Universiteit Gent
Faculteit Psychologie en Pedagogische Wetenschappen
Academiejaar 2011 – 2012

Quality of Life of individuals with an acquired brain injury:
an investigation with the Personal Outcomes Scale

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Masterproef ingediend tot het behalen van de graad van Master
in de Pedagogische Wetenschappen, afstudeerrichting Orthopedagogiek
Prologue

Writing this thesis was an interesting and new experience for me. My previous experiences with people with an acquired brain injury and their life stories made me wonder about the effect of a brain injury on someone’s life. This motivated me to choose the topic of quality of life of individuals with an acquired brain injury as the theme of my master thesis. The support and insights of different people helped me completing this work. That is why I would like to seize the opportunity to thank following people:

The service users of Second Chance, their relatives, partners and personal assistants who volunteered to participate in the study and devoted time to the interviews. Without them, this study would not have been possible;

The team of Second Chance, for helping me organizing the interviews, providing me with a room to administer the interviews, and participating in the study as well;

Prof. Dr. Jos van Loon, my promoter, for supporting me during the writing process, giving me feedback and providing me with many new insights and ideas;

Remco Mostert, for instructing me in the use of the Personal Outcomes Scale, and for answering all my questions regarding the scale;

My parents and Ángel, for supporting me during the writing process, for motivating me and for reading every tiny bit of this thesis.
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# Bibliography
Introduction

1. Context and aim

Quality of life (QOL) has become a common concept in our terminology, not only in academic research but as well in the broader society. An entry at the search engine ‘Google’, for instance, provides over 115.000.000 websites in which the term is mentioned, and the database of Web of Science counts approximately 154.815 scientific articles which have ‘quality of life’ as a topic. Quality of life has been studied over the years in different study fields, like sociology, economics, psychiatry, medicine and psychology (Brown & Brown, 2003; Seed & Lloyd, 1997). In the field of intellectual disability a lot of research has been done about quality of life of people with disabilities. The findings of these researches are not only applicable to people with disabilities, but as well to the society in general (Brown & Brown, 2003; Goode, 1997).

In 2002, Schalock and Verdugo described quality of life as a multidimensional construct. Based on an international literature review, they defined eight core quality of life domains. Today, Schalock and Verdugo’s model is internationally accepted to be a valid and reliable framework to discuss an individual’s quality of life (Gómez, Verdugo, Arias, & Arias, 2011). This theoretical framework was used in 2008 as the fundament for the development of a quality of life measurement instrument, the Personal Outcomes Scale (POS) (Van Loon, Van Hove, Schalock, & Claes, 2008).

Between 2008 and today, the POS has been used in several studies to assess the quality of life of people with disabilities and people without disabilities (De Windt & Lannau, 2009; Moonen, van Loon, Van Hove, Vandevelde, & Claes, 2010; Van Havere, 2011; van Hove et al., 2011; Van Loon, Van Hove, Schalock, & Claes, 2008). In this thesis, a study with the POS about the quality of life of people with an acquired brain injury will be described. This study puts forward to explore two issues. Firstly, the research aims to sketch an overall picture of the quality of life of people with an acquired brain injury. Secondly, the POS will be examined on its adequacy to assess the quality of life of this population.
2. Second Chance Headway Centre (SCHC)

We believe in the right of everyone to an acceptable quality of life and that disability should not be a barrier to obtaining the skills, knowledge and understanding required to achieve a better quality of life (mission statement of SCHC, http://www.schc.co.uk).

The research for this thesis has been carried out completely in the Second Chance Headway Centre in Wakefield, United Kingdom. Therefore, I would like to devote this section to a presentation of Second Chance.

Second Chance is a support group for people with a brain injury and their families. They provide advice, information, support and a specialist day centre. This centre is open five days a week, and helps people with an acquired brain injury in learning vital every-day skills which they might have lost. The service users are supported in coping with the problems arising from their condition, and receive therefore training in for example communication skills, memory skills, concentration, and mobility (Second Chance Headway Centre, 2011).

At the moment, 56 service users attend the day centre. They are supported by a team of 7 people, which consists of occupational therapists and head injury nurses. Second Chance as well counts with the help of over 25 volunteers, who come to the centre on a weekly basis. SCHC has a link with the brain injury association ‘Headway’, and is part of Headway’s network of support groups for people with ABI in the United Kingdom.

The thesis research has been carried out with 47 of the service users, and 47 of their family members, partners or professionals.

3. Design of the thesis

This thesis contains, after the introduction, four chapters. The first chapter contains a literature review in which the construct of quality of life, the measurement instrument ‘Personal Outcomes Scale’ and the concept of Acquired Brain Injury are discussed. This chapter ends with the research questions put forward for this study. A second chapter treats the methodology of the research. The group of respondents and the measurement instruments are described, followed by a brief overview of the successive phases of the procedure and a summary of the methods used to analyse the data. The third chapter sums up the results of the study. It describes the outcomes of the statistical analyses, makes a comparison between different groups investigated with the POS, and contains the
results of the qualitative part of the study. The last chapter is a discussion on the results. This chapter tries to answer the research questions, and lists the limitations of the study and recommendations for future research.

All bibliographical references in this research are formulated following the rules of the American Psychological Association (APA 6th edition, 2010).
1. Quality of Life

Historically, four sources caused the interest in quality of life (Schalock, 2004). A first one is the understanding that wellbeing results from a complex combination of factors (like technological advance, perceptions and environmental conditions). Another source emerged from the normalization movement, which underlined the importance of community-based services to measuring the outcomes from the individual’s life in the community. A third source are the consumer empowerment and patients’ rights movements who emphasized personcentred planning, personal outcomes and self-determination. Finally, the subjective aspects of quality of life and its individual and personal characteristics were introduced by sociological changes. Today, following Schalock, the concept of quality of life has influenced an entire service delivery system. The concept provides a reference to measure and enhance the individual’s well-being. A unified conceptual framework is necessary to guide this current and future process of change.

In what follows, I will give a concise summary of definitions of ‘quality of life’ and its domains. In ‘perspectives on quality of life’ I discuss the perceived difference between the objectivity and subjectivity of the concept, and the difference between quality of life measurements of a population and of an individual. I will continue with some examples of instruments for measurement, e.g. the Personal Outcomes Scale (which will be further described in section 2). To end, the etic and emic properties of the concept will be discussed.

1.1. Quality of life: the concept and its definition

The concept ‘quality of life’ was first referred to in a study of Wolfgang Zapf in the 60s. He defined the concept as being an existing correlation between an objective value of the life standard of a particular group, and the corresponding subjective valuation by this group (like satisfaction and well-being) (Zapf, 1984, cited in Fernández López, Fernández Fidalgo, & Cieza, 2010). From then on, the concept has been defined in different ways whereby a large assortment of aspects of life have been included: health, physical well-being, psychosocial adaptation, the feeling of happiness, et cetera (Fernández López, Fernández Fidalgo, & Cieza, 2010). These aspects come back in the variety of definitions put forward by several authors and researchers. Cummins (1997) for instance, just like
Zapf, sees quality of life as both objective and subjective, and distinguished material well-being, health, productivity, intimacy, safety, community and emotional well-being as features of the concept. Felce and Perry (1997) emphasize that quality of life is a multidimensional concept involving personal well-being. Following them, intimate relationships, family life, friendships, standard of living, work, neighborhood, city or town of residence, the state of the nation, housing, education, health and self are all part of people’s quality of life. Goode (1997) states that quality of life is mostly “an emphasis on promoting a general feeling of well-being, opportunities to fulfill potential and feelings of positive social involvement” (p. 73). Costanza et al. (2008) propose following integrative definition of quality of life: “Quality of Life is the extent to which objective human needs are fulfilled in relation to personal or group perceptions of subjective well-being” (p. 18). The ‘Quality of Life Research Unit’ of Toronto University (http://www.utoronto.ca/qol) define Quality of Life as follows: ‘The degree to which a person enjoys the important possibilities of his or her life’. These possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors. Another definition has been put forward by Schalock, Keith, Verdugo, and Gomez (2009), who see quality of life as “a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. These core domains are the same for all people, although they may vary individually in relative value and importance. Assessment of quality of life domains is based on culturally sensitive indicators” (p. 21). Quality of life has been defined in different ways, and many of these definitions reflect the idea that there exist certain domains which determine a person’s quality of life (multidimensional perspective). Another aspect that returns is the difference between the ‘objective’ and ‘subjective’ qualities of life quality. Both issues will be further explored in following sections, respectively 1.2 and 1.3.

The concept ‘quality of life’ can be separated from related concepts, like functional status, health status, health-related quality of life (HRQOL) and quality of care. Functional status is the degree in which a person is able to perform certain roles, like activities of daily living or a job, without physical or mental limitations. Health status refers to the medical and functional well-being of an individual (Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007). The term ‘health-related quality of life’ is used to distinguish between quality of life in its general sense and quality of life of individuals in health and medical treatment, it addresses the health-related aspects associated with quality of life and is therefore a restricted view of the quality of life concept. The HRQOL tends to concentrate on the negative aspects of disease and injury (Cummins, 1997; Fayers & Machin, 2000; Rosenbaum, Livingston, Palisano, Galuppi, & Russell, 2007). At the other side, the concept as well gives an extra dimension of ‘quality’ to the medical care, where treatment is usually the core focus (Brown &
Brown, 2003). Quality of care is a concept usually used to refer to the quality of the care for people with disabilities. It puts an emphasis on impairment and categorization of people (De Waele, van Loon, Van Hove, & Schalock, 2005). It is important to distinguish these concepts from the construct of ‘quality of life’. Though they may influence or be part of the quality of life of a person or population, they do not solely define it nor do they guarantee it.

1.2. Domains

As already suggested by some of the definitions in the previous part, quality of life is a multidimensional concept. In several sources, authors agree upon the existence of certain life domains that define a life of quality (Brown & Brown, 2003; Costanza et al., 2008; Cummins, 1997; Felce & Perry, 1997; Kane, 2001; Schalock, Bonham, & Verdugo, 2008). Domains refer to the set of factors that define personal well-being. The concept of quality of life is therefore a construct, represented by these life domains. In the literature, there has been found agreement concerning the core quality of life domains (Verdugo, Schalock, Keith, & Stancliffe, 2005). Felce and Perry distinguish physical well-being, material well-being, social well-being, emotional well-being and productive well-being. Cummins discusses evidence for the following domains to influence quality of life: material well-being, health, productivity, intimacy, emotional well-being, safety and community. Kane proposes security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being, and functional competence as quality of life domains. Brown and Brown describe a division in categories of suggested domains about the individual, about what the individual does and about the environment (Table 1). Costanza et al. define some domains they consider to be essential human needs, like subsistence, reproduction, security, affection, understanding, participation, leisure, spirituality, creativity, identity and freedom. They state that quality of life is mediated by the opportunities our society provides to meet these human needs, in the shape of human, social and natural capital, and in combination with policies that should guarantee these opportunities.

Domains can be divided in sub-domains which describe them. Following the Quality of Life Research Unit (http://www.utoronto.ca/qol), quality of life consists of three main domains, of which each is divided in sub-domains (Table 2). The domain ‘being’ refers to basic attributes concerning the individual, ‘belonging’ are the connections between the individuals and their environments, and ‘becoming’ is the achieving of personal goals and the fulfilling of hopes (Renwick et al., 1996, cited in Brown & Brown, 2005). Each individual contributes personal value to these dimensions. Quality of life takes into account the individual perspective and life situation of people.

6
Table 1

*Quality of Life Domains* (Brown & Brown, 2003)

<table>
<thead>
<tr>
<th>About the individual</th>
<th>About what the individual does</th>
<th>About the environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Material well-being</td>
<td>- Work</td>
<td>- Social inclusion</td>
</tr>
<tr>
<td>- Physical health</td>
<td>- Leisure activities</td>
<td>- Rights</td>
</tr>
<tr>
<td>- Psychological well-being</td>
<td>- Personal development</td>
<td>- Safety</td>
</tr>
<tr>
<td>- Spiritual well-being</td>
<td>- Interpersonal relation</td>
<td>- Societal well-being</td>
</tr>
<tr>
<td>- Social well-being</td>
<td>- Intimacy</td>
<td>- Home life / Housing</td>
</tr>
<tr>
<td>- Self-image</td>
<td>- Education</td>
<td>- Community resources</td>
</tr>
<tr>
<td>- Self-determination</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2

*Quality of Life Domains and Sub-domains* (Quality of Life Research Unit, Toronto University)

<table>
<thead>
<tr>
<th>Domains</th>
<th>Sub-domains</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being</td>
<td>Physical being</td>
<td>Physical health, personal hygiene, nutrition, exercise</td>
</tr>
<tr>
<td></td>
<td>Psychological being</td>
<td>Psychological health, cognitions, feelings, self-esteem</td>
</tr>
<tr>
<td></td>
<td>Spiritual being</td>
<td>Personal values, personal standards of conduct, spiritual beliefs</td>
</tr>
<tr>
<td>Belonging</td>
<td>Physical belonging</td>
<td>Home, workplace/school, neighbourhood, community</td>
</tr>
<tr>
<td></td>
<td>Social belonging</td>
<td>Intimate others, family, friends, neighbourhood</td>
</tr>
<tr>
<td></td>
<td>Community belonging</td>
<td>Income, health and social services, employment, education</td>
</tr>
<tr>
<td>Becoming</td>
<td>Practical becoming</td>
<td>Domestic activities, paid work, school or volunteer activities</td>
</tr>
<tr>
<td></td>
<td>Leisure becoming</td>
<td>Activities that promote relaxation and stress reduction</td>
</tr>
<tr>
<td></td>
<td>Growth becoming</td>
<td>Activities that promote the maintenance or improvement of knowledge and skills, adapting to change</td>
</tr>
</tbody>
</table>
Life domains and sub-domains contain certain quality of life indicators. These are perceptions, behaviours, and conditions that operationally define each quality of life domain. Their measurement results in personal quality of life outcomes (Schalock, 2004; Schalock, Bonham, & Verdugo, 2008). The domains, sub-domains and indicators overlap and interconnect, therefore we should think about quality of life in a holistic way. We should consider the individual across all domains of life, and look at the needs of the person as a ‘whole’ (physical, mental, social, spiritual, and so on) (Brown & Brown, 2003; Seed & Lloyd, 1997).

The conceptual framework of quality of life, developed by Schalock, Bonham, and Verdugo (2008) consists of factors, which are divided in domains, which are characterized by indicators, as in Table 3. This model is based on the factors, domains and indicators defined by Schalock and Verdugo in 2002, which is subject of a comparative research of models by Gómez, Verdugo, Arias, and Arias (2011). In this research they showed that this eight domains model is an adequate portrayal of quality of life. The quality of life construct might have a possible hierarchical character though, but following their research in 2011 it is showed not to be necessary to resort the model to a hierarchical structure. One remark hereby is that they tested the model using an objective assessment (GENCAT), and evidence using a subjective structure is still needed. Today, the eight domains model is internationally accepted to be a valid and reliable framework.

The domains and indicators mentioned in this section can be seen and measured in an objective and in a subjective perspective (see section 1.3).

### 1.3. Perspectives on quality of life

Quality of life is a multidimensional construct that has both objective and subjective features (Costanza et al., 2008; Cummins, 1997, 2005; Verdugo, Schalock, Keith, & Stancliffe, 2005). The objective components are external conditions which can be observed and measured within the public domain, they include culturally normative values. Subjective features only exist within the private consciousness of an individual; they reflect the satisfaction with life domains weighted in accordance with their value to the individual. There is now a general agreement that quality of life implies a combination of objective and subjective variables. Both objective and subjective evaluations are valid, complementary indicators of quality of life (Cummins, 1997, 2005). Therefore, both should be included in the measurement of quality of life (Verdugo, Schalock, Keith, & Stancliffe, 2005). Like Costanza et al. (2008) state, “Quality of Life is the extent to which objective human needs are fulfilled in relation to personal or group perceptions of subjective well-being” (p. 18).
Table 3

*Conceptual Framework of Quality of Life* (Schalock, Bonham, & Verdugo, 2008)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Domains</th>
<th>Exemplary indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
<td>Personal development</td>
<td>Educational status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adaptive behavior</td>
</tr>
<tr>
<td>Self-determination</td>
<td></td>
<td>Choices/decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autonomy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal control</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal goals</td>
</tr>
<tr>
<td>Social participation</td>
<td></td>
<td>Social networks</td>
</tr>
<tr>
<td>Interpersonal relations</td>
<td></td>
<td>Friendships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interactions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relationships</td>
</tr>
<tr>
<td>Social inclusion</td>
<td></td>
<td>Community integration/participation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community roles</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Supports</td>
</tr>
<tr>
<td>Rights</td>
<td></td>
<td>Human rights (respect, dignity, equality)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Legal rights (citizenship, due process)</td>
</tr>
<tr>
<td>Well-being</td>
<td>Emotional well-being</td>
<td>Safety and security</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Positive experiences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contentment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Self-concept</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of stress</td>
</tr>
<tr>
<td>Physical well-being</td>
<td></td>
<td>Health and nutrition status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recreation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Leisure</td>
</tr>
<tr>
<td>Material well-being</td>
<td></td>
<td>Financial status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Employment status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Housing status</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Possessions</td>
</tr>
</tbody>
</table>
For the measurement of objective indicators, certain social indicators were defined by, for instance, the US Department of Health, Education and Welfare in 1969. These social indicators reflect the normative values of a population, based on life experience and circumstances. Some aspects in life are shared by most people, which makes it possible to define some general aspects of quality of life that are applicable to people as a group. There exist certain social indicators (mostly social, economic, and health indicators) that are important to most people in society, like housing, social equality, employment, access to health care and others. This conception of quality of life can for example be used to compare the quality of life of large groups (populations), like the quality of life in different countries for instance. These ‘objective’ measures do not take into account indicators like identity, participation, and psychological security (Brown & Brown, 2003; Costanza et al., 2008; Cummins, 1997; Verdugo, Schalock, Keith, & Stancliffe, 2005).

There is a distinction between measuring the quality of life of the population and measuring the quality of life of the individual. The first one concentrates on the defining of objective, social indicators. The latter one requires as well an assessment of the subjective state of a person. Goode (1997), though, warns for reputational data in researching this subjective state, as an assessor might assign a subjective state to someone, based their own opinion on how that person feels. To measure quality of life of individuals, the focus should be on what is meaningful to these individuals. This measurement includes all aspect of the life of a person, and takes into account the environment as well (Brown & Brown, 2003; Cummins, 2005). Therefore the assessment of subjective well-being usually relies upon self-reports of people on satisfaction, happiness, well-being and other factors (Costanza et al., 2008).

Noll (2000, cited in Rapley, 2003) describes this difference as, respectively, the Scandinavian quality of life and the American quality of life. The first one refers to the quality of life of a population, where welfare is defined by the access to resources (like money, property, security, and so on). This approach focuses on the objective indicators of quality of life of the society as a whole. The latter conceptualization concerns quality of life on a societal level. Research out of this approach is based on the assessment of subjective indicators (like satisfaction and happiness).

To conclude, the basic composition of quality of life is the same for everybody. There exists variation in the extent to which the components are individually valued, but there is an identifiable set of core indicators of quality of life that apply to all people (Cummins, 2005). The objective and subjective indicators form the multidimensional construct that is quality of life.
1.4. Measurement instruments

The quality of life concept is today used as a conceptual framework for assessing quality outcomes. It guides quality enhancement strategies and serves as a criterion for assessing the effectiveness of those strategies. For this, adequate and valid research is necessary (Verdugo, Schalock, Keith, & Stancliffe, 2005). Currently, quality of life measurement can be characterized by

(1) its multidimensional nature involving core domains and indicators; (2) the use of methodological pluralism that includes the use of subjective and objective measures; (3) the use of multivariate research designs to evaluate the ways that personal characteristics and environmental variables relate to the person’s assessed QOL; (4) the incorporation of systems perspective that captures the multiple environments impacting people at the micro, meso, and macro levels; and (5) the increasing involvement of persons with intellectual disabilities (ID) in the design and implementation of QOL-oriented assessment, research, and evaluation. (Verdugo, Schalock, Keith, & Stancliffe, pp. 707-708)

Measuring quality of life can focus on subjective well-being or objective well-being. The first one measures the level of satisfaction experienced by a person in reference to the quality of life domains and indicators. ‘Self-reports’ are used in this approach to assess satisfaction, happiness and well-being. The second one focuses on objective indicators of life experience and circumstances related to those domains and indicators. To obtain an objective assessment of a person’s life quality, a valuation of domains and indicators can be acquired by a ‘direct observation’ (Costanza et al., 2008; Schalock, Bonham, & Verdugo, 2008; Verdugo, Schalock, Keith, & Stancliffe, 2005). The results of the measurement of indicators are called ‘personal outcomes’. Though they are measured at the level of the indicators, they get joined to the domain and factor levels for reporting and analysis (Schalock, Bonham, & Verdugo, 2008).

Some examples of measurement instruments developed for the assessment of quality of life are listed below:

- **Quality of Life Interview** (Lehman, 1988, cited in Brown & Brown, 2003)
  Lehman’s interview is focused on assessing the quality of life of people who are chronically mentally ill.

- **Comprehensive Quality of Life Scale** (Cummins, 1993, cited in Brown & Brown, 2003)
  This scale measures objective and subjective areas over seven domains, assessing satisfaction and importance of these domains.
- **Quality of Life Questionnaire** (Schalock & Keith, 1993, cited in Brown & Brown, 2003)
  The questionnaire uses a 3-point rating scale in the areas of environmental control, social integration and community integration.

- **The quality of student life questionnaire** (Keith & Schalock, 1994)
  This questionnaire measures quality of life in adolescence. It contains questions about the factors Satisfaction, Well-Being, Social Belonging and Empowerment/Control.

- **Schedule for Evaluation of Individual Quality of Life** (Hickey et al., 1996, cited in Fayers & Machin, 2000)
  Quality of life is assessed from the individual’s perspective. The respondents can nominate the most important aspects of their quality of life, and give a score to their level of functioning in these areas.

  In this instrument the input from the client, family and professional carer are involved, within the context of being, belonging and becoming.

- **Comprehensive Quality of Life Scale** (Cummins, 2007, cited in Rapley, 2003)
  This scale measures objective circumstances and subjective perceptions of satisfaction in the seven life domains Cummins distinguishes, and provides the subjective weighting of objective factors by their level of importance to the individual.

- **Escala Integral de Calidad de Vida** (Verdugo, Arias, & Gómez, 2006)
  This scale consists of a subjective subscale (with 70 items) and an objective subscale (with 38 items), to measure the quality of life of people with intellectual disabilities. The Escala Integral is based on the eight-domain model of quality of life.

- **GENCAT Scale** (Verdugo, Arias, Gómez, & Schalock, 2010)
  This scale is an objective quality of life questionnaire, designed for social service users. The GENCAT is based on the eight-domain model of quality of life.

- **The Personal Outcomes Scale** (van Loon, Van Hove, Schalock, & Claes, 2008)
  The POS measures a person’s quality of life based on indicators which describe eight quality of life core domains. This instrument will be further described in chapter 2 of the literature review.
1.5. The etic and emic properties of the quality of life concept

In several studies the etic (universal) and emic (culturebound) properties of the quality of life construct have been suggested. Keith et al. (1996, cited in Schalock, 2004) studied the meaning of quality of life indicators in Australia, England, Finland, Germany, Japan, Taiwan (China), and the USA. The concepts rights, relationships, satisfaction, environment, economic security, social inclusion, individual control, privacy, health, and growth and development were rated on the dimensions of value, potency, and activity. This study supported the idea of universality of these concepts, as there was a high level of cross-cultural agreement. Another study was conducted by Schalock et al. (1990, cited in Schalock, 2004), who tested the Quality of Life Questionnaire in Australia, the former Federal Republic of Germany, Israel, and Taiwan (China). The results showed a considerable consistency in the factor scores across these countries, which, again, suggested the etic character of quality of life. In 2005, Schalock at al. directed a research on quality of life indicators in Spain, Central/South America, Canada, Mainland China, and the United States. They found there were similar profiles on importance and use across respondent and geographical groups, but as well significant differences in mean quality of life importance for both groups. The factors on importance and use were generally grouped into the proposed eight core domains. In conclusion, this study demonstrated both the etic and emic properties of the quality of life concept. Another cross-cultural study was the work of Jenaro et al. (2005). Their research in France, Belgium, Italy and Poland confirmed the findings of the study of Schalock et al. (2005). In conclusion, quality of life has etic as well as emic attributes.

2. The Personal Outcomes Scale

The Personal Outcomes Scale has been developed by researchers at Arduin Foundation and Ghent University to measure an individual’s quality of life. Principally, the scale was developed to use with people with intellectual disabilities. Its development has been guided by three trends impacting the field of intellectual disabilities: reframing quality; assessing personal outcomes based on a validated quality of life conceptual and measurement framework; and involving multiple stakeholders in the process of selecting relevant quality of life-related indicator items, administering the assessment instrument, and developing and using the final instrument and resulting data (van Loon, Van Hove, Schalock, & Claes, 2009).

Though the scale was developed to use with people with intellectual disabilities, research has proved the universal properties of the conceptual framework of quality of life underlying the POS (Jenaro et al., 2005; Schalock et al., 2005). For this reason, this study uses the POS as an instrument to assess
the quality of life of people with an acquired brain injury, and at the same time tests the POS on its utility with this specific group.

2.1. A conceptual and a measurement framework

The POS complies with eight principles that should steer the assessment of personal outcomes of quality of life (Claes, Van Hove, van Loon, Vandevelde, & Schalock, 2009). These principles are:

- scale development should be based on a validated QOL conceptual and measurement framework;
- a QOL-outcome measurement instrument has to be theory-based and inductively developed;
- items measuring QOL-outcomes should be constructed in a methodologically sound way;
- a QOL assessment instrument should address construct-related questions;
- data-analysis and feedback should guide the developmental process;
- correlation coefficients among respondents should be acceptable;
- concurrent validity needs to be demonstrated;
- data should be collected in a conversation situation around the answers

The POS is based on a multidimensional conceptual framework (Tables 3 and 4) and a measurement framework (Table 5). The conceptual framework emphasizes the multidimensional and hierarchical characteristics of the quality of life concept and displays its etic and emic properties. It contains three main factors that each consist out of two or three core life domains as defined by Schalock and Verdugo (2002). Each domain is operationalized by domain-specific indicators, which were developed and validated using focus group interviews and expert panel reviews. The domains contain the etic properties of quality of life, and the indicators the emic properties (Schalock et al., 2005). This framework provides the foundation for measuring and reporting personal outcomes; using quality of life-related factors, domains, and indicators in the implementation and evaluation of individualized supports and program practices; and guiding quality improvement strategies. The quality of life measurement framework is based on the conceptual framework (van Loon, Van Hove, Schalock, & Clae, 2009).

In this short review of the POS I will not further include information on the application of the eight principles in the development and the use of the POS. I refer to Clae, Van Hove, van Loon, Vandevelde, and Schalock (2009) for a more complete overview.
Table 4  
*Quality of Life Conceptual Framework* (van Loon, Van Hove, Schalock, & Claes, 2009)

<table>
<thead>
<tr>
<th>Component</th>
<th>Definition and Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL Factor</td>
<td>Higher Order Construct</td>
</tr>
<tr>
<td></td>
<td>(e.g. Independence, Social Participation, and Well-Being)</td>
</tr>
<tr>
<td>QOL Domains</td>
<td>Set of Factors Defining Multidimensionality of QOL</td>
</tr>
<tr>
<td></td>
<td>- Personal Development &amp; Self-Determination</td>
</tr>
<tr>
<td></td>
<td>(Independence)</td>
</tr>
<tr>
<td></td>
<td>- Interpersonal Relations, Social Inclusion, Rights</td>
</tr>
<tr>
<td></td>
<td>(Social Participation)</td>
</tr>
<tr>
<td></td>
<td>- Emotional, Physical, Material Well-Being</td>
</tr>
<tr>
<td></td>
<td>(Well-Being)</td>
</tr>
<tr>
<td>QOL Indicators</td>
<td>QOL-Related Perceptions, Behaviors and Conditions That Define Operationally Each QOL Domain</td>
</tr>
<tr>
<td></td>
<td>- Personal Development: ADLs and IADLs</td>
</tr>
<tr>
<td></td>
<td>- Self-Determination: choices, decisions, control</td>
</tr>
<tr>
<td></td>
<td>- Interpersonal Relations: social networks, friendships</td>
</tr>
<tr>
<td></td>
<td>- Social Inclusion: community integration/ participation</td>
</tr>
<tr>
<td></td>
<td>- Rights: human and legal</td>
</tr>
<tr>
<td></td>
<td>- Emotional Well-Being: safety and security</td>
</tr>
<tr>
<td></td>
<td>- Physical Well-Being: health and nutritional status</td>
</tr>
<tr>
<td></td>
<td>- Material Well-Being: financial status, employment</td>
</tr>
<tr>
<td>Indicator Items</td>
<td>Specific items used to assess personal outcomes on the basis of perceived well-being (self-report) or an objective indicator of the person’s life experiences and circumstances (<em>‘direct observation’</em>)</td>
</tr>
</tbody>
</table>
Table 5

*Quality of Life Measurement Framework* (van Loon, Van Hove, Schalock, & Claes, 2009)

1. Is based on a QOL conceptual framework such as that shown in [Table 4].
2. Focuses on personal outcomes that are person-defined and valued aspirations and measured in reference to QOL domains and indicators.
3. Involves persons with disabilities in the design and administration of the assessment instrument.
4. Measures both subjective (i.e. perceptual) and objective (i.e. life events and circumstances) indicators. Criteria for selecting specific indicator items are that those indicator items: reflect what people want in their lives, relate to current and future policy issues, are those that the service provider has some control over, can be used for reporting and quality improvement purposes, and are relevant to different diagnostic groups and persons without disabilities.
5. Is sensitive to both the etic (universal) and emic (culture-bound) properties of the QOL domains and indicators.
6. Incorporates the systems perspective that captures the multiple environments impacting individuals with disabilities at the micro, meso, and microsystems’ levels.
7. Uses multivariate research designs to evaluate the influence that personal and environmental variables have on assessed QOL-related outcome variables.

2.2. A valid measurement instrument

The Scale has been proved to have a satisfactory reliability and validity for its use with people with intellectual disabilities. The reliability indices include a measure of internal consistency (Alpha coefficients), inter-rater reliability and the consistency between self-report and direct observation. The validity indices include content, construct, and concurrent validity (van Loon, Van Hove, Schalock, & Claes, 2009, 2010a). The validity and reliability of the POS have also been confirmed for other target groups. The POS showed to be a valid measurement instrument in research on the quality of life of users of ADL (Van Havere, 2011), of people with disabilities in Ghent (Van Hove et al., 2011); of people with a PAB (Moonen, van Loon, Van Hove, Vandevelde, & Claes, 2010) and people without disabilities (De Windt, & Lannau, 2009; J. van Loon, personal communication, July 27, 2012).
2.3. Interview and assessment

The POS includes both subjective (self-report) and objective (direct observation) assessment of the core domains. The self-report consists of an interview in which the client is asked for his/her positions concerning the items. If the client cannot respond for him or herself, a person who knows the individual well – a proxy – should answer to the item questions as if he or she were the person (van Loon, Van Hove, Schalock, & Claes, 2009). However, the authors decided that in a next version of the POS proxies will not be used anymore for the collecting of data for the self-report. Instead, more communication aids will be developed to increase the possibility of administering the self-report version of the POS directly with the client. In case this is not possible, two direct observations will be administered (J. van Loon, personal communication, July 20, 2012). The respondent should be well informed about the purpose of the interview, and understand that the obtained information will not be used to evaluate the person’s ability or eligibility for services or supports. The direct observation is an interview with a person who lives or works with the client for a substantial period of time (e.g. parent, relative, support staff, or teacher). He/she is asked to provide a rating of how they see the client’s life events and circumstances (van Loon, Van Hove, Schalock, & Claes, 2009, 2010a).

The interviews and the scoring should be performed by a trained interviewer. It is very important for the interviewer to be sufficiently acquainted with the quality of life framework. In both administering the self-report as the direct observation, the professional should be aware of the cultural characteristics of the respondents. The interviewer will have to adapt to the interviewees concerning interviewing techniques and communication strategies (e.g. the use of prompts or visual tools). There are some guidelines available for the interviewers, which can be found in the POS Administration and Standardization Manual by van Loon, Van Hove, Schalock, and Claes (2009). There is as well training provided by the authors of the POS and other master trainers.

Each item on the POS is evaluated on a 3-point Likert-type Scale. The ratings of self-report and direct observation are summarized on the POS Summary Profile, and are used for analysis, reporting and quality improvement purposes.

2.4. Different uses

The POS outcomes can be used on an individual level and on an organizational level (van Loon, Van Hove, Schalock, & Claes, 2009).
On an individual level the POS provides feedback to the person on his scoring in the different quality of life domains. The data can establish an expectation that change is possible. Moreover, assessing the quality of life of individuals can be part of a person-centred support method. It gives information on the succeeding of quality improvement strategies implemented by the person or an organization (van Loon, Van Hove, Schalock, & Claes, 2009). These outcomes can give feedback on the support and quality improvement strategies, and can be used to adjust wishes, support needs and goals. This support system is used in Arduin Foundation, which will be further explained in the next section (Van Loon, Claes, Van Hove, & Schalock, 2010). POS outcomes can also be used as a confirmation that the organization serving the client is dedicated to a holistic approach. Finally, the POS compares subjective and objective assessments of the quality of life indicators (van Loon, Van Hove, Schalock, & Claes, 2009).

The POS data can be used on organization-level to share information about client outcomes and changes in those outcomes over time. Another function could be to determine which individual, organization-referenced, and community factors predict quality of life outcome scores. In a study of Claes, Van Hove, van Loon, and Schalock (2011) for instance, the influence of support strategies, environmental factors, and personal characteristics on quality of life-related personal outcomes was explored. The findings confirmed that these factors explain differences in quality of life outcome scores. The results of assessments with the POS can as well be employed in quality improvement (van Loon, Van Hove, Schalock, & Claes, 2009). The information about significant predictors of quality of life-related personal outcomes can be used to enhance those outcomes through organization-based quality improvement policy and practices (Claes, Van Hove, van Loon, & Schalock, 2011).

2.5. An example of application of the POS in practice: Arduin

In Arduin, an organization for services to people with intellectual disabilities in the Netherlands, clients are interviewed with the POS every one and a half year. Arduin sets up individualized support plans for their clients, in order to provide the support that the client desires and needs. This system rests on a link between input (perspectives, wishes and goals of a person and support needs), throughput (the individual supports plan) and output (quality of life) (Table 6). To assess the output, POS-scores can be used. The alignment between support needs, the Individual Supports Plan and measuring quality of life with the POS, offers the opportunity to support people methodically in improving their quality of life. The personal outcomes as well provide relevant quality indicators for the organisation, and conditions to guide organizational change and improvement (right to left thinking) (van Loon, Van Hove, Schalock, & Claes, 2010b).
Table 6

*Use of the POS in a Person Centered Support System* (van Loon, Van Hove, Schalock, & Claes, 2010b)

<table>
<thead>
<tr>
<th>Input</th>
<th>=&gt;</th>
<th>Throughput</th>
<th>=&gt;</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The goals and perspectives of a person</td>
<td></td>
<td>• An Individual Supports Plan</td>
<td></td>
<td>• Quality of Life</td>
</tr>
<tr>
<td>• His or her support needs (SIS)</td>
<td></td>
<td>• Based on wishes, goals, perspectives and support needs</td>
<td></td>
<td>• This QOL therefore should be measured as a personal outcome of supports.</td>
</tr>
<tr>
<td>• The quality of his / her life at a certain moment in time</td>
<td></td>
<td>• Which supports are to be given on which QOL-domains</td>
<td></td>
<td>• Personal Outcomes Scale</td>
</tr>
</tbody>
</table>

*= Right to left thinking

2.6. Research with the POS

Between 2008 and today, the POS has been used in studies to assess the quality of life of people with disabilities and people without disabilities (C. Claes, personal communication, August 13, 2012; De Windt & Lannau, 2009; Moonen, van Loon, Van Hove, Vandevalde, & Claes, 2010; Van Havere, 2011; Van Hove et al., 2011).

De Windt and Lannau (2009) compared the quality of life of people with intellectual disabilities with the quality of life of people without disabilities in Middelburg, the Netherlands. They administered the POS to 56 people with intellectual disabilities and 56 people without disabilities. The respondents were chosen by certain characteristics, like age, gender, place of residence (city/rural town) and way of cohabitation (living together/alone). Each person with intellectual disability was matched with someone without disability based on similarities in these characteristics.

Moonen, van Loon, Van Hove, Vandevalde, and Claes (2010) studied the quality of life of people with a Personal Assistance Budget (PAB). They used the POS in part of their research. The respondents were people with physical disability, visual disability, hearing disability, intellectual disability, autism spectrum disorder, chronic illness, and acquired brain injury. In this study, a focus group of experts (service users and professionals) as well assessed indicators for quality of life.
Van Hove et al. (2011) explored the needs of people with disabilities or chronic illnesses in the city of Ghent, Belgium. They interviewed 146 people with the POS. The respondents were part of different target groups, namely people with physical disability, visual disability, hearing disability, intellectual disability, autism spectrum disorder, chronic illness, and acquired brain injury. This study contains two parts. The POS was used only in the first part (2009-2010).

Van Havere (2011) examined the quality of life of users of ADO Icarus and Zewopa. These organizations support people with physical disabilities in activities of daily living. Part of the study was carried out with the POS, with which 117 people were interviewed. There was also another questionnaire conducted, which gave the opportunity for experts (service users and professionals) to comment on the predictors of quality of life and to give an opinion on the POS.

C. Claes (personal communication, August 13, 2012) is carrying out a pilot-study with people with ABI. The goal of this study is to verify if the POS can be used for this target group. 39 people were interviewed with the scale. As this study has not been completely terminated I will only use the average scores per domain obtained in the study, in order to make a comparison with other groups.

3. Acquired Brain Injury

An acquired brain injury (ABI) is an injury caused to the brain since birth (www.headway.co.uk). Over the last two decades the number of people with ABI has increased dramatically. This is due to the medical advances and high-quality technology that entail a greater survival rate of people with ABI, and to the age of speed and risk we live in (more motorways and more cars). Moreover, the victims of ABI tend to be young, with a normal life expectancy. This causes a growth in the number of people suffering from the long-term effects of a severe injury (Powell, 2004). Currently in the United Kingdom each year more or less 135,000 people are confirmed as having ABI. A brain injury can impair physical, mental and emotional abilities. It affects the person’s life, but as well the life of his/her family and close ones (www.headway.co.uk).

In what follows, I will describe the highest risk groups of ABI, and the possible causes of the injury. The types and effects of ABI will be explained, followed by the effects a brain injury has on the family. At the end, recovery and adjustment after ABI and returning to work are discussed.

In literature on brain injuries, the concepts ‘acquired brain injury’, ‘traumatic brain injury’ and ‘head injury’ are often used mixed up or refer to differences between internal and external causes of the
injury. In this review I choose to use the term ‘acquired brain injury’, as all these concepts refer to an injury to the brain acquired after birth. The people with ABI in this research all suffered a brain injury after birth, due to different causes (internal or external).

3.1. Risk groups

The age groups most at risk for ABI are people between 15 and 29 years of age and over 65 years. Men are two to three times more likely to suffer an injury than women. In the age range of 15 to 29, males are even 5 times more likely to suffer a brain injury. Men at this age usually have the injury due to an external cause, as they tend to engage more in risky activities than women (e.g. contact sports, drinking too much alcohol, and so on). The age group over 65 years sustains brain injury mostly by falls, strokes, haemorrhages and tumors (Headway, n.d.; Powell, 2004).

3.2. Causes

There are many possible causes to ABI, which can be classified in two groups: traumatic and non-traumatic. Traumatic brain injury (TBI) is caused by physical damage to the brain, caused by an external force (www.biausa.org). The most common causes of TBI are road traffic accidents (40 to 50%), domestic or industrial accidents (20 to 30%), sports and recreational injuries (10 to 15%), and assaults (10%) (Powell, 2004). To TBI often is referred as ‘head injury’. Non-traumatic brain injury is caused by internal causes, like a stroke, tumor, brain haemorrhage and encephalitis (www.headway.co.uk).

3.3. Types

Types of ABI are classified by the severity of the injury. To determine the severity of a brain injury, the Glasgow Coma Scale is used. Three degrees of injury are distinguished: mild, moderate, and severe ABI. A mild brain injury is often referred to as ‘the unseen injury’. The person experiences a brief loss of consciousness (less than 15 minutes) or has not been unconscious at all. The term ‘mild’ is only used to describe the level of the injury. This does not exclude the injury can have serious consequences. Moderate brain injury refers to the loss of consciousness of between 15 minutes and six hours. A severe brain injury signifies the person is in coma for six hours or more. Depending on the length of the coma, they tend to have more serious physical deficits (Powell, 2004).
More or less 85% of people with ABI have a mild brain injury. People with a mild injury tend to make recovery in 3 to 6 months, but sometimes they can experience longer-term problems. In around 5% of cases, the injury is classed as severe. People with severe injuries usually have complex and enduring problems, and need long-term rehabilitation (Headway, n.d.).

3.4. Effects

The effects of a brain injury depend on certain factors like the type, location and severity of injury. People with ABI can experience several symptoms, which can be mild to severe. These symptoms can be divided into three categories: physical effects, cognitive effects, and emotional and behavioural effects (Powell, 2004).

The physical symptoms can include problems with movement and co-ordination, dizziness, dyspraxia, loss of sensation, tiredness, headache, speaking and swallowing disorders, epilepsy, and bladder and bowel incontinence (Powell, 2004). Most people though, make a good physical recovery. The physical problems are therefore not always so visible, but they can have a serious impact on the daily life of people with ABI (www.headway.co.uk).

The cognitive symptoms affect the way a person thinks, learns and remembers (www.headway.co.uk). This includes memory problems, difficulties with attention and concentration, slow information processing, executive dysfunction (trouble with planning, organizing and problem solving), visuo-spatial and perceptual difficulties, and problems with language skills (Powell, 2004).

The emotional and behavioural symptoms of brain injury are more difficult to see, but can be the most difficult ones to deal with, both for the individual and his/her family (www.headway.co.uk). Emotional and behavioural problems that might occur are for instance agitation, explosive anger and irritability, lack of insight and awareness, impulsivity, emotional flattening, emotional lability, self-centredness, apathy and poor motivation, depression, anxiety, rigidity and obsessionality, and sexual problems (Powell, 2004).

3.5. The effect of ABI on family and partners

ABI has not only a profound effect on the person’s life but affects as well the life of his/her family and close ones, and has this effect even many years after the injury. Close family members, partners or spouses, and children of the person with ABI are usually most affected. Close family members (e.g. parents and siblings) experience high levels of anxiety and even depression after the injury (Powell,
Many persons with ABI return to live at home after the injury and become more dependent on family (Kersel, Marsh, Havill, & Sleigh, 2001). Therefore, many family members are confronted on a daily basis with the problems ABI causes. The most important reasons for stress of family members are the emotional or behavioural problems the injury might cause. Their capacity for coping with the problems related to ABI usually decreases as time passes. Spouses or partners often feel isolated in a relationship where their emotional needs are not met. It has been found that between 40 and 55% of relationships of persons with ABI end in divorce or separation. Relationships formed after the injury have a better chance of success though. Children of people with ABI often experience emotional problems as they have to cope with difficult behaviour of a parent after the injury, and in addition their own needs are often neglected (Powell, 2004).

Relatives of people who have had a brain injury report that the most difficult problems are personality changes, slowness, poor memory, irritability, bad temper, tiredness, depression, rapid mood changes, tension and anxiety, and threats of violence. Families and partners need attention, education, guidance and support to learn to cope with ABI and its consequences (Powell, 2004).

3.6. Recovery and adjustment

Recovery takes place mainly in the first two years after injury. After that, recovery tends to gradually slow down. An important part of recovery is the emotional adjustment. The individual and his/her family and partners have to accept the change ABI has brought into their lives. Time appears to be a great healer at both the level of the injured brain and the person’s emotional adjustment. Guidance should be provided to people with ABI and their close ones, to help them understand brain injury, to offer advice on ways of coping, to help lowering expectations, and to come to terms with the losses and find new meaning in life (Powell, 2004).

Another adjustment which is essential to people with ABI is social reintegration. This refers to integration in the community, the participation in community activities and the social roles a person has. People with ABI experience significant declines in community integration following the brain injury. This depends largely on the support of the environment, as well as the personal characteristics of individuals. Behavioural and emotional dysfunction, which is a well-known effect of ABI, is the major predictor of low community integration. It is necessary to provide resources to support the social integration of people with ABI, like social and cognitive rehabilitation, transportation services and psychosocial support for the person and family. Social integration and participation tend to slowly improve over time (Lefbvre, Cloutier, & Levert, 2008; Willemse-van Son, Ribbers, Hop, & Stam, 2009).
3.7. Returning to work

Returning to work is one of the main goals for people with ABI. Employment is important in structuring life, providing stability and enabling an independent lifestyle (McCrimon & Oddy, 2006). Kersel, Marsh, Havill, and Sleigh (2001) add that unemployment decreases the opportunity to develop social contacts and leisure activities, which leads to increased isolation and higher levels of depression. Returning to work provides people with ABI with a sense of purpose, identity, independence and social inclusion, and reduces their emotional distress from financial burden.

However, especially in the case of people with a severe brain injury, the prospects of returning to work are estimated low. The difficulties that ABI causes can have consequences on a person’s ability to return to a paid job. Of people with ABI 10% to 70% returns to work, depending on the severity of injury, prior work experience, age, education, socio-economic status and social support. 66% of people with severe ABI are unable to return to their jobs or to work in any unpredictable or unstructured environment. This is due to problems with attention, memory, speed of information processing and executive functioning (McCrimon & Oddy, 2006).

4. Research questions

As the literature review shows, quality of life is a very present topic nowadays. Researchers engage in quality of life research, and the Personal Outcomes Scale is currently accepted as a reliable instrument to measure quality of life. This brings me to following research questions, directed to a population of people with an acquired brain injury:

- What quality of life profile characterizes people with an acquired brain injury?
  - Does the quality of life of people with an acquired brain injury differ from the quality of life of other people?
  - Do differences in quality exist between the several life domains of people with an acquired brain injury?
- Is the Personal Outcomes Scale an appropriate measurement instrument to measure the quality of life of people with an acquired brain injury?
  - Is the Personal Outcomes Scale a reliable instrument to measure the quality of life of people with an acquired brain injury?
  - Is the Personal Outcomes Scale a valid instrument to measure the quality of life of people with an acquired brain injury?
Methodology

1. Group of respondents

For this study, 47 people with an acquired brain injury (ABI) of the Second Chance Headway Centre (SCHC) in Wakefield (United Kingdom) and 47 of their family members, partners or professionals were interviewed, respectively with the self-report version and the direct observation version of the POS. The respondent group with ABI consists of 83% men and 17% women with an average age of 45.9. One respondent with ABI out of 47 has a paid job. Living arrangements vary (Table 7). The respondent group for the direct observation consists of 22 professionals, 18 family members and 7 partners (Table 8).

Table 7

<table>
<thead>
<tr>
<th>Characteristics of Respondent Group for Self-Report</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Men</td>
</tr>
<tr>
<td>Women</td>
</tr>
<tr>
<td><strong>Age</strong></td>
</tr>
<tr>
<td>Minimum</td>
</tr>
<tr>
<td>Maximum</td>
</tr>
<tr>
<td>Average</td>
</tr>
<tr>
<td><strong>Living arrangements</strong></td>
</tr>
<tr>
<td>With partner</td>
</tr>
<tr>
<td>With family</td>
</tr>
<tr>
<td>Alone</td>
</tr>
<tr>
<td>Residential care home</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
</tr>
<tr>
<td>Paid job</td>
</tr>
<tr>
<td>No paid job</td>
</tr>
</tbody>
</table>
Table 8

*Characteristics of Respondent Group for Direct Observation*

<table>
<thead>
<tr>
<th>Family</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling</td>
<td>3</td>
</tr>
<tr>
<td>Parent</td>
<td>11</td>
</tr>
<tr>
<td>Child</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
<tr>
<td>Family</td>
<td>18</td>
</tr>
</tbody>
</table>

| Partner    | 7      |
| Professional| 22    |
| Personal assistant | 9  |
| Key worker of SCHC | 11 |
| Carer (residential) | 2  |

2. Measurement instruments

2.1. Personal Outcomes Scale

The POS is based on a conceptual framework, which assumes the multidimensional character of the quality of life concept, and a measurement framework. The instrument has been proved to have a satisfactory reliability and validity, and is therefore considered to be a valid way to measure an individual’s quality of life. Both objective and subjective aspects are measured, by using a self-report version as well as a direct observation version of the scale (van Loon, Van Hove, Schalock, & Claes, 2009). In this research, the POS will be used to evaluate the quality of life of the respondent group with ABI.

The instrument is scored on a 3-point Likert-type scale (3, 2 or 1). Self-report and direct observation ratings are transferred onto the POS Summary Profile by the interviewer. Every item receives a score. The six item scores per domain form together the ‘Domain Score’. The total of the two or three Domain Scores produce the ‘Factor Score’. The three Factor Scores are summed to produce the Quality of Life Index Score for the self-report and the direct observation (van Loon, Van Hove, Schalock, & Claes, 2009).
2.2. Additional questionnaire

All respondents were asked additional questions to obtain their personal opinion on the POS as an instrument to measure quality of life. They are all considered to be experts of ABI, and evaluated the POS on its validity in measuring the quality of life of people with ABI. The questions of this questionnaire were discussed directly after the interview with the POS, as there was already a conversation about quality of life and people were familiar with the instrument and its indicators. Following questions were asked:

- Which topics of the POS would you say are relevant or irrelevant to assess the quality of life of people with an acquired brain injury?
- Which aspects would be particularly important to your personal quality of life?  
  (directed to people with ABI)
- Which aspects would be particularly important to the quality of life of your child/parent/sibling/client?  
  (directed to parent, child, sibling, assistant or other professional of the person with ABI)

3. Procedure

A description of the research phases will be discussed below. These phases are the preparation and training, the recruitment of participants and the administration of the interviews.

a) Preparation and training

To obtain an understanding of the POS, I started with studying the theory behind the instrument. I studied the conceptual and measurement framework on which the POS is based, the need for a valid measurement instrument of quality of life and its possible uses. To do this, I have been provided with a training guide of the POS, articles about its development and the English version of the POS with an attached item description. After examining the available literature on this topic, I received training on the administration and scoring of the POS from a certificated Master Trainer. Due to my localization in the United Kingdom, this training has been effectuated by several phone calls with the Master Trainer and practice interviews in the UK. The training has mainly been carried out in November and December 2011.
b) Recruitment of participants

All participants for the self-report version of the POS were recruited from the 56 service users of the Second Chance Headway Centre. Before starting the research I completed an internship at Second Chance (September 2011 – March 2012), which gave me the advantage of being already familiar with the service users. To recruit participants I talked individually with each service user to inform them about the study and to invite them for participation. All service users that participated did this voluntarily. In the end, 47 people have been recruited for and interviewed with the self-report version of the POS.

To recruit respondents for the direct observation version of the POS, I invited for interview all family members, partners, personal assistants or other carers of the 47 participating service users (I will refer to this group as ‘the carers’). They were explained the goals of the study and the time it would take to complete an interview. All carers who came to Second Chance to accompany the service user or to provide in their transport were invited in person. The remaining carers were contacted by phone or letter. This approach provided 36 respondents. For the remaining direct observations I invited the Second Chance key workers of the participating service users for interview. All respondents have known the service user they were linked with for at least one year.

c) Administration of the interviews

After the recruitment of participants the appointments for interview were scheduled. All appointments were scheduled for the period of March-April 2012. Several appointments had to be rescheduled due to illness or change of plans of the respondents. These were rescheduled for May. The interviews with service users were organized on days they attended the centre, and at an hour that minimally interfered with the activities of the service user on that day. There were no proxies used for the self-reports. Carers’ interviews were usually held at the beginning or end of the working day, depending on their potential working hours and trying to combine the hour of interview with the hour they would be present at the centre for participation or transport for a service user. Between the beginning of March and the end of May all 94 interviews were completed.

All interviews took place in a separate room in Second Chance. This space is known to the service users and accessible for wheelchair users. It provides privacy for the interviewee. All staff was kept informed on the interview schedule and arrangements. In most cases only the respondent would be present for the interview, except for three interviews in which a service user was accompanied by a facilitator (in these cases, this was the personal assistant). These respondents consented the
presence of the facilitator and were aware of his/her role to facilitate the communication and not to answer for them. During the interviews there were smiley faces and pictures available to enhance and facilitate communication when necessary.

Before starting the interview the content and aims of the POS and the research were explained again, followed by some examples of topics which would be discussed. Respondents were informed there are no good or wrong answers for the questions, and that I am interested in their own opinion on the topic. The experience I obtained during my internship at Second Chance helped me with engaging in a conversation about the interests of the service user, which was a starting point for discussing the POS items. Also the interviews with carers followed the pattern of an informal conversation which led to the discussion of the POS items. After each assessment the answers were scored and the Summary Profile was filled out.

Each interview ended with a brief reflection on the POS, in which the indicators and domains were discussed. This consisted out of two questions per person (see 2.2) which were discussed in conversation and written down in a notebook. When all answers were collected, a summary has been made.

All respondents signed an informed consent which shortly described the purpose of the study, and explained the possibility of stopping the interview at any moment without further implications. The informed consent as well guaranteed the anonymity of the respondent. The informed consents were read together and if necessary further explained. Before, during and after the interview, there was time provided for any potential questions on the informed consent, the research or the POS.

4. Data analyses

4.1. Statistical analyses

All POS data were analysed with SPSS version 20.

Firstly, the descriptive statistics of the self-report and direct observation were calculated. These contained the frequencies, minimum and maximum scores, average scores and standard deviations per domain and factor. Secondly, the internal consistency coefficients (Cronbach’s Alpha) of the domains and factors were calculated for both versions of the POS. These coefficients indicate how well the indicators reflect a certain domain. The consistency between both versions of the scale was as well measured, by calculating the Pearson’s correlation coefficients. Finally, the inter-correlations
between the domain scores were evaluated to assess the construct validity of the POS for both the self-report and the direct observation.

4.2. Qualitative analyses

The questions to evaluate the validity of the POS were discussed after each interview. All answers and remarks were written down in a notebook. When all answers were collected, they were compared and classified. This resulted in a summary consisting of comments on the indicators marked as specifically relevant, the indicators marked as irrelevant, and other important aspects of the quality of life of people with ABI.
Results

1. Statistical analyses of the POS outcomes

All descriptive statistics have been determined of both the self-report (SR) and the direct observation (DO) versions of the POS.

First the internal consistency (Cronbach’s Alpha) has been calculated. This indicates how consistent the scores are of the items that form together a domain (6 indicators), a factor (12 or 18 indicators) or a total quality of life score (48 indicators). The closer the Cronbach’s alpha coefficient is to 1, the greater the internal consistency of the items in the scale. Therefore, a high value of alpha suggests that the indicators of the domain are part of the same construct (George and Mallery, 2003). As shown in Table 9, the total score has for both versions of the scale an alpha higher than 0.9, and all factors score higher than 0.8. The indicators per domain have in general a lower internal consistency, with scores between 0.50 (SR)/0.35 (DO) for Physical Well-Being and 0.85 (SR)/0.82 (DO) for Interpersonal Relations. The domain, factor and total scores have a similar internal consistency for the SR as for the DO.

Table 9
Internal Consistency Coefficients (Cronbach’s Alpha)

<table>
<thead>
<tr>
<th></th>
<th>Self-Report (SR)</th>
<th>Direct Observation (DO)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td>.67</td>
<td>.75</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>.75</td>
<td>.76</td>
</tr>
<tr>
<td>Independence</td>
<td>.80</td>
<td>.81</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>.85</td>
<td>.82</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>.76</td>
<td>.75</td>
</tr>
<tr>
<td>Rights</td>
<td>.46</td>
<td>.66</td>
</tr>
<tr>
<td>Social Participation</td>
<td>.86</td>
<td>.86</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>.77</td>
<td>.74</td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td>.50</td>
<td>.38</td>
</tr>
<tr>
<td>Material Well-Being</td>
<td>.64</td>
<td>.61</td>
</tr>
<tr>
<td>Well-Being</td>
<td>.83</td>
<td>.81</td>
</tr>
<tr>
<td>Total</td>
<td>.93</td>
<td>.93</td>
</tr>
</tbody>
</table>
One more remark on the internal consistency concerns the corrected item-total correlation scores for two indicators in the domain of Physical Well-Being. On both the SR and the DO, the indicators ‘sport’ (α=0.10 (SR)/α=0.10 (DO)) and ‘nutritional status’ (α=0.00 (SR)/α=-0.03 (DO)) obtain low scores, compared to the other domain indicators. If these items would be deleted, the Cronbach’s Alpha for the domain would rise. If ‘sport’ would be deleted, Alpha would be 0.56 for ‘Physical Well-Being’ on the SR version and 0.41 on the DO version. If ‘nutritional status’ would be deleted the domain’s Alpha would rise to 0.56 for the SR and to 0.50 for the DO version.

To continue, the Pearson’s correlation coefficients between the SR and DO versions of the POS were determined. As represented in Table 10, there exists a strong, positive correlation for the total quality of life score between SR and DO (r =0.79; p<0.01; n=47). All coefficients have positive signs, which indicate a positive correlation: the variables increase and decrease together. The larger the magnitude, the stronger the relationship between the scores on the SR and the scores on the DO (Jackson, 2009). The domain of Physical Well-Being has a slightly lower consistency between the SR and DO scores (r=0.48; p<0.01; n= 47). The domain of Rights has the strongest correlation compared to the other domains (r =0.80; p<0.01; n=47).

Table 10
Pearson’s Correlation Coefficients Between Self-Report and Direct Observation

<table>
<thead>
<tr>
<th>Domain</th>
<th>Correlation between SR and DO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Development</td>
<td>.75*</td>
</tr>
<tr>
<td>Self-Determination</td>
<td>.66*</td>
</tr>
<tr>
<td>Interpersonal Relations</td>
<td>.71*</td>
</tr>
<tr>
<td>Social Inclusion</td>
<td>.56*</td>
</tr>
<tr>
<td>Rights</td>
<td>.80*</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>.56*</td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td>.48*</td>
</tr>
<tr>
<td>Material Well-Being</td>
<td>.70*</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>.79</strong>*</td>
</tr>
</tbody>
</table>

*p < 0.01
Table 11

**Inter-Correlation Coefficients of POS Domains – Self-Report**

<table>
<thead>
<tr>
<th></th>
<th>PD</th>
<th>SD</th>
<th>IR</th>
<th>SI</th>
<th>R</th>
<th>EWB</th>
<th>PWB</th>
<th>MWB</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD</td>
<td>.53**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>.45**</td>
<td>.56**</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>IR</td>
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<td></td>
<td>.42**</td>
<td>.51**</td>
<td>.58**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SI</td>
<td></td>
<td></td>
<td></td>
<td>.55**</td>
<td>.54**</td>
<td>.50**</td>
<td>.42**</td>
<td></td>
</tr>
<tr>
<td>R</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.28</td>
<td>.64**</td>
<td>.44**</td>
<td>.39**</td>
</tr>
<tr>
<td>EWB</td>
<td>.31*</td>
<td>.53**</td>
<td>.34*</td>
<td>.47**</td>
<td>.24</td>
<td>.58**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWB</td>
<td>.54**</td>
<td>.80**</td>
<td>.76**</td>
<td>.61**</td>
<td>.58**</td>
<td>.58**</td>
<td>.54**</td>
<td></td>
</tr>
<tr>
<td>MWB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>.67**</td>
<td>.84**</td>
<td>.80**</td>
<td>.76**</td>
<td>.68**</td>
<td>.71**</td>
<td>.65**</td>
<td>.90**</td>
</tr>
</tbody>
</table>

** p < 0.01 (2-tailed); * p < 0.05 (2-tailed)

Key: PD (Personal Development), SD (Self-Determination), IR (Interpersonal Relations), SI (Social Inclusion), R (Rights), EWB (Emotional Well-Being), PWB (Physical Well-Being), MWB (Material Well-Being)

Table 12

**Inter-Correlation Coefficients of POS Domains – Direct Observation**

<table>
<thead>
<tr>
<th></th>
<th>PD</th>
<th>SD</th>
<th>IR</th>
<th>SI</th>
<th>R</th>
<th>EWB</th>
<th>PWB</th>
<th>MWB</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD</td>
<td>.46**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td></td>
<td>.32*</td>
<td>.52**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IR</td>
<td></td>
<td></td>
<td>.43**</td>
<td>.45**</td>
<td>.62**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SI</td>
<td></td>
<td></td>
<td></td>
<td>.48**</td>
<td>.58**</td>
<td>.31*</td>
<td>.49**</td>
<td></td>
</tr>
<tr>
<td>R</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.22</td>
<td>.42**</td>
<td>.54**</td>
<td>.51**</td>
</tr>
<tr>
<td>EWB</td>
<td>.41**</td>
<td>.50**</td>
<td>.48**</td>
<td>.53**</td>
<td>.44**</td>
<td>.68**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWB</td>
<td>.51**</td>
<td>.67**</td>
<td>.63**</td>
<td>.53**</td>
<td>.63**</td>
<td>.48**</td>
<td>.53**</td>
<td></td>
</tr>
<tr>
<td>MWB</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>.64**</td>
<td>.76**</td>
<td>.76**</td>
<td>.79**</td>
<td>.70**</td>
<td>.70**</td>
<td>.74**</td>
<td>.82**</td>
</tr>
</tbody>
</table>

** p < 0.01 (2-tailed); * p < 0.05 (2-tailed)

Key: PD (Personal Development), SD (Self-Determination), IR (Interpersonal Relations), SI (Social Inclusion), R (Rights), EWB (Emotional Well-Being), PWB (Physical Well-Being), MWB (Material Well-Being)
The inter-correlations between the eight POS domains can be found in Table 11 and Table 12 (above), respectively for the SR and the DO. In both versions of the scale, the correlation between EWB and PD appears not to be statistically significant. The same applies to the correlation between PWB and R of the self-report version (p=0.1). All other inter-correlations demonstrate statistically significant, positive relationships between the POS domains (Jackson, 2009). The total score correlations with the domain are for both SR and DO significant at the 0.01 level.

2. POS Outcomes comparison

In this research, there exists a positive correlation between both versions of the scale (Table 10), and both scales obtain the same order of domain scores. Therefore, Table 13 includes only the average POS scores for the self-reports of people with an acquired brain injury. They are compared with the self-report average scores of other groups. The outcomes of people with ABI are in general lower than those of people without disabilities. The largest difference in scores can be found in the domains of Personal Development and Interpersonal Relationships. For the group of people with an acquired brain injury of this research, Rights obtains the highest average domain score (15.9) and Social Inclusion the lowest (12.9). In the latter, the indicators of interaction with neighbours, and helping other people in the community and being helped by them, score lowest. The other research with people with ABI as well obtains the lowest score for the domain of Social Inclusion. For the groups of people with disabilities, the domains of Personal Development and Social Inclusion seem to be scored lower compared to the other domains.

3. Outcomes of the additional questionnaire

I provide a summary of the feedback of the respondents (people with ABI, their family, partners and professionals). Reactions were very similar, and are displayed below. The respondents marked some indicators as specifically relevant, questionable or irrelevant for people with ABI, which is described in section 3.1 in three parts. Respondents also indicated some other aspects they find relevant for their quality of life (section 3.2).
### Table 13

**Average Scores per Domain for Different Populations**

<table>
<thead>
<tr>
<th></th>
<th>People with ABI (n=47)</th>
<th>People with ABI(^1) (n=39)</th>
<th>Users ADL assistance(^2) (n=112)</th>
<th>People in Ghent with disabilities(^3) (n=146)</th>
<th>People with intellectual disabilities(^4) (n=186)</th>
<th>People with intellectual disabilities(^5) (n=56)</th>
<th>People without disabilities(^5) (n=291)</th>
<th>People without disabilities(^6) (n=56)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD</td>
<td>14,2</td>
<td>13,4</td>
<td>12,7</td>
<td>13,5</td>
<td>11,4</td>
<td>12,4</td>
<td>12,4</td>
<td>16,4</td>
</tr>
<tr>
<td>SD</td>
<td>15,2</td>
<td>15,3</td>
<td>16,9</td>
<td>16,6</td>
<td>15,4</td>
<td>13,2</td>
<td>13,1</td>
<td>16,9</td>
</tr>
<tr>
<td>IR</td>
<td>14,4</td>
<td>14,5</td>
<td>15,7</td>
<td>14,7</td>
<td>14,9</td>
<td>12,7</td>
<td>12,6</td>
<td>16,6</td>
</tr>
<tr>
<td>SI</td>
<td>12,9</td>
<td>11,3</td>
<td>13,0</td>
<td>12,3</td>
<td>12,3</td>
<td>9,1</td>
<td>9,3</td>
<td>14,1</td>
</tr>
<tr>
<td>R</td>
<td>15,9</td>
<td>13,9</td>
<td>16,7</td>
<td>16,3</td>
<td>15,1</td>
<td>13,1</td>
<td>13,2</td>
<td>17,1</td>
</tr>
<tr>
<td>EWB</td>
<td>15,7</td>
<td>14,2</td>
<td>15,5</td>
<td>15,1</td>
<td>15,7</td>
<td>14,9</td>
<td>15,1</td>
<td>16,4</td>
</tr>
<tr>
<td>PWB</td>
<td>14,6</td>
<td>15,4</td>
<td>13,5</td>
<td>13,6</td>
<td>13,5</td>
<td>14,5</td>
<td>14,9</td>
<td>15,7</td>
</tr>
<tr>
<td>MWB</td>
<td>14,4</td>
<td>13,5</td>
<td>14,2</td>
<td>14,7</td>
<td>13,1</td>
<td>14,1</td>
<td>14,3</td>
<td>14,7</td>
</tr>
<tr>
<td>QOL</td>
<td>117,2</td>
<td>111,2</td>
<td>118,2</td>
<td>116,7</td>
<td>111,0</td>
<td>104,0</td>
<td>104,9</td>
<td>127,9</td>
</tr>
</tbody>
</table>

Key: PD (Personal Development), SD (Self-Determination), IR (Interpersonal Relations), SI (Social Inclusion), R (Rights), EWB (Emotional Well-Being), PWB (Physical Well-Being), MWB (Material Well-Being), ADL (Activities of Daily Life), PAB (Personal Assistance Budget)
3.1. Indicators marked as specifically relevant or irrelevant for people with ABI

Below the indicators marked as very relevant, questioned and irrelevant are listed. All indicators that do not appear in this list were evaluated as ‘relevant’, without any other remarks.

a) Very relevant

‘The opportunity to demonstrate skills’ (domain: Personal Development)

This indicator was marked as very relevant by most respondents (n=57). Many people with ABI feel that their skills are not always adequately assessed by other people. Actions or activities are too often taken over by other people, while the person with ABI feels that this is not always necessary. The respondents stressed the importance of being able to demonstrate abilities, and of adjusted supports to carry out activities with as much independence as possible. Also, they made a comparison with their situation before the ABI, when they usually had more opportunity to demonstrate skills. Not always having this opportunity now, makes them realize the importance of their abilities and exercising them.

‘The opportunity to make choices, and the exercise of choices’ (domain: Self-Determination)

Several respondents (n=20) had similar reactions to this indicator. In their opinion, for many people with ABI it is important to limit choices in order to provide structure to facilitate the choice making. When presented with a complex choice, this might hinder them in making a decision or choice. People with ABI might feel more self-determined when the choice is limited. Some of the respondents as well indicated this does not apply to everybody. Others (2 respondents) indicated the importance of committing mistakes. They felt that everybody should be offered choices, though they might commit mistakes. Choices should be safe though.

‘Respect for decisions made by the person’ (domain: Self-Determination)

People stated to feel very strongly about this indicator (33 respondents). Decisions are not always respected by other people, and the person is not always able to react or defend himself/herself, which causes frustration and a feeling of impotence. Being respected and followed in their decisions is important for their quality of life.

‘Close friends’ (domain: Interpersonal Relations)

This indicator was marked as very important for people with ABI (n=30). They compare their social situation before the ABI with the situation after the ABI, and often find to have lost friends and social interaction. People see this as well as an important aspect of person-
centred care planning. They want to improve relationships with friends, in order to obtain a higher life quality.

‘Successful experiences’ (domain: Emotional Well-Being)
Part of the respondents (n=12) emphasized the importance of this indicator. Some people with ABI would feel they do not have any good qualities or things they are successful in, because they tend to compare their current abilities with those before the ABI. People see this as well as an important aspect of person-centred care planning. It is important to have successful experiences again.

b) Questioned

‘Knowing neighbours by name’ (domain: Social Inclusion)
Several people (n=16) referred to the difficulties people with ABI might have with remembering names of people in the neighbourhood. The focus should be on recognizing people, instead of on their names.

‘Having a paid job’ (domain: Material Well-Being)
One specific remark by respondents (n=12) on this indicator refers to retired people with ABI. People can suffer a brain injury at any moment in their lives. Some people are already retired when they have the injury, but might have had a paid job before the retirement. The respondents did not agree with the scoring applied to this subgroup of people with ABI. Some respondents (n=13) believed having a paid job is not an appropriate indicator for material well-being, as they are paid disability benefits which provide in their material needs. This was contested by others (n=8) who did believe it to be important, as not everybody receives sufficient means or disability benefits.

c) Irrelevant

‘Voting’ (domain: Rights)
The majority of the respondents (n=68) evaluated this indicator as irrelevant. They felt that this indicator is different to the other indicators in the domain of rights. Whereas the other indicators focus on their rights as such, the indicator ‘voting’ emphasizes the exercising of a right. The respondents valued more having the choice to vote or not to vote than exercising the right to vote. Some people (n=9) said to feel uncomfortable with this question.
3.2. Other important aspects of the quality of life of people with ABI

There were some other aspects mentioned during the interview which, following the respondents, are important for the quality of life of people with ABI. These aspects are listed below, and discussed by the domains they were mentioned in:

- Having a paid job or volunteer work
  - Personal Development: the person can develop new skills in a job and is able to demonstrate the skills and good qualities he/she has.
  - Self-Determination: the person will have certain responsibilities at the workplace. Returning to work is as well a personal goal for some persons with ABI.
  - Social Inclusion: a job can provide a person with a role in society, and might enhance social contacts and communication.
  - Emotional Well-Being: having a job provides a certain structure of the day, and can give meaning to the day. Therefore, having a job could have a positive effect on the self-esteem of people.

- Having a partner
  - Emotional Well-Being: many people with ABI lost their partner after suffering the ABI, or find it difficult to start a partner relationship after the ABI. For several people, this has a negative influence on their life quality.

4. Observations and remarks

4.1. Length of interview

Dependent on the respondent, interviews took between 45 minutes and 4 hours to administer. All Direct Observation interviews with parents or partners of the person with ABI took longer than 2 hours. Interviews with professionals took maximum 1.5 hours each. Self-reports took between 1 hour and 3 hours to carry out.
4.2. Facilitation of the communication

Some tools for the facilitation of communication were used during the interviews with the self-advocates. When necessary, smiley faces and pictures were used to visualize the indicators and to enhance the communication in general. All respondents (SR and DO) received a copy of the questions to follow if wished.

For some people, the interview was split into 2 to 4 parts, depending on concentration, tiredness, length of the interview and motivation to continue the conversation.
Discussion and conclusion

1. Discussion

In what follows, I will answer the research questions put forward for this study on the basis of the obtained results (1.1 and 1.2). In section 1.3, the research questions are discussed and related to previous research.

1.1. What quality of life profile characterizes people with an acquired brain injury (ABI)?

This question will be answered by exploring two sub-questions:

- Does the quality of life of people with ABI differ from the quality of life of other people?
- Do differences in quality exist between the several life domains of people with ABI?

a) Does the quality of life of people with ABI differ from the quality of life of other people?

The quality of life outcomes in this research were compared to the average outcomes of other studies using the POS. As I do not have the original databases of these studies at my disposal, no statistical tests could be carried out on this data. The average scores do suggest several differences.

Firstly, the comparison between the quality of life of people with ABI with the quality of life of people without a brain injury is very relevant, as people with ABI have lived a pre-injury life without the disabilities ABI causes in their current life. All domain scores and the total quality of life score of people with ABI are lower than the scores of people without disabilities. This indicates people experience a general decrease in quality of life after suffering a brain injury. The largest difference in scores can be found in the domains of Personal Development and Interpersonal Relationships. Regarding the former, the experts in this study stated that the opportunity to demonstrate skills is very important for people with ABI, as they feel that their skills are not always adequately assessed by other people. Also, they made a comparison with the situation before the injury, and conclude they now have less the opportunity to demonstrate skills. The decrease in interpersonal relationships can be linked to the observation of the experts that people with ABI often lose friends and social interaction after the injury.
Secondly, there are some other observations that indicate similarities and differences in quality of life of people with ABI and other groups. All groups score lowest or second lowest on the domain of Social Inclusion. In contrary with people without disabilities, the groups of people with disabilities score on the domain of Personal Development as well lowest or second lowest. People with ABI though, score higher on this domain than the other groups with disabilities. They have more or less a similar quality of life profile as the groups of users of ADL assistance and people with a PAB. There is a larger difference in score with people with intellectual disabilities; i.e. the domain scores of people with ABI are generally higher. This difference gets smaller in the domains of Emotional, Physical and Material Well-Being.

Summarizing, it may be said that the group of people with ABI differs mostly from the two groups of people without disabilities and the two groups of people with intellectual disabilities (except for the factor ‘Well-Being’). Also, they differ from other groups with disabilities because of their higher average score on the domain ‘Personal Development’.

b) Do differences in quality exist between the several life domains of people with ABI?

The average domain scores for the SR and DO versions of the scale both show the same sequence. ‘Social Inclusion’ has a clearly lower score than the other domains (12,9). This is mostly due to low scores on interaction with neighbours, and helping other people in the community and being helped by them. People with ABI score highest on the domains of ‘Rights’ (15,9), ‘Emotional Well-Being’ (15,7) and ‘Self-Determination’ (15,2).

1.2. Is the Personal Outcomes Scale (POS) an appropriate measurement instrument to measure the quality of life of people with an acquired brain injury (ABI)?

This question will be answered by exploring two sub-questions:

- Is the POS a reliable instrument to measure the quality of life of people with ABI?
- Is the POS a valid instrument to measure the quality of life of people with ABI?
a) Is the POS a reliable instrument to measure the quality of life of people with ABI?

Reliability refers to the consistency of a measurement instrument, and is measured using correlation coefficients (Jackson, 2009). To assess the reliability of the POS in measuring the quality of life of people with ABI, the internal consistency and the consistency between SR and DO were evaluated.

Firstly, the internal consistency (Cronbach’s Alpha) of the items was calculated. This index measures the correlation of indicators within the domains, the factors and the total quality of life score. The total quality of life score counts with a high internal consistency between its indicators (> 0.9). One level back, the factor level, as well has a good internal consistency between items (> 0.8). The domains score differently on internal consistency. ‘Interpersonal Relations’ seems to have a very high Cronbach’s Alpha coefficient compared to the other domains (> 0.8). The domains ‘Rights’ and ‘Physical Well-Being’ have a more questionable internal consistency (≤ 0.5). The former does obtain a higher Alpha for the DO version of the scale (> 0.6). There does exist correlation between most of the items in these domains. In the latter domain though, two of the indicators score very low on correlation with the other indicators (≤ 0.01). From this observation can be concluded these indicators are not consistent with the other indicators of the domain ‘Physical Well-Being’. Yet due to the correlation between most of the items and the existing limitations of the research (section 2), these findings are not enough proof to discard these two domains entirely or to state that the items per domain do not measure the same construct. All other domains have a more acceptable internal consistency (between 0.6 and 0.8).

Secondly, the consistency between both versions of the POS has been assessed. Therefore, the Pearson’s correlation coefficients were determined. These coefficients measure the strength of the correlations between the domain scores and between the total scores of the SR and DO. The more the correlation coefficient approaches 1, the stronger the relationship between the scores on the SR and the scores on the DO (Jackson, 2009). There is a positive correlation for all domains and the total score, which indicates that they increase and decrease together. The SR and DO versions of the POS seem to have a quite strong correlation on each domain (r ≥ 0.5; p < 0.01), though to different extents. There exists a strong, linear relationship between the two versions of the POS (Lawner Weinberg, & Knapp Abramowitz, 2008).

b) Is the POS a valid instrument to measure the quality of life of people with ABI?

Validity refers to whether a measure is truthful, i.e. whether it measures what it claims to measure. To assess the validity of the POS, the construct validity has been used. This assesses the extent to
which a measurement instrument accurately measures a theoretical construct (Jackson, 2009). In this research, the construct validity has been evaluated in a statistical and qualitative way.

Firstly, the construct validity has been measured statistically by calculating the inter-correlation coefficients between the POS domains, for both versions of the scale. The domains should be inter-correlated, but not highly inter-correlated (van Loon, Van Hove, Schalock, & Claes, 2009). Most correlations meet this rational (0.4 ≤ r ≤ 0.9), which indicates that the domains measure the same construct, namely ‘quality of life’. An exception is formed by the correlation between the domains ‘Emotional Well-Being’ and ‘Personal Development’ in both versions of the scale (p=0.06 (SR), p=0.13 (DO)), which is not statistically significant. The same applies to the correlation between ‘Physical Well-Being and ‘Rights’ of the SR (p=0.1). These two correlations between domains reveal a positive yet not statistically significant relationship. Although these correlations are not statistically significant, this does not exclude the possibility of being statistically significant in the whole population of people with ABI. Current results might be influenced by the limitations of the research, like the size of the sample (section 2). All other inter-correlations demonstrate statistically significant, positive relationships between the POS domains (Jackson, 2009). In general, and statistically speaking, the POS domains measure the same construct.

Afterwards, the construct validity was qualitatively assessed. All respondents in this study are considered to be experts regarding ABI. They were asked to evaluate the POS per domain on relevancy for people with ABI. Most indicators were marked as ‘relevant’ or ‘very relevant’ by the experts, though some were evaluated as ‘questioned’ or ‘irrelevant’. I will discuss the indicators marked as questioned or irrelevant shortly, together with other aspects – which are not included in the POS – the experts stated to be relevant. In the domain ‘Social Inclusion’ it was stated that knowing neighbours by name has no link with the quality of life of people with ABI. However, this indicator was seen as relevant if the focus would be put on recognizing neighbours. The indicator ‘voting’ in the domain of Rights was also assessed as irrelevant. Whereas the other indicators of this domain focus on the having of rights, this indicator focusses on the exercising of a right. The respondents felt there was an aspect missing in the domain of Emotional Well-Being, which is ‘having a partner’. In ‘Material Well-Being’, the experts criticized the indicator of ‘having a paid job’ because they felt this had little influence on their economic status, and because several people suffer ABI when they are already on retirement. They did though emphasize the importance of having a job, but would locate this indicator in a different domain. Shortly, only the indicator ‘voting’ was judged to be completely irrelevant for quality of life. All others would be, with adaptations for ‘neighbours’ and ‘paid job’, good and relevant items of the scale.
Another sign for construct validity of the POS as a whole is an observation made during the POS interviews; that is the duration of these interviews. These took between 45 minutes and 4 hours to administer. Mostly the interviews with people with ABI and their parents or partners took longest to complete. These respondents tended to incorporate the items of the scale into a life story. Some people as well mentioned that they found it pleasant to talk about these topics and remarked that the interview helped them to talk as well about difficult or emotional parts of their life or the life of their child or partner. The POS seems to provide an adequate instrument for having a meaningful discussion about quality of life with people.

1.3. Discussion of the results

The quality of life profile of people with ABI can be characterized by its difference with the profile of people without disabilities. On all domains they score less, which indicates they generally have a lower quality of life then people without an injury. It also suggests that people experience a general decrease in quality of life after suffering a brain injury. This could be due to the impairment of physical, mental and emotional abilities a brain injury can cause. ABI affects the person’s life (Powell, 2004; www.headway.co.uk), on several domains of life and in several degrees. A large difference in quality can be found in the domain of Personal Development. This could be due to having less opportunity to demonstrate skills, as the experts in this study stated. Also, the whole range of physical and cognitive problems ABI can cause (Powell, 2004) could produce difficulties with former abilities, which would result in a lower score on personal development. On the domain of interpersonal relationships as well exists a larger difference between both groups. The experts observed that people with ABI often lose friends and social interaction after suffering the injury. This might be due to, for instance, behavioural problems caused by the injury (e.g. anger, self-centredness, and so on), for these are the most difficult problems for the environment to deal with (Powell, 2004).

People with ABI mostly experience a lower quality in the area of social inclusion. This is confirmed by previous studies (Lefbvre, Cloutier, & Levert, 2008; Willems-van Son, Ribbers, Hop, & Stam, 2009), which found that people with ABI experience significant declines in community integration following the brain injury. In general, people with ABI have a higher quality of independence and social participation than people with intellectual disabilities though. These conclusions are based on observations, and not on statistical testing, for which no further conclusions could be deduced from the data. To draw more conclusions on the quality of life profile of people with ABI, further research with the POS, in which the variety of this population is more represented, would be advisable.
During this research, the experts drew special attention to two topics which are of importance to people with ABI. A first topic is having a job. McCrimmon and Oddy (2006) as well stated that returning to work is one of the main goals for people with ABI. Following the experts having a job would improve the personal development, self-determination, social inclusion and emotional well-being of the person with ABI. This confirms Kersel, Marsh, Havill, and Sleigh’s findings (2001) that returning to work provides people with ABI with a sense of purpose, identity, independence and social inclusion, and reduces their emotional distress. It gives people the opportunity to develop social contacts and leisure activities. Employment is also important in structuring life, providing stability and enabling an independent lifestyle. However, the prospects of returning to work are estimated low for people with ABI. They are often unable to return to their previous jobs or to work in any unpredictable or unstructured environment (McCrimmon & Oddy, 2006). A second topic the experts indicated as very important is having a partner. Not having a partner would have a negative influence on the emotional well-being of people with ABI. However, it has been found that between 40 and 55% of relationships of persons with ABI end in divorce or separation. Spouses or partners often feel isolated in a relationship where they have to cope with the problems ABI causes, and where their own emotional needs are not met. This stresses the importance of guidance to both people with ABI and their close ones (Powell, 2004).

The findings of this study recognize the POS as an appropriate measurement instrument to measure the quality of life of people with ABI. Regarding the internal consistency of the domains, ‘Rights’ and ‘Physical Well-Being’ have a more questionable consistency. In research with people with intellectual disabilities (Van Loon, Van Hove, Schalock, & Claes, 2009), these domains as well score lower on internal consistency. Also in accordance with the mentioned research of van Loon et al. (2009), is the consistency between both versions of the POS confirmed in this study. In general the instrument produces consistent results, which underpin its reliability. The indicators of the scale measure the same construct: ‘quality of life’. In addition to measuring this by scoring, the POS also provides a framework to have a conversation with an individual about his/her quality of life. While administering the POS, it is useful to include also qualitative information (feedback from respondents, perspectives on quality of life, and so on). These observations confirm the instrument’s validity. The instrument can therefore be used to assess the quality of life of people with ABI. The reliability and validity of the POS have also been affirmed by other studies with different target groups (De Windt & Lannau, 2009; Moonen, van Loon, Van Hove, Vandeveld, & Claes, 2010; Van Havere, 2011; Van Hove et al., 2011; van Loon, Van Hove, Schalock, & Claes, 2009). These studies support, together with the results of this research, the universal character of the quality of life framework on which the POS is based.
As the POS is an appropriate measurement instrument to measure the quality of life of people with ABI, it can be employed on different levels. Firstly, it can be used for the direct benefit of the individual with ABI. The POS outcomes can offer the person with ABI feedback on his/her quality of life and the scoring on the different domains. They also can be a tool to assess and improve a person-centred support plan, and in this way enhance the individual’s quality of life. An example could be, referring to obtained data in this research, to develop support and goals that help people return to work, or to maintain a healthy relationship with a partner. The POS could be administered to assess this support plan on established evaluation moments, and to adapt the support plans and goals accordingly. Moreover, using the POS for assessment and improvement can be seen as a confirmation that the organization serving the client is dedicated to a holistic approach. Secondly, the POS can be employed on level of the organizations which provide support to people with ABI. It provides them with an instrument to follow up client outcomes and changes in those outcomes over time. The POS outcomes can help to determine which individual, organization-referenced, and community factors predict the quality of life outcome scores. This can offer them a way to evaluate the effectiveness of the support they provide to people with ABI. Using this evaluation of their support methods can lead to organization-based quality improvement (van Loon, Van Hove, Schalock, & Claes, 2009).

2. Limitations of the research and recommendations

There are a number of limitations to consider in this study. Because there was only one interviewer and due to time limits, data were collected of only a small group of respondents (n=47 per version of the POS). These respondents were all volunteers for participation in the research, which might have caused the participation of a certain group of people, who felt motivated to do an interview. All respondents were service users of the Second Chance Headway Centre, which has as consequence that the existing variance of people with ABI was not sufficiently represented in the study. For instance, no hospitalized people with ABI participated, and only 4 people living in a residential care home were interviewed. Also, people with ABI who have a job might not be represented enough. In Second Chance only one service user has a job. Working people with ABI might not have the time or necessity to go to a day centre. Therefore, I believe that the sample used in this study is not completely representative for the whole population. Nevertheless this study has provided certain insight in the quality of life of people with ABI.

One of the variables that might influence the quality of life of people with ABI is the moment when they sustained the brain injury. When time passes, people might learn to cope with possible
disabilities and changes in life that a brain injury can cause. They might recover some abilities they had lost. In future research could be studied with the POS how exactly the passing of time since the brain injury affects quality of life. Following POS outcomes, does people’s quality of life improve when more time has passed since the injury? Also, the variable of age when sustained the injury was not studied in this thesis. An acquired brain injury can be sustained any moment after birth. People who had their injury when they were a toddler might have other perspectives on their quality of life than people who suffered a brain injury when they already had started a family and had a regular job. Another variable which has not been taken into consideration in this study is the degree of the injury. There is a wide range of degree, from people with severe disabilities caused by the brain injury to people with more ‘hidden’ disabilities. In future studies it could be interesting to research with the POS the differences in quality of life of people with different degrees of injury.

3. Conclusion

People with ABI report a lower quality of life than people without disabilities. This indicates people experience a general decrease in quality of life after suffering a brain injury. The largest difference in scores between these two groups can be found in the domains of Personal Development and Interpersonal Relationships. People with ABI also differ in quality of life from people with intellectual disabilities. In general they have a higher quality of life than this group, mostly in the areas of independence and social participation. The domain of social inclusion is the area with which people with ABI are less satisfied.

By confirming the general reliability and validity of the POS for people with ABI, this study recognizes the POS as an appropriate measurement instrument to assess the quality of life of this target group. Therefore it can be employed to give feedback to the individual and to assess and improve his/her person-centred support plan. The POS also can be used to follow up the client outcomes in an organization for people with ABI, and to assess the support an organization provides to its clients. In this way, the POS outcomes could lead to quality improvement.
Bibliography


