

# Post-injury lives

Experiences of persons acquiring impairments in midlife

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REPORT

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Norwegian Social Research

NOVA Report 21/2009

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# Preface

This report is part of a qualitative research project concerning the rehabilitation and reorientation experiences of persons acquiring impairments in midlife. The project has been financed by the Norwegian Foundation for Health and Rehabilitation under the sponsorship of the Norwegian Federation of Organizations of Disabled people. Data collection and storage have been approved by NSD (Norwegian Social Science Data Service). The project has been conducted from 2006 to 2009 by a research team of two persons - the project leader, Reidun Ingebretsen, a psychologist and the first author of this report, Susan Lingsom, a sociologist. Both researchers are middle aged women with personal experience with injury in midlife. All interviews were conducted in Norwegian. Writing this report in English is a re-telling and interpretation of respondent accounts and, in itself, a first step in our analysis. We have chosen to limit direct use of citations in this report. Translations of respondent statements are restricted here to short illustrative sentences and phrases and are set in cursive. All translation is made by the first author.

Our thanks go to the ten respondents who generously shared their experiences and reflections with us in the hope that their stories could contribute to greater understanding and wellbeing of persons acquiring impairments. We will also thank the Norwegian Federation of Organizations of Disabled People for their sponsorship and ongoing discussions and Norwegian Social Research for housing the study. Our colleagues, Kirsten Thorsen, Kirsten Danielsen and Jon Ivar Elstad have read drafts of this report and given us very helpful comments.



# Content

Summary.....	7
1 Introduction .....	11
2 Study methods.....	16
2.1 Sample and recruiting methods.....	16
2.1.1 Criteria and recruitment .....	16
2.1.2 Sample characteristics.....	17
2.2 Data collection .....	18
2.2.1 Multiple interviews .....	19
2.2.2 Interview location .....	19
2.2.3 The interview encounter .....	21
2.2.4 Responses to being interviewed .....	22
2.3 Strengths and weakness of data/method.....	22
2.3.1 Analysis method .....	22
2.3.2 Researcher closeness to the field .....	23
2.3.3 Data strength and weakness.....	25
3 Rehabilitation experiences and reflections.....	26
3.1 Introduction .....	26
3.2 Primary medical rehabilitation .....	27
3.2.1 Thin descriptions of staff and services .....	27
3.2.2 Co-patients for better or worse .....	29
3.2.3 Staging visits.....	30
3.3 Secondary rehabilitation .....	30
3.3.1 Discharge to chaos .....	31
3.3.2 “Nice enough ladies”.....	31
3.3.3 Fighting the system.....	32
3.3.4 New insights and morale boost - secondary in-patient rehabilitation.....	33
3.4 Late phase user organized rehabilitation .....	34
3.4.1 Therapy shopping .....	35
3.4.2 Training opportunities everywhere .....	37
3.5 Ideal rehabilitation.....	38
3.6 Discussion.....	39
4 Back to work .....	42
4.1 Introduction .....	42
4.2 Returning to work.....	43
4.2.1 Early returns.....	43
4.2.2 No pushing.....	44
4.2.3 Initial job adaptations .....	45
4.3 Working post-injury .....	45
4.3.1 Work more important .....	46
4.3.2 Tied to pre-injury employer.....	46
4.3.3 Positive uses of impairment experiences.....	47

4.3.4 Co-worker skepticism .....	47
4.3.5 An ongoing battle.....	48
4.4 Exit from work force .....	49
4.5 Discussion.....	51
5 Managing impairments in daily life .....	54
5.1 Social interaction.....	54
5.1.1 Family – Support and tension.....	54
5.1.2 Friends – Less contact, less initiative, less in common.....	58
5.2 Coping techniques and philosophies.....	60
5.2.1 Reachable objectives and a philosophy of small steps.....	61
5.2.2 Positive thinking – making good days and good stories .....	63
5.2.3 Self care.....	64
5.3 Discussion.....	66
6 Impairment narration.....	69
6.1 Impairment genesis .....	69
6.1.1 High drama .....	70
6.1.2 Low drama .....	71
6.1.3 Performance .....	71
6.2 Impairment effect narratives .....	72
6.2.1 Storylines and delivery.....	73
6.2.2 Silencing .....	75
6.3 Audience Reception.....	77
6.3.1 Interest .....	77
6.3.2 Disinterest and disbelief.....	78
6.3.3 Research team as audience.....	79
6.4 Discussion.....	79
7 Disability identities .....	82
7.1 Injured – not disabled. Respondent self images .....	82
7.1.1 Active and recovering .....	83
7.1.2 Little reference to context and social factors .....	84
7.2 Disability attributes.....	86
7.2.1 Wheelchair as defining attribute .....	86
7.2.2 Passivity and hopelessness – extreme negative stereotypes.....	87
7.3 Rejection of disability identity.....	87
7.3.1 Affirmation of hope.....	88
7.3.2 Cohort, age, and class influence .....	89
7.3.3 Lack of social confirmation with invisible impairments .....	90
7.4 Discussion.....	91
8 Summary and discussion .....	94
Sammendrag .....	105
References.....	109

# Summary

The aim of this study is to increase understanding of living with impairments acquired in adulthood. The study draws on qualitative interviews with ten middle aged, middle class persons who have suffered reductions in functional capacity due to strokes or accidents. Injuries vary by type and severity. This report discusses long term rehabilitation processes and experiences of returning to work. Effects of acquiring impairment on social interaction and family, strategies for coping with impairment, the development and use of narratives concerning impairment, self images and disability identity are also discussed. Events marking turning points in rehabilitation and reorientation and learning processes respondents have undergone over the years post-injury are emphasized. Central concepts of the analysis are illness as biographical disruption, the narrative creation of self, passing as normal, covering and disclosing embodied difference. The report is primarily descriptive, summarizing respondent accounts thematically.

Discharge home from primary rehabilitation marks the beginning of a complex, conflictful time of putting life back together. Late phase user organized rehabilitation is the term chosen to denote the increased influence, knowledge, and responsibility persons acquire over time for their own rehabilitation. For most respondents rehabilitation was a life long post-injury project. It involved therapy shopping, taking breaks from organized training, and seeing training opportunities in everyday life. Respondents called for better coordination of service systems and greater flexibility in interpretation of rules. They expressed interest in continued opportunities for rehabilitation and follow up through counseling. They emphasized the importance of nurturing hope as the primary motivation for perseverance.

Work was central to the identity of our respondents and all but one returned to work for some time. Starting back to work was an important phase in learning about impairments. Work became more important in the lives of some respondents as compensation for other activities they could no longer perform or because success at work required more effort. Some respondents succeeded in adapting work conditions and plan to continue



working until retirement. The majority of our respondents, however, exited the work force temporarily or on a permanent basis. Self esteem appears to be lowered by facing problems at work and/or exiting the work force. Persons on temporary disability pensions retain hope of returning to work. For persons who have struggled for many years maintaining a foothold in the work force or in managing daily life at home, permanent disability pensions can be a relief.

Whole families become impaired, not just individuals. Respondents tried to live family life as “normally” as possible, drawing on family relationships as a source of motivation in rehabilitation. Middle age, middle class persons have many skills and recourses they may draw upon in managing impairment. The most important resource is perhaps the web of family relationships which often characterize middle age positions – children, grandchildren, spouse, siblings, and elderly parents. Family relations represent continuity despite the upheaval of illness and injury as well as practical help and emotional support. Respondents were particularly grateful for how their children had taken the upheaval in family life. Most respondents had less contact, less social initiative, and less in common with old friends post-injury. Pre-injury forms for socializing could be too demanding and there was little done to develop new forms. Social unease and underlying tensions and uncertainties in meetings with able bodied others were reported.

Three major techniques of managing impairment effects were used by respondents. One involved formulating reachable objectives. This assured personal significance to goals and a stream of opportunities for success in meeting objectives. Positive thinking or cognitive self therapy was a second approach. It nurtured hope for improvement and contributed to general wellbeing. The third approach, self care, involved listening to and accepting one’s body and finding balance between doing too much and too little. Coping techniques were rooted in respondent upbringing, pre-injury biographies, and post-injury experiences of what furthers rehabilitation and increases wellbeing.

Most respondents concluded over time that they did not want to draw attention to problems they are facing. They did not want to be seen as whining or self centered. Most had experienced that others were not interested in hearing ongoing stories of impairment effects. Respondents

silenced impairment narratives thus silencing a part of their experiences. Credibility of impairment narratives was particularly an issue for persons with no visible markers of injury. Impairments negatively affected storytelling performance for some.

Reductions in functional capacity may be severe without being self defined as disability. Most respondents defined themselves as being sick or injured, not disabled. Being busy, having high levels of achievement, hope for improvement, and a good life despite functional limitations were rationales for rejecting disability identity. Respondents were strongly oriented towards regaining as much of lost functional capacity as possible. Most were oriented towards reconstructing as much as possible of their pre-injury lives. Biographical disruption caused by injury varied in scope and duration. Most found ways and means of constructing continuity despite changed parameters injuries caused for living in the present.



# 1 Introduction

This report is part of a study which seeks to increase understanding of living with impairments acquired in midlife through injury or sudden illness. The aim is to present respondent experiences and reflections and identify lessons to be learned from them for the betterment of services and the increased wellbeing of persons undergoing rehabilitation and reorientation processes. Long term rehabilitation processes and experiences of returning to work are investigated. Effects on social interaction, strategies for coping with impairment, and the development and use of impairment narratives are discussed. A final theme deals with self image and disability identity. Emphasis is placed on events which marked turning points in rehabilitation and reorientation post-injury and the learning processes and phases respondents have been through.

While primarily descriptive, the analysis draws on a number of theoretical concepts. Central concepts are that of illness as biographical disruption framed by Bury (1982) and narrative construction of self (Somers 1994, Ochs & Capps 1996). Impairments from accidents or sudden illness acquired in midlife represent almost by definition a biographical disruption. Accidents and sudden illness result in unplanned, undesired embodied difference - difference from past self and difference from able bodied others. Disruption is a break from the body as a tacit, taken for granted partner. Disruption includes plans for the future which are no longer fully viable. The ongoing autobiographical narrative by which the self is constructed and performed for self and others is disrupted, the narrative and the narrator threatened.

As pointed out by Williams (2002) the concept of biographical disruption has a middle age, middle class bias in that it assumes an able bodied biography and life plans which do not include illness and impairment. For some people and in some historical and social contexts, disruption is normal. Accident or sudden illness may be anticipated, for example, with family history of illness, violent neighborhoods, risk filled activities, etc. Some people may not expect life to proceed smoothly after plan as no plan

has been made. This study draws on a sample of persons living in a time and place of social stability and prosperity where expectation of continuity and development, of making and following life plans, may be presumed commonplace.

We live in a storied world. We live in and through our stories. We come to know ourselves through the telling/performing of our stories and through the responses of listeners (Frank 1997, Kenyon & Randall 1997). Medved & Brockmeier (2008) summarize the functions of the narrative as the creation of coherence, distancing from events, binding others into communication, evaluation of experiences, and explorations of alternative possibilities. Storytelling requires an audience, if even a research team. Hydén & Brockmeier (2008, p.7) claim that “Telling a story is performing it, acting out a process of interpreting, constituting, and positioning one’s experience. It is an enacting of identity”.

Biographical disruption creates a breach in narrative of self, a broken narrative. A new, amended biography begins taking form through reflection and narration of experiences. The narrative is critical for constructing the self and moving on after a major biographical disruption. In researching disrupted lives Becker (1997) stresses the use of metaphors in narration for bridging the gap caused by disruption and reestablishing bonds to self and the social. People strive for continuity and connection after disruption. Continuity is not used here in a narrow connotation to conjure up images of a seamless return to one’s pre-disruption life. Continuity in the broader sense refers to creating new trajectories linking past, present, and future. Continuity interpreted as transformation redefines and expands on earlier conceptions and values, incorporating disruption and the new situation in the affirmation of self.

The concepts of passing and covering as developed by Goffman (1963) are also central in this study. Passing as normal in Goffman’s terms refers to keeping an attribute ascribed stigma from becoming known to others while covering refers to keeping a known stigmatized attribute as unobtrusive in social interaction as possible. The stigma of impairment may have faded some since Goffman’s time in North America in the 1950’s and 1960’s (Gill 2001, Swain & Cameron 1999). The exclusive definition of normality has been broadened (Shakespeare & Watson 2001). However, passing as normal

and covering impairment appears to remain of great importance for self esteem and social relations in present day Norway (see for example Romsland's 2009 study of persons with acquired cognitive impairments). Silencing of impairment narratives is a representation of covering in social relationships and a representation of present day stigmatization.

Accidents and illness strike people of all ages. A premise of the study is that age matters in how people manage with abrupt reduction in functional capacity due to injury or illness. The study focuses on middle aged persons, people who have been socialized well into adulthood as fully able bodied persons. They have been able bodied when choosing and completing their education, starting work, forming friendships, and finding partners. They have not had to face disability discrimination in entering the labor market, problems of accessibility in schools, or social stigma in forming friendships, finding partners, and having children. Life course timing is but one of many permutations of impairment experience which has not yet received much attention.

Abrupt versus gradual impairment is another of the many permutations of impairment experiences which has yet to receive much attention. Respondents in this study have experienced abrupt reductions in functional capacity. There is a clear demarcation between life pre- and post-injury. Abrupt reduction in functional capacity, as opposed to gradual loss and gradual adjustment to deteriorating health, highlights responses and reflections over biographical disruption and mending broken narratives.

Respondents in this study are ethnic Norwegian, urban, middle class persons with a varied store of social, educational, and material resources at their command for managing impairment effects. They exemplify relative privilege but also the expectations and demands associated with middle class positions. Their chief resource may be located in their biographies and their drive for reconstructing continuity with pre-injury identities.

Norway is a highly developed welfare state with many publicly funded programs and services for persons requiring health care and rehabilitation after injury. It has a comprehensive social security system managing economic benefits and pensions. The Norwegian welfare state context is not in focus in the report although references to context are natural elements in respondent stories. Respondents have been injured in different time periods

and have different meetings with policies and programs specific to the type and severity of their injuries. Here the focus is on the micro level of the respondent experiences and social relations.

A theoretical discussion of acquired impairment and situating the data within the larger context of health and disability literature is beyond the scope of this report but selected themes relevant to invisible impairments and writing impairment narratives have been further developed elsewhere (Lingsom 2008, 2009). Some references are made to recent closely related Norwegian studies on persons with acquired impairment or chronic illness.

The term normal is used loosely in this report as it was used by respondents themselves. Neither they nor we have wanted to give the term a specific meaning and a normative connotation. The term impairment is used as a general reference to long term reductions in functional capacities due to illness or injury. A distinction is made between visible and invisible impairments tying back to concepts of passing, covering, and impairment narration. Impairment effects refer to impairment particulars and the interaction of individual reductions in functional capacity and biography on the one hand, and, on the other hand, social institutions and social practices structuring impairment experiences in different contexts and affecting the psycho-social wellbeing of impaired persons (Wendell 1996, Thomas 1999, Hughes 1999). Respondents preferred the term “injured” and we therefore make general reference to life pre- and post-injury.

The content of this report may be briefly outlined as follows. After this short introduction, study methods are discussed in Chapter 2. Sample recruitment and sample composition are presented. Data collection is described in some detail as an important first step in conveying information on respondent situation and reflections, situating the responses. Researcher closeness to the field under study is also addressed. Analysis methods and the strengths and weakness of the data are outlined. This chapter sets the stage with actors.

The analysis follows a roughly chronological time line. Persons with suddenly acquired impairments often start their post-injury lives in rehabilitation facilities. Chapter 3 discusses rehabilitation experiences. Emphasis is placed on secondary rehabilitation and the ongoing efforts of rehabilitation respondents perform years post-injury.

Going back to work post-injury is an important step in going back to mainstream social life. Chapter 4 discusses respondent experiences going back to work. All respondents were employed at the time of their injuries and had work places to return to after primary rehabilitation. Working experiences post-injury are divided into three phases or themes: returning to work, working life when impaired including job adjustments, and thirdly eventual exits from the work force over time on a temporary or permanent basis.

Chapter 5 discusses coping with impairment effects in daily life addressing firstly interaction with family as a source of support and inspiration as well as tension. The consequences of injuries on the frequency and forms of social interaction with friends and network composition are also discussed. Coping techniques and philosophies for living with impairment effects are the main focus of the chapter. Three major techniques are identified and exemplified – small, reachable objectives, positive thinking, and self care.

Impairment narration is discussed in Chapter 6, beginning with stories of impairment genesis or what happened. Narratives of impairment effects are distinguished as a separate category of complex ongoing stories. Our emphasis is on the use rather than the content of narratives per se. Our concern is with how stories of living with impairment effects are told. To what degree do respondents attempt to involve others, including the research team, in their narratives of recovery and reorientation? Storytelling performance, self censorship, negative audience reception and the struggle for gaining credibility of impairment narratives are discussed.

Chapter 7 deals with self images of disability and what attributes respondents ascribe to disability. Respondents chose in general to distance themselves from disability identities, viewing themselves as injured rather than disabled. The causes of this choice and its implications for the individual and society are discussed.

Chapter 8 gives a general summary and discusses our findings.



# 2 Study methods

## 2.1 SAMPLE AND RECRUITING METHODS

### 2.1.1 Criteria and recruitment

Sample criteria initially called for persons between 40 and 55 years of age who have had a sudden reduction of functional capacity due to injury or illness. Persons were to have completed primary rehabilitation with lasting impairments (i.e. lasting reduction in functional capacity). We sought to interview persons three to six years post-injury so that they would have had time to gain experience living with their impairments. No specification was made as to the type and severity of impairment or its cause. We did require that persons should be able to relate their experiences in verbal communication with researchers. Sample criteria thus excluded persons with severe cognitive impairments and/or severe hearing or speech impediments.

We chose to recruit a sample of ten respondents through the cooperation of primary care doctors in the Oslo metropolitan area. Doctors were deemed to be a comparatively neutral recruitment source as all residents, impaired or not, are registered with primary care doctors. Primary care doctors were also deemed to be in the best position to select respondents from the combined sample criteria of age, impairment history, and communication capabilities. Alternative recruitment through organizations for persons injured in traffic accidents or with specific impairments or health conditions was rejected as potentially biased in terms of identification with organizational politics.

A letter introducing the study was sent to four doctors asking for their cooperation in contacting patients meeting our sample criteria. The doctors were requested to forward introductory letters to prospective respondents with attached forms for signed agreement. The names and telephone numbers of persons willing to participate in the study were to be sent to the research team either by doctors or prospective respondents themselves.

Recruitment through doctor referral proved insufficient to yield the designated sample of ten respondents despite the fact that the doctors have full patient lists totaling approximately 6500 patients. Only five respondents

were directly referred from doctors. The doctors were perhaps too busy to thoroughly search their patient lists. Persons meeting our criteria do not necessarily consult primary care doctors often. Criteria may also have been too complex, with few patients meeting all criteria. Age and post-injury time criteria had to be broadened. Additional recruitment of respondents was accomplished through snowballing, i.e. personal referrals from original respondents to others in roughly similar circumstances. Five of the ten respondents were recruited through snowballing procedures.

Respondents providing snowball referrals are likely to contact persons they have shared experiences with, people whom they like or admire, people with attitudes and characteristics similar to themselves. Both doctors and respondents are likely to provide referrals to persons known to have an interest in telling their stories and/or interesting stories to tell. A consequence of recruitment procedures is that there is little sample variation in social status.

### **2.1.2 Sample characteristics**

Four men and six women compose the study sample. Their age at the time of injury ranged from 22 to 58 years, with an average age of 46.2 years. At the time of the first interview, they ranged in age from 31 to 64 years, with an average of 53 years. With one exception all are married or cohabitating with their pre-injury partner when interviewed. Duration of post-injury experience at final interview ranged from 2 ½ to 17 years. Approximately half of the sample had been injured five years or less, half have been injured for more than ten years. Average time post-injury at first interview was 7.9 years. The cause of injury varies. We use pseudonyms in the analysis. John, Peter, Ellen and Linda have had strokes. George, Tom, Karin, Tina and Mary were injured in traffic accidents. Anna was in a home accident.

The situation at the time of injury was dramatic and serious for some respondents. Others suffered moderate injuries which proved to have long lasting consequences. Injuries are of different types and degree. Physical and cognitive impairments are represented in the sample although these distinctions blur in respondent stories. One respondent is a full time wheelchair user but there are also others with severe to moderate mobility impairments. One respondent is partial wheelchair user. There are others who walk with a cane, brace, or limp. Mobility impairments are also represented by persons

with cognitive injuries which require total concentration as to how far forward and how far downward they should place their feet going down stairs. Cognitive impairments represented in this sample affect primarily the ability to perform several tasks simultaneously, short term memory, and the speed of mental processing. One respondent has partial loss of speech. Psychological difficulties following injury trauma are represented by anxiety, bouts of depression, and uncontrolled mood fluctuation. Several respondents have restricted use of hands and arms. Chronic pain and low stamina are other frequent physical problems. Two respondents need personal care and have personal assistants to help with activities of daily living funded by their municipality. Several respondents have multiple injuries. Some respondents are still in the process of recovering functional capacities - reducing paralysis, improving balance, finding lost words, etc. Some are experiencing reduction in chronic pain and finding better ways of managing pain. In our interviews we gained insight into recovery processes which have gone on for years but which are not finished.

Most respondents have visible mobility impairments but also impairments which are not highly visible. Some impairments are visible only to a trained eye and over longer interaction. Visibility aside, all impairments became known to us only through respondent accounts of impairment effects in daily life. There seems to be little connection between the visibility of impairments and the severity of impairment effects. Cognitive and speech impairments seem to have more far reaching consequences on daily life and social participation than mobility impairments.

Respondents belong to the middle to upper-middle class. All have some form of higher education. Administrative leaders and managers, professionals, and occupations with college or technical training are represented. One respondent was self employed. Two worked in family businesses. Four respondents were employed in the public sector.

## 2.2 DATA COLLECTION

Data collection consisted of multiple, semi structured qualitative interviews which were taped and transcribed. With few exceptions, both members of the research team participated in the interviews. Interviews generally lasted one and a half to two hours. Respondents were interviewed from two to

three times over a two year period and followed up throughout the study period with telephone contact. Data collection was conducted from 2006 to 2009. A total of 23 personal interviews were conducted.

### **2.2.1 Multiple interviews**

Multiple interviews were an important feature of the research design. Multiple interviews allowed us to follow changes over time more closely than possible through exclusively retrospective accounts. Respondents were gaining more experience and could talk about fresh insights. Initial interviews were a cause of new reflections for some respondents. Multiple interviews also allowed us the opportunity to follow up specific lines of questioning after a preliminary analysis of the existing data. Multiple interviews gave us an opportunity to refine our research focus in the course of the study and formulate new questions. One line of questioning which developed in the course of the study regarded the interview experience itself. Respondent reflections complement and enrich our description of data collection. Permission to re-interview was requested after completion of the first interview and was granted by all respondents.

Part of the rationale behind use of multiple interviews was related to self presentation. We assumed that respondent self presentation in the first meeting would be biased towards signature stories, i.e. rehearsed stories that once established required little effort and reflection in the telling. Multiple interviews increased the likelihood that respondents would go beyond rehearsed self presentations. Second and third interviews are likely to be more relaxed and there is likely to be a greater degree of trust and confidentiality. The same applies to telephone contact following the initial interview.

### **2.2.2 Interview location**

Most of the interviews took place at our research institute. Seven respondents chose to come to the institute at least once. One respondent chose home interviews, one respondent chose to be interviewed at a rehabilitation day centre, and two respondents chose their work place for at least one interview.

Making the journey to the institute was demanding for some and respondents gave expression for the effort involved in city travel. The journey typically began before the day of the interview. Many had double

checked the location to be sure where they were going. Several came early to avoid feeling rushed. Several respondents reported making a day out of it. Some had planned a reward for themselves afterwards, for example, a visit to one of the area's many cafés. Several respondents were clearly proud of their achievement in successfully navigating the journey. It expanded their sense of control and opened new territory to their repertoire. One respondent reported that walking to the institute brought back fond memories of pre-injury city strolls.

Respondents who chose meeting at the research institute said that the setting gave added meaning to the encounter. The institute setting increased the sense of professionalism. It underscored the meaning of sharing experiences and reflections and of being open without being too personal. As one respondent said, "*The interview was personal enough*".

Coming to the research institute opens some stories and closes others. The alternative for most respondents would have been their own homes. Had interviews been conducted there, respondents would be receiving researchers as quasi-guests. Respondents and/or their spouses would have felt a need to tidy up the front stage interview location, prepare coffee, etc., as one would for other guests. Family members might have been present during the interview and could hear what was being said. Respondents would have been more likely to tell stories involving family, if even in small talk about photographs on a wall. The one respondent requesting home interviews did so for health reasons and was alone at home. Other respondents thought that home interviews would have been uncomfortable and did not want family and their private sphere to be involved in the study. Some employed respondents reported that they would not have felt comfortable being interviewed at their place of work. One respondent said that had we come to his office he would have simply answered direct questions. It would have been "*a straight interview*" while at the research institute we were "*having an open dialog*".

Respondents choosing to be interviewed at their work place regarded this as a practical arrangement saving time and energy. The rehabilitation day center location was also a practical, time, and energy saving arrangement, easy and not too personal. Respondents did not appear to be concerned about using these locations in self presentation.

### 2.2.3 The interview encounter

Irrespective of location, most respondents needed to be rested prior to the interview, particularly prior to the first meeting. They needed to adjust their weekly schedule to make space for the interview day and a quiet day preceding it. Three respondents told that they had taken pain medication as a precaution or preparation for the day.

The project leader was the principle interviewer. Both researchers sat with a thick interview guide in their laps and took notes. Permission to tape the interviews was given by all respondents. Several respondents asked for, and received, reassurance of confidentiality during interviews when relating to their work places and to events or experiences they regarded as particularly sensitive. Respondents often stopped themselves and asked for reassurance that what they were talking about was relevant. We assured them that we were interested in all they wished to relate. Our ambition has been to be as open and attentive as possible to respondent stories. We asked what had happened and how injury had affected their lives. Follow up questions expanded on respondent stories through active listening and creating a dialog situation. Questions were posed to confirm our interpretation of what respondents were saying.

Our research design involved a semi structured interview. It was not a clinical consultation or a self help meeting for persons with impairments. Some respondents tested limits of the interview situation, fishing for advice in the course of the interview, wondering out loud at what the best course of action might be, and pausing in case advice was forthcoming. While sometimes helping to clarify alternative positions, we gave no advice. Some respondents appealed for recognition of functional improvement, asking if we could see improvement since the initial interview or explicitly showing us signs of improvement.

Respondents had a general tendency to present a brave face and focus on making the best out of a difficult situation. They tended round off critical statements with some positive thought and quickly put a positive expression back on their face if their mask fell when they spoke of something sad or difficult. It appeared important, particularly in the first interview, to present an overall picture of self as being optimistic and positive.

## 2.2.4 Responses to being interviewed

In rounding off interview sessions and later follow ups, respondents were routinely queried as to how they had experienced the interview encounter. Respondents felt good about being interviewed, tired yet invigorated. Several respondents said that they understood their own stories differently or more completely from listening to themselves tell the stories, from hearing themselves talk. Most respondents were not accustomed to anyone showing prolonged interest in their experiences of living with impairments. One respondent summed up the interview by saying, *“It’s really wonderful to talk about all this.”* A respondent who had shed a few tears under the interview was also pleased about the experience. *“I almost never cry anymore. Emotions come when talking about my experiences. I’m glad that I still have my feelings.”* A third respondent termed the first interview as a *“turning point”* in her life. The interview had supported an ongoing process of reflection and boosted her self esteem. A fourth respondent appreciated being interviewed as he regards all opportunities to discuss his injuries as therapeutic even after many years. Participation in the study was seen as a chance to contribute to social understanding of acquired impairment and to be of help to others undergoing rehabilitation. Respondents appreciated feeling that their experiences were interesting and helpful to others. It gave added meaning to their experiences.

## 2.3 STRENGTHS AND WEAKNESS OF DATA/METHOD

### 2.3.1 Analysis method

The method of analysis consisted of three overlapping processes. Firstly, the interview team conducted a debriefing discussion after interviews to discuss initial interpretations of respondent stories, evaluate the interview guide, and suggest topics for further inquiry. Secondly, the analysis consisted of repeated thematic reading of interviewer notes and transcribed texts and listening to taped material. The material was studied from different thematic perspectives as evidenced in this report by chapters on rehabilitation experiences, work life, impairment narratives, etc. Within the selected themes, primary attention was directed to events marking turning points, learning processes and changes over time, summarizing and systematizing the data. Drafts of written analysis were further discussed and revised by the interview team. Thirdly, issues which were open to interpretation or where

data was unclear were identified for investigation in later interviews and/or future telephone contact. Analysis was conducted parallel with data collection.

The thematic analysis form of this report was chosen to provide maximum protection of respondent anonymity while remaining as close as possible to respondent experiences. Respondent accounts are divided up into themes or topics. Respondents varied as to what and how much they wanted to or could tell about different themes. This report is largely a retelling and interpretation of respondent accounts. The use of direct quotations is very limited, often to merely a striking phrase or key concept. Translation from Norwegian to English would, in our view, reduce the authenticity of respondent expression. Moreover as this report covers a number of different themes retelling and summarizing respondent accounts helps limit repetition and allows for a more compact presentation than otherwise possible. More extensive use of respondent citations is planned in reporting in the Norwegian language.

### 2.3.2 Researcher closeness to the field

In our introductory letter to prospective respondents we wrote in general terms that the research team had personal experience with injury in midlife. The doctors recruiting respondents know us. Doctors' knowledge of our stories was significant in gaining their trust and cooperation. At least half of the sample knew some details of researcher injury prior to the first interview having been informed by referring doctors or through snowball recruiting. (Both researchers have been in accidents and have sustained neck injuries.) We asked respondents in the last rounds of interviews what effect, if any, our acknowledged personal experience with injury had had on the interview encounter and their responses.

The most common response was that insider knowledge had helped us ask the "*right questions at the right pace*". Respondents thought that we seemed to know where shoes pinch and what problems impairments represent in daily life. We seemed to understand the efforts involved in daily coping. They felt we were listening closely and understood what they were saying as evidenced by relevant follow up questions. We were not in a hurry. This made it easy for respondents to speak freely. It was "*safe*" to talk. Respondents had time to search for words and think through issues they had not talked about in detail



before. One respondent said it would be difficult to be as open with younger researchers and with male rather than female researchers.

Respondents in general appear to have been so focused on telling their stories they did not think about the personal experiences of the research team during the interviews. After interview sessions, respondents often turned their attention to researcher experiences and asked questions of us, perhaps as a reaction to having revealed so much of their own experiences during the interview. Some personal response was called for when direct questions were posed to us, but we tried to keep our experiences in the background.

Researcher closeness to the field has clearly had significance for our research aims and perspective. Our biographies inform all phases of the project and sharpened our initial interest in opening this field of research. We used our personal experiences with injury in midlife as a resource in developing the interview guide. Personal experiences with injury were used indirectly in our meetings with respondents. Being interviewed by researchers with insider knowledge appears to foster quick creation of trust and a free range of story topics. Respondents may not feel the same need to explain situations as they would have to researchers without impairment experience and therefore feel less hesitation in telling their stories. Having gained trust, we, as insider researchers, perhaps feel freer to probe for details in sensitive matters.

There is always a risk of being too close to the field, of going native, and only hearing selected parts of respondent stories which resonate with our own. There is risk of losing analytical distance and becoming mere microphones for respondents. In analysis phases of a research project, critical distance is required. Some respondents were eager to read what we were going to write about their experiences. At times we have had a feeling that respondents are looking over our shoulders as we write. Our knowledge of them and their trust in us has a strong influence on what we write. The respondents are thus to some degree co-authoring the analysis. We may someday have to account to them personally for what has, and what has not, been written. This is an important dimension of going native. Some respondents identified so strongly with the project aims and had so much to contribute that they could have qualified as co-researchers.

The research team has been aware of the dangers of being too close to the field. A feature of the study design which helped making our closeness to the field into a resource was the composition of the research team. Firstly, we are two researchers with different experiences and degrees of injury. Our biographies thus covered a range of experience related to impairment. Having in addition different professional backgrounds, we came to the interviews and analysis phases with varied perspectives and interests. Being a team helped maintain a professional balance between closeness and distance. The time lapse between initial data collection and final analysis has also helped increase analytical distance.

### **2.3.3 Data strength and weakness**

Multiple interviews are an important asset in this study allowing opportunities to follow changes in respondents' situation and opportunities to develop new lines of questioning. There was an increase in openness after the initial interviews. Trust gained in the first interview helped us to get beyond rehearsed self presentation. It opened for more expression of vulnerability, frustration, and pessimism in later interviews as well as measured optimism.

The sample is small and non random. Generalization from our results, as with other qualitative studies, is limited. Our sample was recruited through a combination of referral from doctors and respondent snowballing. Difficulties in recruiting respondents led us to broaden sample criteria regarding age and time post-injury. It led to a consolidation related to social status. Respondents are middle to upper-middle class adults with higher education. While unsuited for discussing social differences, our data allow us to highlight evaluations and experiences of persons with many material and educational resources at their disposal.

Despite the sample's small size it contains substantial variation. Men and women are represented. There is variation in the type, severity, and cause of injury. Variation in injury is a particular asset in this study as it reduces the focus on specific impairments and undermines the concept of any direct linkage between impairment particulars and impairment effects. There is substantial variation in number of years respondents have lived with impairments. The wide range of time post-injury gives insight into different phases of living with impairments, but limits our ability to discuss specific rehabilitation programs or welfare state social policies.

# 3 Rehabilitation experiences and reflections

## 3.1 INTRODUCTION

This chapter discusses respondents' rehabilitation experiences. Most respondents have participated in formally organized rehabilitation programs. All respondents have worked and continue working on their own rehabilitation. We distinguish between different phases in rehabilitation: 1) primary medical rehabilitation, 2) secondary general rehabilitation, and 3) late phase user organized rehabilitation. Respondent reflections on ideal rehabilitation from their present standpoint are also discussed.

Primary medical rehabilitation begins in somatic hospitals for most respondents and continues within specialized rehabilitation hospitals and treatment centers. Secondary general rehabilitation typically comes after a period of primary medical rehabilitation and involves a variety of formal services and agencies and both community and institutional based programs. Late phase user organized rehabilitation is the term we have chosen to describe ongoing efforts organized as part of daily life by respondents as a continuation of, or alternative to, formally organized rehabilitation programs. The late phase label is suggestive of a temporal dimension and increase over time. User organization refers more to a dimension or aspect of respondent rehabilitation which may be evident throughout. To our knowledge, this third term has not been used elsewhere but the distinction between primary and secondary rehabilitation is commonly used.

Respondents used the term rehabilitation primarily in a narrow sense to refer to professional therapy and training for regaining functional physical capacities. In a broader sense, rehabilitation may also refer to formal and informal efforts aimed at better adaptation of living and working environments, increased social participation, psychological adjustment, and better overall life quality post-injury. Rehabilitation does not refer directly to recovery or improvement but rather to the services, therapies, and efforts aimed at achieving these goals. Rehabilitation is, however, closely associated

with hope for improvement. As long as there is hope for improvement, efforts directed at improvement may be termed rehabilitation.

Some respondents sustained injuries many years ago and their early rehabilitation experiences are distant memories. Several respondents have sustained cognitive injuries reducing recall. Respondents who expressed recall problems were not pressed to give further answers.

## 3.2 PRIMARY MEDICAL REHABILITATION

### 3.2.1 Thin descriptions of staff and services

Stories of injury and intensive care are told with energy and an attention to dramatic detail by most respondents. Storytelling tends to lose its energy when turning to lengthy stays in primary medical rehabilitation facilities. Seven of our ten respondents continued primary medical rehabilitation in specialized facilities for many months after discharge from somatic hospitals. Most respondents spoke little about the content and character of treatments they received while in primary rehabilitation. The first section of this chapter builds on the thin descriptions of services and interaction with others in rehabilitation facilities.

Respondents did tell the names of the facilities they had been in and how long they had been in-patients. Long stays could be regarded as an expression of how serious their injury or illness had been. Comparatively short stays (“*Already after X months...*”) in the rehabilitation facility could be an expression of how hard the respondent had fought his or her way back. Stories of what happened during their stays were primarily related to personal recovery. For some respondents transfer from a somatic hospital to a specialized medical rehabilitation unit heightened awareness of injury. John said, “*When I saw the sign 'Welcome to the X Ward' I understood that 'X' was what I was*”.

Most specialized medical rehabilitation facilities offered single rooms. This was appreciated as a private space for resting and also a space where one could grieve in peace. But the doors did not have locks. Staff and unauthorized others could enter at any time. There was no space for complete privacy.

Depression was expected, almost proscribed. Doctors were quick to proscribe pills according to several respondents. John welcomed all the help he could get to overcome his depression. Ellen fought the diagnosis and proscribed pills, maintaining with conviction that there was an important

distinction between grieving and depression that qualified professionals should be able to perceive. She felt that the nursing staff was spreading information that was outdated and misleading and that respondent questions did not receive serious answers. Doctors and nurses focused more on communicating impairment rather than giving hope and motivation for training.

Negative episodes seem to stand out in respondents' memories more than positive episodes. George recalls the insult of being asked intimate questions by a doctor during staff rounds without receiving any explanation for why the questions were being posed. Ellen remembers being undressed by staff and left sitting naked on the edge of her bed, helpless to cover her self, feeling very small while the staff attended to something or someone else. Several respondents felt reduced to "X" in the institutional setting they suddenly found themselves. John says, "*One's identity is wiped away. There is no opportunity to show that one can still do anything. All focus is on the injury*". A common complaint referred to empty time and/or lack of respect for respondent's time. Evenings and weekends could be terribly boring. Nothing happened. Most of the staff was off work. The program for patients was rest. Resting is not always easy to do on command and amidst trauma. People who have been active in daily life pre-injury are suddenly cast into sterile environments with little opportunity for private initiative. Linda said, "*All the empty time almost drove me crazy*", demonstrating this for us by pretending to pull out her hair.

Confrontations between our respondents and staff appear to have been rare or not something respondents choose to tell about. The only conflict reported was a small episode involving several persons. A respondent told us about a group of stroke patients sitting in a facility's cafeteria talking about getting back their driver licenses, a subject of much concern. A nurse passing their table remarked "*People like you should not be allowed to drive.*" One of the group responded "*People like you (the nurse) should not be allowed to work in rehabilitation*".

It is noteworthy that most of the positive references to staff in primary rehabilitation referred to persons providing training and/or testing of functional capacities - physical therapists, ergo therapists, psychologists, etc. John has good memories of a psychologist who focused on what he could

do, not what he was unable to do at the moment. George praised therapists for providing information about his cognitive injuries at the right time and in the right amount. Too much information, too soon would have been wrong in his view. A factor likely to be involved in positive views of therapists is that the therapists were perceived to be involved in doing something concrete to improve respondents' functional capacities. Therapists may have become associated with positive affect of regaining lost capacities while the general nursing staff may have been associated with negative affect connected injury and dependency.

Positive references were also made to therapists who saw beyond the injuries and interested themselves in the person. Ellen has positive memories of three therapists who "*saw and understood her*". One of them surprised her by arranging a small picnic in a "*make believe forest of three trees by the main entrance*".

### 3.2.2 Co-patients for better or worse

Several respondents spoke about their interaction or lack of interaction with co-patients. Co-patients serve many functions. Co-patients can be a source of information, support and company. Linda recalls that a co-patient told her she had a choice to make. She (the respondent) could remain lame or could work to regain lost functional capacity. Doctors and physical therapists may have said the same, but it is the co-patient's words that are recalled. Ellen says that while each patient was facing different challenges, combining strengths helped to build a positive social atmosphere. A talkative patient with difficulties walking, Ellen teamed up with an ambulatory co-patient with speech difficulties for mutual inspiration and amusement. Joining forces could also help solve some of the practical daily challenges of life in a rehabilitation facility, such as opening the ready packaged individual containers of butter, jam, and other food stuffs at meals with only one functional hand. John found that he could first be "*his old self*" when his depression lifted and he could start joking with his co-patients.

Severely impaired co-patients presented frightening images particularly in the beginning. The depressing sight of severely impaired others provided some respondents with a frame of reference and a determination of distancing themselves from these others. Linda felt comfort in comparing herself to co-patients. She was comparatively "*young and promising*". Several respondents complained about the age composition of the co-patient population. Peter's

only complaint about the primary rehabilitation unit where he spent his first months post-injury was, that there were too many old people. Ellen and Linda also expressed these sentiments although they were quick to reassure us that they liked old people. It was more a question of attitude and expectations of recovery than of age per se. Co-patients who could not, or did not, demonstrate that they were trying to get better were depressing. Most respondents prefer to mix with their own age group. Finding co-patients their own age or younger helped bring forth a positive social atmosphere.

### 3.2.3 Staging visits

Receiving visitors provided a break in the empty hours and was for the most part welcomed but demanding. John recalls staging visits with the intent of presenting himself as fit as possible. He did not want to be seen in a wheelchair and would transfer to a chair in his room when visitors came. One day much to his displeasure, he got the time wrong and his guests “*caught*” him in a wheelchair near the front entrance. Linda was also intent on presenting herself as cheerful and fit as possible for visitors. Some of her friends had dreaded visiting, not knowing how they would find her and what they should say. Linda felt it was her job to ease the tension and make the visitors feel good. Being upbeat took more strength and energy than Linda had. She typically felt exhausted afterwards. Linda had to ask her husband to limit the number of visitors she received and restrict them to good days.

Receiving visits from their children brought “*life and light*” into the rehabilitation units and was greatly valued while at the same time difficult. Respondents were concerned about how the children experienced the visits. Parents felt it could be traumatizing for children to see them injured, particularly in the beginning before parents were able to get up and about some. Parents also felt the sterile institutional setting had little to offer them in creating a good experience for visiting children.

## 3.3 SECONDARY REHABILITATION

Discharge from primary medical rehabilitation facilities can be regarded as the dividing line between primary and secondary rehabilitation. Secondary rehabilitation includes subsequent stays in institutional facilities, participation in community based programs and services, contact with public agencies,

etc. Secondary rehabilitation may be a process with no defined end point. Use of community based services such as physical therapy may begin after discharge from primary rehabilitation and continue for years or for life.

### 3.3.1 Discharge to chaos

Discharge from primary rehabilitation was generally anticipated eagerly a turning point in reclaiming identity, a longed for reunion with home and family. Discharge, however, often involved complications. Some respondents needed physical adaptations made on their homes. Discharge did not take into account how far along the adaptations had come. Tom came home to a house which resembled a construction site and the work continued for months. Most respondents needed services and treatments of different kinds and some needed personal care. Attempts were made by primary facilities to secure seamless transitions between primary rehabilitation and community services but it took time for satisfactory services to be established. Coming home could be more difficult than anticipated. Rehabilitation facilities, while sterile and boring are nevertheless physically adapted for persons with limited functional capacity. Many homes are not. Taking up earlier tasks may be more difficult than imagined, if not each separately, then in combination.

Two respondents needed personal care and initially received traditional home nursing but soon became strongly dissatisfied with the service. Nurses would come at different times than scheduled or forget to come. *“They came early when they **had** to come early and came late when they **had** to come late. One out of about eight times they forgot to come or something went wrong.”* Different nurses would come all the time. The number of people coming in and out of the house was too much to handle. Dependency on home nursing was particularly difficult when integrating services into a family with children. Personal assistants are strongly preferred as a system of care delivery.

### 3.3.2 “Nice enough ladies”

Some municipalities have organized rehabilitation teams to meet with newly discharged patients. Teams typically consist of a home nurse, an ergo therapist, and a physical therapist. Three respondents in our study were met by a municipal rehabilitation team upon discharge to home from primary medical rehabilitation facilities. Tom described the team meeting him as being *“nice enough ladies”* but not very knowledgeable about paralysis or user



rights for technical aids. *“They thought meeting me was very interesting because they didn’t have any experience with my type of injury. They said they’d like to know what kinds of help I needed.”* He felt forced to become their teacher. The team worked well enough for two respondents who had had strokes as the team was better prepared for this type of injury.

### 3.3.3 Fighting the system

Several respondents fronted a major battle with officials in various public agencies in putting the pieces of their lives back together. It took about three years before daily life functioned satisfactorily for Tom. The first year he averaged seven to ten phone calls a day trying to arrange technical aids, care services, and transportation. Tom’s involvement was in part due to an informal agreement he had made with the municipal team whereby he assumed management of his own rehabilitation needs and they signed papers when necessary. Tom was confident that no professional would work as hard on his case as he would. Coordination between the involved public agencies was poor in his experience and even the smallest, most uncontroversial decision could take unreasonably long time. At one point Tom pronounced, *“My disability is threefold: the national social security office, the county dispensary of functional aids, and the municipal social services office”*. Staff turnover and agency reorganization was a problem for some respondents. Ellen says that 23 different social security officers handled her case over a three year period. There was little flexibility in interpreting rules and regulations. Case managers were afraid of doing anything wrong according to the rule book. Agencies almost *“threw”* expensive equipment like electric wheelchairs at her but would not give her the economic benefits she wanted.

Public agencies are seen by several respondents to be primarily oriented towards gate keeping functions and preventing misuse. They are seen to discourage user initiative and influence, *“keeping people in their place”*. Some respondents had the energy, resources and social support post-injury to fight the system. Other respondents did not, largely due to the nature of their injuries. Mary who suffers chronic pain and low stamina expresses resignation and some bitterness about the lack of information provided by public agencies. She says, *“Nobody tells you about the services and benefits you can apply for”*. Some respondents appear to have gone with the flow, accepting what was offered without attempting to influence decisions and the pace of delivery.

### 3.3.4 New insights and morale boost - secondary in-patient rehabilitation

Several respondents experienced in-patient programs in secondary rehabilitation as turning points in their lives post-injury. Positive views of these secondary in-patient rehabilitation programs may be colored by the fact that respondents, in general, were in better health than when they were in primary rehabilitation. They could participate and interact more. Perhaps, most importantly, it was their choice to come, implying motivation and positive expectations.

Two programs have been of particular importance for our respondents. The first program was for persons with cognitive injuries at the region's rehabilitation hospital. It was a major turning point in the lives of three respondents. Participating respondents were given information about cognitive injuries that helped them piece together fragments of their lives and better understand their behavior and emotions. Respondents came to see that the chaos that they had been experiencing first hand was normal, normal for the type of injury they had sustained. Respondents were provided with affirmation that they were "*not dumb*" and given knowledge they could use in daily life when explaining their needs and behavior to self and others. Embodied knowledge from living with their impairments prepared respondents for reception of professional knowledge. First hand experience is perhaps a prerequisite for the layman reception of information on neurological functioning. Programs took place in a group setting. The group setting provided an affirmation that respondents were not alone and some have held contact with group members over time. Participating respondents also appreciated that sessions were arranged for family members.

The second program of special importance was offered at a health sports centre. The centre has an action filled profile, promoting physical activity and a range of indoor and outdoor sports and games. The action filled environment is invigorating and demonstrates that there are many positive sport experiences to be had despite impairments. Co-patients are a select group of impaired persons who want to expand their physical activities in a social setting. There is little need here to distance self from passive others. It is considered an asset of the centre that some of the activity staff used wheelchairs. This staff knows first hand of challenges to be faced by people in wheelchairs. Karin has been at the health sport centre several times

and it has played an important role for her in developing a new social network as well as improving her functional capacities. Ellen has only been there once but felt so enthusiastic about the program and the lively co-patients of all ages that she “*dreams*” of returning. John was inspired by participation in varied physical activities on his first visit but had reservations about participating in social activities such as fireside sing-a-longs where he became highly aware of co-patient impairment. He is hesitant to return as he does not want to identify with his sick side.

Most respondents have had several in-patient stays in secondary rehabilitation. Regaining one’s driver’s license was one common reason for a week long evaluation visit to the region’s rehabilitation hospital. The hospital has a driver training and evaluation program and is the highest authority on impaired persons’ driving ability and vehicle adaptation. Regaining one’s driver license was a high priority for respondents, a milestone, and a great relief. Being able to drive a car greatly enlarges activity radius, restores freedom and flexibility of movement, and a sense of independence that was taken for granted pre-injury. Most respondents have been successful in regaining their driver licenses.

Another type of in-patient rehabilitation was due to new injuries. Two respondents have broken hip bones in falls requiring new physical rehabilitation. These injuries were related to, but different from, their initial injuries. Respondents were rehabilitation veterans during these rehabilitation stays. New injuries may represent a set back in recovery from the original injury but are also a welcome, temporary shift of focus, and a cause for reflection. Broken bones constitute a simpler rehabilitation project than respondents are otherwise engaged in.

### **3.4 LATE PHASE USER ORGANIZED REHABILITATION**

Late phase user organized rehabilitation is the term we have chosen to denote increased respondent influence, knowledge, and responsibility for own rehabilitation over time. There is no clear defining line between secondary and late phase rehabilitation, only a change in perspective. User organized rehabilitation is most evident in the years after basic services and benefits are in place. Some respondents were active in managing rehabilitation services from an early stage post-injury.

### 3.4.1 Therapy shopping

Most respondents take increased control over their rehabilitation efforts over time. One expression of this is that most respondents go shopping for services and therapists of traditional and alternative kinds. Therapy shopping is often a trail and error process – a search for good chemistry between therapist and respondent and a search for treatment that helps in some way. Respondents in late phase user organized rehabilitation take responsibility for organizing a diverse set of training functions. Organization requires a major effort and knowledge of what works, what they like, how much they can do before needing to rest, and when they want a change. Their programs need to be finely tuned to the moment. Carefully constructed therapy regimes can fall apart with personnel changes. Respondents must then tell their stories to new therapists and instruct new assistants. Several respondents feel in retrospect that they have had treatments or therapies which made problems worse, for example, physical training when the respondent should have been resting with pain medication.

Several respondents said they want therapists (and others) to observe and comment on small improvements. There needs to be continuity in attendance and treatment for therapists to be able to do this. It is also a question of attitude. The therapist must be attuned to respondent need for affirmation of improvements, however small. Improvements provide motivation for the hard work of training and give hope of further improvement.

Most respondents have tried many different treatments and programs and are on the lookout for new opportunities and research breakthroughs. Tom and Ellen use the internet actively in their search for information. Newsletters and websites of disability organizations are used by several respondents for information and networking. Word of mouth or the jungle telegraph is perhaps the most important source of information and inspiration. Lay referrals are important in finding “*good therapies*” and “*good therapists*”.

Most respondents use publicly funded services and therapies, but are not limited to these. Having a sound economy allows middle class respondents the freedom to look around for alternative treatments which are not publicly funded. The cost of alternative therapies plus taxi transportation

can be high. One respondent used 50 000 to 100 000 Norwegian kroner yearly on alternative therapies.

Therapy shopping can be difficult. Respondents report that it is hard to find group activities that fit just right. Respondents had tried group training in warm water pools, speech therapy groups, self help discussion groups, etc. Other participants are often seen as being too impaired, having different attitudes or aims, or not being of the right age and gender. Respondents appear to use a highly individualized measurement scale in evaluating group composition, looking unsuccessfully for persons who resemble or complement themselves. Even respondents who participate in group activities do not necessarily feel that they fit in with the others. Perhaps the responsibility and inward focus of the late phase user organized rehabilitation promotes an individualized view of impairment.

Respondents who do not have many therapy options are careful not to be seen to be critical. *“When you don’t have many choices of places then you are scared to be critical in case you lose what you have.”* Therapists expect patients to work with them and follow their guidance. Patients who are not trying to get better are difficult to treat and are not offered follow up according to one respondent. She tries her best to be a cooperative patient.

Respondents take control of rehabilitation by taking pauses when they get fed up with one activity or therapist. They move on to something or someone else or take a break for a while, *“a little vacation”*. When rehabilitation is a life long process, shifting therapists, training activities, and taking pauses in training may be means of upholding the promise of improvement.

Therapy shopping and orchestrating long term rehabilitation efforts is not a goal for all respondents. Peter appreciates being in programs where professional staff take responsibility for content and social interaction. He is not out on his own shopping for new therapies and therapists. Mary feels the responsibility heavy to bear and would appreciate more support. Still, most respondents find it natural to exert increased influence in organizing and integrating long term rehabilitation efforts into their daily lives. They seek information and accumulated knowledge, becoming the experts on their impairments and on rehabilitation opportunities.

### 3.4.2 Training opportunities everywhere

Training opportunities are everywhere for those who look for them. More precisely, opportunities are everywhere for those who see the potential and define everyday activities as training. Anna, for instance, always takes the stairs instead of the elevator, even when going up many flights of stairs. It represents a challenge and a test of character. There is no question of taking the easy way out and the exercise is good for everyone according to this respondent. “*Seven flights of stairs, no problem.*”

Several respondents concentrate on training energy conservation. George makes a game of planning activities in order to avoid unnecessary movement, for example, trying not to open the refrigerator more than once when getting food stuffs for making dinner. Rationing energy is all important for respondents with severely limited stamina. In multi-story homes, respondents with limited energy work at limiting the number of times they need to go up and down stairs. Almost all respondents have an ongoing need to space their activities, ration their strength, and plan ahead. Training in spacing activities, rationing energy, and detailed planning are unavoidable features of post-injury life. When respondents overstep their limits, they pay a stiff price but they also want to be as active as possible. We will return to self care in Chapter 5.

Many respondents organize their training in a manner which reinforces regularity. Tom begins every morning with an hour physical exercise assisted and re-enforced by the morning arrival of his personal assistant. John does exercises every morning and evening. He says “*discipline is the key*” to rehabilitation after discharge from in-patient facilities. Most respondents have a fixed weekly schedule of training activities. Reflection over the training potential in everyday activities also reinforces regularity.

Many respondents eventually return to activities they had participated in pre-injury as their preferred source of training. For those who can walk, walking is a major training activity, preferably outdoors in uneven terrain to train balance. Fresh air and outdoor activities are effective mental health treatments and linkages between pre- and post-injury identities for most respondents. Family members and friends often play an important supportive role in adapting pre-injury activities to post-injury capacities.

### 3.5 IDEAL REHABILITATION

Respondents were asked what an ideal rehabilitation facility or program would be from their present standpoint. Respondents needed prompting before opening to thoughts about what an ideal rehabilitation program would look like for them.

Several respondents express an interest in returning to secondary rehabilitation facilities they had been in before. The health sports centre mentioned earlier plus another active training centre in the region are regarded as good places to be and respondents would willingly return. Respondents want their capabilities to be seen and acknowledged as well as recognition of their loss and their efforts dealing with impairments. Linda says, “*An ideal rehabilitation program would see me as a whole person, not just see the part which is broken*”. A discussion partner is high on Mary’s want list. She is tired of physical training but would greatly appreciate someone with time to talk with her. George misses long term, systematic follow up by rehabilitation professionals. Injured persons should be able to take contact with rehabilitation professionals when they feel a need. Professionals should also call in discharged patients every couple of years for consultations.

Ellen wants lively activity and social interaction in her ideal rehabilitation – adventure, excitement, and laughter. Peter wants traditional physical training in a well defined and comfortable context. John wants physical challenges without having to mix with too many visibly impaired people. Mary wants rest from the overwhelming responsibility of managing daily life and own rehabilitation. The variation in responses underscores the need to tailor fit rehabilitation programs to users. It suggests that variation in needs increases over time as respondents establish ownership over rehabilitation processes. In late phase rehabilitation there is clearly a need for a diverse set of programs and/or careful screening and composition of patient groups. It is not likely to be successful if an action oriented person is placed together with a person seeking rest.

We asked respondents general questions about what they learned in and through rehabilitation experiences. Ellen eventually learned to reorient her goals. In the beginning she had been focused on getting back to her pre-injury state. She has learned that there is no going back but that she has become/is becoming something else which can be just as good. Linda says

she has learned endurance and the importance of not giving up. John learned where his cognitive weaknesses are and thus is better able to organize compensation for reduced capacity. Karin learned to use professionals for counseling and problem solving and to “*let friends be friends*”. We will return to respondent rehabilitation approaches in Chapter 5.

### 3.6 DISCUSSION

The Department of Health and Social Affairs has defined rehabilitation as time limited, planned processes with clear goals and implementary tools where multiple actors cooperate in giving needed assistance to users’ own efforts in order to achieve best possible functional capacity, independence and social participation (St.meld. nr. 21, 1998–1999). This definition may suit formal services, but does not cover the lived experience of persons who have acquired long term reductions in functional capacity. We have discussed rehabilitation from the perspective of respondents, with an emphasis on respondents’ (users) own efforts years post-injury. Respondents have said that as long as there is hope, efforts aimed at improving functional capacity may be called rehabilitation. The principle conclusion from this chapter is that rehabilitation is a life long, post-injury project for our respondents, not a time limited, planned process with clear goals and means of achieving these goals. From the respondents’ perspective goals were formed along the way and tools were fashioned in a trial and error process. Much effort is required of impaired persons after the “formal” rehabilitation programs are over.

The general goal for respondents was to regain as much as possible of the functional capacity lost in injury, to “*reach their post-injury potential*” and promote overall life quality. The goal of rehabilitation services and therapies should therefore explicitly include user empowerment preparing patients this life long project. User empowerment may involve training in use of internet for information gathering and networking. Management skills in dealing with public agencies and a better overview of user rights and available services, technologies, and benefits are needed if users are to take control of their rehabilitation projects. User empowerment also includes follow up and training in relation to the themes discussed in the coming chapters of this report - going back to work (Chapter 4), effects on family and social relations and coping techniques in managing impairments in daily life (Chapter 5),



impairment narration and meeting audience disinterest or disbelief (Chapter 6), and self images of disability (Chapter 7). Respondent accounts challenge the concept of time limited, clearly planned and coordinated rehabilitation.

There are limits to how much and what kind of information can be packed into primary medical rehabilitation. Users need time to gain first hand experience living with impairments. But there could be more systematic follow up and counseling of patients after discharge from primary rehabilitation and more support of user initiative and recognition of user responsibility for ongoing efforts integrating rehabilitation into daily life. There is a fine balance between drawing a picture of endless applications and system conflict, on the one hand, and giving the impression, on the other hand, that impaired persons will be taken care of and have no need for personal initiative, skill, or knowledge. Ways and means of supporting user initiative and responsibility in rehabilitation clearly warrants further research.

Most of the stories told from primary medical rehabilitation referred to the social side of life in institutional settings - interaction or lack of interaction with co-patients, the importance of visitors, concern for guests and frustrations of "*empty time*". Taken together these stories suggest that more support of the informal social relations would be beneficiary. Patients need meeting places, room for initiative, and opportunities for informal activities both for themselves and for visitors.

The lack of confrontation stories in primary medical rehabilitation involving our respondents may be indicative of high professional quality in the rehabilitation facilities. It may, however, also reflect the traumatized, dependent state respondents were in at the time. It may also be partly the result of the social skills of educated middle class respondents in reading situations, adjusting themselves as well as possible to institutional routines, and to being agreeable patients. In the retelling of experiences years later, respondents may desire a self presentation which de-emphasizes tension. As earlier mentioned, respondents had a general tendency to focus on positive experiences and round off critical statements with some positive thought, like closing a door on unpleasant memories.

Conflict and frustration play a significantly larger role in secondary rehabilitation experiences, in particular with regard to contact with public agencies and use of traditional home nursing. It is noteworthy that the

respondents who quantified their complaints made stronger arguments than those who did not talk in numbers. Saying that one has waited X weeks, called Y times, or had Z case officers is more powerful than saying one has waited a long time, called often, and told one's story to many case officers. Some of our respondents are aware of the advantages of speaking in quantitative terms. Respondent expressed need for better coordination between services assisting them in secondary rehabilitation and more forthcoming information on available services and benefits. In late phase rehabilitation the responsibility of coordinating efforts and finding suitable tools was on respondents' shoulders.

It is difficult to assess what role class and education play in respondent rehabilitation. Injuries depleted the stamina and reduced social and educational skills associated with middle class positions for some respondents. The most active respondents have still had many social, cultural, and material resources at their disposal post-injury. They possessed system knowledge and management skills pre- and post-injury. Middle class respondents have the economic resources to purchase alternative therapies should they chose. They can supplement or replace the publically funded system of services. However, high expectations of service efficiency and high levels of user initiative can bring forth frustrating confrontations with public agencies. High social status appears to offer little protection against conflicts in secondary and late phase rehabilitation.

# 4 Back to work

## 4.1 INTRODUCTION

Conventional wisdom and public policy support the idea that returning to work is not only a goal in rehabilitation and good social economics, but also healthy medicine for persons who have acquired impairments. Going back to work signifies in some sense going back to “normal”. It puts the impaired person back into mainstream society. All respondents in this study were engaged in income producing work at the time of injury. They all had white collar occupations although there was variation in work place characteristics, job requirements, and work histories. The critical point here is that all respondents had, in principle, a work place to return to. The respondents in this study have long experience living with impairments. This allows us the opportunity to follow their post-injury work histories over time. We will divide the discussion of respondent experiences into three basic phases or themes: 1) returning to work, 2) working life when impaired, and 3) exits from the work force. The discussion will raise questions as to the significance work has had for respondents.

Few direct questions were posed in the interviews regarding work and working life. Respondents were queried about pre-injury occupation and current working status as background information. Respondents were asked whether they had experienced changes in their job situation as a consequence of their impairments. Most of the information collected about work and working life came spontaneously from respondents in response to our invitation to tell us what has happened. Respondents with long experience living with impairments have long stories to tell and may have difficulties recalling the timing of early events. We have not pressed respondents for details of timing as this would interrupt the flow of their stories and distress those with recall problems. Our data on timing and duration is thus sketchy and will be used accordingly.

## 4.2 RETURNING TO WORK

### 4.2.1 Early returns

All but one of our respondents returned to work post-injury in some fashion and for some time. The discussion of returning to work will begin with concept of early return. Early return can be considered in objective terms as time lapsed since injury, but what is early and what is not, is strongly influenced by the nature and severity of the injury. Early return here is mainly in subjective terms related to respondents' self presentation, determination to return to work as soon as possible, and perceived progress of recovery and rehabilitation processes.

Work was central to the identity of most respondents. There was no question in their minds that they would go back to work as soon as possible and as much as possible. Respondents typically framed their stories as early returns. The question of timing appears to have major significance in self presentation. It seems to be a sign of moral character. It also seems to be a means of containing and controlling injury, making it smaller, and less serious. Respondents appear to have believed, at least initially, that the faster one returned to work, the better for their health.

Several respondents continued working or nurtured work orientation throughout a lengthy period of primary medical rehabilitation. Tom followed up work commitments while in rehabilitation facilities traveling by bus, ferry, and taxi from the rehabilitation hospital to business meetings in the city, wanting to prove to himself that he could still manage the professional aspects of his job and the practical aspects of travel. Ellen continued working as she regarded performing her work as necessary for her "*mental rehabilitation*". George felt forced to return to work early as his employer was preparing to fire him. He had to go back to work early - to fight for his job and his self esteem as an "*irreplaceable*" member of the team.

Anna and Mary did not stop working initially. They did not take their neck injuries very seriously in the beginning and it seemed only natural to continue working, taking only minimal sick leave. Doctors encouraged them to keep active (within reason). Mary also felt an obligation to keep working as she had sole responsibility for her work tasks. "*Keeping going in my job was in my thoughts all the time*".

Graded rehabilitation benefits and/or disability pensions reduce the economic consequences of not working or working reduced hours. Previous work histories secured most of our respondent's high levels of disability benefits. Most had also working spouses. The economic incentives for returning to work were thus not critical for this sample as they might be for a sample of younger, single persons. Returning to work was more about identity and normalizing daily life than about income.

Several respondents returned to work long before the full implication of their impairments had become manifest to themselves and others. Karin returned to work early in relation to her cognitive injuries and her understanding of them. Her vocational rehabilitation officers may have seen re-entry as a test to see what she could do. An experience that Karin shared with several other respondents was that it took two – three years before she began to understand her impairments. Starting back to work was an important learning experience. It prepared the ground for further rounds of rehabilitation.

#### 4.2.2 No pushing

Some of the respondents experienced that social security and vocational rehabilitation officers were more of a hinder than a help because they were in a hurry to return to their work. One respondent was self employed and did not seem to fit into the prescribed role of an impaired person seeking re-entry into the labor market. She could get sorts of help that she did not need, such as help to write job applications, but she had difficulty getting support she needed to keep her firm alive while her work capacity was limited. After rounds with complaints, sick leave and rehabilitation benefit rules were re-interpreted, allowing her to earn income to cover office expenses without sacrificing benefits. A respondent needing an adapted car for transportation to and from work struggled for more than a year in getting necessary support, suffering much red tape and humiliations along the way. These respondents felt that social security and vocational rehabilitation officials only wanted them to go back to work “*sort of*”, meaning not really or not too much or too fast. *“You are not supposed to come to them and think you are someone. The so-called help system wanted to keep me in my place. They didn’t understand why in the world I wanted to go back to work when it is so difficult to deal with the*

*practicalities...*” “*They had never heard of a seriously impaired person running her own business.*”

Vocational rehabilitation officials did, however, play an important role in getting some respondents with cognitive injuries back to work. Tina, in particular, received encouragement that was needed and much appreciated. She needed time, understanding, and a boost of confidence in returning. Her case officers provided it. Vocational rehabilitation officials supported also two other respondents in making “trial returns” to their previous work places.

#### **4.2.3 Initial job adaptations**

Employers were generally portrayed as trying to ease the return to work and helping to make initial job adaptations. Respondents gave little indication that employers represented an obstacle for them. Most of the respondents were well established in their work places prior to acquiring impairments. Two respondents were engaged in family businesses, a factor which may account for added flexibility on the part of employers.

Returning to work at one’s previous place of employment did not mean returning to exactly the same job and working conditions. Most respondents reported changes in work hours and job responsibilities. Reduction in work hours was most common. Most respondents reduced work hours initially from full time to half time or less. Several respondents changed their work tasks and/or work location as a direct consequence of their injuries, some with sadness, some with a sense of relief. Tom was forced to drop some of his earlier functions and working methods to accommodate his impairments, and find new ways to put his experience to use. John switched to a position in his firm with less travelling, less responsibility, and less stress and was glad for the change. Mary moved her work home so that she could work when she felt up to it, dividing the day into small work episodes and long rests. Karin moved to a quiet office where she could be more protected from noise.

### **4.3 WORKING POST-INJURY**

The stories of working life related in the interviews are being told through the perspective of the present. An implication of this for our data is that persons who remain in the work force are less likely to discuss difficulties in

working life than persons who have stopped working. Complaints about working life are narrative elements leading up to, and legitimizing, exit from the work force. Appreciating the context of these accounts does not undermine their validity. We might equally well postulate that respondents who continue working will tend to suppress stories of work related distress. Most respondents reported a mixture of struggle and achievement. Working with impairments is different and often more difficult than working without impairments, despite job modifications.

#### 4.3.1 Work more important

Important pre-injury, work became even more important post-injury for some respondents. The loss of opportunities to engage in active leisure activities as they had pre-injury left more time for work and gave work added meaning as a source of variation in daily life and a source of affirmation for some. Work represented a major source of continuity. Work became more important for some because it required so much more concentration and effort of them post-injury when laboring with reduced functional capacity.

Toms works full time and more now, using evenings as well as day time. John thought at one point about changing jobs and lowering ambitions. However, within a few years time he regained his identification with his pre-injury work. Work is the arena where he can most easily see his recovery process and his achievements. Work achievements contribute to the social invisibility of impairments. George is proud that colleagues of many years standing are ignorant of his injuries. It demonstrates that his work performance is well up to par and that others do not think of him as being impaired. Tina says, *“My job was almost my very life”*. About five years post-injury Tina began a period where she *“played healthy”*, repressing impairment for self and co-workers. She did not want to disappoint anyone. She wanted everyone to be satisfied with her work. Tina says, *“It’s so wonderful to receive compliments and recognition.”*

#### 4.3.2 Tied to pre-injury employer

Two respondents tried without success to find new jobs with new employers. It was a difficult and distressful experience for both as their impairments were highlighted in the job application process. One respondent came out of the process with an understanding that no employer would

hire someone with her impairments. Her only choice was to hold on to the job she had. Another respondent became adept in sounding out prospective employers for their openness towards employees with impairments. She could tell within minutes whether employers were interested in learning about her qualifications or if they were interested in discouraging her from applying. Discouragement was subtle, for example, an emphasis on the amount of travel associated with a job. Job offers were not forthcoming.

A third respondent was, however, successful in switching employers post-injury, much to his personal satisfaction as the new employer was informed of his impairments and did not regard them as impediments.

#### **4.3.3 Positive uses of impairment experiences**

Several respondents felt impairment experiences had given them insights and skills which could be used or useful in their work. Respondents gave examples of increased empathy with co-worker problems, becoming better listeners, helping non-disabled others lower stress levels, and attempts to help other impaired persons. Being open about the cause and practical consequences of visible impairments when leading a meeting, one respondent felt she helped the non-disabled audience to relax a bit, “*lower their shoulders*”, and concentrate better on the day’s program. Being cognitively impaired gave one respondent feeling of special insight into the world of dement elders. She felt she understood the chaos dement elders were experiencing because she experienced and could reflect upon her own chaos. She felt at ease with dement elders and able to successfully reach out to them.

Several respondents felt that their experiences with impairment could and should be used to help others. Some had jobs where they could address these issues directly, for instance, by holding lectures for health and service professionals and policy makers. Some used their free time participating in traffic safety courses and other teaching programs.

#### **4.3.4 Co-worker skepticism**

Two respondents with invisible impairments told about negative reception by co-workers. Karin, who was finding her old job beyond her post-injury cognitive capabilities, felt harassed at work. She was trying her best but was being criticized by co-workers who had little understanding or empathy with her situation. They pressed her to carry her weight in a hectic work environ-



ment. Some implied that she was getting off easy by having reduced hours and complained that she was leaving more work for them. She felt that some thought she was malingering. Tina also received co-worker comments she interpreted as derogative and spiteful. Tina says that any time something went wrong at work, such as mislaid messages or forgotten meeting schedules, it was commonly assumed to be her fault. Some colleagues believed she was faking injury. She did not have the capacity to fight against the many verbalized and silent accusations. She registered the accusations and was wounded by them.

#### 4.3.5 An ongoing battle

Metaphors of ongoing battle, of fighting, of victories, and defeats were common in respondent stories. These are metaphors often chosen in presentation of self to convey perseverance, adherence to core social values, and to heighten self esteem when experiencing discontinuity. For the most part the implied enemy in the metaphor was the self struggling to understand and integrate impairment effects in daily life, particularly chronic pain and limited stamina. Anna felt that working was an ongoing “*battle*” with herself between “*No, now I must do some work*” and “*No, now I can’t*.”

Impairments were perceived as the core problem in the ongoing battle of working life alongside pre-injury personality and career ambitions. An outer enemy in the battle was rarely identified but some respondents experienced co-worker criticism as mentioned above. Ellen’s work requires active self promotion in securing job contracts. She acknowledges that impairment effects have taken a toll on her self esteem. It is more difficult for her to “*sell herself*” now.

Initial job adaptations were often not sufficient to compensate for impairments in the long run. Some respondents experienced a series of job adaptations and recall them as a string of failures. Work loads are not easily reduced proportionally to reduced hours. Respondent expectations and ambitions regarding work performance are not easily changed from pre-injury levels. Work loads tend to spill over in white collar occupations, particularly if one has worked full time earlier and if full time work and flexibility are the norm. Several respondents reported difficulty in keeping work loads at manageable levels. George was one who had difficulty saying no when asked to take on a responsibility. He did not attribute this to his

impairment. He had always been like that. Being impaired, however, made him more vulnerable to the consequences of ongoing negotiations with self and others over work loads.

Some respondents were resourceful in forming alliances with co-workers and others to compensate for reduced functional capacities and successfully fill work requirements. John made sure that his co-workers double checked his work involving numbers and calculations as he felt this was his weak point. Battles may be won through allies.

#### 4.4 EXIT FROM WORK FORCE

One respondent exited the work force immediately after sick leave. Linda did not return to work post-injury. She was approaching 60 years of age and felt that early retirement on a disability pension was acceptable. Linda had been in middle management. The firm was in a process of re-organization. With her knowledge of the office and the firm she could not conceive of a suitable position for herself given her health problems. Her impairments precluded working in the short run and in the long run she would be an ordinary early retirement pensioner.

Three male respondents are working full time or close to full time and plan to continue working until normal retirement. A self employed woman flexibly combines work income and disability pension. These respondents have primarily physical impairments which do not represent insurmountable obstacles in their work. Five respondents (one man and four women) returned to work for a shorter or longer period but are currently out of the work force receiving disability pensions. Cognitive impairments, speech loss, low stamina, and chronic pain proved particularly difficult to combine with employment. This section refers to the experiences of respondents who worked post-injury but who are now disability pensioners.

Disability pensions come two main forms, a temporary, time specific pension (2–5 years) and a permanent pension. Pensions are also graded to encourage combination with work. Temporary disability pensions are a formal expression of hope that difficulties working will diminish. Despite this, one respondent was offended when a rehabilitation officer congratulated her on receiving a temporary disability pension.

When the gap between pre- and post-injury job capabilities is too great, going back to work loses connotations of normality and continuity. Peter was first offered a position with substantially lower pay and responsibility than he had had pre-injury. He had been an office manager. The new position was adapted to his post-injury capabilities but combined with his injuries it represented to him an unacceptable fall in work status. He tried it for a while but soon opted out for a temporary disability pension which paid more than the new position. He hopes for a better job opportunity in the future as his functional capacities slowly improve. A temporary disability pension represents more continuity in income and status for Peter than the rejected job situation. An activity center helps provide him with structure and social interaction.

Laboring with chronic pain Mary suffered a mental breakdown after about three years of working post-injury. She became a permanent disability pensioner. Mary is convinced that early return to work has had long term negative consequences for her health and her life. Had she not worked so hard in the beginning she feels that she would be capable of half time employment today. Mary says, *“Losing contact with work is losing contact with social life.”*

Anna is less adamant about the negative effects of returning to work early, but wonders if recovery from her injuries would have been faster and more complete had she taken it easier in the beginning. She accepts after some inner struggle that she cannot work at the moment but is convinced that this is only temporary. Anna views her temporary disability pension as extended sick leave benefits.

Few have tried harder to gain a post-injury foothold in the work force than Karin. Life became only work and sleep for Karin when she first returned to her job. She was too fatigued after work to partake in any social activities or normal activities of daily living. A three day weekend was not enough to rest up. A series of job adaptations and vocational training to a new occupation were tried without success. She is currently a temporary disability pensioner finding volunteer work to be a satisfactory alternative to the fixed schedule and responsibility of paid work.

Tina gained more than a foothold in work. She worked for more than ten years post-injury but she performed her work with intermittent sick

leaves at serious cost to her personal and social life and to her psychological health. “*Playing healthy*” was not a sustainable situation. Tina eventually suffered a mental breakdown, forcing her to apply for a permanent disability pension. Exiting the work force after years of working experience post-injury was viewed a major turning point. It was viewed at first as a sign of failure and personal defeat, a blow to self esteem. The initial psychological response of defeat was not long lasting. When Tina was granted a permanent disability pension, she was psychologically prepared and had plans for informing others. While it had been a difficult decision for her to exit the work force, she was relieved and cheered by openness of her future prospects. Several respondents reported quickly changing their attitudes towards disability pensions in a more positive direction.

## 4.5 DISCUSSION

Return to work may be thought of in many different ways. It may be thought of in terms of pace or speed of returning to work post-injury, how quickly a person gets back in the saddle. It may be thought of in terms of work histories - the number of years one remains in the work force post-injury and/or the number of hours worked. Return may also be considered in relation to job relevancy and/or the goodness of fit to the individual, life quality, self esteem, and identity.

Early returns have advantages and disadvantages. Returning quickly, the worker will not have been forgotten by colleagues. The return is likely to be surrounded by the good will accorded to persons demonstrating success in overcoming illness or accident. Expectations of the respondents, employers and co-workers are likely to be that working life will gradually go back to normal and that pre-injury performance standards still apply. Disadvantages of early return may be that the worker has not had sufficient time to recover and recoup their resources to adequately perform their job. High expectations may not be easy to fulfill. Physical and psychological health may suffer as a consequence. The difference in the person’s work capabilities pre- and post-injury may be glaringly apparent to all. Co-workers may have problems welcoming back an earlier colleague whose capabilities are clearly reduced. Continuity may be stressed at the cost of rethinking options and investigating new opportunities.

The advantages of trying to return early and thus staying in the loop of work relationships may outweigh potential dangers. It is only in work environments that worker capabilities are put to ongoing test. In a French study Ville (2005) argues that persons with acquired impairments are often forced to return to work by the social security system before they have had opportunity to complete necessary biographical work linking pre- and post-impairment identities. We have found little indications that respondents have been forced back to work, except perhaps by their own strong work identities. Based on our study, it may be argued that biographical work is itself an ongoing process which is fuelled by meetings with the social. Going back to work post-injury is part of the process of learning about impairment effects. It took years for many respondents to gain understanding of impairments effects and how to best manage in daily life. Most were working while they were learning.

Continuing labor market participation is more significant than early return. Working until normal retirement age may be a goal. Some succeed. It is more questionable to use work hours as a measure of success, with full time work the goal. It is important to consider the price of employment for the individual and his or her overall life situation. Two respondents in this study worked themselves into mental breakdowns despite reductions in work hours. The personal costs of employment success may be so high that the term is questionable.

All male respondents spoke of being strongly oriented towards their work pre-injury. The strong work identities helped three of the four men in our study to return early to work with job adjustments if necessary and to reclaim their work identities. Strong work identity “pushed”, however, the fourth man out of the labor market at least temporarily as reduced functional capacity hindered him from returning to his old job. Several of the female respondents also had strong work identities pre- and post-injury but there was more variation in work identities among the women than among the men. Some women worked in family enterprises, interweaving work and family identities. Female respondents, in general, expressed less satisfaction than the males regarding job adaptations and relationships with co-workers. Female respondents voiced concern over the price work exacted on their

personal health and energy and the price it exacted on family relationships. Male respondents did not voice the same concerns.

This study has shown that most respondents did return to work post-injury. However, most respondents exited the work force after shorter or longer periods of struggle. It is important to emphasize that respondents are telling ongoing stories. Many of those not currently working hope to return to work force. Temporary disability pensions appear to be successful in allowing recipients to retain hope of further recovery from injury and hope of returning to work. Our findings point to the difficulties of participating in the labor force with impairments and the difficulties of adapting jobs to suit individual impairments, particularly cognitive impairments and speech loss. The struggle to remain in the work force is central to continuity in respondent identity and to concepts of normality as also shown in other recent Norwegian studies of working with impairments (Elstad, Grue & Eriksen 2005, Myrvang 2006).

Exiting the work force after long struggle is a relief for some as also shown in the above studies. An important question is whether there exist alternatives for social participation for middle aged persons who do not feel able to work, for example, opportunities within the voluntary sector, activity centers, etc. to help structure the week and boost morale.

Respondents often found it difficult to meet work expectations. The flexibility that the white collar occupations offered was both an advantage and a disadvantage. Job responsibilities in these occupations are often the result of formal and informal negotiation. An important question is what could have been done to lower the price of working for impaired persons. What could have enabled respondents to continue work without sacrificing personal and social wellbeing? Perhaps some returned to work too early. Perhaps a more ongoing involvement of employers in adapting working conditions and performance expectations, monitoring and influencing co-worker response, and sustaining an open dialog with impaired workers would have enabled more respondents to continue in the work force. Impaired workers share responsibility for adaptation of work conditions. Respondents here as in Elstad, Grue & Eriksen (2005) and Myrvang (2006) tended to keep health problems private in efforts to function as well as possible in work life. Ongoing negotiations require openness on both sides.

# 5 Managing impairments in daily life

This chapter addresses impairment effects in daily life. What consequences have impairments had on social interaction? What coping techniques and philosophies have respondents developed over the years post-injury?

## 5.1 SOCIAL INTERACTION

### 5.1.1 Family – Support and tension

All respondents were married or cohabitating at the time of injury. All but one have children. Most had at least one child living at home when injuries occurred. All respondents have close relatives living in the vicinity. In the years post-injury many have become grandparents. The point to be made here is that adult family relationships were well established pre-injury and continued life course development post-injury.

#### *Increased focus on family*

A common response post-injury was to spend more time with close family members and to give higher priority to family relationships. Family becomes more important on many levels. On the practical level, spouses and older children often assume substantially greater responsibilities for family work and household chores post-injury. Husbands, wives and to a lesser degree children had to take on new roles and responsibilities when respondents became impaired, adjusting their lives to accommodate injury in the family. On an emotional level, most respondents express gratitude to family members for making it through the trials of adjusting to impairment. Closeness is not taken for granted. Experiencing the vulnerability of the body, some respondents reflect on the vulnerability of relationships. Respondents are particularly grateful for how their children have taken the upheaval of family life post-injury. Children's wellbeing and continued closeness is of prime concern. Several respondents thought that coping with injuries was harder on their spouses than on themselves. They, the respondents, are in the center of attention, recipients of help, bearers of injury. Able bodied spouses have their family life radically changed. *“It's almost more difficult for*

*them (family members) to adjust to my new life because their bodies are as they were before. It is more difficult for them than for me really as I am right up in it.”*

Most respondents feel their family relationships are rewarding and robust. Anna, for instance, feels her family is very close and that “*as long as relationships to my closest family are good, my life is okay*”. Her health concerns are of lesser importance. Several male respondents are quick to assure us that their family relationships are rock solid and give us no reason to doubt them. George feels that he is closer his wife and children because of his impairment experiences. He says he has learned a lot about loss and now is trying to use his experiences in ways which help family members when they encounter difficulties as most people do sooner or later. Several male respondents also feel that they have a better balance in life post-injury between work and family and between male oriented and family oriented leisure activities.

Family and home are closely associated. Respondents tended to increase time spent in the private sphere of the home. For our respondents, the home is the site of maximum control over their environment and maximum flexibility to accommodate impairments. The physical environment is adapted to their needs. If they need to rest, they can rest. They can start and stop activities as their bodies dictate without further explanation.

### *Inspiration*

Family can represent a source of inspiration in rehabilitation. Respondents worked to regain lost functional capabilities and manage impairment effects as well as possible for themselves, but also for their children, spouses, parents, etc. Ellen feels family responsibility strongly and regards it as an important resource in her rehabilitation. Co-patients in primary rehabilitation commented, “*Poor you that have small children to care for*”. She felt, “*Poor you who don’t*”. Thoughts of her children keep her trying her utmost. She wants to demonstrate to her children that it is possible to be sick and live a life which is good to live. It is in her view a major contribution to the children’s upbringing and future welfare. Mary takes comfort from what her injuries have taught her now grown son. He has learned that “*life does not always go as planned. But it’s important that he doesn’t see it daily*”. Mary makes a major effort to be at her best functional level when her son comes home for visits.



### *Caregiving*

Some respondents receive care with personal hygiene, dressing, etc. from family members. The respondents feel that these care arrangements are reliable and practical. “*We are a functional unit and can travel when we will.*” “*We have a lot of fun together.*” Family caregivers receive some economic compensation from the municipalities or social security system. Respondents are concerned family caregivers have enough respite and that family caregivers feel free to take time off from care responsibilities. Respondents told of adjustments they are willing to make such as sleeping with leg braces on or how they can call in public services to provide personal care for a specific time so that family caregivers can go away for a holiday.

Dependence on services from outside the household is always a difficult matter but it is particularly difficult in households with children. Parent’s impairments lead to a stream of strangers in the house, strangers who assist parents but who also can have responsibility for assisting children. Impaired parents evaluate services from the perspective of the whole household and, particularly, from the perspective of the children. Parents can “*swallow camels*” (in accepting help from strangers) but children can’t. Parents draw the line when helpers overstep their roles and take on children’s upbringing. Parents are still “*the parents*”.

### *Work support*

Several respondents told of family support and encouragement in their work. Tom’s wife helps him get off to the office on time and is as flexible as his business schedule demands. Public home nursing services could not deliver the same effective punctuality or flexibility. When John first returned to work his wife asked him every day about his lunch break. A small detail, but for John, entering the firm’s large lunch room in the beginning, was frightening unless he had arrangements to eat with someone. His wife pushed him gently so that he did not retreat into the social isolation of his office. Tina says her husband has been very supportive of her emotional ups and downs related to work stress, canceling work trips when he knew she was feeling down, being there for her when she needed him. It is not likely that respondents would have the capacity to work as much as they have without family support.

### *Frustrating limits*

Extended family relationships are important for most respondents. Several respondents have elderly parents. Impairments limit respondents in filling extended family roles as they wished. Respondents have more time on their hands than usual for their age group but also less stamina, strength and agility. It is difficult to visit and assist aging parents as often as they would like. Mary says, “*It is bad enough to not be able to visit mother in the nursing home. In addition I have to defend myself (in relation to siblings and the health services) because I can’t manage.*” Several respondents feel restricted in their ability to be active grandparents. George is unhappy that he cannot get down on his knees to play with his grandchildren. Anna has to limit baby sitting and make sure that her grandchildren do not suddenly hug her or hang on her neck.

### *Tension*

Impairments are often a source of tension in family relationships. Respondents told of many ways that impairments required consideration and influenced family life. Mary, for example, is hyper-sensitive to sound. Repeatedly asking family members to be quiet, turn down their music, etc. is difficult and ineffective. They forget and have problems understanding her problems. Peter has difficulties with speech. His teenage children do not wait long enough for him to find the words he is searching for. They finish his sentences for him and are off. Several respondents say that they have become more irritable post-injury and have difficulty controlling emotions. Linda has a bad conscience about being irritable towards her husband, being a “*witch*” at times. She feels that she does not count as much as before in the family and that she is not consulted in decision making. Before her injury she was the primary organizer of family life. Karin sometimes feels that family members worry too much about her. She struggles to demonstrate her independence.

Two respondents have relationships which have been badly damaged by pressures of living with impairment effects. One man is pessimistic as to the future prospects of his marriage. Five years post-injury he feels that impairments have reduced the marriage relationship to mere practicalities of living under the same roof. One woman broke off a relationship with her partner a few years post-injury. She felt he was better off without her and that he needed to get on with his life.

### 5.1.2 Friends – Less contact, less initiative, less in common

Most respondents report having many friends and at least some close ones they can confide in. Impairments have, however, influenced social interaction patterns in many ways.

#### *Social contact – frequency and form*

Contact frequency with friends is often reduced post-injury. Most respondents do not have the capacity, time, or interest in maintaining pre-injury contact frequency with all their friends. Ellen told friends at one point that she wanted to spend her time with her family. Friends could either accept that or not. While rarely stated directly, respondents indicated that their impairments also affected the forms and frequency of social contact their spouses participated in. Social interaction is likely to be reduced also for the spouse since much socializing was family or couple based. Mary makes a major effort at giving and attending large parties a few times a year for her husband's benefit as he misses their pre-injury social life.

Several respondents say they take less initiative to social contact post-injury and that they lack sufficient initiative to reciprocate and hold contact with a large circle of friends. Several respondents need much rest before social events and much rest afterwards. It is difficult to judge how much rest will be needed on both ends. A means of creating flexibility several respondents resort to is accepting social invitations conditionally, allowing for second thoughts.

There is some suggestion that respondents do not feel as welcome as before. Linda does not often call her friends on the telephone any more. She feels that she has nothing to contribute in social conversation as she no longer works or does much of anything. She has lost belief that she is an interesting person to socialize with. Mary says *“Our life here is that everything goes really fast, you are supposed to do everything, and everything is supposed to be perfect. I understand that they (her pre-injury social circle) don't have time for someone who is injured.”* Karin is aware that her friends are uncertain when they invite her to parties, telling her, for example, that it will be a late night which implies that it might be too much for her.

Impairments influence what form of contact respondents can engage in. Physical accessibility of meeting places is an issue for some. For most

respondents short visits or events are better than long ones. Large parties are dropped for the most part as being too strenuous. Small gatherings are best. Attending movies or concerts is a problem for several respondents as sitting is painful and crowds are threatening. Several respondents emphasize that they want to be able to make a quick retreat when they have had enough, taking care, for example, to have an aisle seat at a theater performance. Participation in social and cultural activities is, in general, an important source of continuity between pre- and post-injury identity but most respondents find their options reduced. They fall out of step with their friends and associates by not participating as before and in the same manner as before.

Respondents hold on as best they can but often feel relegated to the sidelines of social forms they do not fully master. For Tom the practicalities of sitting in a wheelchair with a cocktail class in one hand, peanuts in the other, and wheeling the chair in a crowded room of standing people at a party is too much. Tom seeks out a quiet corner with chairs, transfers if possible to a chair, and waits to see what happens. He says, "*It is often something nice.*" When pre-injury forms for socializing prove too demanding, few respondents took initiative in devising less demanding alternatives. Impairments do not necessarily change respondent ideas of how socializing should be performed. Anna feels that she must clean her house before receiving visitors. But she often does not feel up to cleaning. Rather than invent new forms of social contact and lower or adjust her standards, Anna quietly reduces socializing. Ellen, on the other hand, reports a high degree of innovation and her friends seem to reciprocate. Ellen goes along on all kinds of trips, participating as much as possible, resting in between, and glad that her friends will still have her along. At home she keeps entertaining simple so that she can retain the role of hostess.

Social contact with work colleagues is strongly influenced by impairment. Most respondents eventually left the labor force and have lost contact with work colleagues. Peter had most of his pre-injury social network connected to his work place and leaving his job left him without many friends. Respondents who continue working often have little capacity for cultivating social relationships with colleagues outside work hours.

### *Choosing friends*

While most friendships are maintained to some degree, others are let slide. Selection is largely based on how friends react to the respondent's new situation. Some respondents had friends who had earlier sought much attention, advice, and sympathy. If these people could not understand that respondents were now in need of receiving rather than only giving, the relationship faltered. Over the years, Mary has divided friends and relatives into two categories - the minority who empathize with her and the majority who do not understand. She does not answer the telephone if the caller is from category two. *"I don't use energy on those who don't show consideration."*

Three respondents spoke of forming new friendships. Karin likes being with people who accept her as she is now. These tend to be new friends rather than her old ones. Many of her old friends expect her to be as she was before. They keep encouraging her to try situations she does not feel able to master. She can see that her *"failures"* make old friends feel sorry on her behalf. She sees *"the hurt in their eyes"* and is, in turn, wounded by their sadness. Ellen has formed new friendships in a more instrumental fashion in the process of networking to find inspiration through disability organizations and personal referrals. New friends come in addition to, rather than as replacements for, old ones for Ellen. When Tina stopped working, she started a number of new activities that have brought new social contacts into her life. We will return to social relationships in Chapter 6.

## **5.2 COPING TECHNIQUES AND PHILOSOPHIES**

Respondents told of various techniques and philosophies they had developed over the years in managing impairment effects. Their means differed as respondents themselves differed in circumstances, personality, impairment particulars, etc. but we can distinguish three major strategies: 1) reachable objectives, 2) positive thinking, and 3) self care. An important factor underlying coping techniques and philosophies is that respondents identified with the techniques and philosophies and explained them in biographical and psychological terms of their lives and identities pre-injury.

### 5.2.1 Reachable objectives and a philosophy of small steps

Defining an objective and working towards it is a major technique for strengthening a sense of control and purpose. Respondents operate with different variations of this technique. Four respondents have had pre-injury experience with endurance sports where they learned to focus on reaching the next water stop. In more general terms, they had experience dividing up long term goals into component steps and taking one step at a time. Living with impairments was readily likened to endurance sports by these respondents, a long series of new objectives. The practice of defining objectives has two primary consequences. Firstly, it constructs and assures a personal significance to the goal. Secondly, it creates opportunities for experiencing success in reaching the objective. A component of the technique according to several respondents is to allow oneself a moment of satisfaction upon reaching an objective.

Karin is a strong advocate of the philosophy of small steps, small reachable objectives. Small reachable objectives give her a sense of her life “*being on track*”. Karin turns daily living into a system of reachable objectives with the dual underlying purpose of improving her functional capacity and contributing to a good life. At her last interview, Karin was working on her short term memory by reading ten pages a day in a thick, small print history book, discussing the content with another person in order to anchor content firmly in her mind. She has objectives in many areas, things she wants to do. Karin is careful not to tell her family and friends about her objectives. Her objectives are held private because she feels that others get “*pushy*” in their encouragement if they learn about her plans saying things like “*Of course you can do that. You’ve done that before.*” Karin’s objectives are small steps but reaching them is no small matter for her. She says that she is realistic when defining objectives and that there is a difference between being realistic and being negative. She does not always manage what she sets out to do but defines the act of trying as her immediate objective. She feels good when she achieves her objective and plans rewards for herself.

Ellen also practices the art of setting small reachable objectives for herself. She says with self irony that she is “*pathologically*” attuned to accomplishment. Objectives are often related to physical recovery of functional capacities but may also be related to life quality. At one point in

rehabilitation she had an objective of “*experiencing a moment of pleasure every day*”. Ellen works at having her level of ambition higher than her ability. She rewards herself upon reaching objectives with contemplation of the achievement. Objectives can also concern relationships with others. Ellen says that she always accepts offers of assistance whether she wants or needs help or not. She says, “*Accepting help is an act of care. There is much care and consideration to others involved in accepting help.*”

John is practical. He wants to see results. In setting objectives, he visualizes concrete achievements. An objective for him at one point was to regain sufficient balance by the coming summer to walk with his son at the family’s ocean cabin. He has had many objectives related to confirmation of his pre-injury identity, showing to self and others that he is still the person he was. John has always been restless and is continually on the outlook for small victories and confirmation from others of these new victories. He is testing limits all the time, wondering what he can manage. An objective one day was to explore the city on his own, just to see how far he could get and how it felt. Two years later, the objective was travel in other countries. Objectives or goals are necessary for achieving victories. Small reachable objectives create opportunities for a steady stream of victories and good feelings of achievement.

Tom is not a small step sort of person. He is convinced that to get what he wants he has to be willing to take risks. He has to “*break through barriers, a hundred, five hundred times*”, and has to build up the courage to do so. He set off on his first risk filled journey leaving the rehabilitation hospital for a trip on his own into the city only days after he was able to sit in a wheelchair. The objective of the trip was to deliver a business presentation and confirm to himself and others that he was still to be reckoned with at work. The hospital staff advised against the trip, saying it was far too early and far too strenuous. He fell out of the wheelchair on route and had to be piled back in but he made the trip. Tom takes risks but is not a dare devil. He analyses the situation carefully, dividing it into a series of steps. He makes contingency plans and thinks through worse case scenarios to prepare his defense. He controls risk as best he can while still confronting and experiencing it.

All respondents had goals of reducing impairment and improving functional capacities. Goals of improving performance may in part be social convention and politically correct self presentation. Persons with acquired

impairments are perhaps expected to be continually working on increasing functional capacity just as sick persons are expected to do their best to recover from illness.

### 5.2.2 Positive thinking – making good days and good stories

Positive thinking is a cognitive social approach to coping with and shaping impairment effects. A cognitive approach or cognitive self therapy in layman's terms is a general expression for mind over matter. The power of conscious thought processes is channeled for achieving self defined end states. Unstated but understood as a premise here the conscious thought processes are positive, emotionally uplifting, and perhaps physically healing. Two respondents, Ellen and Anna, made extensive use of a cognitive approach of positive thinking.

Ellen learned as a child and has practiced throughout her life a form of cognitive self therapy. She learned how to produce and embody hope. She learned it from her parents, particularly from her mother, and from her grandmother. Ellen excelled at developing a “*never-give-up*” spirit. Ellen has learned from her grandmother that “*Every experience can be of use*”. She can tell herself upon waking up in the morning that today is going to be a good day. It makes no difference how she feels when waking, whether she is sad, angry, in pain or happy. She tells herself that today will be a good day and in repeating this, moment by moment, the day becomes a good day. It becomes a good day for Ellen and those around her. Good days are shared events.

A component of Ellen's positive cognitive approach is a tendency to round off every critical sentiment or sad thought with a positive trailer. She searches for and finds a positive ending or interpretation. Ellen uses different pitches and tones of voice. She uses a forceful and varied adult range of neutral, positive, and critical voices. In addition she uses a soft, comforting, higher pitched voice, the kind adults often use when speaking with small children. This soft voice is used in first and third person referring to self and others. It is used when relating positive emotional episodes, constructing positive endings, and summoning hope. Ellen also collects stories of recovery for hope and inspiration, stretching the text book time limits for neurological recovery by many years.

Anna uses the coping technique of positive thinking in a different manner than Ellen. Anna uses it for reducing the spread of impairment



effects and their integration into self. Anna works at keeping impairment effects small and separate from the larger whole of her self image. Anna sees herself as a healthy person both in her dreams and while awake. She has always expected to be fit until she is very old. She feels she is twenty years younger than her actual age and is filled with positive energy. She keeps her impairment separate and small by focusing on all the positive factors in her life. She has had, and still has, a good life. She thinks about how lucky she is being a member of a closely knit family, about the interesting people she has met in her life, the places she has been, the things she has done, and the things she will do in the future. She does not allow impairment effects to impinge on all her positive experiences. She has confidence in her ability to “*bounce back*”.

Tom has developed a coping technique which can also be termed a form of cognitive self therapy and which is an effective social tool. He calls forth humor as his weapon. Over the years he has developed a means for dealing with difficulties and embarrassments that he has not managed to avoid despite careful planning. When in the middle of a trying situation related to his impairments Tom tries to ask himself, “*How long will it be before I can laugh over this incident?*” Unpleasant events make “*good stories*” - eventually. Humor helps take out the sting of embarrassment and/or humiliation. It restores his self esteem.

Almost all respondents conclude that nothing positive comes from negative thinking. They try to focus on positive thoughts and get what satisfaction they can in experience of the moment. Children and grandchildren are named as important sources of positive thought. No one escapes negative thoughts or bad days. Ellen says “*Bad days are to rest in.*” Again, very experience has some use. Respondents did testify to feeling responsible for comforting able bodied others and for presenting self in a positive, optimistic manner. They wore a happy face mask, with mild, gentle, careful smiles.

### **5.2.3 Self care**

A general principle underlying techniques of coping with impairment effects in daily life is care of self. Some respondents spoke specifically about acquiring or increasing knowledge, understanding, and control of their bodies. As previously mentioned, several respondents experienced turning

points in their lives in secondary rehabilitation when professional knowledge was combined with embodied knowledge of impairments. Self care is also closely related to user organized rehabilitation and the ongoing efforts of respondents to recover lost capacities. Respondents spoke less of self care than of setting objectives and positive thinking but self care principles were expressed in many different ways. Respondents who have long experience living with impairments place more emphasis on self care than respondents recently injured. Self care involves balancing between doing too much and doing too little.

Mary was the primary spokesperson for self care principles. She has learned to know her body. She works with her body rather than against it, getting the rest she needs, and shielding herself from noise and overexertion through careful planning. She lives life “*in first gear*”, going slowly, and strictly rationing her limited energy. Because she knows her body she can make choices, plan ahead, and prepare for participation in activities of high personal importance. Mary feels that she is being as active as possible and is skilled at holding pain at tolerable levels. Mary says she has “*a Masters degree in patience*”. Self care includes cultivating a positive attitude and taking pleasure over small things and fond memories. Self care for Mary also involves reintroducing pre-injury creative hobbies into her life. Creative pursuits are her “*rescue*”.

Karin formulates self care in her objectives of increasing knowledge, understanding, and control of her body and mood fluctuations. Karin wants to be more balanced and better “*grounded*” in the world around her. She terms the phase she is now in as a “*care-for-me period*”. She is working on building herself up through exercise, activities, and rest, balancing between doing too much and too little. She is building herself up by allowing herself to put her own welfare first. Karin does not think of this self care period as a life style or permanent situation. It is a means to an end of increasing energy and capacity. It comes after a long period of struggle and failure, a period where performance demands and her own ambitions exceeded her capabilities.

Tina has also come to a self care phase after years of struggle. Exiting the work force has left Tina with the opportunity and challenge of structuring her life in ways which feel good to her. Tina has not previously allowed herself the liberty of focusing on her own needs and developing her

own interests. She has always been “*a fighter*” but she has always been fighting for others, not herself. She now seeks to change her orientation.

George has only moderate interest in self care in terms of resting and taking care of his body. George is afraid of becoming a “*sofa-sitter*”, gaining weight from lack of exercise, and giving in to his pain. He is afraid of doing “too little”. He prefers to keep busy with a full schedule of activities, some of which tax his physical capacities to the limit. His version of self care is different. George seeks opportunities for deeper discussions with others who can give him “*feedback and corrections*” of his interpretations and manner of expression. He feels safer he is on the right tract when close friends confirm it.

### 5.3 DISCUSSION

Household members observe respondent efforts and may have close understanding of impairment effects. Biographical disruption caused by injury is perhaps felt most keenly in the family but the family is, at the same time, a fundamental source of continuity and the foundation of post-injury self. This study has not addressed family impairment effects directly. Most respondents spoke in little detail about the consequences of their impairments for various members of the family. However, there is support for the general conclusion that whole families are strongly affected when a member acquires impairment. Impaired persons are in a web of relationships all of which become subject to impairment effects. An open question is whether family members receive sufficient support from rehabilitation counselors, relatives, friends, school teachers, etc. in dealing with upheaval in family life. Most of our respondents tried to live family life as normally as possible for themselves and for the benefit of the others. Children and grandchildren provided an especially strong trajectory linking past, present, and future. A common response to impairment was to increase focus on family relationships, a fundamental back to basics.

Most of the respondents in this study had large social networks pre-injury. A common response to impairment was to reduce the frequency of contact with friends. Over time there could be some changes made in the social circle but for the most part social networks were said to be stable despite being less active and having less in common than before. Old friends

helped bridge the biographical disruption of illness, representing an important source of continuity in life. Respondents gave expression both of the support provided by friends, but also some of the burdens of maintaining contact. Reciprocating initiatives was difficult for some as they lacked pre-injury stamina and initiative and pre-injury forms for socializing were demanding. Respondents also gave expression of underlying tension in social relationships with old friends and dilemmas connected to encouragement and assistance. Encouragement was sometimes interpreted as being pushy or as a lack of understanding of reduced functional capacity. Offers of assistance were sometimes made when no assistance was wanted, leaving impaired persons with the burden of instructing others how to give help combined with the burden of graciously accepting help. We may assume that there is uncertainty on both sides, uncertainty among relatives and old friends and uncertainty among persons acquiring impairments about what to say, how to act, and how to interpret the other. Uncertainty is always present in social interaction but is heightened by embodied difference, biographical disruption caused by impairment, and social unease non-disabled others have in meetings with impaired persons.

Lowered self esteem seems to be a common consequence or response to acquired impairment. It is masked in meetings with others by a positive self presentation, a happy face, and modest smile. Some reduction in social initiative can be directly related to impairment particulars, communication difficulties, chronic pain, reduced stamina, etc. but lowered self esteem in itself will negatively affect social initiative. Lowered self esteem and happy face masks are clearly complex constructions. Respondents' own pre-injury socialization has perhaps contained discriminating attitudes and experiences, preparing them for responding to impairment and the difference between pre- and post-injury identities in this manner. Perhaps lowered self esteem is the consequence of post-injury learning experiences in rehabilitation, in the work place, family or social life. Falling out of work was falling out of social life according to one respondent. Some felt work "failure" as a blow to self esteem. Keeping up with the pace of social life and the full range of activities middle age, middle class persons tend to participate in is difficult when able bodied, worse when impaired. Falling out of step in social activities is also falling out of the social. One respondent said she had lost belief that she was

an interesting person to socialize with. How, why, to what degree, in what contexts, and for whom self esteem is undermined post-injury, are questions warranting further research.

Respondents relied separately or in combination on coping strategies of small reachable objectives, positive thinking, and self care. Personal significance is invested in construction of small reachable and opportunities for experiencing success are created. Positive thinking focuses on what is good with life and nurtures hope. Self care builds up respondents by learning to know and accept their bodies and allowing themselves to put their own welfare first. Professional knowledge increased understanding of embodied differences laying a foundation for self care but respondent understanding did not, in and of itself, translate into self care. Several respondents reported low levels of self care and having difficulty adjusting to post-injury's changing body parameters. Self care involves learning to listen to the body's signals but also seeking out and constructing an understanding and hopeful context (Heggdal 2003).

It is an open question whether other age or class populations would place equal emphasis on these strategies. It is noteworthy that respondents explained the first two approaches in terms of their upbringing and pre-injury experiences. They did not credit rehabilitation counseling as a source of learning. Difficulties in learning self care, the third approach, were also explained in terms of their upbringing and pre-injury life. Most had learned self control and care for others, not self care. Studies of self care have concluded that knowing when one has done too much and overstepped embodied limitations may be difficult, but it is even more difficult knowing when one has done too little as no warning signs or symptoms appear (Corbin & Strauss 1991).

# 6 Impairment narration

This chapter concerns respondents' perceptions and reflections about impairment narration and audience reception. Our focus is on the use of narratives of impairment genesis and impairment effects in daily life, and on storytelling performance and audience response. Narrative theorists claim that we live in a storied world. We live in and through our stories. We come to know ourselves through the telling/performing of our stories and through the responses of listeners. The narrative is critical for constructing the self and moving forward after a major biographical disruption. Respondents in our study have had years of post-injury experience with impairment narration. They have had many different stories to tell or perform and many different audiences.

Stories of the event causing injury, of what happened, come as a first response to biographical disruption. Telling them in the interview encounter years post-injury as stories of a distinct and distant event are rehearsed performances. Stories of impairment effects, on the other hand, are ongoing stories with changing events and varying distance. Telling these stories in the interview encounter is a more interactive process, with interviewer prompting and encouragement as a component of authorship. Some of these stories have been told or performed many times before; some are emerging in the interview process. Most research on illness narratives deals with clinical encounters. Our focus is on the use and reception impairment narratives receive in the social world outside the clinical encounter – with friends, work associates, family, and the research team.

## 6.1 IMPAIRMENT GENESIS

Impairment genesis narratives refer stories about the event or cause of injury. Respondents talked freely and in detail about the cause of their injuries in our interviews. We will here distinguish between narratives of high and low dramatic content and narrative performance.

### 6.1.1 High drama

Most respondents had been injured in dramatic circumstances in the sense that injuries occurred suddenly, were potentially life threatening, and/or required hospitalization. Dramatic genesis meets almost by definition the requirements of a good story. Something big happened. Wheels were set in motion. When there is high drama to the injury and its surrounding circumstances, narratives of impairment have a solid structural base upon which to build.

Four respondents have had strokes. Respondents who had strokes experienced an abrupt loss of control over parts or functions of their bodies, such as one sided paralysis and loss of powers of speech. They all retained consciousness and hearing, some understanding what was happening, some confused. One respondent had a few moments “rational time” before loss of functions where he managed to call in sick for work. The shock of experiencing loss of bodily control is long lasting. Losing powers of speech while retaining consciousness and hearing, one is suddenly separated from the social world. Respondents told in detail of being rushed to hospitals and acute treatment. When telling about stroke experiences, respondents reflected over their family backgrounds and lifestyles for possible explanations for stroke occurrence. Narratives about strokes emphasized, in addition to the “*unreal*” nature of the experience, a number of contextual factors. Timing and location were important. Respondents had not suffered strokes when they were alone. They are grateful that household members or other persons had been able to find them and call for medical help. The possibility of stroke reoccurrence in an “*unsuitable public place*” is distressing, a source of ongoing anxiety. Respondents are grateful that they were not doing anything hazardous for themselves or others at the time of the stroke. One respondent often reflects over “*luck within unluckiness*”. Had his stroke come a few hours earlier, it would have happened while he was driving a car filled with children.

Three respondents have been in dramatic accidents of various kinds. A life threatening car crash and a pedestrian run over by a truck represent the high end of the dramatic scale of accidents along with a bicycle accident, sending the rider flying over the handle bars and breaking his neck. High drama may be seen as a combination of acute circumstances and embodied consequences.

One respondent became highly involved in telling his dramatic story. George says, “*At one point, two-three years post-injury, I became my accident or my accident became me. I used every opportunity I could find to tell about the trauma of the car crash and intensive care*”. Tom, who was injured flying over the handle bars of his bicycle, readily tells his story when asked or when he feels it is useful. Bicycle accidents have high status according to Tom. They put him at the top of the “disability hierarchy”, injured rather than ill, injured while performing an active sport rather than falling down stairs. Tom tells strangers (taxi drivers, etc.) he was injured in a bicycle accident so that strangers will regard him as anybody else and be at ease.

### 6.1.2 Low drama

Accidents with low drama, where nothing serious seemed to happen and there was no immediate flush of activity, lack certain key components of a good story. Low drama injuries constitute special challenges in formulating credible narratives of impairment genesis. This applies particularly if the accidents result in serious long term injuries.

Low drama injuries in our study are represented by two minor car accidents and home accident. It may be coincidental but the three respondents involved were middle aged women and two of the three sustained neck injuries. None saw an immediate need for medical treatment. There was no big flush of activity. Family observers were present in two of the three cases and supported the low drama interpretation.

Mary managed to drive home after a tail gait car accident, but was in a daze, “*outside herself*”. She knew something had happened and lay down on the sofa to recover. She remained here a week. Tina was sent home after a brief medical check for a minor concussion after her traffic accident. Anna waited several days before visiting a doctor after being hit on the head by a falling box. No one took these events very seriously at the time, least of all the respondents. Mary is a special case in point as her story begins as a non-story. She had suffered a type of injury she did not believe existed, a whip lash injury.

### 6.1.3 Performance

Independent of the type of accident or injury, much of the drama of impairment narration is in the style, energy, and skill of the storyteller.



George has what he calls “*clear body language*” and is fast, sharp, and temperamental. His style is dramatic and adds to the drama of his story. Karin was run over by a truck which in and of itself is highly dramatic. She, however, has no conscious memories from the accident or early hospitalization and only second hand memories from medical rehabilitation. Karin tells her story in a flat, non-dramatic style without emotion because she is only repeating what she has been told by others. Without emotion and energy, there is no drama to the performance.

Performance – physically, spatially, and bodily – of the genesis story varies greatly among respondents. Since these are old stories which have been told and retold for years, their performance in the interview situation may reflect audience response over time. Stories change in each retelling. The interview encounter is a fresh opportunity to bring back the genesis story in an uncontested stream. Some respondents were accomplished storytellers irrespective of impairment. Others were hampered by their impairments and had perhaps never been skilled storytellers. Impairments which negatively affected story performance were, for example, speech difficulties, slow cognitive functioning, low stamina, and physical paralysis. In many social settings these performances are likely to be incapable of attracting and holding an audience. In the slow room of the interview the performances were powerful enough.

## 6.2 IMPAIRMENT EFFECT NARRATIVES

Narratives of impairment effects are complex, multifaceted stories. The embodied particulars of each respondent’s injury, what problems they face in daily life because of their injuries, and what they do to manage as well as possible are the primary components. Most respondents have had some recovery since their injuries and hope for further recovery. Recovery is also a central story component. Narratives of impairment effects, as conceived here, cover a wide range of topics including rehabilitation and employment experiences, meetings with the health and social service bureaucracies, post-injury family and social life and, largely due to our prompting, impairment narration itself. Respondent accounts covered a long and varied time span. Narratives of impairment effects are ongoing stories.

Respondents told of physical, cognitive, and emotional difficulties often making comparisons with the life they had lived pre-injury. Almost all respondents tell that they have been highly fit physically and highly active socially pre-injury. The abrupt genesis of impairment highlights change pre- and post-injury. Pre-injury activity levels may be perceived in relation to post-injury lives and visa versa. Narratives of pre-injury lives which make claim of socially valued traits such as being highly active socially appear important in relating who the respondent “really” is/was. Good pre-injury health is given credit for the reducing impairment severity and speeding recovery. Impairments were in general described in a matter-of-fact tone with little expression of emotion. Respondents in this study have had years to overcome initial grief over lost functions and as earlier mentioned, recovery is an ongoing process for many.

The focus here is on respondent use of impairment effect narratives in everyday life. To what degree do respondents tell others of their physical, cognitive or emotional limitations and how impairments affect daily life? To what degree do they tell about frustrating or gratifying meetings with social institutions and practices and do they attempt to involve others in their recovery or reorientation by telling their stories?

### **6.2.1 Storylines and delivery**

Good stories are part content, part delivery. The content aspect involves conflicts, resolutions, and change. It involves emplotment. Storylines varied substantially among respondents even within the structure provided by our interview guide. George’s story of impairment effects is a short version of his accident story with a positive twist. George can list up a number of impairments and still feels a keen sense of loss for his pre-injury capabilities, but the story he tells is that the accident has enriched him as a person. The accident forced him to slow down and has enabled him to become a better, more empathetic person. Men, according to George, are experts at running away. Men keep emotions under control and relationships at a distance by being active. His traffic accident was “*almost a necessity*” for him to be able to develop his communicative, relational side. Ellen also emphasized the learning value of injury. It was an opportunity to demonstrate to her children, self, and others how to nurture hope. She could show that difficulties can be

managed, the healing powers of hope, and that one can live a good life despite impairment.

Tom's story focuses less on physical impairments and value changes and more on frustration over poor coordination of service delivery and the practical difficulties of getting daily life to function after discharge from primary rehabilitation, getting quickly back to work, an adapted car, reliable personal care, etc. He can tell stories of disabling social structures and practices, "*wasted time*", but also of eventually overcoming practical difficulties and moving on with his life.

Mary's story is about gaining credibility. Mary longs for understanding and recognition of the weight she is carrying on her shoulders. Over time Mary has developed an impairment effects narrative based on her frustrating contact with authorities of different kinds – doctors, social security officers, insurance companies, and her disappointment of not being understood by relatives and family friends. She tells, for instance, in detail about an early consultation with a doctor who had granted her a few weeks sick leave after her accident. The doctor questioned her about how the sick leave had been spent. The doctor assumed that Mary had spent her days in town with friends, having a fine time. At that point Mary was exhausted from sleep deprivation and in so much pain that she needed assistance getting from home to the doctor's office. She most certainly had not been having a fine time in town or any where else. Mary has developed this narrative to a signature story.

Delivery is a specially challenging when the storyline lacks conflict and resolution and when there is little change and only "small" daily events to talk about. Tina has pondered over the years how to effectively narrate impairment effects. She has concluded that the first principle of effective narration is that the narrative must be short. She has experienced that people get bored listening to long stories and once she gets started it is difficult to stop. The narrative must also be told with energy and fit into the flow of the conversation. Tina has difficulty finding cue words which allow her to fit in a short story and difficulty holding on to her audience. Social conversation today is fast paced. She feels that people in her social circle are always competing for the position of storyteller. Speed in picking up on cue words and a good amount of self confidence are needed to gain and hold the

attention of an audience all of whom want to talk about their own stories. Tina as well as several other respondents lacked both necessary speed and self confidence.

### 6.2.2 Silencing

Over time respondents generally conclude that they do not want to talk much about impairments effects. They go to parties to have fun just like everyone else, not to talk about impairments and related issues. Discussing topics of interest pre-injury demonstrates and forges continuity between pre- and post-injury identities. Discussing topics of common interest resists reduction to a diagnosis and lessens or avoids stigmatization. Respondents seem to consider narratives of impairment effects as private, or belonging to the intimate and therapeutic spheres. Some consider performing narratives as too demanding. They want others to understand and show consideration without their having to say anything. Silencing is a question of degree, not an either/or situation. It does not stand in contrast to only talking about impairment effects as all respondents have many stories to tell. It refers to almost never telling impairment stories, to consciously trying to remove embodied difference and impairment effects from social discourse.

Anna has suffered a neck injury. She has been and remains in general skeptical towards neck injuries. She perceives neck injuries as being low status, socially suspect complaints, typical for middle aged women and not something she likes being associated with. In addition Anna views impairment narratives as whining. The last thing she wants to be is a complainer when she has so much in her life that she is grateful for. She has had a strict upbringing of self discipline and not calling attention to her self. She has been taught to ignore her body, for instance, going to school even when sick. Anna has strong role models she admires in older relatives who, despite chronic pain and impairment, are always a pleasure to be with. Anna answers direct questions from friends but does not want “*to entertain*” her social circle with her health problems. She thinks that most of her friends believe she is fully recovered from her accident. If she were to mention impairments, friends would exclaim “*Are you still having problems from that?*”

George stopped talking about impairment effects a few years post-injury. Even in conversations where his accident story could easily fit in, he prefers now to remain silent. If someone sees him halting and asks the

reason he replies that he has just stumbled. If someone tells him he is a good dancer he does not tell them how much it hurts to move. He does not tell others that he needs time to think things through before making decisions. He makes excuses “*to win time*”, such as that he needs to discuss the matter with his wife. While some may sense his physical impairments, George thinks that no one outside the close family knows of his chronic pain or of his cognitive injuries. George has always kept impairments hidden at work. He has become more serious and more selective as to which topics of conversation he is willing to enter into. Trivialities, like the color of the dinner plates, are not his cup of tea.

Close family and friends know about Karin’s cognitive impairments, but few are fully aware of the extent of her need for planning and concentration. People forget and talk to her, for example, while walking in the woods, forcing her to divide her attention between listening and walking. Karin looks people over before telling them about her situation. She tells people about her impairments on a-need-to-know basis. She does not want to walk around with a sign on her brow saying “*Brain injury*”. Karin has constructed a few short stories/explanations that she can reel off without much thought. Karin understands that it is difficult for others to understand her situation. She says, “*How can others understand when I don’t understand it myself?*” Karin also learned in secondary rehabilitation “*to let friends be friends*”, i.e. to save problems and impairment effect narratives for health professionals and counselors.

Tom and Ellen have visible impairments and, as a consequence, tell a non-verbal impairment narrative whenever seen by others. They do not have the same option of silencing impairment narratives as respondents with invisible impairments do. Tom and Ellen were both active persons pre-injury and continue to be active post-injury making public appearances and speaking to different audiences. In their experience it is an advantage to verbalize the genesis of their impairments from the start. Otherwise, Ellen reasons, the audience will be sidetracked into wondering what had happened to her, rather than concentrating on what she has to say. Both respondents use personal experiences of living with impairments in presentations to increase audience understanding of impairment effects and general disability issues. These respondents appear to be more at ease in explaining impair-

ment effects than most, perhaps due to their occupational backgrounds, perhaps as they have been forced to gain much experience in explaining impairments. While capable of formulating effective impairment narratives, these respondents gave little indication that they did so often in personal social exchanges. Ellen says “*I do my crying in the shower*”.

## 6.3 AUDIENCE RECEPTION

### 6.3.1 Interest

In early phases post-injury, impairment narratives have appeal of being news, particularly genesis narratives answering the question “What happened to you?” Linda feels that people are interested in learning all they can about strokes in general and the best possible acute care following strokes as a safety precaution in case it should happen to them or their loved ones. Their interest is instrumental. However Linda strongly dislikes people asking her what happened and upon hearing that she has had a stroke saying things like, “*Oh a stroke! How horrible! What a tragedy!*” reaching out and patting her on the arm. She is trying to incorporate the stroke experience into her life, making it smaller and less traumatic, and reducing the fear of a reoccurrence. Other people’s exclamations of tragedy do not help.

Most respondents reported having some intimate friends they can talk with, some who are willing and able to enter longer and deeper discussions. Tina has a rotation plan to avoid burdening her friends with her problems. She thinks through who she has not talked with for a long time. Anna is beginning to reflect upon the ethical issues of telling half truths or avoiding telling the truth when friends ask her how she is doing. If one always answers “*Yes, thank you. I’m getting better.*” friends are kept at an arms distance and deprived of opportunities of deeper involvement.

Respondents with visible impairments report that non-disabled others often feel tension meeting them. Tension may be thought of as a negative form for interest. Years post-injury, Tom continues to be surprised over the unease many non-disabled people have in encounters with people who have visible impairments. Ellen notes that while many adults are frightened, children are not. Children are very interested. Their curiosity often gets the better of them and adults rush to teach children to not interact or stare. Tom and Ellen supplement their non-verbal narrative with a short verbal or

behavioral story. Tom, for example, quickly tells others that if he wants help he will ask for it. Ellen invites curious children to take a ride with her on her electric wheelchair, making it sound exciting and fun, and dispelling the otherness attributed to her.

### 6.3.2 Disinterest and disbelief

Interest in impairment narratives decreases over time. Recovery is a slow, ongoing process with little news value to others than respondents and therapists. Most respondents have experienced that questions of “How are you?” are polite social intercourse, not invitations for telling their impairment narratives. Narratives of impairment effects are not welcome guests at parties or in everyday conversation.

George says that people withdrew from him when he talked non-stop about his accident. He could see that friends politely lowered their eyes or moved away out of hearing when he got started telling about his dramatic accident. He had to (re)learn social codes for conversations. A major turning point was when he was confronted with being self centered because of all his impairment narration. People were not interested in hearing the short version of his story either, even when it was given a positive twist.

In the late 1990’s when Mary had her accident, whip lash injuries were subject of much public debate. There was much skepticism about connections between acute injuries and long term physical and psychological problems. Whip lash injuries were often seen to be containers for numerous underlying complaints. Mary says that there are still people in her social circle who do not believe or comprehend the extent of her injuries. She understands that her behavior is confusing to others who do not see the choices she is forced to make. Few know how little she can do before she needs to rest. Her own behavior is used by others as evidence she is malingering. Mary exerts herself to the limit in social interaction on occasion. Some people have confronted her with statements like “*If you can go to a party at X, then you can come to Y.*” and “*Pull yourself together, you can do it. It’s only a small thing.*” Such statements wound Mary because they indicate that the speaker has no idea of Mary’s problems.

Respondents with impairments which are not readily visible have in general problems with audience disbelief. Their appearance undermines the credibility of their narratives. Respondents protested against general

demands for visual markers. Tina, for example, says she has pride as well as impairments. She does not want to walk around looking sick just to get people to believe her. People tell her she looks healthy and has good color in her face from outdoor exercise, meaning she cannot be so badly off. They ask to see scars after her accident but she has none.

### **6.3.3 Research team as audience**

As reported earlier, most respondents were invigorated by the opportunity the interview encounter represented for telling their impairment narratives, particularly narratives of impairment effects. Most respondents formed their narratives with us more or less directly as quests and saw participation in a research project as a vehicle for reaching out to others. They had been changed by their injuries and had learned something valuable that they want to pass on to others. Telling stories to us provided narratives added social purpose as data in a research project. The research design with multiple semi-structured qualitative interviews opened for stories to develop in the course of our meetings, creating a new or greater sense of coherence and meaning for some respondents in interaction with researchers. Some respondents wanted us to help further structure their narratives and were confident that we would be able to draw out the lessons learned through our analysis, thus re-enforcing their image of a quest. Perhaps our most important function was to provide an attentive audience who did not contest the performance of respondent stories. Pace was essential here. The interviews were unhurried. Many respondents have had difficult experiences gaining credibility for their narratives and in performing narratives in fast moving conversation. When first given central stage, stories poured out.

## **6.4 DISCUSSION**

Dramatic accidents lend structure upon which to build impairment narratives, non dramatic accidents do not. Impairments which are not readily visible have in addition a major problem gaining credibility (Stone 2005, Lingsom 2008). Bulow (2008) claims that unless one tells a convincing story, illness becomes contested and the person's moral conduct is called into question. People with invisible impairments may be suspected of malingering and using their health problems to obtain advantage. Persons with socially



contested impairments may become subject to self doubt. Social credibility is distinct from clinical credibility and lacking tests and measurements, it may be more dependent on narrative performance. Respondents with invisible impairments resisted making themselves look sick or having signs around their necks announcing impairment. Their appearance gives them outward normality and continuity with pre-injury identity.

Narratives of impairment genesis are naturally dominant in early phases post-injury and may continue as a short story of explanatory nature in later years. Narrations of impairment effects are ongoing stories. Daily life with impairments generates material for new stories. Most respondents recalled early periods post-injury when they told their impairment narratives actively, but later on they stopped. The grounds for silencing impairment narratives varied. Some respondents did not want to hear themselves telling these narratives. Hearing themselves talk brought problems home, made them larger than respondents wanted.

Respondents in general regarded it important to avoid complaining. The social importance of avoiding complaints has also been found in Norwegian studies of chronically ill (Elstad, Grue & Eriksen 2005, Myrvang 2006). Some respondents wanted to tell impairment narratives but did not succeed in gaining and holding an audience and structuring a credible narrative. Audiences expressed disinterest, moving away and changing subjects. Audience disinterest and/or disbelief taught respondents to silence their impairment narratives.

Social interest is in news and in recovery stories. Key components of narratives are temporal coherence, events and consequences, something happens and something changes. Perhaps one problem with narratives of impairment effects is that there is not enough happening to construct a narrative of interest to others, few new events, little change, and thus little dramatic effect. Possible storylines may cast the storyteller in a negative light, as subject to frustrating meetings with services and uncomfortable meetings with the social. Impairment particulars negatively affected storytelling performance of several respondents.

Meeting incredibility and audience disinterest over time is likely to lower storyteller self esteem and reduce narrative performance capabilities in a negative spiral further limiting narration. Telling stories is a necessary

process in evaluating experiences and alternative possibilities. It is a process of creating meaning and connecting to others. The silenced narrator is estranged from sharing impairment experiences and thus estranged from construction of an embodied post-injury self in communication with others. Silencing is two-sided, interrelated social practice – impaired persons do not want to tell/perform impairment narratives. Their friends and associates do not want to listen. The consequences of silencing impairment narratives on the psycho-social wellbeing of impaired persons and the construction of post-injury identity warrant further study.

A further consequence of silencing impairment narratives is that the social room excluding these stories remains unchallenged. Omitting the experiences of disability from cultural representations of life in society is a major dimension in the cultural construction of disability according to several authors. Wendell (1996, pp. 42-43) writes “The lack of cultural representations of experiences of disabilities not only contributes to the otherness of people with disabilities by encouraging the assumption that their lives are inconceivable to non-disabled people but also increases non-disabled people’s fear of disability by suppressing knowledge of how people live with disabilities.”

# 7 Disability identities

This chapter discusses disability identity - how respondents see themselves in relation to disability and how they understand disability. Respondents were asked whether they regarded themselves as disabled. References respondents made to disabled persons or to what respondents thought being disabled meant were noted in interviews, even as passing remarks. Respondents in this study have reduced functional capacity of varying type, degree and prognosis. They have been in accidents or had strokes. The question here is how they relate experiences of reduced functional capacity to concepts of having a disability or being disabled.

Disability represents not only impairment but also entitlement. Confirmation of disability opens doors to various social benefits. It calls for consideration and offers of assistance. It offers more flexibility in social expectations of what activities are to be performed and how. The complementary obligation a disability identity places on impaired persons has traditionally been a display of gratitude for whatever assistance is received and, in general, non-obtrusive behavior.

## 7.1 INJURED – NOT DISABLED. RESPONDENT SELF IMAGES

Respondents in our study have serious long term reductions in functional capacity. While most respondents retain hope for improvement of functional capacity, they understand that some degree of impairment will follow them throughout their lives.

Only one respondent, Tom, a full time wheelchair user, acknowledges he is disabled and has a physical disability. He quickly adds that he is also privileged. Tom is sensitive to the fact that many disabled persons have “*greater difficulties, steeper hills, and less social support*” than he has. He risks making “*less successful*” disabled persons feel badly if he shows his positive, pragmatic approach to living with impairment, how active he is, and much he has achieved post-injury.

Other respondents did not see themselves as being disabled or having a disability. Most were forthcoming in acknowledging long reductions in functional capacity. They did not, however, regard these as constituting disabilities and making them disabled. Disability was kept at arms distance. The term as an identity label was foreign to them.

### 7.1.1 Active and recovering

Explanations and reflections about why they did not see themselves as having a disability or being disabled varied. The most common explanations involved high activity levels, minor impairments, invisible impairments, and a focus on recovery, improvement, and increased wellbeing.

#### *Being busy*

Despite serious, long term reduction in cognitive capacity and greater limitations in daily life than many wheelchair users she has met over the years, Karin does not apply the term disabled when referring to herself. She does not say she has a disability. Karin does not feel need to consider herself disabled because she is active, with a full weekly schedule and plans for the coming months to look forward to. She travels. She has her means of coping. She has been in an accident and has been injured.

While admitting to having several kinds of reduced functional capacity due to an accident many years ago, George does not regard himself as having a disability. He answers the question as to whether he regards himself as disabled with an emphatic “No”. Continuation of a high level of activity at work, in volunteer organizations, and on committees demonstrates to self and others that he is not disabled. George says, “*I don’t know what it means to be disabled*”.

#### *Minor impairment/ invisible impairment*

Tina thinks it would be wrong of her to use the term disabled. If pressed she tells people she has suffered a minor head injury in a car accident. She does not wish to use the term disabled to justify her actions or make excuses for her uneven level of achievement. Claiming disability when impairments are not visible, when impairments relate directly to communication abilities, and when activity and achievement levels are high, is too difficult.

Anna was injured in an accident a few years ago but continues to feel healthy and does not regard herself disabled. Anna experiences reduction in functional capacity when pain suddenly cuts through her “*like a knife*”. Still, she regards the effects of her impairment as so small that she should be capable of tolerating them and she expects her situation to improve. Disability is more serious than reduced functional capacity to her way of thinking. When Anna thinks of disabled people, she thinks about physically disabled third world poor, for example, land mine victims without means of support.

Mary has lived for many years with serious impairment after an accident. Her activity level is severely restricted and she is in chronic pain. Mary has difficulty convincing others of her impairment and is resigned to this situation. People either believe her or not. Mary’s self presentation is now well rehearsed. “*I am not disabled, impaired, or ill. I am injured. My life was turned upside down in a car accident.*”

#### *Getting better*

Although conscious of reduced physical and cognitive capacities after his stroke John does not regard himself disabled or having a disability. John is intent on returning to the activities of his pre-stroke life and presenting positive sides of self rather than impairments. As he continues to “*score victories*”, the self image of being disabled and having disabilities is kept at bay.

A partial wheelchair user after a stroke, Ellen, does not see herself as disabled or having a disability. Sometimes she refers to being or having been ill. Others times she says she is healthy. To some degree she rejects the concept of reduced functional capacity. She cites examples of persons who have accomplished extraordinary feats despite functional limitations. She prefers to say her functional capacities are “*changed*” rather than “*reduced*”. Ellen uses her energy on positive thinking of recovery.

### **7.1.2 Little reference to context and social factors**

Social and contextual factors defining or creating disabilities were rarely mentioned directly. It is noteworthy that concepts associated with the social model of disability, i.e. that social structure and practice disable people with impairments, are largely absent in respondent reflections on reduced functional capacity and disability. Respondents viewed disability more in the

traditional medical model as being located in the individual and his or her functional limitations. There was also limited reference to functional limitations being determined by context, i.e. that one may be limited/disabled in one context but not in another.

There were exceptions. The two respondents using wheelchairs felt disabled by poor building and transportation accessibility. Respondents requiring personal care described problematic dependency on the reliability and continuity of home nursing services. Several respondents spoke of early battles with the system of social services and benefits (Chapter 3), and vocational rehabilitation officers not working hard enough to get them back to work (Chapter 4). Respondents with cognitive impairments spoke in general of the hurried pace of social conversation and poor social climate for meaningful discussions as barriers limiting their participation. All respondents spoke of preconditions for their participation in social settings – activities of short duration, low noise levels, few people, easy access, readily available exits, etc. A major contextual dimension for respondents with mobility impairments was between even and uneven terrain and between winter's snow and slippery ice and summer's clear sidewalks. There was thus reference to contextual factors but most references contained no suggestion of social responsibility disabling environments. Respondents who were anxious in traffic or who were sensitive to sound, for instance, had no visions of a city without traffic, people, and noise. Norway's winter climate was just that, Norway's winter climate.

An under-communicated contextual dimension for all was between home and the world outside. At home the respondents were in maximum control over their environment and optimal management of their impairments. In the private sphere of the home, respondents felt less impaired. One respondent suffering a stroke about five years ago says she sometimes feels disabled in situations she does not master, for example attempting a pre-injury pursuit like cross country skiing or hiking. At home, in her daily routine, she feels she is in control and manages and therefore does not feel disabled.

## 7.2 DISABILITY ATTRIBUTES

The short presentation of respondent self images as injured is suggestive of meanings attached to disability identity in urban, middle aged, middle class, Norwegian society. We cannot generalize from our small sample of persons who have acquired impairments in midlife but we can reflect upon what may underlie upon respondent answers.

### 7.2.1 Wheelchair as defining attribute

Respondents appear to define disability in terms of physical impairments, and, in particular, the ability to walk. The wheelchair is a powerful symbol and almost synonymous with disability for most of our respondents. Walking with poor coordination and/or with pain and limited stamina was not associated with disability because the person is on their own two feet with or without various technical aids – crutches, braces, canes, etc. As George says, “*Halting once in a while is not a disability*”. Most respondents had visible difficulty walking but managed after their fashion for shorter or longer distances. Most respondents had mobility impairments but as long as they could stand and walk short distances they did not regard themselves disabled.

Respondents do not appear to consider pain, cognitive impairments, and psychological problems in their self presentation of disability. George for example, makes no reference to his cognitive impairment, chronic pain, and other health problems, when evaluating disability. He placed all emphasis on mobility limitations. Mental health difficulties such as anxiety were low on disability hierarchy judging from respondent efforts at covering over emotional distress in daily life by “*playing healthy*”, keeping a happy face or withdrawal from the social. Our data suggest that cognitive impairments are low on “the disability hierarchy”. Respondents with cognitive impairments were careful to explain that they were not “*dumb*”, and careful to exclude cognitive functioning in considering personal disability. Romsland (2009) argues that cognitive functions represent the essence of self and normality in today’s society and that cognitive injuries are regarded as highly stigmatizing particularly among the educated middle class.

Disability – having a disability or being disabled, are vague concepts for persons with impairments. There appear to be few markers that clearly define disability for our middle aged sample outside the ability to stand and

walk. This suggests that there is substantial leeway in using disability in one's self image. Impairment effects may be severe but not self defined as disability. Pain and limited stamina may severely limit functional capacity but it is an open question how debilitating they must be before disability images come to mind. Similarly it is an open question how severe cognitive impairments, short term memory losses, etc. must be before disability claims are deemed appropriate by self and others.

### **7.2.2 Passivity and hopelessness – extreme negative stereotypes**

Respondents expressed many underlying negative associations with disability. Disability appears to be seen as a master status by our respondents, an identity that overshadows and undermines other identities. It appears to be seen as a global status referring to all areas of functional capacity rather than a reference to reduction in specific functional capacities. For our respondents passivity appears to be the dominant negative characteristic attributed to disability. Respondents viewed disabled others as people who are “*parked*”, i.e. people who are not going anywhere. They are people who do not have full activity calendars, people at the “*end-of-the-line*”, passive pensioners who just sit.

Hopelessness appears to be another dominant negative trait attributed to disability. Disability - either having a disability or being disabled - is associated with permanence and lack of hope for recovery, improvement, and/or development. Disabled others are people far worse off than respondents perceive themselves to be. Disabled others are people who let health problems dominate their lives and who “*give in to pain*”. Disabled others do not feel healthy and younger than their years. On the contrary, disability is associated with old age stereotypes. Disabled others are not seen to have a range of social, cultural, and material resources at their command and much to be thankful for. Disabled others are seen as having low or vulnerable self esteem, easily wounded by “*more successful*” impaired persons.

## **7.3 REJECTION OF DISABILITY IDENTITY**

The disability label was rejected at first by almost all respondents. Other labels are more acceptable to respondents and considered more accurate. Respondents have been injured and have reduced functional capacity.



Reduced capacity, even severely reduced functional capacity, is not considered the same as having a disability. By making disability incompatible with activity, health, hope, joy, and personal development, respondents can distance themselves from the label. Their daily lives demonstrate to self and others that they are not disabled. Respondents appear to construct a heightened stereotype of disability as a personal reference. While expressing personal distance to disability, our respondents also express empathy, even increased empathy, for persons with severe impairment. They are saying that their own problems are small in comparison.

### 7.3.1 Affirmation of hope

Rejection of a disability identity for some is an affirmation of hope for further recovery from their injuries. Being injured or ill conjures images of recovery. Rejection of disability reduces the impact of impairments, making impairment effects less intrusive and less permanent. It allows focus to shift from impairments to the whole person, to abilities rather than limitations, and to substantive interests beyond self.

It seems that negative stereotypes associated with disability serve a motivating function for persons with acquired impairments. Negative stereotypes seem to help distance themselves from their unplanned, undesired situation and help them work hard in rehabilitation and managing daily life. It may be a means of breaching the gap between pre- injury and post-injury, reconnecting with their earlier, non-disabled selves. Rejection of disability can be interpreted as a defense mechanism used by persons in a vulnerable situation, a technology of the self. Rejecting disability images is perhaps necessary for the continuation and construction of other self images.

Persons acquiring impairments in late middle age have an option to regard themselves as being old before their time rather than as disabled. One respondent likened injury to ageing and said being injured “*was like getting old all of a sudden*”. In old age, embodied difference, physical complaints, and lowered activity levels are expected and therefore normal. Our respondents tended to reject this option just as they rejected personal disability identity. Several nurtured earlier self images as being younger than their years. Even feeling one’s chronological age created distance to disability, passivity, and permanence of impairment. Most respondents were in family relationships

extending over several generations. Having both elderly parents and children helped respondents maintain a subjective age equal to their chronological age.

### 7.3.2 Cohort, age, and class influence

Age cohort may be a central factor in rejecting self images of disability. Our middle aged respondents have been socialized into adulthood as able bodied in a society which has tended to classify persons as either/or, disabled or not, based on a medical model of disability and the individuals' functional capacity. The images of disability which dominate among persons who are middle aged today were formed in a time when people with impairments were more segregated to the private sphere and/or institutions and less active in public spaces and discourses. This supported stereotypes of passivity. Attention was not directed to contextual factors of enabling or disabling environments. Our study indicates that disability continues to be a highly negative charged identity status for middle aged, middle class respondents.

Middle aged persons with acquired impairments are likely to live their lives in the company of able bodied persons and have little social contact with impaired persons with similar health circumstances. Several respondents are or had been members of diagnosis or impairment organizations but had had little social contact with similarly impaired persons through these organizations. Most contact with other impaired persons has been in rehabilitation settings. Respondents appeared to derive identity objectives as individuals, not from association with organized groups of disabled others. With younger persons, new cohorts, or for persons with select impairments, this may differ as disability associations become more active and disability claims a larger, more diverse role in public discourse. However, the fragmentation and specialization of disability organizations by diagnosis and cause of injury undermines the common ground for a disability identity. Persons can identify themselves for example with being stroke survivors or traffic accident victims but still not see themselves as being disabled. The meanings attached to being disabled are undoubtedly changing, but these changes are outside the scope of this study.

Social class may also be a factor in identifying with disability, as our middle class respondents have a diverse set of resources that help them manage impairment effects - resources and privileges that respondents do

not associate with disability. They are conscious of their economic privilege and their educational, cultural, and social skills. The social model of disability centers on social oppression as the defining experience of disability. Declining to take on disability identity may mean that our middle class respondents do not perceive or wish to present themselves as being subject to social oppression.

### **7.3.3 Lack of social confirmation with invisible impairments**

The disability identity of persons with invisible impairments gets little or no social confirmation in everyday life. This may be appreciated at times by respondents who have little desire to develop or claim a disability identity. At times the lack of recognition for the problems faced in daily life may be burdensome.

Identities are developed and changed in social interaction. Chapter 6 discussed impairment narratives and concluded that impairment narratives were in general “unwelcome guests” in social exchanges. Respondents themselves were often eager to avoid talk of impairment. To the degree impairment narratives are silenced by self or others, respondents lack the means of building a disability identity which represents their experience. Narrators require an active audience, responses from active listening, and challenges of communication. Lacking creditability of their impairment narrative and/or lacking audience, persons with impairments become subject to definitions imposed by others. Well meaning offers of encouragement and compliments such as “*You look so well.*” and/or assumptions of recovery as the natural course after injury undermine the development of a disability identity.

Confirmation of impairments may be found in clinical assessments, disability pensions, and membership in organizations based on diagnosis or cause of impairment (traffic accident associations, stroke associations, etc.) However, it is an open question how these types of institutional confirmation interact with or are interpreted in relation to the absence of disability confirmation in everyday social interaction.

## 7.4 DISCUSSION

While respondents readily acknowledged long term reductions in functional capacities due to illness or injury, i.e. impairments, most did not consider themselves as disabled or having a disability. The disability label was too big, too serious, too permanent, and perhaps too frightening to associate with. Respondents are oriented towards hope for improvement and living life as actively as possible. They were injured, not disabled. Negative stereotypes of disability provided personal defense against threatening changes in their self images. Wheelchairs represent the defining symbol of disability as respondents focused on mobility impairment. Elstad, Grue & Eriksen (2005) also found that self images of disability among persons with rheumatic disease were strongly connected to reduced mobility but that even among persons with reduced mobility only half regarded themselves as disabled.

Cognitive impairments appear to be highly stigmatizing and kept covered as well as possible as also found by Romsland (2009).

Respondents appear to have heightened common stereotypes of disability. They seem to have more extreme negative stereotypes of disability than we assume present in the general population. It is an open question whether our respondents are merely voicing common types and levels of stigma directed towards impaired adults. Perhaps their experience with impairment allows them to go beyond politically correct non-stigmatizing attitudes middle aged, able bodied persons might be expected to present in face-to-face interviews. It may be noted that our sample is not drawn from membership lists of disability organization, but most respondents were or have been members in organizations related to their diagnosis or type of accident. Little research has been conducted on disability stereotypes and the interface between disability stigma and age. It is reasonable to assume that stereotypes and their expression in social practice change over time and vary within the population. Disability stereotypes among impaired and able bodied persons alike warrant broader study.

Rejection of personal disability identity has been found in other studies. In Elstad, Grue & Eriksen (2005) as in our study, most respondents did not feel that their situation was serious enough to warrant the disability label. Taking on disability in midlife appears too difficult, too dramatic, and, in the opinion of most of our respondents, uncalled for. Respondents have been

able bodied well into adulthood. Their personal identities are anchored in embodied sameness, not difference. In an UK study of wheelchair users Watson (2002) found respondents did not choose to privilege disability as an identity, regarding themselves as ordinary people. Watson sees this as subtle means of resistance to the social norms and practices which place great weight on embodied difference and which operate with a disabled/non-disabled dichotomy. His respondents were conscious of embodied difference but rejected it as a defining dimension in their lives. Their concepts of normality were wide and flexible enough to accommodate their experiences.

When persons with long term reduced functional capacity decline to associate with disability, they contribute nothing to changing the social construct of disability and reducing its social stigma. If they continue to regard disabled others as people far worse off than themselves, passive end-of-the-liners without hope of improved functional capacity or development, they perhaps heighten negative stereotypes of disability for self and others. Were they to claim a disability identity they would add to both the size and the diversity of the disability community. Their perseverance, hopes for the future, and emphasis on continuing to live their lives to the full while attending to impairment, would, if combined with disability identity, challenge dominate disability concepts.

Dealing with disability is a continuing struggle – not a battle to be won once and for all (Zola 1982). Social images of disability have swung from impairment as personal tragedy and destitution to the supernormal, i.e. impaired persons who overcome all obstacles and accomplish far than ordinary able-bodied people. Perhaps there is room for a middle ground of sharing experiences of both continuity and discontinuity post-injury. There is clearly cause to dispel the identification of disability with passivity and hopelessness and there is clearly cause to dispel either/or conceptions of disability.

Our respondents have been socialized in a time when disability identities were perhaps to a larger degree than now an either/or identity. Being disabled or having a disability was rarely seen in combination with other identities. Rejecting self image of disability appears to help bridge the gap between pre- and post-injury identity. While negative disability stereotypes may serve as personal defense mechanisms, they may also have wider

personal and social consequences. Responsibility for challenging negative social stereotypes of disability do not rest solely on the shoulders of adults acquiring impairments, but neither are these persons exempt from responsibility shared by all. The causes and effects of negative disability images warrant further research.

## 8 Summary and discussion

This report is part of a study seeking to increase understanding of long term rehabilitation and reorientation processes of persons living with acquired impairments. The aim of the study is to present respondent experiences and reflections and identify from them lessons to be learned for the betterment of services and wellbeing of persons undergoing rehabilitation and reorientation after injury. It is based on qualitative interviews with a sample of ten middle aged, middle class respondents from the Oslo area who have suffered strokes or been injured in traffic or home accidents. Physical and cognitive impairments of varying degrees are represented.

Key concepts in this report are illness as biographical disruption, narrative construction of self, passing, covering, and disclosing impairment. The analysis is a retelling, interpretation, and thematically structuring of respondent accounts according to a rough chronological time line of post-injury experience. Post-injury lives often begin to take form in rehabilitation, most return to work after a period of rehabilitation and recovery, techniques for coping with impairment, changes in social relations, self image and self presentation, etc, develop over time after gaining first hand experience living with impairments. In practice there is much overlap in the timing involved in different themes and variation in sequences. Rehabilitation processes are ongoing efforts. Going back to work may start early. Effects on family and social life, self image, and storytelling occur at all stages along the way. The orderly progression of the thematical structure in the report does not do justice to the interdependence, interaction, and simultaneity of experiences.

### *Rehabilitation experiences*

Rehabilitation experiences and reflections are discussed distinguishing between primary, secondary, and late phase, user organized rehabilitation. Rehabilitation refers here to the efforts aimed at achieving recovery or improvement and better life quality post-injury. Rehabilitation is closely associated with hope for improvement. As long as there is hope for improvement, efforts aimed at improvement may be termed rehabilitation.

From the perspective of persons with acquired impairments rehabilitation is often a life long, post-injury project.

Discharge home from primary rehabilitation marks the beginning of secondary rehabilitation and a difficult phase of putting life back together. Home nursing services were not seen as able to deliver reliable service, particularly in families with small children. The stream of strangers entering the house was problematical. Personal assistances were preferred. Several respondents felt they were discharged to chaos and had to fight case officers and rules in various poorly coordinated public services and agencies. It could take years before services and benefits were in place to user satisfaction. Respondents battling with the system felt public agencies discouraged user initiative and influence, keeping people in their place as passive recipients. Respondents battling with the system were busy people in a hurry, knowledgeable about their rights.

In-patient programs a few years post-injury were major events in the lives of respondents with cognitive impairments. They had by then gained much first hand knowledge of living with embodied difference and could relate to information and interact with health professionals in a productive manner. They learned in the programs that the chaos they had been experiencing was normal, normal for their types of injuries. A health sports centre also provided morale boosts and showed that there were sport adventures to be had despite impairments.

Late phase user organized rehabilitation refers to the increased influence, knowledge, and responsibility people claim for their own rehabilitation over time. For most respondents it involved a degree of therapy shopping for services and therapists of traditional and alternative kinds, a trial and error process searching for good chemistry and effect. Middle class respondents had economic recourses to look outside the realm of publicly funded services. Taking pauses in therapy was an important aspect of user control. Shifting therapists, training activities, and taking pauses in training may be a means of upholding the promise of improvement. Training opportunities are everywhere for those who look, for example, physical training by taking the stairs instead of using the elevator. Some respondents trained energy conservation by extensive planning in daily life.



Several respondents are interested in returning to secondary rehabilitation facilities for new stays. Some want stimulation, some more systematic training and some respite from responsibility. Many have difficulty fitting into community based group programs. Perhaps tolerance for difference is greater in institutional settings. Variation in desired content shows the significance of tailor fitted programs and the need for careful screening and emphasis on group composition.

### *Back to work*

Going back to work signifies in some sense going back to normal. Work was central to the identity of middle aged, middle class respondents. Respondents talked about how early they returned to work and how important it was to demonstrate to self and others that one could still perform work post-injury. Several respondents returned to work before the full implications of their impairments were known. Starting back to work was an important learning process, a phase in learning about impairment effects, and creating a post-injury identity. In hindsight some respondents blamed early return to work for being detrimental to their health. There appears to be no reliable way of judging the right time for returning to work other than through trial and error.

Work became more important to some respondents as compensation for other activities they could no longer perform or because extreme focus on work was necessary for achievement post-injury. Some respondents successfully adapted their jobs environments and formed functional alliances with co-workers. Working life was, however, an ongoing battle for many. Initial job modifications were not sufficient for them to compensate for impairments in practice. Some experienced attempts at working as a series of failures. Work loads were not easily reduced proportionally to reduced work hours. Respondent ambitions and co-worker expectations were not easily altered. Impairments made working life more difficult, job modifications aside. Female respondents in general voiced less satisfaction than male respondents with co-worker relationships and job adaptations and more concern over the price work exacted on family and self. Problems in work life and exiting the work force lowered self esteem. Family support was often important in enabling respondents to work as much as they did.

Three respondents are working close to full time and plan to continue until normal retirement. One is combining work and a disability pension. Five respondents worked for some time and some degree but are currently receiving full disability pensions. Those who are receiving temporary disability pensions see these as extended sick leave benefits and a formal expression of hope that difficulties working will not be permanent. Opportunities for social participation for those unable to work, for instance in the volunteer sector, activity centers, etc. were important in structuring daily life and maintaining morale.

#### *Relations with family and friends*

A common response post-injury was to spend more time with close family members and give higher priority to family relationships. Whole families become impaired, not just individuals. Respondents are in webs of relationships with aging parents, siblings, spouses, children, and grandchildren. Respondents tried living family life as “normally” as possible. Respondents were particularly grateful for how their children have taken the upheaval in family life post-injury. For several respondents children were an important resource in rehabilitation, a source of continued motivation to try ones’ utmost. Respondents felt that showing children that life did not always precede as planned and that one can live a good life despite impairment are major contributions to children’s upbringing.

Impairments pose burdens and create tension within families. The division of labor within families is shifted with substantially larger responsibility placed on able bodied spouses for both household work and emotional support. Younger and older generations are affected when middle aged persons become impaired. Family life is challenging for most people. Counteracting added burden and reducing tension, impaired persons can give family life more attention than pre-injury and use their experiences with loss to become more empathic.

Participation in social and cultural activities was in general an important source of continuity between pre- and post-injury identity but most found their options reduced. The frequency and form of contact with friends were affected by impairment. Most respondents did not have the capacity or interest in maintaining pre-injury contact frequency with friends. There was

less contact, less social initiative and less in common post-injury. Large social circles are commonly regarded as resources, but reciprocating initiative is demanding. Impaired persons held on as best they could in social forms they did not fully master, often out of consideration for spouses. There seems to be little flexibility in their social circles for developing new forms for socializing. Respondents' social initiative declined in part as a consequence of impairment particulars, for instance, pain or reduced stamina. Lowered self esteem appears also to be an important factor.

There were underlying tensions in social relationships and dilemmas connected to encouragement and assistance. Friends often offered encouragements but encouragements were sometimes interpreted as being pushy and/or lacking understanding. Respondents testified to feeling responsible for comforting able bodied others who feel unease in the presence of impairment. Friendship networks remained stable despite less activity. Old friends thus helped bridge the biographical disruption of injury and represented an important source of continuity.

### *Coping techniques*

Three major means of managing impairment effects are discussed. Respondents relied on strategies of formulating small reachable objectives, positive thinking, and self care. The first two approaches were grounded in their upbringing and pre-injury experiences. Formulating small, reachable objectives assures personal significance to the goals and creates opportunities for experiencing success in reaching objectives. They keep the person moving in the right direction and give a sense of being on track. Positive thinking is a cognitive social approach to coping with and shaping impairment effects. Respondents focus on making good days and good stories. Positive thinking constructs hope for recovery and for wellbeing. It lets respondents rest in gratitude of fond memories and all that remains good in their lives. A key feature is the conviction that every experience can be of use. The third approach, self care, was learned over time when living with impairments was painful or difficult. Respondents focused on acquiring knowledge, understanding, and control of their bodies. They built themselves up by taking care of, and accepting, their bodies, balancing between doing too much and too little, and allowing themselves to put own welfare first.

These coping techniques were developed and refined in years of first hand experience living with impairments. It is important to note that coping techniques were firmly rooted in respondent biography and thus in themselves represent continuity despite disruption. The coping techniques contained the essence of motivation and perseverance necessary for meeting challenges of everyday life. They represent hard learned lessons and are perhaps respondents' primary message to newly impaired persons. They demonstrate the need for professionals working in rehabilitation to "see" the person and build on their biography in counseling.

### *Impairment narration*

Impairment narratives are critical for constructing the self and moving forward after a major biographical disruption. Narratives create coherence and bind others into communication. In our discussion of impairment narratives we distinguish between genesis narratives and performance of high and low dramatic content. Low drama injuries constitute special challenges in formulating credible narratives of impairment. When there is high drama to the injury, narratives have a solid structural base upon which to build. To sustain drama this structural base must be supported by energy and skill in the performance of the storyteller. Genesis narratives refer to distinct, distant events while narratives of impairment effects are ongoing stories. Our primary focus has been on respondent use of impairment narratives in everyday life. To what degree do respondents tell others of their impairments and how impairments affect daily life?

Most respondents have gone through a phase of telling about their injuries but conclude over time that they do not want to talk much about impairment effects. They do not want to draw attention to problems they are facing. Cognitive impairments in particular are kept hidden. Talking about impairment was seen by some to be associated with complaining or whining which was the last thing they wanted to be associated with. Talking too much about impairments can earn a person the label of being self centered. Self confidence and the feeling that one has something of interest to contribute to social conversation were negatively affected by impairment experiences. Other people were generally not thought to be interested in listening to impairment narratives. Credibility is particularly at stake in cases

of invisible impairments where there are no readily visible markers of injury. Non-disabled others often do not believe or comprehend the extent of injuries. Impairments particulars could affect storytelling performance making it difficult to attract and hold an audience irrespective of story content. Audience disbelief and disinterest is likely to lower narrator self esteem and reduce narrative performance capabilities. Impaired persons learn to silence stories involving impairment.

Impairment narratives may be silenced by choice and/or audience reception. Silencing may prevent talking “too much” about impairment and thus help social integration post-injury and help support preferred identities “untouched” by reduced functional capacity. Silencing impairment narratives may, however, also increase the likelihood of talking “too little” about embodied experiences and slow the integration of impairment into post-injury identity. Stories are told with and through bodies. Silencing embodied experience may in the long run estrange the storyteller from self and others. Social recognition of the efforts made to manage impairment in daily life was desired by several respondents, but unlikely to be given when narratives are silenced.

### *Disability identities*

Most respondents did not see themselves as being disabled or having a disability. They readily acknowledged long term reductions in functional capacities but did not regard these as being disabilities. They were injured, not disabled. Being busy, having high levels of achievement, and a good life despite functional limitations were key rationales for rejecting personal disability identities. The wheelchair is a powerful symbol and almost synonymous with disability for most of our respondents. As long as one could walk, disability identity was kept at bay. Reductions in functional capacity can be severe but not self defined as disabilities.

Our results indicate that disability is a highly negative identity status for middle aged, middle class persons with acquired impairments. Disability was associated with hopelessness and passivity, “*being parked*” and “*giving in*”. Rejection of a disability identity is an affirmation of hope for further recovery from injuries and a means of making one’s impairments smaller and less permanent. Negative stereotypes of disability appear to serve a

motivating function for persons with acquired impairments, a defense mechanism necessary for construction of preferred identities and continuity between pre- and post-injury identities. Rejection of a personal disability label seemed to bolster a vulnerable self esteem.

Socialized in a time when disability was an either/or status and disabled persons were segregated to the private sphere or institutions, our middle aged respondents have little connection with newer, more diverse meanings of disability. Our respondents have not had much opportunity to develop a disability identity in association with others in similar circumstances, nor, perhaps, have they seen much cause to do so. Most respondents were or have been members in organizations specific to their injuries, but membership does not appear to have generated identification with having a disability or being disabled.

When persons with long term reductions in functional capacity decline to associate with disability they contribute nothing to changing the social construct of disability and reducing its social stigma. Were they to claim disability identities, their perseverance, hopes for the future, and emphasis on living their lives to the full despite acquired impairments would challenge either/or concepts of disability and help dispel identification of disability with passivity and hopelessness.

#### *Life course timing*

An underlying premise of this study is that it matters at what age impairments are acquired. Our respondents were adults when injured. They had been able bodied in childhood and adolescence. They had been able bodied when choosing and completing their education and entering the labor market, finding partners and having children. They have thus not had to face disability discrimination in any of these highly formative stages of the life course. Respondents had many resources to manage impairments with mid-life positions in a web of family relationships being the most important. Midlife family positions represented continuity despite disruption and provided many respondents with strong motivation and support for rehabilitation. Respondents were oriented towards returning as much as possible to their pre-injury selves. Middle age persons well satisfied with their situation pre-injury are less apt to desire change and perhaps less apt to use impair-

ment as an opportunity for change beyond the minimum required by the particulars of their injuries. Most respondents continued to emphasize pre-injury life in self presentation. Abrupt versus gradual reduction in functional capacities also heightens the position of pre-injury life in self presentation.

### *Turning points*

Post-injury lives were marked with a series of turning points, events which stood out clearly as important in hindsight. Discharge home from primary medical rehabilitation reunited respondents with their families and home environments, beginning the integration of impairment into post-injury identity. Regaining one's driver's license and/or obtaining a suitably adapted vehicle gave back a freedom and flexibility of movement previously taken for granted. Going back to work was a major step in bridging pre- and post-injury life and getting back into mainstream society. New in-patient rehabilitation programs after a few years were turning points for respondents with cognitive impairments integrating professional and embodied knowledge of impairment effects. Activity and sports programs also provided major morale boosts. Turning points were identified in social interaction as respondents had to relearn social codes. Talking too much about injuries could cause others to lower their eyes and move away. The storyteller could be regarded as self-centered. For some respondents the biographical disruption initiated by injury became again manifest years later in exiting the work force after struggling to maintain a foothold. Turning points continue to emerge. For some respondents participating in the interview was, in itself, a turning point, helping to increase self insight and self esteem.

### *Respondent agenda*

Some respondents had a clear agenda in meeting with us, a message they wanted delivered further to health and service systems. One message was that neck lash injuries should be taken seriously from the start by health authorities to avoid long term debilitation. Another message for rehabilitation personnel was that hope is fundamental as motivation for rehabilitation and the source of healing and wellbeing. Hope should be nurtured rather than killed with "*professional realism*". A third message was the need to better the coordination, efficiency and flexibility of public services meeting

persons newly discharged from primary rehabilitation so that all newly injured persons will not have to struggle to claim their rights. Respondents wanted opportunities for continued contact and consultation with rehabilitation professionals as a safety net and safety valve for keeping on track and as a source of recognition and understanding. Clinically oriented feedback was outside the scope of this study, but desired by several respondents.

### *Enlarging the narrative room*

Most respondents found that telling their stories to the research team as a receptive audience gave them added insight into their own situation and added meaning to their experiences. Our job was to extract from respondent accounts what lessons there were to be learned in order to help others and increase understanding of living with impairment. The analysis would tell others of hard earned knowledge impaired persons carry with them in silence. Perhaps therefore our final conclusion is that narrative room needs enlargement. Impairment narratives in all their manifold should be encouraged rather than silenced. Telling/performing narratives is critical for self esteem, construction of coherence after biographical disruption, and inclusion in the social. The narrative room could be enlarged already from the start in primary rehabilitation with the introduction of impairment narratives and biographical accounts of living with impairments.

### *Questions for further research*

As with most studies questions for new research are generated in the course of analysis. There are always issues outside the scope of a study which call for more attention, perhaps different methods, other samples, etc. In this study we have identified the following areas as particularly warranting further research:

- \* Research into user empowerment and methods for supporting user initiative and responsibility in rehabilitation preparing users for what may be a life long project.
- \* Research into ways of lowering the personal cost of labor market participation for impaired persons to allow them to remain working as long as possible and research into the role of alternative forms for social



participation for persons unable to work, for example, opportunities within the voluntary sector, activity centers, etc.

\* Research into effects on family and support of families as a whole when a member is injured, i.e. support from rehabilitation counselors, relatives and friends, and school teachers in dealing with upheaval in family life, evaluation of services from perspectives of children, etc.

\* Research comparing coping strategies of different groups, e.g. different age groups, social classes, cohorts, etc. and research on the significance of biography in general. This would include comparative studies of abrupt injury versus gradual loss of functional capabilities and/or congenital impairments.

\* Research on the causes and consequences of silencing impairment narratives for the psycho-social wellbeing of impaired persons and the construction of post-injury identity, as well as research on disability stereotypes and the causes and effects of negative disability images.

# Sammendrag

Målet med denne studien er å få økt forståelse for mestring etter skader som medfører nedsatte funksjonsevner. Studien bygger på kvalitative intervju med ti middelaldrende personer som har opplevd brå endringer i funksjonsevner etter hjerneslag eller ulykker. Skadene varierer i type og alvorlighetsgrad. Rapporten drøfter langsiktig rehabiliteringsprosesser og erfaringer med å vende tilbake til arbeidslivet. Effektene av funksjonsnedsettelse for sosial interaksjon og familieliv, strategier for mestring og fortellinger om sykdomshistorien blir diskutert. En siste tema er selvbilde og funksjonshemming. I analysen vektlegges vendepunkter i rehabilitering og dagligliv, slik de har erfart det i årene etter skaden oppstod. Sentrale begreper i analysen er sykdom som biografisk brudd, narrativ selvkonstruksjon og normalitet. Rapporten er primært deskriptiv med utgangspunkt i ulike tematiske perspektiver på intervjupersonenes fortellinger.

Utskriving fra primær rehabilitering markerer ofte begynnelsen på en vanskelig tid, der bitene i livet settes sammen igjen etter skaden. Det kunne ta år før tjenester og trygdeordninger var på plass til brukerens tilfredshet. Over tid utviklet intervjupersonene økt innflytelse, kunnskap og ansvar for sin egen rehabilitering. Dette beskrives som 'brukerorganisert rehabilitering i senfasen'. For de fleste var rehabilitering etter skaden et livslangt prosjekt. Det består blant annet av organisert trening og "terapi-shopping", men også treningspauser og søken etter treningsmuligheter i dagliglivet. Intervjupersonene syntes det var behov for bedre koordinering av tjenester og større fleksibilitet i tolkingen av regler og retningslinjer for offentlige ordninger. Det ble gitt uttrykk for ønske om langsiktig oppfølging i rehabiliteringsprosessen. Betydningen av håp som kilde til utholdenhet, motivasjon og livskvalitet ble understreket.

Arbeid stod sentralt i våre intervjupersoners selvoppfatning. Alle bortsett fra én gikk tilbake til arbeidet etter skaden, i alle fall for en stund. Å komme tilbake til jobben var et skritt mot 'normal' tilværelse. Det representerte ny læring om egne funksjonsevner. For noen ble arbeidet ekstra viktig som erstatning for aktiviteter som ikke lenger kunne utføres. For andre ble

arbeidet en mer sentral del av livet fordi det krevde mye mer av deres krefter etter de ble skadet. Noen lyktes med tilpasningen til arbeidet og vil fortsette i jobben til pensjonsalderen. De fleste av våre intervjupersoner har sluttet i arbeidslivet – midlertidig eller permanent – fordi belastningene ble for store. Midlertidig uførepensjon kan sees som et formelt uttrykk for håp om at vanskelighetene ikke blir permanente. Å få en permanent uførepensjon etter mange års slit med å klare seg på jobb og hjemme kan oppleves som en velfortjent anerkjenning av ens anstrengelser. Selvfølelsen kan imidlertid påvirkes negativt både av problemer med å klare jobben og av å måtte slutte i arbeidslivet.

Hele familier blir funksjonshemmet, ikke bare enkeltindivider. Intervjupersonene prøvde å leve et så vanlig familieliv som mulig. Familieforhold og egen rolle i familien virket som motivasjonskilde i rehabiliteringen. Middeldrende middelklassepersoner har mange ferdigheter og ressurser som kan være til nytte i mestring av funksjonsnedsettelse. Den viktigste ressursen er trolig selve veven av familierelasjoner som kjennetegner livsfasen 'midt i livet' – barn, barnebarn, ektefelle, søsken, gamle foreldre, m.v. Familierelasjoner representerer kontinuitet til tross for omveltning i helseforhold, samt mulighet til praktisk hjelp og emosjonell støtte. Intervjupersonene var spesielt takknemlige for den måten deres barn hadde taklet omveltningen i familielivet på. Flere intervjupersoner hadde mindre sosial kontakt, mindre sosialt initiativ og mindre til felles med gamle venner etter skaden. Samværsformer som var vanlige før skaden kunne vise seg å være for krevende etter skaden, uten at det dermed var lett å utvikle nye kontaktformer. Spenninger og usikkerhet i møter med funksjonsfriske ble rapportert.

Tre strategier for mestring av funksjonsnedsettelse drøftes. En strategi er å sette små, oppnåelige mål for seg selv. Det gir mange muligheter for å lykkes i å nå målene. Positiv tenking eller 'kognitive egenterapi' er en annen strategi der en skaper gode dager og gode historier som gir næring for håp om bedring og høyere livskvalitet. Den tredje strategien, å ta vare på seg selv, innebærer å lytte til og godta kroppen og å finne en balanse mellom å gjøre for mye og for lite. Mestringsstrategier ble knyttet til oppvekst, livshistorie før skaden, og erfaringer underveis med hensyn til hva som bidro til rehabilitering og økt velferd.

De fleste intervjupersonene konkluderte over tid med at de ikke hadde lyst til å snakke mye om skadene med venner eller kolleger. De ønsket ikke å trekke oppmerksomheten mot de problemene de møtte i hverdagen. De ville unngå at andre skulle betrakte dem som sutrete eller selvsentrerte. De opplevde heller ikke at andre stort sett var interessert i deres fortellinger om skadenes innvirkninger på livet. Det kunne føre til taushet rundt viktige deler av deres erfaringer. Det er spesielt problematisk for personer med usynlige funksjonsnedsettelse å få andre til å forstå deres problemer. Selve funksjonsnedsettelsen hadde i noen tilfelle negative innvirkninger på fortellerferdighetene.

Nedsettelse av funksjonsevner kan være omfattende uten at den enkelte dermed definerer dette som 'funksjonshemminger' og uten en ser på seg selv som 'funksjonshemmet'. De fleste så på seg selv som skadet eller syk, ikke som funksjonshemmet. Mye aktivitet, gode mestringsmåter, håp om bedring, samt et godt liv til tross for funksjonsnedsettelse var hovedgrunner til å avvise en identitet som funksjonshemmet. Intervjupersonene var opptatt av å gjenvinne så mye som mulig av tapte funksjonsevner. De ville gjenskape så mye som mulig av sitt liv slik det var før skaden. Det biografiske bruddet skaden medførte, varierte i størrelse og varighet. De fleste fant måter å rekonstruere kontinuitet på til tross for de endringer funksjonsnedsetter skapte i dagliglivet.



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