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Participation in everyday occupations among persons with stroke in Iran

Mandana Fallahpour

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An exploration of perceived participation, associated  
factors and lived experience

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***Dedicated with my love to:***

*My very kind parents who have generously filled my heart and soul with their pure love in each moment of my life, have been my best teachers and my best friends and have been all my reasons in my heart to be who I am ...*

## ABSTRACT

The general aim of this thesis was to explore and describe perceived participation in everyday occupations, and the factors associated with participation among persons with stroke in a sample from Iran. Furthermore, the aim was to describe and understand the lived experience of participation in everyday occupations following stroke.

This thesis was based on four studies. The first three studies were performed using quantitative methods and the last study used a qualitative method. In **Study I** the focus was on producing the Persian version of the Impact on Participation and Autonomy (IPA) questionnaire and the psychometric evaluation of the translated version to be used for persons with stroke. In **Study II** perceived participation and autonomy was described among persons with stroke, and different aspects of functioning and contextual factors associated with participation after stroke were explored and identified in the sample. In **Study III** the Persian translated version of the Occupational Gaps Questionnaire (OGQ) and the LiSat-11 checklist were produced and psychometrically evaluated to use for persons with stroke. Moreover, this study focused on describing occupational gaps after stroke and exploring their relation to different aspects of functioning and perceived life satisfaction. In **Study IV** the lived experience of participation in everyday occupations was explored among persons with stroke using the phenomenological approach.

The findings of **Study I** demonstrated that participation can be measured as two different but related dimensions, performance-based participation and social-based participation. The findings of **Study II** showed that most participation restrictions were perceived in autonomy outdoors activities. It also identified physical function, mood state, and access to caregiving services as the most influential variables associated with dimensions of participation. The findings of **Study III** supported the psychometric properties of the Persian versions of the OGQ and the LiSat-11, and found “helping and supporting others” and instrumental activities of daily living to be the most common occupations in which individuals perceived gaps in participation. This study also identified the combination of three factors of physical function (including ADL ability), motor function and perceived life satisfaction as being the most influential factors associated with occupational gaps after stroke. The findings of **Study IV** showed that in order for individuals to adapt to their new life after stroke and *be able to live their life*, both *doing* and *identity* should be addressed in rehabilitation as the aspects defining the phenomenon of participation.

In conclusion, this thesis contributes by generating new knowledge regarding the definition of the concept of participation. The findings highlight the importance of both dimensions in the facilitation of adaptation and participation in everyday occupations. Moreover, this thesis emphasises the importance of providing culturally sensitive rehabilitation based on the individuals’ needs and consistent with the sociocultural context when planning appropriate rehabilitation interventions. As a first exploration of participation in everyday occupations after stroke in an Iranian context, this thesis provides instruments for measuring participation and life satisfaction for use in clinical practice and research within rehabilitation in Iran.

Key words: stroke, participation, activities of daily living, autonomy, ICF, occupational therapy, rehabilitation, phenomenology

## LIST OF PUBLICATIONS

This doctoral thesis is based on the following four papers, which will be referred to in the text by the Roman numerals:

- I. Fallahpour, M., Jonsson, H., Joghataei, M. T., & Kottorp, A. (2011). Impact on Participation and Autonomy (IPA): Psychometric evaluation of the Persian version to use for persons with stroke. *Scandinavian Journal of Occupational Therapy*, 18(1), 59-71.
- II. Fallahpour, M., Tham, K., Joghataei, M. T., & Jonsson, H. (2011). Perceived participation and autonomy: Aspects of functioning and contextual factors predicting participation after stroke. *Journal of Rehabilitation Medicine*, 43(5), 388-397.
- III. Fallahpour, M., Tham, K., Joghataei, M. T., Eriksson, G., & Jonsson, H. Occupational gaps in everyday life after stroke and the relation to aspects of functioning and perceived life satisfaction. *OTJR: Occupation, Participation, and Health* (published online, in press).
- IV. Fallahpour, M., Jonsson, H., Joghataei, M. T., Nikbakht Nasrabadi, A., & Tham, K. Lived experience of participation in everyday occupations after stroke: a phenomenological approach (in manuscript).

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## LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
BI	Barthel Index
CI	Confidence Intervals
EPP	Empirical Phenomenological Psychology
FMA	Fugl-Meyer Motor Assessment
HADS	Hospital Anxiety and Depression Scale
IADL	Instrumental activities of daily living
ICF	International Classification of Functioning, Disability and Health
IPA	Impact on Participation and Autonomy
LiSat	Life Satisfaction checklist
MMSE	Mini-Mental State Examination
MnSq	Mean Square
MOHO	Model of Human Occupation
OGQ	Occupational Gaps Questionnaire
OT	Occupational Therapy
PCA	Principal Component Analysis
SD	Standard Deviation
SIS-16	Short version of Stroke Impact Scale
WHO	World Health Organization





# 1 INTRODUCTION

*“I just want to say, you are seeing me with my situation. Do you think I can recover by the Norouz fest (the Persian New Year/ spring fest)? (she starts crying...) Will I get better? Can I feel fine in my mind? Can I take care of my guests again by myself? Now when you are here in my home, I'd like to offer you a cup of tea by myself. I don't like to ask others to do that for me. I'd like to invite guests to my home and cook dinner for them by myself...”* (Quote from a participant in study IV)

During my clinical experience over all these years of working as an occupational therapist, I have got almost this same question from most of my clients diagnosed with stroke. I have been thinking about how difficult it is to answer this question posed by somebody who is looking at me with tears in her eyes, sad emotional pain, and a strong desire and wish to get back to her former life; to be able to participate in her desired occupation. However her question evoked a lot of other questions. Do we really give appropriate rehabilitation to persons with stroke in Iran and elsewhere? Do we really know what they need and how they wish to participate in their everyday occupations to be able to live their life again? Do we provide our rehabilitation services based on their occupational needs for participation? Are we giving services properly to enable persons with stroke to participate in everyday occupations? These and a lot of similar questions that make me scared of the responsibility that we have; that of doing our best to help them as rehabilitation professionals. My clinical experience reminds me of the rehabilitation structure and the current occupational therapy services provided for persons with stroke in OT clinics in Iran. It reminds me of the gap in giving occupational-based and client-centred occupational therapy services in the rehabilitation routines currently provided for stroke clients. Being a PhD student at the Division of Occupational Therapy at Karolinska Institutet gave me the great opportunity to learn about the critical approach and occupational perspective stressed by the education and research at the division. These two main approaches have taught me to critically ask questions in research and apply the occupational perspective, and use its potential for health and well-being to provide the best services in occupational therapy. This thesis aimed at acquiring more knowledge about participation in everyday occupations in my home country where occupational therapy is bio-medically focused and where there is a need to change our OT paradigm to a client-centred occupational-based approach. However the best solution is to build knowledge based on systematic

research and by going back to the individuals themselves as the main source of information provision concerning their needs and desires in rehabilitation. Therefore, the overall aim of this thesis was to explore and describe perceived participation in everyday occupations, and the factors associated with participation among persons with stroke in sample from Iran. Furthermore, the aim was to describe and understand the lived experience of participation in everyday occupations following stroke

## **2 BACKGROUND**

The focus of this thesis is on participation in everyday occupations, the associated factors and also the experiences of persons with stroke in an Eastern socio-cultural context, Iran. In order to facilitate an understanding of the focus of the study, and the rationale for the thesis, a theoretical background explaining the conceptual framework is provided in this chapter. The background aims at presenting the conceptual framework; providing an overview of the related concepts used in this thesis. Different theoretical perspectives have been used in order to obtain a better understanding of the focus of this thesis.

The main perspective governing the theoretical and conceptual framework of this thesis was the occupational perspective. This perspective was primarily based on human occupation as described by different theoretical models among which the Model of Human Occupation was prominent (Kielhofner, 2008) together with general occupational science assumptions as formulated by Townsend and Polatajko (2007). The International Classification of Functioning, Disability and Health (ICF) was also used in this thesis as the WHO's framework for classifying and measuring health and disability at individual and population levels. The phenomenological perspective as described by Empirical Phenomenological Psychological (EPP) method (Karlsson, 1995) was also used in a part of this thesis as the third perspective (study IV).

### **2.1 THE OCCUPATIONAL PERSPECTIVE**

The main focus of this thesis is on how persons with stroke perceive their participation in everyday occupations using both quantitative and qualitative methods. Therefore, occupation has become an important concept for consideration in this thesis. The occupational perspective was applied in all four studies in this thesis.

#### **2.1.1 Occupation as the core in occupational perspective**

This concept has been the central concern in both occupational therapy and occupational science disciplines and the main focus of education, practice and research. As Dunton (1919) states:

*“Occupation is as necessary to life as food and drink. Every human being should have both physical and mental occupations. All should have occupations which they enjoy, or hobbies. Sick minds, sick bodies and sick souls may be healed thru occupation.”(Dunton, 1919, p.10)*

In this thesis, *occupation* is defined as “groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)” (Townsend & Polatajko, 2007, p.17). In this definition, the term occupation refers not only to work, but also to all manner of human doing, be it self-care, productivity, or leisure. This definition emphasises the personal meaning and value in an individual’s everyday life and also the importance of cultural and environmental aspects in occupations (Townsend & Polatajko, 2007).

Participation in occupations of everyday life provides opportunities to acquire skills and competencies, to connect with others, and is a means of finding purpose and meaning in life. Enabling individuals to participate in everyday occupations that are meaningful to them, that provide fulfilment, and engage them in everyday life with others should be the main focus of occupational therapy (Law, 2002). In order to do so, there are basic assumptions that it is important to consider when performing studies about occupation. Dunton suggested two primary assumptions; that the occupation is a basic human need; and that occupation has the potential to be therapeutic (Dunton, 1919). These two main assumptions have led to further assumptions such as the *occupational perspective* stressed by Polatajko and collaborators (2007). To discuss this briefly here, they concluded that according to the first primary assumption mentioned above, occupation is a basic need for the human as an occupational being. Therefore engagement in occupation should be viewed as a basic human need and an important requirement for health and well-being. In other words, any possible reason that reduces an individual’s participation in occupation would negatively influence the individual’s health and well-being. Based on the second assumption, occupation has potential therapeutic value. Occupation brings meaning to life as it is deeply grounded in human existence. This meaning is acquired by the culture and the individual. Occupations contribute to the individual’s social and self-identity, they connect the individual to others and to his/her past, present and future. Occupations organise time and bring structure to individuals’ life, bringing rhythm to their days and organise their time, leading to the formation of habits and routines. And last but not the least, occupations are idiosyncratic, pointing to occupation as a personal experienced concept (Polatajko, et al., 2007).

In study III, a new concept named “*occupational gaps*” has been used to identify the gaps that might occur when an individual cannot participate in a desired occupation. Occupational gap refers to a gap occurring between what an individual wants and needs to do and what he or she actually does (Eriksson, Tham, & Borg, 2006). In study IV, an occupational perspective was used to describe the meaning structure of the lived experience with respect to the phenomenon which was *participation in everyday occupations*.

The occupational perspective used in this thesis is in accordance with Jonsson (2008) and Hammell (2009) who view the concept of occupation as a complex and experience-based concept in nature, dependent on the subjective experience for categorization and this is in accordance with a number of researchers’ corresponding view regarding participation (Borell, Asaba, Rosenberg, Schult, & Townsend, 2006; Haggstrom & Lund, 2008; Hammel, et al., 2008).

This thesis aimed at advancing our knowledge regarding “participation in everyday occupations”. In order to do so, it is relevant to start with the ICF general definition of participation which is the most common definition in use worldwide and then move on to more specifics relating to the applied theoretical model based on the occupational perspective as used in this thesis, with the ultimate goal of generating new knowledge regarding the concept definition.

### **2.1.2 Participation**

In this thesis “*participation in everyday occupations*” is viewed from the perspective of the WHO’s definition in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) and the concept of occupational participation used in *Model of Human Occupation* (MOHO) (Kielhofner, 2008).

The concept of *participation* according to the ICF has been defined as “involvement in a life situation” or “the lived experiences of people in the actual context in which they live” (WHO, 2001, p. 229). Participation as outlined by the ICF has become a key outcome of occupational therapy, rehabilitation and other disciplines providing health care services (Dijkers, 2010; Hemmingsson & Jonsson, 2005). This definition has been widely used as an international classification by multidisciplinary professionals in rehabilitation (Haggstrom & Lund, 2008; Hemmingsson & Jonsson, 2005). However

the ICF definition has been criticised for its lack of conceptual clarity in defining and explaining participation. The ICF definition of participations is vague and provides little specificity about what type of involvement is meant or which life situations are considered (Whiteneck & Dijkers, 2009). Furthermore, the ICF has been seriously criticised for excluding the subjective experience of the individual in the operationalisation of participation (Haggstrom & Lund, 2008; Hemmingsson & Jonsson, 2005; Ueda & Okawa, 2003) which is an obvious limitation since it ignores important components of the concept of participation (Hemmingsson & Jonsson, 2005). There is also a lack of differentiation between activity and participation in the ICF (Coster & Khetani, 2008; Perenboom & Chorus, 2003; Whiteneck & Dijkers, 2009). As a result, although improving participation is suggested as a crucial goal in rehabilitation, the clinical implication is limited by the lack of clarity concerning the operational definition of this concept (Haggstrom & Lund, 2008). As a consequence of this limitation this thesis will use both the ICF definition as the current international classification and an occupational perspective specifically applied in occupational therapy to define participation.

The concept “participation in everyday occupations” in this thesis refer to the concept of occupational participation used in the Model of Human Occupation (MOHO) (Kielhofner, 2008). The MOHO focuses on *human occupation* which refers to the doing of work, play, or activities of daily living within a temporal, physical, and socio-cultural context that characterizes much of human life (Kielhofner, 2008). The concept of *occupational participation* used by the MOHO refers to “engagement in work, play, or activities of daily living that are part of one’s sociocultural context and that are desired and/or necessary to one’s well-being” (Kielhofner, 2008, p.115). The MOHO emphasises that participation involves not only performance but also the subjective experience of engagement; and that occupational participation implies doing things of personal and social significance. Consequently, occupational participation is both personal and contextual. Participation in occupation might involve doing a variety of things. Each time a person does one of these separate acts, the person is performing. Therefore, according to the MOHO, *occupational performance* refers to doing an *occupational form*. Since individuals’ performance of occupational forms includes different things that are part of their everyday routines, habituation (roles and habits) can have an important impact on performance. Performance is also significantly influenced by the environment (Kielhofner, 2008).

The Model of Human Occupation is ultimately concerned with individuals' participation and adaptation in life occupations. The model stresses the extent to which individuals can participate in everyday occupations and achieve a state of positive adaptation. *Occupational adaptation* refers to the construction of a positive occupational identity and achieving occupational competence over time in the context of one's environment. This definition points to two distinct and interrelated elements of occupational adaptation. *Occupational identity* refers to who one is and wishes to become as an occupational being generated from one's history of occupational participation. *Occupational competence* refers to the degree to which one is able to sustain a pattern of occupational participation that reflects one's occupational identity (Kielhofner, 2008, 2009).

In this thesis studies I and II used the concept of participation as generally used by the ICF and studies III and IV used this concept from an occupational perspective as participation in everyday occupations. The concepts of occupational identity, occupational competence, and occupational adaptation were used in study IV.

### **2.1.3 Environment and culture**

The Model of Human Occupation stresses that occupation results from an interaction of the inner characteristics of the individual (volition, habituation, and performance capacity) with the environment (Kielhofner, 2008). The MOHO defines *environment* as the particular physical, social, cultural, economic, and political features within one's context that have an impact on the motivation, organisation, and performance of occupation (Kielhofner, 2009). Occupation and the environment have a reciprocal relationship in which each of them impacts on the other. The environment is multifaceted; it includes everything from the physical world to sociocultural mores (Townsend & Polatajko, 2007).

The MOHO stresses that since the physical and social environments are interpreted and formed by culture, it is important to recognise *culture* as a pervasive characteristic of the environment. Culture is defined as the beliefs and perceptions, values and norms, customs and behaviours that are shared by a group or society and are passed from one generation to the next through both formal and informal education (Kielhofner, 2008). Culture is the medium through which individuals make sense of their doing. Individuals of a culture engage in occupations that are part of that culture. Furthermore they



recognise the significance of what they do by virtue of how their culture views and makes sense of it (Yerxa, et al., 1989). There are a variety of subcultures within most cultures such as urban, rural, ethnic, and other subcultures (Kielhofner, 2008). It is important to consider culture as one of the variables in all forms and types of research as recommended by The American Occupational Therapy Association (Wells & Black, 2000).

In this thesis, a number of environmental factors were considered as variables in studies I-III. The sociocultural findings regarding the phenomenon of participation in everyday occupations were discussed in study IV. Moreover, the sociocultural aspects of participation in the findings were reflected upon in all four studies of this thesis. In studies I and II three instruments were translated into Persian following a translation and cultural adaptation procedure.

## **2.2 INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH**

The *ICF* was presented by the *World Health Organization* (WHO) in 2001. The ICF has provided a common framework and terminology, and an international and inter-professional basis for understanding, studying and describing health and health-related states for researchers, practitioners and consumers of health-related services. The ICF has organised the information into two parts: a) functioning and disability, b) contextual factors. The ICF emphasises that an individual's *functioning* and *disability* are considered to be dynamic interactions between *health conditions* and *contextual factors*. Functioning and disability are divided into two components. The first component is *body functions* and *body structures*, and the second component is *activity* and *participation*. Body functions can be defined as the physiological functions of body systems. Body structures are defined as the anatomical parts of the body such as organs and limbs (WHO, 2001).

The ICF defines activity as the execution of a task or action by an individual. Participation is defined as an individual's involvement in a life situation. This definition represents the societal perspective of functioning. The presence of a restriction in participation is determined by comparing the individual's participation profile to "that which is expected of an individual without disability in that culture and society" (WHO, 2001, p. 213). The ICF also defined participation as including the concept of

involvement which might further be defined as “taking part, being included or engaged in an area of life, being accepted or having access to needed resources” (WHO, 2001, p. 15). Activity and participation are classified within a common list, but are coded with two qualifiers, capacity and performance. Although the definition of participation emphasises individuals’ subjective experiences (the lived experience), using these two qualifiers indicates that the only way of coding participation in the ICF is through the observed performance. Thus, the ICF has limitations regarding the provision of information about how the subjective experience of participation in daily life should be taken into account.

The ICF has divided contextual factors into the two components *environmental factors* and *personal factors*. Environmental factors are defined as the factors making up the physical, social, and attitudinal environment in which individuals live and conduct their lives. These factors might influence the individual’s functioning. The environmental factors might have a facilitating or hindering impact on all components of functioning and disability. Personal factors are not further classified by the ICF (WHO, 2001).

In this thesis the ICF classification and terminology was used in studies I-III to categorise the variables and the definitions in the studies to be able to use the same international language for comparing and discussing the findings with possible studies from other countries.

### **2.3 THE PHENOMENOLOGICAL PERSPECTIVE**

The *phenomenological perspective* (Husserl, 1970) was used in study IV in this thesis, and integrated into the data analysis by using the Empirical, Phenomenological, Psychological method (EPP) (Karlsson, 1995). The EPP-method is a qualitative, descriptive and interpretive method focusing on describing the meaning structure of the phenomenon based on individuals’ life-world experiences (Karlsson, 1995). The psychological perspective in the analysis was replaced by an occupational perspective which focused on the participants’ everyday occupations experiences.

Phenomenological research which is based on the philosophy of Edmund Husserl (1859-1938), aims at better understanding the lived experiences and how the studied phenomenon presents itself through individuals’ lived-experiences in their life world, with the ultimate purpose of understanding the essence of the phenomenon (Husserl,

1970; Merleau-Ponty, 2002). Husserl believed that in order to solve the problem of a dehumanised science, the everyday human world should be reinstated as the foundation of science. He viewed phenomenology as the first philosophy and the guiding foundation for all scientific thinking. The way to accomplish the new foundation, as he believed it was “to go to the things themselves”. The phenomenological expression of “going to the things” means that, the researchers should stand in such a way that things can show themselves to them, and that “the thing” is understood as a phenomenon. The phenomenon is the central concept within phenomenology (Dahlberg, Drew, & Nyström, 2001).

In phenomenology, human experience is characterised by the *natural attitude*. The natural attitude as Husserl outlined it is the everyday immersion in one’s existence and experience in which we take for granted that the world is as we perceive it, and that others experience the world as we do. In the natural attitude we do not critically reflect on our action and response to the world, but we just do it, and we just are. The concept of *life-world* emerged from Husserl’s notion of natural attitude, and was later extended by Merleau-Ponty (2002) by emphasising the importance of *lived-world*, that is the world we have access to through our bodies. In Merleau-Ponty’s understanding, all knowledge that we develop is embodied knowing. The notions of subjective body and embodied knowing are other aspects of the natural attitude and the life-world approach. It is the *lived body* that offers the connection to the world and carries out all living actions (Dahlberg, et al., 2001). The lived body is the taken for granted place from which individuals exist and from which they attend and act on the world (Merleau-Ponty, 2002).

The reason for applying the phenomenological perspective in study IV in this thesis was to focus on describing and understanding the meaning structure of the phenomenon of participation in everyday occupations expressed and characterised in the participants’ described life-world experiences. This analytic approach made it possible for this thesis to extract the essential meaning of the phenomenon and discuss it at a theoretical level.

## **2.4 AUTONOMY AS A CONCEPT LINKED TO PARTICIPATION**

Literature regarding the conceptualisation of participation stresses the importance of aspects such as *subjective experience* and *individual perspective* in the

operationalisation of participation when assessing participation (Cardol, De Jong, & Ward, 2002b; Dijkers, 2010; Haggstrom & Lund, 2008; Hammel, et al., 2008; Whiteneck & Dijkers, 2009). One of the main serious problems with the operationalisation of participation in the ICF is introduced as the exclusion of subjective experience of autonomy (Hemmingsson & Jonsson, 2005). Cardol and colleagues noted that the concept of participation is fundamental for rehabilitation, but it is often measured in terms of normative outcomes rather than the subjective experience of individuals (Cardol, et al., 1999a; Cardol, et al., 2002b). They suggested that the concept of *autonomy* is crucial for the accurate operationalisation of participation and should be considered as a prerequisite for participation and thus the ultimate goal for rehabilitation. According to them, the concept of autonomy adds a personal perspective to the assessment of participation (Cardol, et al., 2002b). Perenboom and Chorus (2003) argued that participation and performance are not synonymous. They defined participation as involvement in life situations which also includes the concept of autonomy and this concerns to what extent individuals are able to control their own lives, even if they are not essentially performing the activities by themselves. Therefore, not only the actual performance is a key indicator for assessing participation, but also the fulfilment of personal goals and societal roles.

Autonomy can be viewed not only as a key determinant of participation (Cardol, et al., 2002b; Perenboom & Chorus, 2003), but also as a conceptual base for differentiating the boundary between activity and participation which was discussed in studies I and II. Autonomy, as Cardol et al. (2002b) concluded, is based on the notion of respect for the thoughts, will, decisions and actions of other persons. They referred to the individual-liberal view, which stresses freedom of choice and action, as the most influential model of autonomy in Western society. However research in this area has raised questions about whether the principles of autonomy and self-determination are truly respectful and acceptable for all people in all cultures and whether they are viewed in the same way worldwide. There are societies in which the societal rather than the individual concerns are prioritized (Wells & Black, 2000). In a recent study by Dijkers (2010) autonomy is categorised as the ability to make choices, to have control, independence, and self-determination.

Cardol and colleagues (2002b) note that autonomy is not a state of being, but rather something individuals develop in the course of their lives. They emphasised that in

order to understand the meaning of autonomy in relation to a disabling condition, it is essential to distinguish between decisional autonomy and executional autonomy. Decisional autonomy is the ability to make decisions without external restraint or concern. Self-realisation is an important product of decisional autonomy which is the individual's ability not only to make choices freely and independently, but also to shape his/her life into a meaningful existence which expresses individuality. They stress the importance of taking all aspects of autonomy into consideration in the rehabilitation process, decisional, executional, and self-realisation. Accordingly participation should be understood in the light of autonomy in terms of individual preferences. They suggested that the process of enabling in rehabilitation should be considered to be the ultimate goal, i.e. to regain and retain the highest possible level of autonomy in order to develop participation (Cardol, et al., 2002b).

In this thesis, participation was assessed based on the concept of autonomy in studies I and II. In study III, the concept of autonomy was also considered since the OGQ was developed based on personal wishes and desires. Study IV has also arrived at interesting findings regarding autonomy as part of the meaning structure of participation in everyday occupations.

## **2.5 LIFE SATISFACTION**

In this thesis *life satisfaction* is defined according to the definition of this concept from Fugl-Meyer, Branholm and Fugl-Meyer (1991) who state that the individual's life satisfaction is seen to reflect the extent to which the individual achieves his/her goals. Empirical research has found participation to be one of the most significant predictors of life satisfaction after stroke (Edwards, Hahn, Baum, & Dromerick, 2006; Eriksson, Kottorp, Borg, & Tham, 2009; Hartman-Maeir, Soroker, Ring, Avni, & Katz, 2007). Life satisfaction is considered to be the overall goal for rehabilitation in Western countries (Eriksson, et al., 2009; Eriksson, Tham, & Fugl-Meyer, 2005; Fugl-Meyer, et al., 1991). Therefore, the empirical literature regarding life satisfaction has viewed life satisfaction as being an outcome variable and has explored predictors of life satisfaction after stroke. A longitudinal study of older persons with stroke receiving home rehabilitation services revealed that although they recovered significantly in most aspects of functioning, the majority perceived their lives as dissatisfying even one year after stroke (Ekstam, Uppgard, von Koch, & Tham, 2007). This finding underscores the complexity of everyday life after stroke and which aspects might impact on

participation. Although previous research has focused on participation in general and the associated factors, no study has explored how different aspects of functioning and perceived life satisfaction influence participation in everyday occupations after stroke. This exploration was performed in study III in this thesis and the sociocultural findings regarding life satisfaction have been presented in that study.

## **2.6 STROKE AND PARTICIPATION WORLDWIDE AND IN IRAN**

### **2.6.1 Stroke epidemiology**

Stroke is a major public concern and among the most common causes of death and disability worldwide (Geyh, et al., 2004; Johnston, Mendis, & Mathers, 2009). According to the WHO report regarding the global burden of stroke in 2004, about 15 million people worldwide have stroke annually. About one third of these strokes lead to death, and one third of those afflicted live with permanent disability (WHO, 2008). More than 85% of strokes occur in low-income to middle-income countries (Johnston, et al., 2009). According to the report published and presented by the Ministry of Health and Medical Education (Naghavi, 2003), the rate of death due to stroke has been estimated to 39 per 100.000 in 18 provinces of Iran in 2001 and everyday 68 people die due to stroke. The results of this study revealed that 9.8% of all the deaths in all age groups were due to cerebrovascular accident and most of the people were women older than 50 years.

According to evidence from a recent population-based study in Iran, the Mashhad Stroke Incidence Study (MSIS), stroke incidence in Iran is considerably greater than in most Western countries, with stroke occurring at younger ages. Despite a relatively low crude annual incidence rate of first-ever stroke, 139 per 100 000 inhabitants, rates adjusted to the European population aged 45 to 84 years were higher than in most countries included 616 ischemic strokes, 94 intracerebral haemorrhages and 12 subarachnoid haemorrhages (Azarpazhooh, et al., 2010).

The findings of a study in northern Iran between 2001 and 2003 show a mean age of 68.1, ranging from 30 to 90 years. About half of the hospitalised clients were male, about 70% were older than 65 years of age and more than 90% were from urban areas. Stroke subtypes were 67.2% ischemic stroke, 28.4% intracerebral haemorrhage, and 4.4% subarachnoid haemorrhage (Ahangar, Ashraf Vaghefi, & Ramaezani, 2005).

## 2.6.2 Participation in everyday occupations after stroke

Stroke is defined as an acute neurological dysfunction of vascular origin with rapid onset of symptoms according to the affected regions of the brain (WHO, 1989). The literature illustrates that stroke affects individuals' functioning in terms of impairments and activity limitations leading them to experience a chronic disability (Geyh, et al., 2004). Many persons with stroke are not able to resume the former life roles they had or engage in various activities as they did in the past (Desrosiers, et al., 2006). Empirical research has shown that participation can be markedly restricted after stroke (Clarke, Black, Badley, Lawrence, & Williams, 1999; Desrosiers, et al., 2008; Desrosiers, et al., 2006; Desrosiers, Noreau, Rochette, Bravo, & Boutin, 2002; Sturm, et al., 2004) which in turn impacts individuals' life satisfaction (Edwards, et al., 2006; Hartman-Maeir, et al., 2007). Many people who have experienced stroke become dependent on other people's support in everyday occupations (Warlow, 1998). Stroke consequences also affect family functioning and family members as the main caregivers (Blake, Lincoln, & Clarke, 2003; Clark & Smith, 1999; Ekstam, 2009; Ekstam, Tham, & Borell, 2011). Although previous literature has discussed participation restrictions and different factors associated with participation after stroke as mentioned above, there are three important points regarding participation that are lacking and this gap of knowledge necessitates this research project.

*Firstly*, most of the literature regarding participation after stroke relates to studies performed in the Western world, and research about this subject in the non-Western world is very limited. The literature from non-Western countries has also been discussed in the related studies in this thesis (studies II and III). *Secondly*, from an occupational perspective, although previous research has focused on participation in general and the associated factors, it has not focused specifically on participation in everyday occupations. This aspect of participation needs further exploration to fulfil important goals in rehabilitation. In this thesis studies III and IV fulfil this aim. *Thirdly*, no studies have been published in Iran specifically focusing on participation in everyday occupations after stroke. Although more than 85% of the strokes occur in low to middle-income countries, most research is conducted in high-income countries (Johnston, et al., 2009). There is an obvious lack of knowledge regarding participation in everyday occupations and the factors associated with participation after stroke from this perspective in Iran which represents a different sociocultural context. The findings of different studies in this thesis support the sociocultural aspects of participation. The

findings of these studies provide the possibility for future cross-cultural studies to compare this knowledge with that of studies conducted in Western societies.

## **2.7 OCCUPATIONAL THERAPY AFTER STROKE IN IRAN**

This chapter presents reflections on the current occupational therapy provided for persons with stroke in Iran. However firstly, stroke rehabilitation in Sweden is briefly described. Stroke is the second leading cause of death in the world, and about half of those who survive are dependent in their self-care activities six months after stroke (Legg, Drummond, & Langhorne, 2006). In Sweden, rehabilitation after stroke among persons of working age typically occurs in specialised brain injury rehabilitation units in hospitals early after onset. In acute care after stroke, evidence shows that stroke units provide a better outcome in terms of survival, discharge destination, dependency and long-term rehabilitation during first year post-stroke than treatment in general medical wards (Erikson, 2009; Socialstyrelsen, 2005-2009). Interventions in post-stroke rehabilitation vary depending on in which phase after onset they are conducted (Lexell, 2007). Interventions in the sub-acute phase focus on reducing impairments and activity limitations in order to fulfil the goal of achieving independence in daily activities (Erikson, 2009; Socialstyrelsen, 2005-2009). The Swedish national evidence-based guidelines for stroke care (Socialstyrelsen, 2005-2009) recommend early discharge from hospital (stroke units) in combination with multidisciplinary rehabilitation at home. Therefore, persons with stroke who are restricted in ADL-functioning should receive ADL-training in the home environment through home rehabilitation. If the in-patient and out-patient rehabilitation is offered in hospital rehabilitation settings in the sub-acute phase, the later phases of rehabilitation include community-based rehabilitation based on collaboration between the medical services and resources in the community (Erikson, 2009).

Stroke patients are among the most common diagnostic categories of clients admitted to occupational therapy clinics in Iran. The results of a descriptive study revealed that 54% of clients with neurological diagnoses who had been admitted to occupational therapy clinics in four hospitals in Teheran were stroke clients and men were in the majority (Fallahpour & Dehkordi, 1996). Enabling individuals to participate in everyday occupations should be an important goal for rehabilitation as recommended in occupational therapy literature (Kielhofner, 2008; Law, 2002; Townsend & Polatajko, 2007). The benefits of participation in everyday occupations have been discussed



earlier in the related chapter. However this goal is not fully fulfilled for persons with stroke in Iran with current rehabilitation services. There are a few gaps in the present structure in the provision of appropriate rehabilitation for individuals with stroke as presented below. The findings of empirical research also demonstrate a lack of adequate care and appropriate access to rehabilitation services for persons with stroke in Iran (Dalvandi, et al., 2011; Dalvandi, Heikkila, Maddah, Khankeh, & Ekman, 2009)

*Firstly*, occupational therapy services are not available in all hospitals, either public or private in the country. Therefore, for a person who gets a stroke and is hospitalised in the acute care ward, there are no systematically available OT services in the medical and health care system structure as are provided in Sweden. The only rehabilitation services available for them in most hospitals in the acute phase are physical therapy services. Moreover, even for those hospitals in which OT services are available, the OT ward admits persons with stroke as outpatients not inpatients in the acute phase. In addition to the OT wards in these hospitals, there are public or private outpatient OT clinics providing occupational therapy for persons with stroke in the community. However the main problem is that everybody diagnosed with stroke is not referred to OT clinics by their physicians as within a systematic routine plan in the medical system.

*Secondly*, for those persons with stroke who are admitted to OT clinics, the occupational therapy routine lacks an occupational perspective to enable persons in their participation in everyday occupations as is potentially possible. Occupational therapy after stroke in Iran does not prioritise enabling ADL-functioning and participation in everyday life. OT after stroke in Iran is basically medically-oriented and the biomedical perspective is still preferred, focusing on body function level rather than the occupational perspective as recommended by contemporary literature (Kielhofner, 2009). Due to a traditional focus in occupational therapy on functional training of performance components, limited knowledge has been acquired regarding occupational problems and needs following stroke. As a result, rehabilitation for the individual after stroke lacks plans for enabling them in their participation in their different areas of everyday life. More information about occupational therapy in Iran can be found elsewhere (Fallahpour, 2004; Rassafiani & Zeinali, 2007).

The findings of the different studies in this thesis have provided the opportunity to gather more knowledge about participation in everyday occupations after stroke in this sociocultural context. This, in turn, provides opportunities to formulate strategies for developing culturally sensitive rehabilitation based on the participants' needs and also consistent with the socio-cultural context for the planning of appropriate rehabilitation interventions.

## **3 RESEARCH AIMS**

### **3.1 GENERAL AIM**

The overall aim of this thesis was to explore and describe perceived participation in everyday occupations, and the factors associated with participation among persons with stroke in sample from Iran. Furthermore, the aim was to describe and understand the lived experience of participation in everyday occupations following stroke.

### **3.2 SPECIFIC AIMS**

- To evaluate the psychometric properties of the Persian version of the Impact on Participation and Autonomy questionnaire (IPA-P) to be used for persons with stroke (study I).
- To describe perceived participation and autonomy among a sample of persons with stroke in Iran, and also to identify different aspects of functioning and contextual factors predicting participation after stroke (study II).
- To psychometrically evaluate the Persian version of the OGQ and LiSat-11 checklist, to describe the presence of occupational gaps after stroke in a sample from Iran, and to explore the relationship between occupational gaps and different aspects of functioning and perceived life satisfaction (study III).
- To describe and understand the lived experience of participation in everyday occupations among persons with stroke, and to identify what characterised the phenomenon of participation in everyday occupations (study IV).

## **4 METHODS**

The research in this thesis is aimed at advancing our knowledge about participation in everyday occupations after stroke. For this purpose both quantitative and qualitative methods were used to explore and describe perceived participation in everyday occupations, the associated factors and lived experiences of persons with stroke. The first study focused on producing the Persian version of the Impact on Participation and Autonomy questionnaire (IPA-P) and the psychometric evaluation of the translated version to be used for persons with stroke. In the second study perceived participation and autonomy were described among persons with stroke, and different aspects of functioning and contextual factors associated with participation after stroke were explored and identified. In the third study the Persian translated version of Occupational Gaps Questionnaire (OGQ) and the LiSat-11 checklist were produced and psychometrically evaluated. Moreover, the third study focused on describing occupational gaps after stroke and exploring their relation to different aspects of functioning and perceived life satisfaction. In the fourth study the lived experiences of persons with stroke regarding their participation in everyday occupations were explored using in-depth interviews. An overview of the studies and methods used in the thesis are presented in Table I.

Table I: Overview of the four studies included in the thesis.

	Study I	Study II	Study III	Study IV
Design/research approach	Quantitative, cross-sectional, instrument evaluation and cross-cultural adaptation	Quantitative, cross-sectional, explorative	Quantitative, cross-sectional, instrument evaluation and cross-cultural adaptation, explorative	Qualitative, explorative, phenomenological
Focus	Psychometric evaluation of the Persian version of IPA to be used for persons with stroke	Describing perceived participation and autonomy after stroke and exploring the associated factors	Psychometric evaluation of the Persian version of OGQ and LiSat-11, describing occupational gaps after stroke, and exploring the associated factors	Exploring lived experience of participation in everyday occupations after stroke
Participants	Persons with stroke living at home (n= 102) (sampling 1 for studies I to III)			Persons with stroke living at home (n= 8) (sampling 2 for study IV)
Data collection (methods and assessment instruments)	Questionnaire administered by interview, observation, medical records  IPA MMSE FMA BI	Questionnaire administered by interview, observation, medical records, questions on contextual factors IPA MMSE HADS FMA SIS-16 BI	Questionnaire administered by interview, observation, medical records  OGQ LiSat-11 MMSE HADS FMA SIS-16 BI	Open-ended in-depth interviews with interview guide
Context of data collection	Clinical settings (four university hospitals and rehabilitation clinics)			Participants' homes
Data analysis	Rasch analyses, descriptive statistics, correlation analyses	Rasch analyses, descriptive statistics, regression analyses	Rasch analyses, descriptive statistics, correlation & regression analyses	Empirical phenomenological psychological method (EPP)

## 4.1 PARTICIPANTS

Two samplings were performed in the thesis. The first sampling was performed for studies I-III, the quantitative studies in the thesis, and the second sampling for study IV which was qualitative. Each sampling is described separately below. The characteristics of the participants in different studies are presented in Table II.

Table II. Characteristics of the participants in the thesis.

Characteristics	Studies I-III %	Study IV n
Number of participants (n)	102	8
Age (years)		
Mean (SD) <sup>a</sup> / range	58.3 (11.9)/27-75	57.1 (9.6)/45-68
Time after stroke (months)		
Mean (SD)/range	17.7 (10.1)/5-36	15 (8.3)/5- 26
Gender		
Male/female	58.8/41.2	4/4
Type of stroke		
Ischemic/haemorrhagic	86.3/13.7	5/3
Hemisphere lesion		
Right/left/other	51.0/44.1/4.9	4/4/-
Marital status		
Single/married/widowed or divorced	2.0/83.3/14.7	1/7/-
Educational status		
Illiterate/primary/secondary/academic	26.5/34.3/26.5/12.7	1/2/3/2
Employment status		
Employed/homemaker/retired/unemployed	18.6/33.3/24.5/23.5	2/3/2/1
Living status		
Living alone/living with others	5.9/ 94.1	1/7

<sup>a</sup>Standard Deviation

### 4.1.1 Studies I – III

Participants in studies I – III were recruited from all the individuals diagnosed with stroke who had previously been admitted to two neurological wards at two university hospitals and two university rehabilitation clinics in Tehran between May 2003 and March 2007. They also had to meet the following inclusion criteria: (1) had a confirmed diagnosis of a first-ever stroke, (2) were no older than 75 years of age, (3) had their stroke between five months and three years prior to inclusion, (4) were able to communicate in Persian when responding the questions, (5) had sufficient cognitive function verified by scores greater than 22 on the Mini-Mental State Examination scale (Folstein, Folstein, & McHugh, 1975), (6) had no evidence of co-existing diagnosed disorders leading to disabling conditions, (7) were not diagnosed with subarachnoid haemorrhage type of stroke, (8) lived in Tehran or surrounding

areas, and (9) were living at home. In total, 131 people who met the inclusion criteria were identified from the database at the four centres. They were invited to participate in the study, and 102 agreed to participate and gave their informed consent.

#### **4.1.2 Study IV**

The sample in study IV comprised of eight individuals with stroke (four of each gender) who had previously been admitted to a neurological ward at a university hospital in Tehran. In order to collect rich and varied data representing the phenomenon, the principle of divergence (Patton, 1990), from participants with a wide range of experiences, they were selected based on various characteristics. Informants who could provide rich data representing the phenomenon were selected (Dahlberg, et al., 2001). The inclusion criteria for this purposive sample were: (1)  $\leq 75$  years of age, (2) diagnosed with a first-ever stroke occurring between 5 and 36 months prior to inclusion, (3) living at home, (4) having experiences of participation in everyday occupations, (5) sufficient cognitive function to remember and share the experiences verified by scores greater than 22 on the Mini-Mental State Examination scale (Folstein, et al., 1975), (6) able to respond to questions and describe their experiences in Persian. The participants received information about the study verbally and in writing and gave their informed consent to participate in the study.

## **4.2 DATA COLLECTION**

### **4.2.1 Studies I – III procedure**

Participants in studies I – III were met and assessed by the researcher, specifically for this research project, in the clinical settings in which they had previously been admitted as a person diagnosed with stroke during the period between May 2003 and March 2007, i.e. in the hospitals or rehabilitation clinics. The data collection for studies I – III was carried out between May 2006 and March 2007. The participants who met the inclusion criteria were informed orally and in writing about the study and the data collection procedure and invited to participate in the study. The evaluation session began by collecting the data regarding contextual factors and health conditions. The session then continued by assessing different aspects of functioning and participation. Instead of having to complete the answers by themselves, all the participants were interviewed to acquire their responses to the Persian version of IPA and OGQ items as well as the HADS, SIS-16, and LiSat-11 items. This decision was made by the research group in order to be able to include the

illiterate participants, who comprised 26.5% of the sample in studies I- III. The participants were instructed how to respond and score the items before they were assessed by the researcher.

#### **4.2.2 Assessment instruments**

Two instruments were used specifically to assess participation in studies I – III; they were the Impact on Participation and Autonomy, and the Occupational Gaps Questionnaire. A number of instruments were used in this research project to assess different aspects of functioning in the sample, including body function and activity in studies I - III. The assessment protocol in the research project also included questions concerning aspects relating to contextual factors and health conditions. Each assessment is described separately below.

##### *4.2.2.1 Impact on participation and autonomy questionnaire (IPA)*

The IPA was used in studies I and II to assess participation in the sample (Cardol, et al., 2002a; Cardol, de Haan, de Jong, van den Bos, & de Groot, 2001; Cardol, de Haan, van den Bos, de Jong, & de Groot, 1999b). The IPA is a generic self-report questionnaire (Kersten, 2007) measuring perceived participation and autonomy using 32 items in five domains addressing different life situations including: autonomy indoors (7 items); family role (7 items); autonomy outdoors (5 items); social relations (7 items); and work and education (6 items). This questionnaire also examines individuals' perceived problems with participation, using 9 items covering 9 different aspects of participation and autonomy (sub-domains). The perceived participation and autonomy for each item is graded on a five-point rating scale, ranging from 0-4 (very good to very poor). The second scale addressing perceived problems is scored on a three-point rating scale, ranging from 0-2 (no problem to severe problems). The psychometric evaluation of the original version of the IPA has demonstrated different aspects of its validity, reliability and responsiveness to change (Cardol, et al., 2002a; Cardol, et al., 2001; Cardol, et al., 1999b). As the questionnaire was not available in Persian in study I, the Persian translated version of the IPA was first produced following the translation procedure. The translated version (IPA-P) was then psychometrically evaluated using the Rasch measurement model. Rasch-generated person estimates were then used for correlation and regression analyses in studies I and II. In line with the original studies (Cardol, et al., 2001; Cardol, et al., 1999b), the



work and education domain and the IPA second scale have not been examined in this thesis. The translation process will be described specifically in a separate section.

#### *4.2.2.2 Occupational Gaps questionnaire (OGQ)*

The OGQ was used in study III to assess perceived occupational gaps in the sample as developed to measure participation in everyday occupations by focusing on gaps (Eriksson, 2007). An occupational gap is defined as a gap that occurs between what an individual wants and needs to do and what he or she actually does. The presence of occupational gaps in the Swedish version was examined in 28 activities, including eight instrumental activities of daily living, six social activities, 10 leisure activities and four work-related activities. There were two questions connected to each activity. The questions were “Do you perform the activity now?” and “Do you want to perform the activity now?” If a person responded “yes” or “no” to both of these questions, then there were no occupational gaps, but if the response was “yes” to one question and “no” to the other, this was considered to constitute an occupational gap (Eriksson, et al., 2006). The psychometric evaluation of this instrument found acceptable psychometric properties for the OGQ to measure occupational gaps among persons with ABI (Eriksson, et al., 2009). As the questionnaire was in Swedish, the Persian translated version of the instrument was first produced in study III. The raw scores from OGQ-P were then Rasch analysed to be examined psychometrically in study III. Rasch-generated person measures were finally used for correlation and regression analyses in the same study. The translation process provides further details of the three items added in OGQ-P.

#### *4.2.2.3 LiSat-11 checklist*

The LiSat-11 checklist was used in study III to assess perceived life satisfaction in the sample (Fugl-Meyer, Melin, & Fugl-Meyer, 2002). An individual’s life satisfaction is seen to reflect the extent to which the individual achieves his/her goals (Fugl-Meyer, et al., 1991). The LiSat-11 has been proved to be psychometrically promising using both traditional (Fugl-Meyer, et al., 2002) and modern statistical analyses (Eriksson, et al., 2009). This checklist consists of 11 items assessing overall and domain-specific life satisfaction including vocational, financial and leisure situations, social contacts, sexual life, activities of daily living (ADL), family life, partner relationship and physical and psychological health. The perceived satisfaction for each item is graded on a 6-point rating scale ranging from 6 (very satisfying) to 1 (very dissatisfying) (Fugl-Meyer, et

al., 2002). The scores on LiSat-11 are dichotomised into “satisfying vs. very satisfying” and “rather satisfying to very dissatisfying”, which is a valid scale reduction (Eriksson, et al., 2009). As the checklist was not available in Persian, the translated version was produced in study III. The raw scores from LiSat-11-P were then Rasch analysed to be examined psychometrically in study III. Rasch-generated person measures were finally used for correlation and regression analyses in the same study. The translation process will be described in a separate section.

#### *4.2.2.4 Mini-Mental State Examination scale (MMSE)*

The MMSE was used to assess cognitive functions in all four studies in this thesis and it is widely used as a screening tool for cognitive level in persons with cognitive impairments (Folstein, et al., 1975). For this purpose the Persian version of the MMSE was used (Froughan, Jafari, Shirinbayan, Ghaemmagham Farahani, & Rahgozar, 2008). A total MMSE score greater than 23 has been established as being within the normal range. The psychometric properties of the instrument have been supported by previous research (Folstein, et al., 1975; Froughan, et al., 2008). Participants with a MMSE score greater than 22 were included in the research project. The total score range was used for regression analyses in studies I - III.

#### *4.2.2.5 Hospital Anxiety and Depression Scale (HADS)*

The HADS was used to examine mood state in the sample in studies II and III (Zigmond & Snaith, 1983). The Persian version of the HADS was used for this purpose (Montazeri, Vahdaninia, Ebrahimi, & Jarvandi, 2003). This thesis only used the depression scale of the instrument comprising seven items addressing the mood state. This scale ranges from 0 to 21, with a cut-off score of above 10 indicating a depressed state. This questionnaire has proved to be psychometrically sound for use in different populations (Bjelland, Dahl, Haug, & Neckelmann, 2002; Montazeri, et al., 2003). A total score range of 0 to 21 was considered for regression analyses in studies II and III.

#### *4.2.2.6 Fugl-Meyer Motor Assessment (FMA)*

The FMA was used to assess motor function in the sample in studies I – III (Fugl-Meyer, Jaasko, Leyman, Olsson, & Steglind, 1975). The FMA evaluates motor function in the upper and lower extremities with a total maximum score of 100 defining normal motor function. The maximum score is 66 and 34 for the upper and lower

extremities respectively. A score of less than 50 represents severe motor impairment. Scores between 50 and 84 represent marked motor impairment. A score of 85 to 95 indicates a moderate impairment, and finally a score of 96–99 implies only a slight impairment (Fugl-Meyer, 1980). The psychometric properties have been supported (Gladstone, Danells, & Black, 2002). A total score range of 0 to 100 was considered for regression analyses in studies II and III.

#### *4.2.2.7 Short version of Stroke Impact Scale (SIS-16)*

The SIS-16 was used to assess perceived physical function (including perceived ADL-ability) in studies II and III (Duncan, Lai, Bode, Perera, & DeRosa, 2003). For this purpose the Persian version of the instrument was used in this thesis (Nourizadeh, 2006). The SIS-16 is an instrument specifically designed for measuring a wide range of post-stroke physical limitations comprising 16 items assessing three dimensions of hand function, mobility and activities of daily living (ADL). The person's score ranges from 1 (does not do at all) to 5 (not difficult at all). In the data analyses the aggregated score ( $= [\text{mean}-1 / 5-1]*100$ ) was used. The SIS-16 has been supported psychometrically in terms of reliability, validity and responsiveness over time (Duncan, et al., 2003). A total score range of 0 to 100 was used for regression analyses in studies II and III.

#### *4.2.2.8 Barthel's ADL Index (BI)*

The BI was used to assess dependence in ADL in studies I – III (Mahoney & Barthel, 1965) and categorised into three grades of dependency. For this purpose the Persian version of the instrument was used in this thesis (Oveisgharan, et al., 2006). The BI scores show the level of dependency in ADL, ranging from 0 to 100. Scores less than 60 (0-50) indicate major dependency, 60-90 moderate dependency and greater than 90 (95-100) independency (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005). The psychometric properties have been supported for use in persons with stroke (Oveisgharan, et al., 2006). A total score range of 0 and 100 was used for regression analyses in studies II and III.

#### *4.2.2.9 Aspects relating to contextual factors and health conditions*

The assessment protocol also included questions regarding aspects relating to contextual factors and health conditions. Aspects relating to contextual factors included personal and environmental factors. The personal factors included age,

gender, marital status, educational status, employment status and living status. The environmental factors included ethnicity, access to caregiving services and access to rehabilitation services. Educational status was checked using the medical records and during the personal interview. Access to caregiving services included both physical and emotional support that the person received from formal and/or informal caregivers and/or community resources in order to be able to perform the daily life activities. Aspects relating to health conditions included type of stroke, hemisphere lesion, time after stroke verified by medical documents, such as computed tomography (CT) scan, magnetic resonance imaging (MRI), or medical records available at the hospital or clinic.

### **4.2.3 Translation process**

In this thesis only three instruments were not available in Persian to use for studies I-III. These three instruments were the Impact on Participation and Autonomy questionnaire (IPA), the Occupational Gaps Questionnaire (OGQ) to assess participation and the LiSat-11 checklist to assess life satisfaction in the sample. These three instruments were translated into Persian following a strict translation procedure. A forward-backward translation procedure was performed based on related principles and guidelines for the cross-cultural adaptation process of self-reported measures (Beaton, Bombardier, Guillemin, & Ferraz, 2000). Figure 1 illustrates the different stages in the cross-cultural adaptation process used in this research project as recommended for use in self-report measures (Beaton, et al., 2000). With the agreement of each developer, the translation procedure used the English version of the IPA and LiSat-11 and the Swedish version of the OGQ. The back-translated versions and the reports of the whole procedure followed were approved by each instrument developer. A few changes were made in the OGQ-P to modify the questionnaire culturally and three items were also added. No specific changes were made in the Persian version of IPA and LiSat-11, and no item was added to them cross-culturally. In the Swedish version of the OGQ, there is only one item for shopping and it covers grocery shopping. The “non-grocery shopping” item was added in the IADL domain of the OGQ-P. The general item writing in the Swedish version of the questionnaire (OGQ-S) was divided into two different items in OGQ-P namely “simple writing” (letters, diary, etc.) and “creative writing” (poems, novels, etc.). The OGQ-S classifies religious activities as a social activity. In Iran where religious activities are performed both individually and together with others, they cannot be classified as social pursuits.

Therefore, the item “religious activities” was modified to encompass both individual and social dimensions. Since there were only four domains in the OGQ-S, religious activities were classified as leisure activities in OGQ-P although ideally they do not fit into the definition of leisure. This merits consideration in future studies and the cross-cultural development of the OGQ. Finally “helping and supporting others” was also added to the social activities domain as a new item in the OGQ-P. Consequently, the OGQ-P included 31 items covering four domains as in the original version.

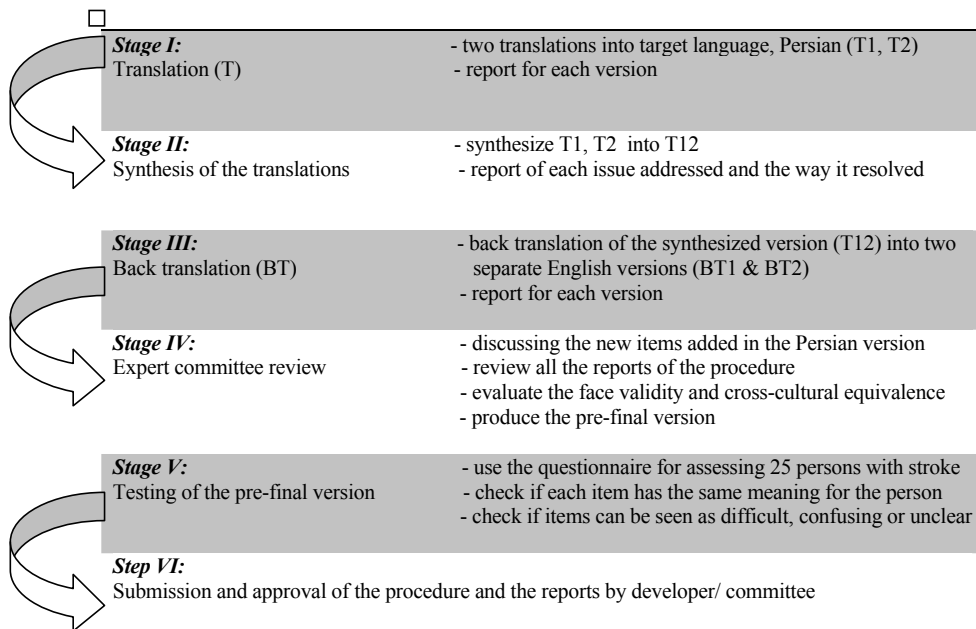


Figure 1- Graphic representation of the cross-cultural adaptation process used in the studies I and III.

#### 4.2.4 Study IV

The data was collected by the researcher between January and November 2009. Each participant was interviewed once. All the interviews took place in the participants’ homes except for one participant who preferred to have the interview in the researcher’s office. The researcher met the participants twice, the first time in order to establish a relationship and to inform the participants about the study and the ethical issues, and on the second occasion for the in-depth interview. Each interview lasted about 90 to 120 minutes, and was tape-recorded and transcribed verbatim within a week. The interview questions were informal and open-ended based on an interview

guide that followed the principles for qualitative interviewing (Kvale, 2007), and they focused on the participants' experiences of participation in everyday occupations after stroke. The participants were invited to concretely describe their current experiences of participation in everyday occupations compared to before stroke in detail and to give specific examples. In order to get an overall description of their everyday (day to day) experience of living with stroke, they were asked to describe an ordinary day and the activities in which they were involved before and after stroke. More specific follow-up questions were also asked about their valued everyday occupations and also the concrete situations they perceived as problematic for their participation. Field notes were taken after the interviews as the validation of participants' narratives to help the researcher to understand their described life-world experiences during the analysis, however they were not used in any further analysis.

### **4.3 DATA ANALYSIS**

#### **4.3.1 Rasch analysis**

Rasch analysis was used to implement the psychometric analyses of the three instruments in studies I and III. For this purpose the Persian translated version of the IPA, the OGQ and the LiSat-11 were produced and used for psychometric evaluation. The objective was to (a) convert the ordinal data into equal-interval measures in logits; (b) to ensure of the validity of all instrument scale scores as a valid measures for use in linear regression analyses; and ultimately, (c) to examine whether the items from each scale could measure a unidimensional construct (Bond & Fox, 2007). According to the simple Rasch model assertions for estimation of a person's abilities and item difficulties, it is assumed that, (a) the easier the item, the more likely it is to be passed by all the persons than a more difficult item, and (b) the more able the person, the more likely it is that he/she can respond more difficult items than a less able person. Rasch analysis thus aims at examining if the responses generated from persons and items follow what was expected in relation to these assertions. If the responses fit the assertions in the Rasch model, the raw scores can validly be transformed into interval measures and the scale can be considered to have acceptable psychometric properties (Bond & Fox, 2007). Several aspects of psychometric properties of a scale can be investigated when implementing psychometric evaluations using Rasch analysis. In this thesis rating scale functioning, internal scale validity, person response validity, and person separation were examined using the Winsteps computer program, version 3.63.0 (Linacre, 2006).

Initially, rating scale functioning was examined to make sure that there was no measure disordering as indicated by: (a) at least 10 observations of each category, (b) a regular observation distribution, (c) monotonically advancing average measures for each category, and (d) outfit mean-squares values less than 2.0 across rating scale categories (Linacre, 2002a).

In the next step, the internal scale validity and person response validity were examined using goodness-of-fit statistics. Rasch analyses generate goodness-of-fit statistics for both items and persons expressed as the mean square (MnSq) values and standardised z-value indicating the degree of match between expected and observed responses. The criteria for acceptable goodness-of-fit for both items and persons were set at infit MnSq value  $\leq 1.4$  (Wright & Linacre, 1994) with an associated standardised  $z \leq 2.0$  (Linacre, 2002b) supporting internal scale validity and person response validity respectively. At least 95% of items and participants should demonstrate acceptable goodness-of-fit to the model in accordance with previous studies (Eriksson, et al., 2009; Nilsson & Fisher, 2006; Patomella, Tham, & Kottorp, 2006). Furthermore, a principal component analysis (PCA) of the residuals was applied to further evaluate the unidimensionality of the scales (Linacre, 1998). The criteria for the principal components analysis (PCA) in study I were that the first latent variable should explain at least 60% of the total variance and that any other factor should not explain more than 5% of the variance (Linacre, 2005). The criterion for the first component was that it should explain above 50% of the total variance in the dataset for study III (Smith, 2002).

Finally person separation statistics were examined to indicate whether the items of each scale could separate persons into different levels of abilities, thereby supporting the sensitivity of the measure. In study I, it was considered that the criteria of 0.80 for minimal acceptable person separation reliability associated with a value of 2.0 for acceptable person separation index differentiated persons into three or more groups of participation (Fisher, 1992; Wright, 1996). In study III the OGQ and LiSat-11 must detect at least two distinct groups in the datasets supporting the sensitivity of the measures among the participants evaluated (Fisher, 1992).

Rasch-generated person measures produced from Rasch rating scale analyses (studies I and III) were later used in the next step of the analysis, the regression analyses in study II and study III.

### **4.3.2 Additional statistical analyses**

Many statistical methods were used in studies I – III. All the statistical analyses in these three first studies were performed using SPSS software program, version 15 and 17 (SPSS, Inc., Chicago, IL).

#### *4.3.2.1 Study I*

Descriptive statistics were used to describe the characteristics of the participants. Pearson product-moment correlations were used to evaluate the correlation between different domains of IPA-P. Rasch-generated person measures were used for each domain for the analyses. The same analysis was used to evaluate the correlation between two dimensions of participation, performance-based participation and social-based participation.

#### *4.3.2.2 Study II*

Descriptive statistics were used to describe the characteristics of participants with respect to different aspects of functioning scores, contextual factors and health conditions. Descriptive analysis was also used to show the frequency distribution of perceived level of participation separately for each IPA domain according to the mean score for the original domain. The mean score for each IPA domain was calculated to provide more description regarding the perceived level of participation and autonomy in each domain. The associations in this study between different aspects of functioning, contextual factors and health conditions with each dimension of participation were examined. For this purpose, univariate regression analyses were used for the continuous independent variables, and the univariate analysis of variance (Uni ANOVA) for categorical variables. The univariate analyses were used to guide the choice of which variables should be included in the linear multiple regression analyses. Two different multivariate regression analyses were conducted including all identified significant independent variables from the first step analyses in order to explore the final model explaining each dimension of participation.

#### *4.3.2.3 Study III*

Descriptive statistics defined the characteristics of the participants, different aspects of functioning scores and life satisfaction, and the distribution of occupational gaps. Since the measures of life satisfaction and occupational gaps were normally distributed, Pearson product–moment correlation was used to examine the association



between them. Univariate regression analyses were used to examine the associations between aspects of functioning and occupational gaps. A multivariate regression analysis followed, including all identified significant independent variables from the first step analyses, to explore the final model explaining occupational gaps.

### **4.3.3 The empirical, phenomenological, psychological method (EPP)**

In study IV the interview data were analysed using a qualitative method, the Empirical, Phenomenological, Psychological method (EPP) (Karlsson, 1995). The EPP method is a qualitative, descriptive, and interpretative method which focuses on describing the meaning structure of the lived experience related to a phenomenon (Karlsson, 1995). Similar to several previous studies (Erikson, Karlsson, Borell, & Tham, 2007; Eriksson & Tham, 2010; Guidetti, Asaba, & Tham, 2007; Lampinen & Tham, 2003; Tham, Borell, & Gustavsson, 2000; Tham & Kielhofner, 2003), the psychological perspective in the analysis, was replaced by an occupational perspective, focusing on the individuals' experiences of everyday occupations. The data were analysed following five steps in the EPP-method. The first four steps were performed separately for each participant. In the final step, all the interviews for the eight participants were analysed and synthesised. First the interviews were read thoroughly by the researcher to get a good grasp of the whole interview and to understand each participant's original experiences. After reading all the interview data, each interview was analysed separately following steps one to four. The attitude of the authors was open and throughout the analysis they bracketed previous knowledge of participation in everyday occupations based on theoretical knowledge and occupational therapy and occupational science concepts.

Step one of the EPP analysis involved thoroughly reading and re-reading each interview transcript to gain an empathetic and holistic understanding of the interview. In the second step the meaning units in the interview were identified each time there was a shift in the meaning in the interview. The third step involved analysing and interpreting each meaning unit in the light of the whole interview in order to describe the implicit and explicit meaning embedded in the facts relating to the phenomenon, described by the participant. In the fourth step, the transformed meaning units were synthesised into a summarised situated structure, and each interview was presented in the form of a synopsis with different themes describing the phenomenon. In the fifth

step, the situated structure for each participant was synthesised into a general structure for all eight participants. In this step there was a move from situated structure to a general structure of the phenomenon which ran across all the participants' interviews, describing the characteristics of the phenomenon.

From step three, the analysis was performed in English by the first author where each meaning unit was interpreted and transformed into the researcher's language. In regular meetings including the first and the last author each step in the analysis and the interpretations were examined and discussed until it was ascertained that the final interpretations best characterised the experience of each participant and the essence of the phenomenon. The language translation was checked by one of the Persian co-authors specifically responsible for that since all the interviews were conducted and transcribed in the Persian language. All the authors were involved in the step-five analysis in order to question the interpretations and discuss alternative ways of understanding the experiences of the participants. The authors discussed alternative interpretations until the most likely ones were identified. The analyses were discussed and refined several times until a horizontally consistent interpretation was reached. Finally, the findings were presented to experienced researchers in the field of occupational therapy and expertise in stroke rehabilitation, as a validation of the findings.

#### **4.4 ETHICAL APPROVAL**

The research project, including all the four studies and the procedures, was approved by the National Ethical Committee of the Ministry of Health and Medical Education in Tehran, Iran.

## 5 FINDINGS

All four studies focus on participation in everyday occupations after stroke using both quantitative and qualitative methods. The findings includes five main parts: (a) psychometric evaluation of the Persian-produced instruments to measure participation (studies I and III), (b) describing participation in everyday occupations in the sample using a quantitative method (studies II and III), (c) describing different aspects of functioning, contextual factors and health conditions in the quantitative studies (studies I- III), (d) exploring the factors associated with participation in everyday occupation (studies II and III), (e) describing the lived experience of participation in everyday occupations in the sample using qualitative method (study IV). Below, the synthesised results are presented separately in the five themes.

### **5.1 MEASURING PARTICIPATION: PSYCHOMETRIC EVALUATION OF PERSIAN PRODUCED INSTRUMENTS TO BE USED FOR PERSONS WITH STROKE (STUDIES I & III)**

In this thesis two instruments were used to measure participation in everyday occupations, IPA to assess participation and autonomy in study II and OGQ to assess gaps in participation in everyday occupations (occupational gaps) in study III. One instrument was also used to assess life satisfaction in study III. As a preparatory step before starting the explorative analyses for studies II and III, since these instruments were not available in Persian, the Persian translated version of these three instruments was produced and cross-culturally adapted for use in the Persian language in studies I and III. Then the psychometric properties of the Persian version of these instruments were examined using Rasch measurement model in the same studies. The results for the psychometric evaluation of these three instruments were reported as below.

#### **5.1.1 Psychometric properties of the IPA-P to measure participation and autonomy: two dimensions of participation (study I)**

In study I the aim was to evaluate the psychometric properties of IPA-P scale I to use for persons with stroke. The results of study I showed that IPA-P scale I could not measure perceived participation as one unidimensional construct, but supported two different but related constructs. Table III presents a summary of the results for the separate psychometric properties of the domains of IPA-P.

Table III. Summary of results regarding psychometric properties of domains of IPA-P in the sample (n = 102).

IPA domains	Autonomy indoors	Family role	Autonomy outdoors	Social relations	Combined domains <sup>a</sup>
Number of items	7	7	5	7	19
Rating scale functioning	Acceptable	Acceptable	Acceptable	Acceptable	Acceptable
Item goodness-of-fit, n (%)	7 (100) fit of items	6 (86) fit of items	5 (100) fit of items	7 (100) fit of items	18 (95) fit of items
PCA %					
1 <sup>st</sup> component <sup>b</sup>	59	83	75	74	81
2 <sup>nd</sup> component <sup>c</sup>	12.1	4.0	7.8	7.8	2.8
Person goodness-of-fit, n (%)	99 (97) fit of persons	96 (94) fit of persons	96 (94) fit of persons	97 (95) fit of persons	94 (92) fit of persons
Person separation index	1.74	2.51	1.96	1.57	3.57
Person reliability	0.75	0.86	0.79	0.71	0.93

<sup>a</sup> Combination of IPA-P domains, autonomy indoors, family role, and autonomy outdoors.

<sup>b</sup> Variance explained by measures in percentage.

<sup>c</sup> Unexplained variance explained by 1<sup>st</sup> contrast in percentage

The results of Rasch rating scale analysis for each domain met the criteria for rating scale functioning and showed acceptable internal scale validity, person response and person separation. However according to the results of the Pearson correlation analysis on Rasch-generated person measures between four domains, three domains: autonomy indoors, family role and autonomy outdoors with a correlation coefficient greater than 0.60 were combined for further Rasch analysis. Due to the lower correlations than the criteria in the study ( $r > 0.60$ ) between social relations domain and three other domains, the social relations domain items were considered as another set of items for perceived participation and autonomy (see Table IV). The results of the Rasch rating scale analysis of three combined domains met the criteria for rating scale functioning. The results of the Rasch rating scale analysis demonstrated acceptable goodness-of-fit for the combined domains, supporting the unidimensionality and internal scale validity. One of the items in the combined domains, item 4a, “spending money as one wishes”, (infit MnSq = 2.10;  $z = 6.0$ ) did not fit the Rasch model. The results also revealed that 94 out of 102 participants showed acceptable goodness-of-fit (92%) to the Rasch model. The person goodness-of-fit in combined domains did not meet the criteria but was still marginally lower than the criteria for acceptable person response validity.

Table IV. Pearson correlation matrix between Rasch-generated measures of four domains of IPA-P.

IPA domains	Autonomy indoors	Family role	Autonomy outdoors	Social relations
Autonomy indoors	-----	0.75 <sup>a</sup>	0.61	0.47
Family role		----	0.71	0.53
Autonomy outdoors			-----	0.52
Social relations				-----

<sup>a</sup>Correlation coefficient. Correlation is significant at  $p < 0.05$  level (two-tailed)

The person separation reliability of 0.93 associated with the person separation index of 3.57 indicated that the items of the combined domains were able to reliably separate participants into at least four different levels of participation which is higher than each of the included domains. Finally, the principal components analysis of residuals (PCA) revealed that the combined domain items accounted for 81% of the variance in the data set. The second component also met the criteria, further supporting the unidimensionality in the dataset (see Table III).

The results of the Rasch analysis of all the domains together (26 items) could not support the scale as a unidimensional construct. The results of this final analysis are described in detail in study I. It was concluded by following these analyses that the IPA applied in an Iranian context supports two unidimensional constructs, which can be used to validly estimate perceived participation among persons with stroke; they were called performance-based participation and social-based participation. The results of the Pearson correlation analysis between the Rasch-generated person measures of the performance-based participation and social-based participation revealed a significant association between these two constructs ( $r = 0.58$ ;  $p < 0.001$ ). However the size of the correlation was less than 0.60 thus supporting that these two sets of items are related, but different constructs of participation in this sample.

### 5.1.2 Psychometric properties of the OGQ-P to measure occupational gaps (study III)

In study III, one of the aims was to evaluate the psychometric properties of the OGQ-P for use in further analyses in the same study. The distribution of persons on measure of

occupational gaps ranged from -3.86 to 0.90 (Mean = -1.41, SD = 1.08). The distribution of measure of occupational gaps was normally distributed. The results of the Rasch rating scale analysis on data from OGQ-P met the criteria for rating scale functioning. The results showed acceptable goodness-of-fit to the Rasch model for all 31 items indicating that OGQ-P can be considered as unidimensional, thus providing the evidence for internal scale validity. The results demonstrated that 98 out of 102 participants showed acceptable goodness-of-fit (96.1%) to the Rasch model, thus supporting person response validity. Furthermore, the person reliability of 0.74 associated with the person separation index of 1.67 revealed that items of OGQ-P could reliably separate participants into two distinct groups. Finally the principal component analysis of residuals revealed that the OGQ measures explained 43% of the variance in the data set which was close to but still less than expected (50%) (Smith, 2002). As no additional factor explained more than 5% of the variance in the dataset, we concluded that the measures could still be used as valid estimations of occupational gaps in the sample.

### **5.1.3 Psychometric properties of the LiSat-11-P to measure life satisfaction (study III)**

In study III one of aims was to evaluate the psychometric properties of the LiSat-11-P for use in further analyses in the same study. The distribution of persons on measure of life satisfaction ranged from -1.64 to 2.19 (Mean = 0.04, SD = 0.60). The distribution of measure of life satisfaction was normally distributed. The results of the initial Rasch analysis on data from the LiSat-11 met the criteria for rating scale functioning. The results revealed acceptable goodness-of-fit to the Rasch model for all 11 items indicating that the LiSat-11 can be seen as unidimensional, thus providing the evidence for internal scale validity. The results demonstrated that 96 out of 102 participants showed acceptable goodness-of-fit (94.1%) to the Rasch model, thus supporting person response validity. Furthermore, the person reliability of 0.78 associated with the person separation index of 1.86 revealed that items of the LiSat-11-P could reliably separate participants into two distinct groups. Finally, the principal component analysis of residuals revealed that the LiSat-11 measures explained 74 % of the variance in the dataset. The second component also met the criteria, further supporting the unidimensionality in the dataset.

## **5.2 PERCEPTIONS OF PARTICIPATION IN EVERYDAY OCCUPATIONS AFTER STROKE (STUDIES II & III)**

In study II perceived participation and autonomy was described in the sample. In study III occupational gaps which were gaps in participation in everyday occupations were described in the same sample.

### **5.2.1 Perceived participation and autonomy among persons with stroke (study II)**

The descriptive results of perceived participation and autonomy in the sample are presented in Table V. The least restrictions were perceived by participants in the autonomy indoors and social relations domains. Most reports of very good to fair participation were found in the autonomy indoors, social relations and family role domains, respectively. In the autonomy indoors domain 100% of the participants perceived their participation to be very good to fair; 7% of whom perceived no restrictions in their participation, and no one reported perceiving poor or very poor participation in that domain. In the social relations domain only 2% reported poor or very poor participation and autonomy, and the rest reported their participation to be good to fair. In the family role domain 75.5% of the participants reported their participation as being good to fair. The most participation restrictions were reported in the autonomy outdoors domain (32.4%) where the participants perceived their participation to be poor or very poor. Most reports of poor to very poor participation were found in autonomy outdoors and family role domains, respectively (see Table V). The findings of gender comparison for each of the four domains showed one significant gender difference, that of the family role domain, but not in any other domains.

Table V. Frequency distribution of perceived level of participation and autonomy for each domain, based on domain mean scores, measured by IPA-P in percentage, in a sample (n = 102)

IPA domains	Mean <sup>a</sup> (SD) Range	Domain mean scores <sup>a</sup>		
		Very good 0 %	Good - Fair 1-2 %	Poor-Very poor 3-4 %
Autonomy indoors (102) <sup>b</sup>	0.96 (0.6) 0 – 2.71	6.9	93.1	--
Family role (102)	1.96 (1.1) 0 – 4	1.0	75.5	23.5
Autonomy outdoors (102)	2.35 (0.9) 0.2 – 4	--	67.6	32.4
Social relations (102)	1.48 (0.7) 0.14 – 3.57	--	98.0	2.0

Each domain mean score was estimated only if at least 75% of the items were responded to by the participant

<sup>a</sup> Higher scores represent more restrictions in participation and lower level of participation

<sup>b</sup> The number of participants who answered at least 75% the items.

### 5.2.2 Perceived occupational gaps in everyday life among persons with stroke (study III)

The most common gaps (perceived by  $\geq 30\%$  of participants) can be found in Table VI. The most common gaps were perceived in “helping and supporting others” followed by different instrumental activities of daily living (IADL). The most common gaps in each domain were gaps in: grocery shopping in IADL, outdoor life leisure activities, helping and supporting others in social activities and finally working full- or part-time in work activities.



Table VI. Distribution of perceived occupational gaps in the sample using the OGQ-P (n=102).

Activity	Gap% <sup>a</sup>
<b><i>Instrumental ADL</i></b>	
Grocery shopping	<b>55.9</b>
Non-grocery shopping <sup>b</sup>	<b>46.1</b>
Meal preparation	<b>30.4</b>
Doing laundry	29.4
Cleaning	<b>38.2</b>
Light maintenance (home, yard, car)	<b>45.1</b>
Heavy maintenance (home, yard, car)	<b>33.3</b>
Economy management	<b>36.3</b>
Transportation	<b>48.0</b>
<b><i>Leisure activities</i></b>	
Sports	23.5
Outdoor life	<b>34.3</b>
Hobbies	12.7
Cultural activities	10.8
TV/ video/ radio	4.9
Reading newspaper	11.8
Reading periodicals/ literature	14.7
Simple writing (e.g., letters, diary) <sup>b</sup>	23.5
Creative writing (e.g., poems, novels) <sup>b</sup>	3.9
Games	13.7
Computer	9.8
Religious activities (individual, social) <sup>b</sup>	23.5
<b><i>Social activities</i></b>	
Spending time with family	12.7
Spending time with relatives, friends, neighbours	23.5
Helping and supporting others <sup>b</sup>	<b>56.9</b>
Activities in societies, social groups or unions	<b>30.4</b>
Going to restaurants & café <sup>c</sup>	24.5
Traveling for pleasure	<b>32.4</b>
<b><i>Work or work-related activities</i></b>	
Working full or part time	29.4
Studying full or part time	7.8
Taking care of and raising children	10.8
Voluntary work	16.7

<sup>a</sup> Items in bold indicate most common gaps

<sup>b</sup> New items added to the OGQ-P

<sup>c</sup> Missing data to answer this item = 1

### **5.3 ASPECTS OF FUNCTIONING, CONTEXTUAL FACTORS, HEALTH CONDITIONS AND LIFE SATISFACTION (STUDIES I-III)**

The descriptive characteristics of participants in terms of different aspects of functioning, contextual factors, health conditions and life satisfaction in studies I- III are presented in Table VII. Among these 102 participations, 43% were independent in ADL, 46% were moderately dependent and about 11% were severely dependent. The evaluation of motor function in terms of the participants' level of impairment showed that 30% of them had severe impairment, 25% marked impairment, 19% moderate impairment, 17% slight impairment and 9% had no motor impairment. Twenty-nine percent of the participants were depressed. In study III the distribution of level of global life satisfaction was estimated for the participants based on the raw scores. About 58% perceived their life as a whole as satisfying or very satisfying, and 41% perceived it as rather satisfying to very dissatisfying.

Table VII. Aspects relating to functioning, contextual factors and health conditions in the study (n=102)

Variable <sup>a</sup>	Total	Variable <sup>b</sup>	Total
Age (Year)		Cognitive function	
Mean (SD)	58.3 (11.9)	Mean (SD)	26.3 (2.5)
Range	27- 75	Range	23-30
Gender		Mood state	
Male	60 (58.8)	Mean (SD)	7.8 (4.9)
Female	42 (41.2)	Range	0-20
Marital status		Motor function	
Single	2 (2)	Mean (SD)	68.4 (30.6)
Married	85 (83.3)	Range	8-100
Widowed/divorced	15 (14.7)		
Educational status		Physical function including ADL ability	
Illiterate	27 (26.5)	Mean (SD)	66.2 (21.5)
Primary	35 (34.3)	Range	9.4-100
Secondary	27 (26.5)		
Academic	13 (12.7)		
Employment status		Independence in ADL	
Employed	19 (18.6)	Mean (SD)	82.6 (18.9)
Homemaker	34 (33.3)	Range	20-100
Retired	25 (24.5)		
Unemployed	24 (23.5)		
Living status		Mobility	
Living alone	6 (5.9)	Using wheelchair	1 (1)
Living with others (family, relatives, friends)	96 (94.1)	Using walking aid	29 (28.4)
		No aid	72 (70.6)
Access to caregiving services		Type of Stroke	
No support is needed	23 (22.5)	Ischemic	88 (86.3)
Receiving support	73 (71.6)	Hemorrhagic	14 (13.7)
No support but needed	6 (5.9)		
Access to rehabilitation services		Hemisphere lesion	
Receiving services	82 (80.4)	Left hemisphere	45 (44.1)
No services	20 (19.6)	Right hemisphere	52 (51.0)
		Others	5 (4.9)
Ethnicity		Time after stroke(months)	
Azeri	24 (23.5)	Mean (SD)	17.7 (10.1)
Baloch	2 (2.0)	Range	5-36
Gillak	11 (10.8)		
Kurd	3 (2.9)		
Persian	62 (60.8)	Measure of life satisfaction <sup>c</sup>	
		Mean (SD)	0.08 (0.74)
		Range	-1.64- 4.15

The values for categorical variables are given in frequency and percentage in parenthesis: n (%)

<sup>a</sup>Aspects relating to contextual factors

<sup>b</sup>Aspects relating to functioning, health conditions and life satisfaction

<sup>c</sup> The descriptive statistics for life satisfaction are presented based on Rasch-generated values

SD = standard deviation; ADL = activities of daily living

## **5.4 THE FACTORS ASSOCIATED WITH PARTICIPATION AFTER STROKE (STUDIES II & III)**

In study II one of the aims was to identify different aspects of functioning, contextual factors, and health conditions predicting two dimensions of participation, performance-based participation and social-based participation. In study III one of the aims was to explore the relationship between occupational gaps and different aspects of functioning and perceived life satisfaction. The results are presented separately for each study as below.

### **5.4.1 Different aspects of functioning and contextual factors associated with two dimensions of participation (study II)**

The results of the univariate analyses between different aspects of functioning, contextual factors, and health conditions and two dimensions of participation found age, educational status, access to rehabilitation services, cognitive functions, mood state, motor function, physical function, dependence in ADL and mobility significantly associated with performance-based participation. The results of the same analyses found access to caregiving services, mood state, physical function, and dependence in ADL significantly associated with social-based participation. No gender difference was found in the results of the univariate analyses with two dimensions of participation.

The results of the multivariate regression analyses found physical function and mood state to be the most influential variables associated with performance-based participation. It demonstrates that having higher levels of physical function and higher scores for mood state could be associated with higher levels of performance-based participation, which explained about 67% of the total variance. In this model, physical function alone explained 62%, and mood state explained 5% of the total variance in performance-based participation. Mood state, physical function, and access to caregiving services were found to be the most influential variables associated with social-based participation, which could explain 42% of its total variance. This means, higher scores for mood state, higher levels of physical function, and having access to caregiving services contribute significantly to higher levels of social-based participation. In this model, mood state alone explained 29% of the total variance in social-based participation. Physical function explained 7%, and access to caregiving services explained 6% of the total variance in social-based participation.

#### **5.4.2 Occupational gaps and their relation to functioning and life satisfaction (study III)**

The results of the Pearson correlation analysis between the two measures of occupational gaps and life satisfaction indicated a moderate correlation between them ( $r = 0.461$ ;  $p < 0.001$ ). The results of the univariate analyses between aspects of functioning and life satisfaction, and occupational gaps as the dependent variable found mood state, motor function, perceived physical function, independence in ADL, and life satisfaction significantly associated with occupational gaps. No gender differences were found in the results of the univariate analyses with respect to the measure of occupational gaps.

The results of the multivariate analyses demonstrated that perceived physical function including ADL ability, motor function, and measure of life satisfaction were those most highly associated with occupational gaps, which explained about 51% of the total variance. Thus, having greater physical function and ADL ability, a higher level of motor function and a higher level of life satisfaction could be associated with a lower extent of occupational gaps. In this model, perceived physical function including ADL ability alone explained 39% of the total variance in occupational gaps, motor function explained 7%, and the measure of life satisfaction explained an additional 5%.

#### **5.5 LIVED EXPERIENCE OF PARTICIPATION IN EVERYDAY OCCUPATIONS (STUDY IV)**

In study IV the aim was to describe and understand the lived experience of participation in everyday occupations among persons with stroke, and to identify what characterised the phenomenon of participation in everyday occupations. The findings are presented in a meaning structure of the phenomenon comprising three main characteristics. The first characteristic, *“I am not able to do as before”* described how the participants’ experience a tremendous change in their “doing” in different areas of everyday life. Losing former everyday routines, losing being a subject to act and decide, and losing former roles and authority in the family were identified as sub-characteristics. The second characteristic, *“I am not the same person - discovery of a different self”* described how the participants’ change in their perception of their being in the world, physically as well as socially. A senseless body – affected side as an object, discovering who they are through what they do, and discovering a different self in communication

with others, were all identified as the sub-characteristics. Finally, the third characteristics *“I am not living my life”* described how the participants could not live their lives the way they used to before their stroke and how they experienced dissatisfaction in their everyday life. The process of the phenomenon could be expressed by how the changes in *“what they do after stroke”*, interacted with changes in *“who they are after stroke”* which were both connected to a *“disengagement in everyday life that threatened their whole existence”*.

## 6 CONCLUSION OF FINDINGS

The findings of *study I* showed that the IPA-P could not validly measure perceived participation as a unidimensional construct, but supported two different but related constructs. Performance-based participation consisted of 19 items including three IPA domains: autonomy indoors, family role and autonomy outdoors. Social-based participation consisted of seven items from the social relations domain. The findings supported the psychometric properties of two constructs of perceived participation in the sample.

The findings of *study II* showed that the majority of the sample perceived their participation and autonomy as being good to fair in the different domains of their participation except in the autonomy outdoors domain, in which one third of the participants perceived their participation to be poor to very poor. The finding identified physical function and mood state as the most influential variables associated with performance-based participation after stroke. The most influential variables in social-based participation were identified as mood state, physical function and access to caregiving services.

The findings of *study III* supported the psychometric properties of the Persian versions of the OGQ and the LiSat-11 in the sample. The findings showed that the most common occupational gaps were perceived in the new item added to the OGQ-P, “helping and supporting others” followed by IADL items. Moreover, the findings identified the combination of three factors of physical function including ADL ability, motor function and perceived life satisfaction as being the most influential factors associated with occupational gaps after stroke.

The findings of *study IV* showed that the phenomenon of participation in everyday occupations encompassed a meaning structure comprising three main characteristics: (1) I am not able to do as before, (2) I am not the same person – discovery of a different self, (3) I am not living my life. The process of the phenomenon was expressed by how the changes in “*what they do after stroke*”, interacted with changes in “*who they are after stroke*” and made them experience “*not living their life*” in the way they used to before stroke.

## **7 DISCUSSION**

The focus of this thesis has been participation in everyday occupation after stroke. Participation is an important aspect of health and well-being (Law, 2002) and is suggested to be a key outcome of rehabilitation programmes for persons with a variety of diagnoses including stroke (Dijkers, 2010). Therefore, it is crucial to understand what it means to experience participation. One of the most common definitions of participation, used worldwide, is the ICF definition “involvement in a life situation” (WHO, 2001). However the ICF definition of participation has been criticised due to its lack of conceptual clarity and for providing little specificity about what type of involvement or life situation is meant (i.e. Whiteneck & Dijkers, 2009). Consequently, there is a knowledge gap regarding the clarification of the definition of this concept for clinical purposes. The discussion of the results of this thesis will begin by arguing that participation has two dimensions. By that, it challenges occupational therapy literature that mostly stresses the performance aspect of participation. It also challenges the social science perspective that focus solely on social participation. This thesis will argue that in order for persons after stroke to adapt to their new life and find satisfaction, attention must be paid to both “doing” and “identity” with regard to the experience of participation. Based on this background the thesis suggests an expansion of the ICF definition of participation. Further, in the main findings the socio-cultural aspects and the factors associated with participation will be discussed.

### **7.1 DISCUSSING THE MAIN FINDINGS**

#### **7.1.1 Participation as a multidimensional concept**

One of the main findings in this thesis is that in study I, participation could not be measured as a unidimensional construct. Performance-based participation and social-based participation were identified as two constructs validly measured by IPA-P in study I. Performance-based participation consisted of 19 items including a combination of three IPA domains: autonomy indoors, family role, and autonomy outdoors. Social-based participation consisted of seven items including the social relations domain. Performance-based participation is the first construct in which “doing” is the main aspect of participation. Social-based participation is the second construct in which the main aspect here is “being with others” and social relationships.



The empirical findings of study I point towards multidimensionality in the concept of “participation” and they raise critical questions about measuring participation as a unidimensional construct, as originally assumed in the IPA. Performance-based participation and social-based participation might be impacted differently by impairments and disabilities. It can be assumed that stroke might affect social aspects in another way than performance – especially if cognitive functions are less influenced.

The empirical findings in study I show an interesting divergence from one group of studies made in Western countries on IPA in which participation was found to be a unidimensional construct in different diagnostic samples (Cardol, et al., 2001; Cardol, et al., 1999b; Franchignoni, Ferriero, Giordano, Guglielmi, & Picco, 2007; Kersten, et al., 2007; Lund, Fisher, Lexell, & Bernspang, 2007; Sibley, et al., 2006). To our knowledge, this was the first study of IPA in a non-European country. Differences in cultures and societal traditions concerning family-orientation might be one possible explanation. In Iran which is a very family-oriented society, the family is the strongest social environment in which to take care of ill or disabled family members, with clear roles and distinct expectations regarding caregiving and support within the family context. This point was particularly discussed in studies I and II in this thesis. Empirical findings of a recent sociological study shows that the family is the pivot of the culture and the core of the social networks in Iran and individuals maintain close ties to their kin throughout their lives (Bastani, 2007).

However what speaks against this socio-cultural explanation is that another group of studies made in Europe and North-America has also discussed participation as a complex and multi-dimensional construct that has potentially different dimensions (Haak, Dahlin-Ivanoff S., Fange A., Sixsmith J., & Iwarsson S., 2007; Haak, Fange, Horstmann, & Iwarsson, 2008; Haggstrom & Lund, 2008; Hammel, et al., 2008; Whiteneck & Dijkers, 2009). As Whiteneck and Dijkers (2009) stressed, an important measurement issue that is certainly problematic in operationalising participation is determining the dimensionality of participation. They concluded that there might be various distinct dimensions to consider rather than one single dimension of participation. Bedell (2006) found in a psychometric study on participation of children with acquired brain injury that participation assessments might measure one construct with two different dimensions including participation in movement-related activities and participation in communication and school-based social activities. Haak and

colleagues (2007) from their qualitative study on experiences of participation in relation to the home among very old Swedish people found performance-oriented participation and togetherness-oriented participation as two kinds of participation. A follow-up analysis on two dimensions that had emerged found them related but different (Haak, et al., 2008). Borell et al. (2006) concluded from their study on experiences of participation among individuals living with chronic pain that being active and being social were two different aspects of participation.

The findings of study IV about the meaning structure of the phenomenon of participation in everyday occupations can also be interpreted as reflecting the experience of two dimensions of participation, one oriented towards doing and one oriented towards how individuals view themselves in their socio-cultural context. The findings from study IV show that both are needed to experience participation and contribute to how individuals live their lives.

Altogether it seems reasonable to assume that participation could be seen as an international concept through cultures, as was originally the aim in the creation of the ICF (WHO, 2001), but that it has potential dimensions that are important to reconsider in the process of conceptual definition and redefinition of participation. Participation as a broad international concept has to be explored in different cultures to operationalise possible dimensions that must be taken into account when developing instruments to properly measure participation. The empirical findings of this thesis stress the importance of these considerations. Future studies, using both qualitative and quantitative methods, are suggested to explore the potentially different dimensions of participation in different cultures and societal backgrounds, especially non-Western contexts.

### **7.1.2 The essential meaning of participation in everyday occupations**

The findings of study IV generated new knowledge regarding the concept of participation and the definition of this concept. In study IV both phenomenological and occupational perspectives were applied when analysing the data. The meaning structure of the phenomenon of participation in everyday occupations comprised three main characteristics. The first characteristic, “I am not able to do as before” expressed participants’ changes in their “doing” in different areas of everyday life. The second characteristic, “I am not the same person - discovery of a different self” expressed

participants changes in their perception of their being in the world both personally and socially. The third characteristic “I am not living my life” expressed the overall changes in the way they live after stroke. The presentation of meaning structure also included the process of the phenomenon which was expressed by the interaction between the first two characteristics and how they were both connected to the third characteristic, making the individuals feel they were not living their life the way they used to before stroke.

#### *7.1.2.1 Participation means more than different areas of everyday life*

Previous empirical studies have defined participation as a complex and multidimensional concept encompassing not only the observed performance of activities, but also the subjective experience of participation. These studies mainly describe different areas of everyday life as different aspects of participation (Borell, et al., 2006; Haak, et al., 2007; Haggstrom & Lund, 2008; Hammel, et al., 2008) as well as the barriers and environmental factors (Forhan, Law, Vrkljan, & Taylor, 2010). There is only one study with the same study phenomenon, participation in everyday occupations, and it concerned adults with obesity. However as the authors state, their study was limited to provide insight into the meaning of occupation for adults with obesity (Forhan, et al., 2010). The most significant finding in study IV was that the meaning of participation in everyday occupations revealed something more than just different areas of everyday life by emphasising three important aspects essentially defining the concept of participation; how changes in individuals’ doing were related to their identity/existence and their satisfaction in a dynamic process. These findings also reflect the experience of two dimensions of participation discussed earlier, one oriented towards doing and one oriented towards how individuals experience themselves in their socio-cultural context. The findings in study IV emphasise the importance of both dimensions in order for individuals to live their lives.

#### *7.1.2.2 Dimensions to facilitate adaptation and participation in everyday occupations*

Study IV demonstrated that the “discovery of a different self” encompassing personal, social and occupational dimensions of identity was one characteristic in the meaning structure of the phenomenon of participation in everyday occupations. This finding is in line with how previous literature discussed the association between occupation and identity (Christiansen, 1999; Laliberte-Rudman, 2002; Unruh, 2004). Occupational

identity, defined as the cumulative sense of who individuals are and wish to become as occupational beings generated from their history of occupational participation, was conceptualised as the primary means by which people express their sense of self (Kielhofner, 2008). Also Klinger's (2005) study of occupational adaptation after traumatic brain injury further supported the link between identity and occupation in which occupational adaptation was defined as "changes or adaptations in doing that enable people to respond to internal or external stressors in order to preserve occupational participation" (p.9). Reframing self-identity was suggested to be an important aspect of rehabilitation after brain injury. In line with this, Eriksson and collaborators found that by searching for a new sense of self through doing, persons with stroke adapted to their new everyday life situation (Eriksson & Tham, 2010).

The new finding in this thesis is that, the "discovery of a different self" as one characteristic of the phenomenon of participation in everyday occupations significantly interacted with participants' "doing" as another characteristic, and that these aspects are essential in arriving at the third characteristic, "being able to live life". These three key characteristics and their dynamic process defined the essential meaning of participation. The findings of study IV emphasise that all these three aspects are essential elements for experiencing participation which is important to consider in defining this concept.

The findings of study IV support how occupational adaptation is conceptualised in the Model of Human Occupation (MOHO). Perceived competence and identity in everyday occupations are two important components of occupational adaptation (Kielhofner, 2008). The significant changes participants experienced in their sense of self after their stroke seem to fit very well into occupational identity as a component interacting with occupational competence, the other component, leading to occupational adaptation (Kielhofner, 2008, 2009). The study IV findings give empirical support to the view that when the participants experienced a loss of competence and identity after stroke, they had not yet adapted to the new life situation which was related to their loss of experienced competence and identity after stroke, and this made them feel they were not living their lives.

Study IV supports the close association between occupational participation and occupational adaptation, and emphasises this link in enabling individuals in the rehabilitation process. These findings show that in order for individuals to adapt to their

new life after stroke and be able to live their lives again, both doing/competence and self/identity should be addressed in rehabilitation. This highlights the importance of both dimensions to facilitate adaptation and participation in everyday occupations.

### *7.1.2.3 Autonomy as an essential precondition for participation*

The findings of study IV emphasise the importance of autonomy in the experience of participation. Autonomy covers aspects such as choice, control, independence and self-determination. Being a subject and the doer does not only include performing, but also making choices and decisions. This means doing without being a subject (in the study expressed as being an object) seems to equate to only performance without a sense of engagement. Study IV showed that individuals could be satisfied with their participation in different everyday occupations if they could be active subjects. Being an active subject included objective and subjective aspects, which implies being able to both perform and decide as a doer. This empirical finding is in line with Cardol and colleagues (2002b) who stress the concept of autonomy as crucial to the proper operationalisation of participation and Perenboom and Chorus's (2003) definition of participation as the involvement in life situations that also includes the concept of autonomy. The empirical findings of study IV in this thesis regarding the importance of autonomy and being a subject in relation to participation validate the IPA as a person-perceived questionnaire able to assess autonomy, essential for measuring participation.

In conclusion our findings regarding participation in everyday occupation can be used to expand and enrich the more general definition of participation as suggested by the ICF: "involvement in a life situation" (WHO, 2001). In an expanded definition *participation* might be seen as *the involvement in a life situation with performance and/or social dimensions where autonomy is experienced*.

### **7.1.3 The family as both an enabler and a hinder for participation**

Empirical literature from Iran shows that family is in the centre of the social network throughout the life span (Bastani, 2007). The findings of this thesis support the importance of the family as a strong unit in a variety of ways in this context. The findings support the importance and necessity of having access to social support as an environmental factor influencing social participation, as well as its importance in person-environment interaction to enable participation post-stroke. Western studies have found social support to be an important factor facilitating participation after stroke

(Beckley, 2006; Clarke, et al., 1999; Guidetti, Asaba, & Tham, 2009). However the findings from this thesis and two other studies from Iran (Dalvandi, et al., 2011; Dalvandi, et al., 2009) reveal that the family is the main provider of social support for the person with stroke in this context. Therefore, the family needs and concerns in connection to persons with stroke should receive more attention in stroke rehabilitation.

In study I and II one possible explanation for the two dimensions of participation was concluded to be the cultural differences and societal traditions regarding family-orientation. It was discussed that in an extended-family oriented society like Iran with clear roles and distinct expectations regarding the provision of support, the family context shapes and reflects their social environment. It can be assumed that this approach can influence social-based participation to a different extent than performance-based participation.

In study II the analysis of gender comparison of perceived participation in each IPA domain revealed only one significant gender difference and this was in the family role domain. The findings showed that men perceived less participation and autonomy in their family role compared to women. One possible explanation is that as men in this socio-cultural context traditionally have the role of the head of the family, this role might impact their perceived participation and autonomy to a larger extent than the women's role for domestic and household responsibilities.

The findings of study II also found access to caregiving services as an influential factor associated with social-based participation. Among the participants who received caregiving services in performing their daily activities over 95% received support from informal caregivers who were mostly their families. Only about 8% received support from formal caregivers or from community services. This shows the significant contribution of the family in providing caregiving as a social support unit. The findings thus support the importance of taking the family system seriously into consideration in stroke rehabilitation as a key factor to facilitate social participation in this socio-cultural context. These findings also reflect the necessity and importance of future studies from the family perspective among persons with stroke in this context in order to plan appropriately for both the client and the family as a unit in the rehabilitation process.

Study IV has also highlighted the importance of the family. The participants in study IV, regardless of their gender or their various former roles, described how losing their main life role affected their importance and authority in the family, confirming the importance of their family role as their main concern regarding participation in everyday life. From a gender perspective, although there are differences in the way they fulfil their roles, both genders stressed the role the individual traditionally was expected to fulfil in the family; the value and importance of the individual in the family. One interpretation of this finding is that the socio-cultural importance of the family role in this family-oriented context had coloured the participants' experiences of losing their main life roles and this was closely related to their participation in everyday occupations.

Another important finding in study IV was the importance of the way the family/caregivers treated the individuals when giving help and support and how this contributed to preserving the sense of being a subject and giving the participant a sense of engagement and satisfaction. These findings support the view that the family/caregivers' view of the person with stroke as a subject rather than an object is apparently important in preserving the individual's autonomy and is a key precondition for participation. The empirical findings of study IV show and stress the importance of the family as the individuals' key social environment and how this heavily influences the individuals' perception of themselves as being subjects and not an objects, and in accepting their different self/identity after stroke.

In summary the findings concerning the central role of the family clearly show that family support could be one strong means of facilitating participation for the individuals; by creating opportunities for the preservation of their former important roles as much as possible and thereby a sense of satisfaction with their identities. Altogether from the empirical findings, this thesis emphasises the importance of the family and its place and the value of being closely involved in the rehabilitation team in the recovery process.

#### **7.1.4 Participation restrictions and the factors associated with participation after stroke**

Altogether from the descriptive findings of studies II and III it can be concluded that most participation restrictions were found in areas that are mainly physically

demanding such as autonomy outdoors domain (study II) and different instrumental ADL domain items (study III). This thesis has studied different factors associated with participation among participants through studies II and III. The empirical findings in study II indicated that physical function and mood state were found to be the most influential variables associated with performance-based participation as one dimension of participation after stroke. These findings also showed that physical function, mood state and access to caregiving services were revealed to be the most influential factors associated with social-based participation as another dimension of participation. Study II emphasises the importance of these three factors in explaining participation after stroke. Moreover the findings of study III identified the combination of three factors of physical function including ADL ability, motor function and perceived life satisfaction as the most influential factors associated with occupational gaps in rehabilitation after stroke.

Altogether from the findings of studies II and III, this thesis emphasises the importance of physical functioning, mood state, access to caregiving services and perceived life satisfaction as factors associated with participation after stroke. These findings regarding aspects of functioning associated with participation are in line with previous literature (Clarke, et al., 1999; Desrosiers, et al., 2008; Desrosiers, et al., 2006; Desrosiers, et al., 2002; Eriksson, et al., 2006; Sturm, et al., 2004), but this is not the same for perceived life satisfaction. Previous literature has found participation to be one of the predictors of life satisfaction after stroke as an outcome variable in rehabilitation (Edwards, et al., 2006; Eriksson, et al., 2009; Hartman-Maeir, et al., 2007). Although findings from previous research have focused on participation in general and the associated factors, no study has explored whether different aspects of functioning and perceived life satisfaction influence participation in everyday occupations. This was a new finding in this thesis in which life satisfaction is identified as an influential factor associated with participation after stroke.

The findings of study III revealed that the measure of life satisfaction could explain only 5% of the occupational gaps among participants. This low figure is probably due to the importance of functioning in explaining participation, rather than life satisfaction. It also highlights that life satisfaction could be a culturally dependent concept influenced by cultural and religious beliefs and values. In the Iranian context, feeling satisfied with what individuals have or who they are, is a religious value insomuch as



life is precious and something for which to be grateful. A cultural meaning such as this could be the possible reason for more than half of the sample (59%) reporting they were satisfied to very satisfied with their global life. Comparing the findings with the corresponding Western study reveals that 35% of that sample reported they were satisfied to very satisfied with their global life (Eriksson, et al., 2009). This could demonstrate cultural differences in the view of life satisfaction between the two contexts. This thesis suggests considering life satisfaction earlier on in stroke rehabilitation as a factor contributing to enhanced participation in everyday occupations, and not just as a goal in the rehabilitation process. More specific research should be performed to study how this goal might be fulfilled in rehabilitation.

The findings of studies II and III support the importance and priority of functioning in explaining participation. Previous literature reflects different views in relation to the importance and priority of the factors explaining participation after stroke. Sturm and colleagues discussed how the interventions that reduce impairment and disability are possibly also most effective in reducing participation restrictions (Sturm, et al., 2004). In contrast, Whiteneck and Dijkers argued that environmental factors are more important in explaining participation restrictions than activity limitations and impairments (Whiteneck & Dijkers, 2009). This is something to be studied further and clarified in future research to assess the impact of contextual factors on participation in this context.

#### **7.1.5 Instrument development and cross-cultural adaptation**

In this thesis, the Persian version of three instruments was produced following the guidelines for the process of cross-cultural adaption of self-reported measures (Beaton, et al., 2000). Two of these instruments were specifically developed to assess participation, and one to assess life satisfaction. As mentioned in method section, the IPA-P was produced to assess perceived participation and autonomy, and the OGQ-P to assess gaps in participation in everyday occupations (occupational gaps). Life satisfaction was also assessed by the Persian version of the LiSat-11. Although the main aim of this research project has not been instrument development and psychometric evaluation, this step had to be performed as a preparatory step before starting the explorative analyses. Similar to the English version of the IPA, the item “helping and supporting other people” was included in the IPA-P due to the cultural

relevance in this context. Consequently, the IPA-P also included 32 items as did the English version.

In the translation process of these three instruments, most changes were made in the OGQ-P to modify the questionnaire culturally by adding three new items and changing the examples for the items. The new items were “non-grocery shopping”, “creative writing”, and “helping and supporting others”. Item “religious activities” was also modified to encompass both individual and social dimensions, and not just as a social pursuit as considered in the original OGQ in Swedish. Although adding some items such as “helping and supporting others” can reflect the socio-cultural aspects, the empirical findings of Western studies also support the importance of this aspect of participation. For instance Borell and collaborators found “doing something for others” to be an important aspect of participation among persons with chronic pain (Borell, et al., 2006) and in a study of very elderly persons in Sweden “performing for others” was a part of their participation experience (Haak, et al., 2007). The changes in the OGQ-P should be considered the in future international development of the OGQ.

The cross-cultural adaptation of the self-reported questionnaires is essential for use in a new country, culture, and language. This necessitates applying a unique method to provide the equivalence between the original and target versions of the questionnaire. This procedure requires not only translating the items linguistically, but also adapting them culturally to preserve the content validity of the instrument at a conceptual level across different cultures. The term “cross-cultural adaptation” is utilised to encompass a process that focuses on both languages in translation and the cultural adaptation issues in the process of providing the questionnaire for use in another context. This process allows increased confidence in applying the questionnaire for outcome evaluations in research studies (Beaton, et al., 2000). It can be concluded from the findings of study III concerning the cultural adaptation of the OGQ that, it is sometimes difficult to compare the results of two cultural contexts as some items are added or changed, but the results would be more accurate to use in the target culture.

Another finding in connection with instrument development is that the findings of study IV validate the IPA in terms of considering autonomy as important when measuring participation.

## **7.2 METHODOLOGICAL CONSIDERATIONS**

In this thesis different designs and methodological approaches have been utilised in four studies which all contribute different perspectives to the findings of the thesis. Choosing appropriate methodological approaches in research projects is important and challenging. Applying each specific methodological approach has strengths and weaknesses and can influence the research findings. Therefore, it is essential to reflect on how the methodological approaches applied in this thesis might have influenced the findings.

### **7.2.1 Sampling**

All four studies in this thesis recruited people with stroke who were able to communicate in the Persian language to respond to the questions and share their experiences. The studies also included those who had sufficient cognitive function. Although this approach could limit the studies with respect to generalising the findings to all people with stroke, this decision was made to prevent those with a possible diagnosis of dementia and to ensure that participants were able to understand and respond to the questions, thereby providing more valid and reliable data. This approach has been commonly applied in several previous studies among persons with stroke (Clarke, et al., 1999; Desrosiers, et al., 2006; Desrosiers, et al., 2002) .

Another limitation of studies I-III was that the sample was not representative of the whole population of persons with stroke in the country. Iran, being an extensive country, has people with different ethnic backgrounds and has no national registry for persons with stroke. However the sampling was performed in Tehran, the capital of the country, which made it possible to recruit a variety of ethnic backgrounds in line with the ethnic distribution of the country (The World Factbook). The sampling was performed in four university hospitals or clinics in different geographical locations in Tehran to increase diversity and heterogeneity in sampling. Two of these centres were neurological hospital wards from two university networks covering all regions in Tehran. All these centres were public and in urban areas, and the findings might have been different in private hospitals or clinics, and in rural areas due to other environmental factors to be considered as variables. Consequently, the generalisation of the findings for all persons with stroke in Iran is limited.

### **7.2.2 Data collection (methods and assessment instruments)**

Due to the fact that 26.5% of the sample were illiterate, all the participants in studies I-III were interviewed to acquire their responses to items of the self-reported questionnaires including the IPA, OGQ, LiSat-11, HADS, and SIS-16. As these instruments were originally developed as self-report assessments, the results might have been influenced by the procedure of interviewing the participants. To prevent this possibility the researcher had a strictly neutral attitude during the interviews with the participants and answered only direct questions regarding the explanation of different items. The decision to carry out personal interviews was made to allow the possibility of including the illiterate participants. Otherwise, the choice of excluding one quarter of the sample could also be judged as having a significantly negative influence on the study.

One limitation in study II might be that it was not possible to fully assess the impact of contextual factors on participation due to the low number of environmental factors included in the study. This was the first exploratory study of participation after stroke in Iran based on the ICF. More future research has to be conducted specifically focused on the environmental factors in connection with participation after stroke in the Iranian population. The socio-cultural aspects that explain participation should also be further studied in this context.

Another limitation in studies I and II might be not including the second scale of the IPA-P in the study. This decision was made as this scale focuses on another construct, namely problems with participation. Future studies are essential to psychometrically examine this second scale and the possible factors explaining this construct in the IPA. Moreover, these studies excluded the work and education domain in the analysis due to the low number of applicable participants. Previous studies were also limited in applying this domain in the analysis (Cardol, et al., 2001; Cardol, et al., 1999b; Franchignoni, et al., 2007). Future studies on larger samples are needed to explore how this domain could influence participation.

One limitation of study IV was having only one in-depth interview with each participant. However for data collection, the researcher and participants met twice. The first occasion was to create a relationship of trust to facilitate a good and in-depth

interview on the second occasion. The decision was made to include eight participants (instead of four) to get a more divergent sample to study the phenomenon.

### **7.2.3 Methods for data analysis**

A large number of variables were examined in study II as that study was the first exploratory study on participation after stroke and the associated factors consistent with the ICF in Iran. It might be argued that the generalisability and the statistical power could have been greater if the sample size had been larger. However the statistical solution for this limitation was that despite the limited sample size, each variable was analysed univariately with each dimension of participation as the dependent variable. Then as a second step, the independent variables significantly associated with each dimension were included in the multiple regression analysis with each dimension as the dependent variable. Applying this two step analysis made it possible to exclude those independent variables that were not statistically correlated with the dependent variables, and to reduce the number of variables for the multiple regression analysis.

In study IV applying phenomenology as the approach to analyse the data was an efficient method to provide the essence of the phenomenon by highlighting what it is (what happens, i.e. characteristics 1 & 2) and what it is aimed at (characteristic 3) (Bontje, Kinebanian, Josephsson, & Tamura, 2004). These themes seem consistent with this explanation, thereby contributing to the trustworthiness of the study.

In study IV one possible limitation was the language translation issue. The analysis was performed in English from step three where the meanings units were transformed into the researcher's language. Since the authors were from both Iran and Sweden, this approach provided the opportunity for all to discuss the data analysis. During this process, the researcher went back to the Persian data when necessary. Moreover, the translation, as an interpretive act, was taken into account (van Nes, Abma, Jonsson, & Deeg, 2010). For example, Persian sayings in the data were discussed to preserve important meaning in the translation process.

## **7.3 ETHICAL CONSIDERATIONS**

All four studies, I-IV, in this thesis were approved by the National Ethical Committee of the Ministry of Health and Medical Education in Iran. All the participants in the four studies gave their informed consents both orally and in writing to participate in the

studies. All the participants and their close family (spouse or children) were given verbal and written information about the study including the focus, aim, methods and procedures and their participation. The participants were not forced to take part in the study and they decided freely. They were assured about the confidentiality and were entitled to withdraw from the study in any time. The data collection methods were safe with limited risk and free of charge for the participants. All the data collected were assigned with a code number to maintain privacy and prevent identification.

There are several ethical dilemmas that are encountered and have to be taken into consideration when performing research. One dilemma might be the number of assessments for the participants in studies I-III. They could feel tired if all the assessments are performed by the researcher on one occasion, leading them to feel forced to answer the questions and this could also influence the results of the study. In order to prevent this, the researcher met the participants twice in the clinical setting to which they had been previously admitted and collected the data on two occasions.

Another dilemma might be that of excluding the persons with stroke who had major cognitive and communication problems. These individuals could possibly have been interested in participating in the study if they had been asked by the researcher. However the decision concerning inclusion criteria was made in order to provide a sample that was able to share their experiences by answering the questions. Another dilemma might be the possibility that the participants had expectations of receiving treatment or feedback from the researcher. All the participants were informed before giving their consent about this issue and their contribution in the research project. However, the researcher did provide some consultations based on the evaluation outcomes and the participants' obvious needs in the rehabilitation process. They were referred to medical and health professionals to receive the services they needed in their rehabilitation process. All these consultations were provided after completing the data collection and did not interfere with the data collection. All the participants were extremely eager to be assessed and/or share their experiences after their stroke.

Yet another dilemma might be the data collected by the researcher but not presented in the thesis due to further future analyses. However the only data that was not reported was the data for the IPA-P scale II regarding problems with participation in studies I and II and the descriptive data for the items of the LiSat-11 describing life satisfaction

in the sample in study III. The participants' participation in the research project had no impact on them getting health and rehabilitation services, in fact most of them were referred to appropriate health care professionals to get their required services. None of the participants indicated any negative experiences of participating in the four studies.

A further dilemma could be how to handle emotions projected by the participants during the interview especially in study IV. The participants in this thesis eagerly shared their experiences and had a strong desire to talk about their situations. They were never left alone when expressing their feelings concerning the consequences of their stroke and they were supported by the researcher. They were satisfied with their interview and were emotionally stable when they left the data collection session.

The final possible dilemma could be the questions about private issues such as sex life and intimate relationships. In this context there was a trusting and respectful relationship between patient and health care professionals in which the clients eagerly spoke about their experiences and situation. This cultural acceptance could be one possible approach for preventing this dilemma.

## **7.4 IMPLICATIONS**

### **7.4.1 Implications for stroke rehabilitation in Iran and worldwide**

The empirical findings of this thesis contribute new knowledge that can be implemented in occupational therapy as well as in stroke rehabilitation. Occupational therapy after stroke in Iran basically applies traditional Western models for stroke rehabilitation as standard procedure. This comprises the application of various therapeutic methods provided by bio-medically focused textbooks and articles. The biomedical perspective, which is still preferred, focuses on body function level in the provision of occupational therapy services rather than on the occupational perspective described in contemporary literature and research within the area of occupational therapy and occupational science. The findings of this thesis emphasise the importance of providing culturally sensitive rehabilitation based on the participants needs and also consistent with the socio-cultural context when planning appropriate rehabilitation interventions. The empirical findings of this thesis can not only be implemented in stroke rehabilitation in Iran, but also worldwide by providing empirical evidence from a non-Western society and comparing it with research on participation after stroke in

Western societies. Below, the most important clinical implications are further developed.

- Based on the findings, the newly translated instruments in this thesis can be used for assessing persons with stroke in an Iranian context for clinical purposes. However the IPA-P scale I measures participation within two different but related dimensions.
- The findings of studies I and II indicate that both performance-based participation and social-based participation should be taken into consideration in stroke rehabilitation. This is also in line with study IV that highlights the importance of both the “doing” and the “self/identity” aspects in facilitating participation in everyday occupations. Enabling individuals in their “doing” is addressed in current stroke rehabilitation interventions in Iran. However, the findings of this thesis show that for individuals to adapt to their new life after stroke, by being able to live their lives, both doing and identity must be addressed in rehabilitation to facilitate adaptation and participation in everyday occupations.
- Studies II shows the importance of physical function, mood state and access to caregiving services as factors associated with two dimensions of participation. These factors should thus be considered in facilitating participation in the rehabilitation process.
- The findings of study III emphasise the importance of a combination of physical function, motor function and life satisfaction as factors associated with gaps in participation in everyday occupations after stroke. The findings from this study suggests that professionals should consider life satisfaction earlier in the stroke rehabilitation process as a factor contributing to enhanced participation in everyday occupations and not just as a final goal for rehabilitation. For example, if one of two male individuals with stroke, and at the same level in terms of their functioning and severity of stroke, is more dissatisfied with different areas of his life, this dissatisfaction can imply a greater extent of restricted participation for him than for the other person.



- The findings of studies II and IV emphasise the particular importance of the family and caregivers as the main source of caregiving services provision and this is a key-factor in the rehabilitation process both facilitating and inhibiting the individual's participation. Occupational therapists and other rehabilitation professionals should prioritise family-oriented interventions with the following aims:
  - To support the client in maintaining their family-role as much as possible.
  - To educate and involve the whole family in the rehabilitation programme to facilitate adaptation for the client with respect to his/her subjectivity and to better accepting his/her different self after stroke.
  - To support the family in adaptation to both performance-based and social-based participation by finding possible ways to “make it happen but differently”.
  
- In this thesis, studies II and III demonstrate that the participants perceived their most common restrictions and gaps in outdoor activities and instrumental activities of daily living since these activities are physical demanding. This finding provides support for view concerning the necessity of environmental facilities and modifications in order to facilitate their participation. The findings also provide evidence of the necessity of ADL training in rehabilitation interventions. However current rehabilitation services in Iran lack both these important components.
  
- The findings of study III also support the importance of addressing the occupations such as “helping and supporting others” that are important from an individual perspective in this socio-cultural context, but are not taken into consideration in rehabilitation interventions based on applying the bio-medical model. Although these occupations are not related to the individuals' personal independence, they do stress the importance of preserving relationships and might, in this context, be a socio-cultural rehabilitation priority for persons with stroke.

#### **7.4.2 Implications in relation to ICF and participation**

The most obvious implication of the findings in relation to the ICF model is that the subjective experience has to be central in participation. In the further operationalising

of the concept the two dimensions of performance-based participation and social-based participation should be discussed. The same goes for autonomy as an underlying prerequisite for participation. This thesis, as well as other research within occupational therapy, has conducted extensive empirical studies on participation. It is important that this research becomes a part of the dialogue regarding participation with the aim of developing the classification to more effectively address participation as essential in an international model of health.

## 7.5 FUTURE RESEARCH

Findings from this thesis suggest a number of priorities for future research as below:

- *Psychometric evaluation and cross-cultural studies* - Prior to the wide clinical use of the Persian-translated instruments, further studies are suggested to examine the psychometric properties of these instruments in other diagnoses in this context. Future studies are also essential to examine the psychometric properties of the second scale in the IPA-P, and also to examine how the work and education domain could influence participation. Furthermore, the psychometrical evaluation of the translated instruments in other non-Western cultures is suggested, and more specifically that of the IPA. Future cross-cultural studies are needed in order to compare the findings between different cultures and the potential possible categorisation that can be used in the future development of participation instruments.
- *Exploratory studies on the factors associated with participation in everyday occupations* – Future studies should be performed focusing specifically on environmental factors in relation to participation after stroke in the Iranian population. Qualitative studies will be beneficial in finding out more sociocultural aspects explaining participation in this context. This thesis also suggests future studies regarding the examination of life satisfaction as a possible predictor in other cultures.
- *Family- focused studies* – The findings in this thesis demonstrate the importance of the family as a key sociocultural environment. These findings reflect the necessity and importance of future studies from the family perspective among persons with stroke in this context. This is in order to plan

appropriately for both the client and the family as a unit in the rehabilitation process of providing client-centred and culture-sensitive occupational therapy interventions. Moreover, family needs as the main provider of social support should be explored extensively.

- *Qualitative and quantitative studies to identify individuals' needs* - in relation to their participation in everyday occupations for the provision of appropriate social support services for persons with stroke at a national level and within the health care system in the country.
- *Occupation-based intervention studies* – more specifically focusing on the three characteristics that emerged from this thesis as the essential meaning of participation in everyday occupations as well as on both aspects of “doing” and “identity” in order to enable individuals in their participation and life satisfaction
- *Longitudinal qualitative studies* – more specifically on individuals' participation in everyday occupations and their adaptation after stroke. These studies can be beneficial in the planning of appropriate future intervention studies.

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