the field of asylum seekers so far primarily consists of descriptive studies, as the ones including intervention are usually limited to persons who have received asylum or are part of special intervention programmes for torture survivors. This thesis has a descriptive purpose in order to be able to develop adequate rehabilitation intervention targeting occupation, or even better, prevent the problems related to occupations described in this sample.

# Conclusion

This thesis is the one of first steps in describing asylum seekers and torture survivors' occupation-related problems, on which an occupation targeted rehabilitation, can be based. The thesis is based on explorative studies of asylum seekers and is the first focusing on occupations, and should thus be seen as mainly generating hypotheses and research questions for future research. The results of the thesis, however, point to a need for developing adequate occupation-focused interventions for asylum seekers and torture survivors. It is the, not wholly unambitious, hope of the author that the thesis will be a step towards interventions targeted at enabling occupation for asylum seekers and torture survivors.

The results showed that when a major change in a person's life-situation, such as fleeing, and lack of occupations occurs, it was followed by depression and general health problems, as seen in the asylum seeker sample in this thesis. The findings suggest that by having a daily life dominated by limited and unsatisfactory occupations, there is a risk of not being able to maintain and/or enhance the competencies and performance abilities, important for developing and maintaining physical, mental and social well-being. The findings in the case study and the statistically significant association between the accumulation of physical torture methods and ADL motor ability shows that torture might not only influence health, but also occupation regarding skills, and on the lifetime and daily levels too.

"I want to stay here and live a normal life, like others. I want to be sure that I'm in a safe place. I want peace and quiet now. This is all I want." 25 year old Iranian male.

Though this thesis covers meaningful occupations, it does not cover what is the most important and meaningful aspect in an asylum seeker's life. The above quote shows the need for a 'normal' life as expressed by a young man who had been exposed to torture, but also the need to be sure to be in a safe place. A 'normal' or daily life is the focus of occupational therapy and occupational science and therefore it is imperative that occupational therapists take part in the development of interventions in order to enable daily occupations for a group as vulnerable as asylum seekers and torture survivors.

Another important aspect, not covered in this thesis, in relation to asylum seekers' and torture survivors' occupation-related problems is the one of gender differences. It was not part of this thesis, but a gender difference could very well influence occupations, but this is yet again another topic which needs further research.

Occupational therapists and other health-care workers primarily meet asylum seekers and torture survivors in ordinary practice, which seldom leaves room for the specialised treatment needed. Due to the lack of knowledge and maybe even avoidance of including such matters as torture and trauma into occupational therapy research and practice, there is a risk for lack of adequate treatment.

However this thesis suggests that support in finding meaning and purpose through occupations, structuring daily life and maintaining ADL ability is needed. Additionally, the consequences of time spent in a centre and the experience of occupational deprivation might negatively influence the possibility of a transition back to a balanced and satisfying daily life, once the asylum seeker is granted his or her residence permit. The new Danish legislation allowing for accommodation outside the centres and the opportunity to seek paid employment, may prevent further loss of occupations and decline in ADL ability and health as described in this thesis. Though a very positive development in the Danish legislation, this opportunity is only eligible six months after entry, and the asylum seeker has to be granted permission to do so. The findings in this thesis indicate that some have a need for rehabilitation from the time at their arrival, and that some had developed a need after only 10 months. In other words, it is still imperative to develop specialised knowledge and intervention targeted at enabling occupations among the target group. Identifying and targeting those at risk or in need of rehabilitation at arrival and applying adequate rehabilitation intervention before the transition into the host country would enhance quality of life for the asylum seeker, and possibly even make the transition easier.

# Implications for research

The problems related to occupation described in this thesis show that it is imperative to initiate further research within occupational therapy in order to be able to develop adequate rehabilitation interventions targeted at enabling occupations for asylum seekers and torture survivors as well as describing the group in more detail. Due to limited knowledge, further research should be initiated incorporating both researchers and clinicians not only within occupational therapy, but also other professionals within health care and social work.

This thesis is the first to describe occupation on three levels in a group of asylum seekers and torture survivors and further research within this field could be:

- Development of programmes, focusing on the prevention of the experience of occupational deprivation, decline in satisfaction with daily occupations and ADL ability during the asylum period.
- Development of special rehabilitation programmes for asylum seekers and torture survivors, focused on enabling occupation and the transition back to 'normal' life.
- Development and/or test of adequate research methods are a must. Even though human occupation is universal, and all humans have occupations related to needs and wants, the occupation-centred tests developed and tested in a western context should be further tested and adapted to suit the sample group in question.
- A specific focus on the value of occupations and its relation to sense of coherence and/or the ability to develop resilience could be relevant factors to include in research on asylum seekers and torture survivors.
- Assessing the relationship between ADL ability and the SDO variables in larger samples of asylum seekers and torture survivors.
- A focus on the importance of a structured day in order to see whether this has any influence on health and wellbeing among asylum seekers and torture survivors, and whether there are any differences between tortured and non-tortured.
- Sufficiently powered longitudinal studies, including larger samples of both tortured and non-tortured asylum seekers, are needed in order to describe the difference, if any, in problems related to occupation and to target rehabilitation intervention adequately.



- Sufficiently powered studies focused on whether there are any gender differences regarding occupation related problems.

# Dansk sammenfatning/Danish summary

## Baggrund

Aktiviteter og aktiviteters betydning for mennesker er omdrejningspunktet for ergoterapi og aktivitetsstudier. Denne Ph.d. afhandling har et aktivitetsperspektiv, baseret på at mennesket er et aktivt væsen, og at man gennem aktiviteter kan opnå livskvalitet i ens hverdag. Aktiviteter er her ment som deltagelse i arbejde, leg, husholdning eller i al almindelighed de aktiviteter, som er nødvendige og/eller ønsket, og som giver mening i den socio-kulturelle kontekst man befinder sig i.

Faktorer som fremmer livskvaliteten er gennem aktiviteter at kunne tage vare på familie, venner og andre, at kunne bibeholde evnen til at engagere sig og deltage i dagligdagen og tage beslutninger vedrørende ens eget liv og aktiviteter. Om der er mulighed for dette er afhængigt af om de fysiske, social og legale omgivelser giver adgang til meningsfulde aktiviteter og dermed livskvalitet. Ved at være i omgivelser som ikke støtter muligheden for at have en meningsfuld hverdag, indskrænker det menneskers mulighed for at kunne deltage og engagere sig, og dermed indskrænkning og tab af livskvalitet.

## Asylansøgere og mangel på aktivitet

Ved at flygte oplever asylansøgere en stor ændring i deres liv (Bhugra & Becker, 2005; McElroy et al., 2012), som påvirker deres hverdag og livssituation på mange niveauer. Asylansøgere er en gruppe i samfundet som ikke har samme mulighed for at deltage i samfundet på lige fod med resten af befolkningen i værtslandet, da de er afskåret fra arbejde og uddannelse i længere perioder (DIS, 2013b). Ændringer i livet er i sig selv ikke noget som kun asylansøgere oplever, men problematikkerne opstår når muligheden for at få nye aktiviteter og tilpasse sig til de nye omgivelser er nærmest ikke-eksisterende på grund af deres legale situation (Whiteford, 2000). Livet i et asylcenter giver mulighed for aktiviteter, men i begrænset omfang, og ikke altid noget hvor asylansøgeren kan bruge sine kompetencer. Ved gennem længere tid at være foruden de aktiviteter, som er med til at give dagligdagen mening og noget at stå op til, oplever mange asylansøgere et aktivitetstab (McElroy et al., 2012; Whiteford, 2005). Dette kan på sigt være med til at asylansøgeren endvidere oplever et tab af identitet og selvværd (Bhugra & Becker, 2005;

McElroy et al., 2012). Tabet af aktivitet kan medføre at asylansøgeren ikke kun oplever tab af identitet, men på sigt også tab af de kompetencer og evner han/hun besidder, hvilket i sidste ende kan medføre dysfunktion (Whiteford, 2000), og der af følgende problemer med integration i værtslandet, hvis hun eller han opnår asyl.

## **Asylansøgere og sundhed**

Det er vel beskrevet at asylansøgere, og især de som har været udsat for tortur, har dårligere helbred end den almene befolkning (Masmas et al., 2008), og end de som har fået tildelt asyl (Carswell et al., 2011; Ryan et al., 2008). De mest almindelige symptomer blandt asylansøgere er psykologiske symptomer, så som generaliseret angst, depression, dårlig søvn og koncentrationsbesvær, som ofte er udløst af stress eller traumer. Smerter, både lokale og generelle, er det største fysiske problem. Dette er ikke usædvanligt, da en stor del af personer med traume-relateret stress ofte lider af smerter (Egloff, Hirschi, & von Känel, 2013). Smerter efter tortur kan ofte, men ikke altid, kædes sammen med tortur metoden, som eksempel sammenhæng mellem smerter i fødder og læg efter systematiske slag på fodsålerne (Amris et al., 2007). Disse helbredsproblemer, som ses hos både asylansøgere og torturoverlevende, medfører gerne problemer med at strukturere en hverdag og udføre hverdagsaktiviteter. Dette kan på sigt medføre isolation og yderligere tab af aktiviteter og evnen til at udføre aktiviteterne, samt nedsat livskvalitet.

## **Formål med de 4 delstudier**

Det overordnede formål med denne Ph.d. afhandling var at sætte fokus på de problemer, som asylansøgere i centre i Danmark oplever i forhold til aktiviteter set i et livsperspektiv, i relation til daglige aktiviteter og i udførslen af aktiviteterne. Ydermere var det formålet at beskrive tortur og helbredstilstand hos deltagerne, samt om dette påvirkede deres evne til at udføre hverdagsaktiviteter eller oplevelse af tilfredshed med de aktiviteter, som var til rådighed.

## **Metode**

Studie I var baseret på feltobservationer, uformelle konversationer og narrative interview med tre mænd fra henholdsvis Afghanistan og Iran. En tematisk analyse blev brugt for at afdække om deltagerne oplevede tab af aktiviteter, samt om de kunne bruge deres kompetencer fra tidligere aktiviteter under deres tid i et asylcenter.

Studierne II til IV var baseret på interview spørgeskemaer og observation af asylansøgerens evne til at udføre en almindelig hverdags opgave. Treogfyrre deltagere fra Afghanistan, Iran og Syrien blev inkluderet, og 17 af disse deltog i en op følgende undersøgelse efter 10 måneder. Spørgeskemaerne omhandlede tilfredsheden med daglige aktiviteter og antal aktiviteter, samt om asylansøgeren havde været udsat for tortur og

om asylansøgerens selvvaluerede helbred, hvad angår smerte, depression og alment velvære. Data blev opgjort med statistiske analyser.

## Kliniske implikationer

Resultaterne viste at asylansøgere oplevede tab af aktiviteter, på grund af de begrænsede muligheder. Dette medførte at de havde svært ved at opleve mening i hverdagen, da de ikke kunne udnytte de kompetencer de havde. De brugte de aktiviteter der var til rådighed, som en måde til at få tiden til at gå og til at fortrænge alle tanker om deres asylsag. De opgav lav tilfredshed med de aktiviteter som var tilgængelige, og havde nedsat evne til at udføre hverdags opgaver få uger (<4) efter ankomsten. Dette viste at nogle af asylansøgerne havde behov for hjælp til at klare hverdagen hvad angik indkøb eller tungere husholdningsopgaver. Nogle få havde ydermere behov for hjælp til påklædning og personlig pleje. Efter 10 måneder i et asylcenter var evnen til at udføre hverdags opgaver yderligere reduceret, i et omfang som var klinisk relevant. Antallet af aktiviteter og tilfredsheden med aktiviteter ændrede sig ikke efter 10 måneder, men viste en 40% lavere tilfredshed end raske danskere. En stor andel (77 %) af asylansøgerne havde været udsat for tortur. Størstedelen af asylansøgerene led af smerter, samt depression og lavt selvvalueret helbred. Dette forværredes, lige som evnen til at udføre aktiviteter, yderligere efter 10 måneder i et asylcenter.

Der var overraskende ikke nogen forskel i aktivitetsudførelse på torturerede og ikke torturerede ved ankomsten til Danmark. Efter 10 måneder fandt man en association mellem antal af fysiske torturmetoder, som deltageren havde været udsat for, smerte og de motoriske færdigheder. Der blev ikke fundet nogen associationer mellem tortur og tilfredshed og/eller antal aktiviteter, hverken ved inklusion eller 10 måneder senere. Psykologiske symptomer og smerte var associeret med antal aktiviteter og tilfredshed med aktiviteter efter 10 måneder, hvilket viste at de som oplevede større tilfredshed med aktiviteterne havde bedre selvvalueret helbred. Antallet af aktiviteter var også associeret til selvvalueret helbred, hvilket kan tyde på at jo mere man har at lave, jo bedre er ens helbred, til trods for at aktiviteterne ikke blev opfattet som tilfredsstillende.

Studierne peger på at der er behov for at iværksætte rehabiliteringsindsatser for de asylansøgere som allerede ved ankomst har nedsat evne til at klare en almindelig hverdag. Dernæst er der behov for at der iværksettes mulighed for at man kan forebygge fald i ADL evne, så der ikke i løbet af opholdet i Danmark opstår yderligere behov for rehabilitering.

Konklusionen er at nogle asylansøgere, og heriblandt tortur overlevende, ved ankomsten til Danmark havde nedsat evne til at udføre daglige aktiviteter og udviste behov for rehabilitering for at kunne klare en almindelig hverdag. Den nedsatte evne til at udføre aktiviteter faldt efter 10 måneder i et asylcenter, og dermed opstod der et øget behov for rehabilitering. Asylansøgerne gav ikke udtryk for tilfredshed med de aktiviteter, som var til rådighed, hvilket var relateret til deres selvvaluerede helbred. Derimod var der en positiv association mellem antal af aktiviteter og selvvalueret helbred ved followup.

Dette kunne tyde på at jo mere man har at lave, jo bedre er ens helbred, til trods for at aktiviteterne ikke blev opfattet som tilfredsstillende.

Det er derfor nødvendigt at intervenere overfor denne gruppe, så der ikke forekommer et stort aktivitetstab, tab af aktivitetsevne og lav tilfredshed, som kan medføre problemer med at varetage en almindelig hverdag, nedsat livskvalitet og dårligt helbred.

- Der er behov for udvikling af rehabiliterings og forebyggelses indsatser for asylansøgere og torturoverlevende, med fokus på deres aktiviteter og struktur i hverdagen, mens de opholder sig i et asylcenter.
- Der er behov for specielle rehabiliteringsindsatser for asylansøgere og torturoverlevende, som retter sig mod at fremme aktivitet og lette overgangen til et normalt liv i værtslandet.
- Da de fleste undersøgelses instrumenter er udviklet og afprøvet i en vestlig kontekst er der behov for at udvikle instrumenter og teste eksisterende, så de kan tilpasses målgruppen.
- Studier med fokus på aktiviteternes værdi, og den forbindelse der kunne være til oplevelsen af sammenhæng og/eller modstandskraft hos asylansøgere og torturoverlevende.
- Longitudinelle studier med flere deltagere og større statistisk styrke for at afdække om der er forskel på torturerede og ikke-tortureredes aktivitetsproblematikker, så rehabiliteringsindsatsen kan målrettes bedst muligt.
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