MASTER´S THESIS IN HEALTH SCIENCE

WHAT MAKES LIFE WORTH LIVING? LIFE SATISFACTION AFTER MODERATE AND SEVERE TRAUMATIC BRAIN INJURY.

ARTICLE 1: Factors influencing Life Satisfaction in the years after moderate or severe Traumatic Brain Injury.

ARTICLE II: What makes life worth living? A Phenomenological study of satisfied individuals 5-7 years after Traumatic Brain Injury.

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Preface

«Among all the joys in life, the greatest joy we can experience is to discover our own inherent possibilities and talents, because what we discover is something we can´t lose, something we can manage ourselves and something that we do not need to thank others for».

Bente Clod, Danish author

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I also wish to express my gratitude to colleagues and former colleagues at the Department of Acquired Brain Injury at Trondheim University Hospital. You have all shared the passion of enhancing the life and health of individuals after acquired brain injury and inspired me to write this thesis. A special thanks to Tor Ivar Hansen, Thorbjørn Brandt and Monica Buseth for insight, questions and feedback and a big thank you to Otto Aarhaug, research assistant in the "Head Injury Project", for helping me in the recruitment process. Also, I want to acknowledge former patients that have provided me with insight on life after TBI through the years.

Lastly, my deepest gratitude is reserved for my family. Dear Christina, Mie Solveig and Marius, thank you for not kicking me out of our house! You´re providing me with much needed support, either through shorter or longer breaks playing with a bouncing ball or an ant, or by helping out with the everyday demands that I have not had time to attend to. Also, a big thank you to my mother, Ellen, for always being there for all of us.

Main introduction

I have always been interested in the perspective of what creates health, and how this can add to the perspective of avoiding sickness and disease. Working with individuals who experience major alterations in their lives I have learnt a lot about what they have come to see is important. This master thesis is an elaboration of these perspectives and of great interest for my professional career.

The master thesis consists of two articles. The first article provides an overview of the literature on life satisfaction after moderate and severe TBI. It points to a number of factors and discuses which factors show the most influence. The literature review is the background for the phenomenological article. It looks at 7 satisfied Norwegian adults 5-7 years after TBI exploring what they think being satisfied with life is all about. The phenomenological article also discusses the findings to see how they can be understood through Antonovsky´s sense of coherence. Hopefully, the thesis can provide some insight and contribute to further development so that researchers and practitioners can continue working towards a long term goal of creating a satisfying life for as many individuals as possible after TBI.

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Submitting the studies

Both articles in this thesis are written for the journal Disability and Rehabilitation. Article 1 belongs under the heading «Perspectives in Rehabilitation» while article 2 belongs under the heading «Research Paper».

Disability and Rehabilitation seeks to encourage a better understanding of all aspects of disability and to promote rehabilitation science, practice and policy aspects of the rehabilitation process.

In Disability and Rehabilitation there is no word limit, but succinct and well-constructed papers are preferred.

Word count for article 1: 3984

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ARTICLE I

Perspectives in rehabilitation

Factors influencing life satisfaction in the years after moderate or severe traumatic brain injury.

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Abstract

Objective: The purpose of this study is to review the literature on factors influencing life satisfaction for adults after a moderate or severe traumatic brain injury.
Methods: Pubmed, PsycInfo, SweMed+ and Scopus were queried for studies pertaining to life satisfaction for adults after a moderate or severe TBI. Additional studies were identified through searching bibliographies of related publications.
Results: Titles were read for all matches in the searches, and abstracts were read for all matches exploring satisfaction with life. 42 articles were chosen for discussion in this review. The results show that life satisfaction is negatively influenced by cognitive functioning and depression, and positively influenced by productivity, participation in leisure activities, social integration, higher age and personality. Two important findings are that work status after TBI influences life satisfaction while work status prior to TBI does not, and that motor functioning does not influence life satisfaction directly in the longer term.
Conclusion: Life satisfaction is a heterogenous concept involving numerous factors. When planning interventions after TBI, rehabilitation professionals should acknowledge the importance of an individual approach exploring meaningful activities and targeting social participation to influence life satisfaction.

Keywords: Traumatic brain injury, head injury, TBI, life satisfaction, satisfaction with life, long term outcome

Introduction

A traumatic brain injury (TBI) is defined as ”an alteration in brain function, or other evidence of brain pathology, caused by an external force” [1]. TBI is commonly classified by the Glasgow Coma Scale into mild, moderate or severe TBI [2]. Severity of injury is associated with prevalence of negative outcomes and symptoms, whereas prevalence is highest among those with moderate or severe TBI [3, 4]. TBI occurs twice as often in males as in females, and in Europe TBI accounts for the greatest number of total years lived with disability resulting from trauma [5]. Falls are the leading cause of TBI in northern Europe and in the US, while traffic accidents make up the majority of TBI cases in southern Europe [6]. Improvements in acute care and early intervention have led to decreased mortality, leading to more people surviving, but with a life-long disability [7] This leads to increased economic burden for society [8].

Disturbances of cognition, mood, behaviour and changes in a person´s character or personality are some of the most debilitating aspects of TBI [9]. In a review of long term consequences after TBI, Wilson, Stewart [10] state that disability, limitations to activity, limitations to societal participation, cognitive deficits, emotional problems, behaviour change, increased risk of comorbidities and shorter life expectancy are long term consequences of TBI. These outcomes are not fixed, but improvement and deterioration may occur many years after injury. Common changes after TBI are decreased cognitive function [11, 12, 13, 14, 15], increased prevalence of depression and loneliness with a high burden placed on relatives [16, 17, 18], fatigue [11, 13, 19] , lack of awareness [20, 21], communication difficulties [11, 22], behavioural changes [9, 11, 23] and changes in emotional functions [11, 23, 24]. In a metasynthesis of qualitative research, Levack, Kayes [25] reviewed 23 studies representing the lived experience of 263 people with TBI. The time perspective in this process is not set, but it is emphasized that recovery from TBI is not a linear path from loss and suffering to recovery and reconstruction but a lengthy, non-linear, iterative process. They found eight

interrelated themes describing the experience of life with TBI; The experience of loss is divided into three; 1) disconnect with pre-injury self, 2) mind/body disconnect, and 3) social disconnect. These experiences lead to 4) emotional sequelae. In coping with their situation, people with TBI draw on 5) internal and external resources to progress from their losses. 6) Reconstruction of identity, which includes acceptance of their new self and 7) reconstruction of their place in the world, which includes the support by family and friends. Through this they get to a 8) reconstruction of personhood where they feel like a complete individual and are also accepted as one by other people. [25].

Life satisfaction is viewed as an independent dimension of the overarching term subjective well-being. Well-being consists of three dimensions; Positive affect, negative affect and life satisfaction. While positive and negative affect is about people´s evaluations of the events that occur in their lives, life satisfaction refers to an individual´s cognitive appraisal of his or her overall life. Life satisfaction is a complex interplay of cognition, culture, personality, goals and resources, and the objective environment [26]. What separates life satisfaction from quality of life is that it assesses an individuals' conscious evaluative judgment of his or her life by using the person's own criteria [27].

Major life events (like a TBI) can cause life satisfaction to deviate from an equilibrium state that is unique to each individual [28], but people often adapt their goals to what is possible for them [29]. After TBI, individuals typically report lower life satisfaction than comparison groups [30, 31, 32]. Moreover, significantly lower life satisfaction has been found for moderate to severe TBI compared to mild TBI [31].

Understanding the long-term consequences after TBI is important because this knowledge will allow identification of risk factors for poor outcomes and appropriate targeting of healthcare resources and interventions [10]. A higher level of life satisfaction is considered as a long-term goal after TBI [33], and identifying factors that predict long term

outcomes are imperative to improve life satisfaction after TBI [34]. Studies on long term trajectories after TBI show that for some individuals life satisfaction differs over time [35], which suggests that life satisfaction can be increased. Therefore, studies on factors that can enhance life satisfaction are of great importance. To deepen our insight regarding the individual level characteristics that promote or prevent adaptation, this study will review the literature on factors influencing life satisfaction after moderate or severe TBI.

Method

This article is a literature review [36]. Searches were conducted by the author in the following databases: Pubmed, PsycInfo, Scopus, and SveMed+. The search terms used were combinations of "life satisfaction" or "satisfaction with life" and "traumatic brain injury". This search was carried out between October 24th 2017 and May 22nd 2018. Titles were read for all matches in the searches, and abstracts were read for all matches exploring satisfaction with life or using satisfaction with life scales for adults with moderate or severe TBI. Inclusion criteria for this study included:

- Language of publication restricted to English;
- Studies published in peer review journals;
- Studies on adults with moderate or severe TBI.

Exclusion criteria for this study included:

- Non-English language publications;
- Studies on paediatric TBI;
- Research on mild TBI only;
- Studies on acquired brain injury;

- Studies on quality of life[1];

[Insert figure 1 here: Flow chart]

580 potentially relevant abstracts were found from the initial searches of the journal databases in October and November 2017. All abstracts were assessed and analysed by the author. 228 abstracts were immediately excluded as per the inclusion criteria. The remaining 352 abstracts were analysed for relevance, with 319 excluded as they did not involve life satisfaction, traumatic brain injury or adults. Many of the abstracts also were found in more than one of the journal databases. A further 7 abstracts were included from cross referencing the papers found. A supplementary search was conducted May 15th 2018 in one of the databases (Psycinfo) to include publications from 2018, resulting in a further 2 abstracts included. Finally, 42 papers were chosen for discussion in the review.

Results

[Insert table 1 here: Studies on life satisfaction in moderate and severe TBI]

34 of the 42 studies chosen were US studies, and 14 of these were from the same database (TBIMS), The remaining 8 studies were from countries in Europe.

[Insert table 2 here: An overview of life satisfaction measurements]

The International Classification of Functioning, Disability and Health (ICF) classifies health-related function and dysfunction in a biopsychosocial perspective as a complex interaction

[1] Studies comparing life satisfaction and quality of life were included.

among biological, social and contextual factors of the individual and the environment [37]. The ICF focuses on body functions and structures (impairments), activities (limitations) and participation (restrictions). Contextual factors are divided into categories of personal and environmental factors. Challenges in all of these domains might affect life satisfaction. The following section will present the results through the factors of the ICF.

Body functions and structures (impairments)

Injury severity

Findings on the influence of injury severity on life satisfaction in individuals with TBI are mixed; Several single studies show no significant relationship between injury severity and life satisfaction [31, 38, 39, 40], while a few studies show that greater injury severity predicts lower life satisfaction [41, 42, 43, 44]. Also, Wood and Rutterford [42] found that injury severity as an outcome predictor reduces as time from injury progresses. In a meta-analysis on TBI outcome, measures of injury severity are most weakly associated with measures of satisfaction of life, indicating no relationship between the two [4].

The passage of time

Cicerone and Azulay [32] found that time since injury made a significant contribution to global life satisfaction at least 6 months after TBI. Also, Wood [45] states that with the passage of time, many individuals with TBI make adjustments to compensate for early disability, leading to a reduction in social handicap with a corresponding improvement in life quality and personal satisfaction. In a study of 67 individuals 6-15 years after TBI, Jacobsson, Westerberg [46] found that time post injury was more influential than sex, age at injury and injury severity in explaining life satisfaction. Research on the same subjects but with a different life satisfaction measurement found that time post TBI was not related to life satisfaction [31].

Studies on life satisfaction trajectories show a decrease early after TBI [30, 47, 48] an increase from year 1 to approximately year 10, and then a decrease from year 10 below the initial year 1 measure 20 years after injury [49]. Williamson, Elliott [50] argue that time is no longer a significant predictor 10 years after TBI. The different studies all report high variability in life satisfaction scores among the participants [30, 31, 47, 48, 49, 50]. Four life satisfaction trajectory groups have been suggested; stable high satisfaction, stable dissatisfaction, initial satisfaction declining and initial dissatisfaction improving [35].

Motor functioning

One cross-sectional study [51] found better functional outcome 3 months and 1 year after TBI to be a significant predictor of life satisfaction. Also, longitudinal studies show that motor functioning at rehabilitation discharge is associated with life satisfaction 1 year after TBI, but not after 2 years [52], that motor functioning the first 5 years after TBI is associated with life satisfaction [47], and that greater motor functioning is associated with increasingly positive life satisfaction trajectories over 10 years [50]. However, three different longitudinal studies show that motor functioning did not significantly predict life satisfaction 1 to 5 years after TBI [35, 38, 40]. In a meta-analysis of prospective studies functional outcome is the strongest predictor of global outcomes 1 year after TBI, but weakly associated with 1-year quality of life (including life satisfaction scores) [4].

Cognitive functioning

Studies have observed a positive relation between better cognitive functioning and higher life satisfaction [35, 40, 46, 53]. Positive relations between low life satisfaction and low cognitive functioning is also reported [54]. This involves decrease in the ability to think and remember [41]; lack of reminding in self-care [55]; impairment in working memory [42]; and social communication skills problems [56, 57].

Among 96 patients with TBI, impaired self-awareness at rehabilitation admission was an important factor in determining life satisfaction scores at acute rehabilitation discharge [58]. However, Goverover and Chiaravalloti [39] argue that self-awareness is not significantly associated with subjective self-reports of life satisfaction.

Depression

Frequency of depressive symptoms is inversely correlated with life satisfaction [39, 58, 59]. Life satisfaction scores show progressively and significantly worse outcomes from no depression, to minor depression, to major depression [60]. Absence of depressive symptoms is a significant predictor of higher life satisfaction [51, 52], although absence of depression does not guarantee higher scores [61]. High life satisfaction is strongly associated with fewer emotional disturbances [46], and life satisfaction is negatively related to emotional distress [52, 62]. Low life satisfaction is associated with low scores on mood and affect [54]. In a longitudinal study, Juengst, Adams [35] found that depressive symptoms were strong predictors of life satisfaction trajectories the first 5 years post TBI.

Other impairments

In a state-wide population-based survey in the US, Whiteneck, Cuthbert [63] found that TBI may serve to both cause disability directly and exacerbate the influence of other etiologies. Other factors influencing life satisfaction in single studies are preinjury conditions (psychiatric and substance use problems, severe sensory dysfunction, learning problems or prior TBI) [38], preinjury history of substance abuse [52], history of mental health service utilization [34], and no associated spinal cord injury [53]. In a study of 2701 adult Coloradoans, Whiteneck, Cuthbert [43] found that approximately twice as many individuals reported activity limitations and low life satisfaction after TBI if they were not hospitalized.

Activities (limitations) and participation (restrictions)

Meaning in life

Participation in meaningful activities like home, work or leisure activities or engagement in meaningful life roles such as worker, lobbyist and friend is predictive of greater life satisfaction [35, 44].

Low life satisfaction is associated with low purpose and meaning in life [54]. Also, among Veterans, having an active duty status at the time of injury predicts life satisfaction 1 year after TBI, and the authors suggest that a possible explanation might be that the injury carries meaning because it was sustained while serving one´s country [34].

Return to work after TBI

Individuals who are productive after TBI have higher life satisfaction [31, 32, 53, 55, 64, 65, 66]. In a study by Machamer, Temkin [41] 6 months after TBI the greatest decrease in life satisfaction was because of the decreased ability to work and receive adequate income. Cicerone and Azulay [32] found that greater life satisfaction for individuals after TBI was associated with working part-time or being a student or a volunteer, intermediate satisfaction for those working full-time, and the lowest life satisfaction among those who were unemployed.

Research on the relationship between being productive prior to TBI and life satisfaction after TBI show mixed results. Davis, Sherer [38] found that preinjury functioning (education, productivity/employment) accounted for 2,9 % of the variance in life satisfaction 1 year after TBI. Williamson, Elliott [50] found that higher earnings the last year before injury and fewer weeks in paid competitive employment predicted higher life satisfaction. Gause, Finn [34] found that Veterans who were employed or enrolled in school at the time of injury were found to have significantly lower satisfaction 1 year after TBI.

Leisure/recreational activities

Machamer, Temkin [41] found that the greatest decrease in life satisfaction after TBI was in the ability to participate in leisure and recreational activities, and Cicerone and Azulay [32] found that leisure/social activities contributes to global life satisfaction. In an analysis of 5573 interviews, Philippus, Mellick [67] found attendance at religious services to be associated with fewer depressive symptoms, more frequent social participation, and greater satisfaction with life 1, 5, and 10 years after TBI.

Social integration

More than 1 year after TBI social integration is a significant, unique predictor of life satisfaction [66]; 2 years after TBI current social integration is associated with life satisfaction [52]; and 6-15 years after TBI high life satisfaction is strongly associated with social participation [46]. Also, life satisfaction is positively associated with community involvement [62].

Environmental factors

Marital status

Regarding marital status, one study found that singleness is significantly associated with decreased life satisfaction [50], while other studies found that being married or cohabiting influence life satisfaction [31, 34, 66]. Johnson, Resch [48] found no significant relationship between marital status and life satisfaction.

Social support

A few studies have looked at whether social support from others influences life satisfaction. Higher family satisfaction is associated with increases in life satisfaction for individuals with less functional impairment [48]. Social support perceived by caregivers moderates the adverse effects of TBI on life satisfaction in individuals with TBI [68].

Physical surroundings

Considering physical surroundings 1 year post TBI, transportation, the surroundings (lightning, noise, crowds), government policies, attitudes, and the natural environment (temperature, climate, terrain) were the environmental barriers with the greatest reported impact. However, the reported impact of barriers was relatively low (did not surpass a value of 1.5 out of a possible 8) [69].

Personal factors

Personality factors

Rutterford and Wood [70] suggest that personality factors (self-esteem, extroversion, and lack of neuroticism) significantly influence life satisfaction and other long-term outcomes more than 10 years after TBI. In a study among 65 persons with mild complicated to severe TBI, hope, zest, humour and perseverance are among the strongest predictors of life satisfaction [71]. Self-efficacy predicts satisfaction with life [32, 70, 72]. Jacobsson, Westerberg [64] suggest that individuals own perception of the TBI has a strong influence on life satisfaction. Sense of coherence (SOC) has been shown to be strongly associated with life satisfaction among persons with TBI [46], and the relationship between life satisfaction and SOC has been suggested as being bidirectional, i.e., a strong SOC might lead to high life satisfaction, and vice versa [73]. Higher levels of resilience were related to greater life satisfaction 3, 6, and 12 months after TBI [74].

Age

Older age is a significant predictor of life satisfaction [46, 50, 51, 53]. Age at time of injury is significantly related to a few of the domains in life satisfaction [31]. In a US population 5 years after TBI dissatisfaction with life was stable until 30 years of age, whereas dissatisfaction increases peaking in the age group 40-49 years old before dissatisfaction

decreases steadily as people get older [75]. Juengst, Adams [35] found that those over 60, when compared with those under 30, were most likely to have high satisfaction and were more likely to have improving satisfaction, even if it was initially low. Gause, Finn [34] found that older individuals reported lower satisfaction with life, but this is not necessarily a contradictory finding considering a low median age (27 years) in their population (Veterans). On the other hand, Resch, Villarreal [47] found no significant relationship between age and life satisfaction trajectories in the first 5 years following TBI.

Sex

While Cicerone and Azulay [32] found that sex makes a significant contribution to global life satisfaction at least 6 months after TBI, a number of studies show no relationship between the constructs at different time points post TBI [31, 35, 47, 50, 76].

Minority populations

In a literature review, Arango-Lasprilla and Kreutzer [77] found 2 out of 4 articles documenting racial disparities in quality of life/life satisfaction after TBI that were disadvantageous to minorities in relation to whites. In a longitudinal study, Williamson, Elliott [50] found that black race was associated with lower life satisfaction, and that their life satisfaction decreased over time whereas white participants´ life satisfaction increased. Pierce and Hanks [66] also found a significant correlation between ethnicity and life satisfaction.

Education

Considering education, the findings are mixed: Anke, Andelic [51] found that low education predicted higher life satisfaction, contrary to prior studies showing that higher education predicts higher life satisfaction [50]. Juengst, Adams [35] found no relationship between education level and life satisfaction.

Discussion

The studies described herein have all shone light upon the myriad of factors that might influence life satisfaction. The findings in this study support that outcomes in TBI are not fixed long term, but both improvement and deterioration can occur many years after injury [10]. For most factors their relationship with life satisfaction is inconclusive because of mixed results or few studies, but this study shows that life satisfaction is negatively influenced by cognitive functioning and depression, and positively influenced by productivity, participation in leisure activities, social integration, higher age and personality factors.

Regarding body functions and structures, two factors influencing life satisfaction stand out: Cognitive functioning and depression. Better cognitive functioning and fewer depressive symptoms are shown to be positively related to life satisfaction while decreased cognitive functioning and more depressive symptoms are negatively related to life satisfaction. While Individuals own perception of their TBI have a strong influence on life satisfaction [64], it can be complicated by impaired self-awareness. Impaired self-awareness after TBI is frequently reported, especially after severe TBI [20], and has been suggested as a mediator for life satisfaction in some of the studies in this literature review. It is important to note that life satisfaction is a person´s subjective evaluation of life as a whole, and that lack of awareness does not invalidate one´s subjective evaluation of life satisfaction [66] while, on the other hand, acknowledging that impaired self-awareness might mediate results. An example is from the studies by Mailhan, Azouvi [78] and Jacobsson, Westerberg [46] where impaired self-awareness has been suggested to mediate injury severity´s influence on life satisfaction. Research on life satisfaction after TBI could increase validity by including measurements on impaired self-awareness or by using qualitative approaches.

No association between motor functioning and life satisfaction in the long term after TBI was surprising. A suggested explanation is that motor function might have an indirect effect rather than a direct effect; decreased mobility might reduce individuals´ ability to

participate in meaningful activities [35, 40]. Also, the individuals included in one of the studies had higher levels of functional independence than individuals not participating in the study, which might have influenced the relationship [38].

In the activities and participation section, participation in meaningful activities like work, leisure and being a friend influences life satisfaction. An important finding is that work status after TBI influences life satisfaction to a greater extent than work status prior to TBI. In a study of the components of the ICF, Pierce and Hanks [66] found that participation was the strongest predictor while activities were a significant, but weaker, predictor of life satisfaction, and that the only individual variables evaluated that were significant predictors of life satisfaction were social integration and productivity. This is in line with other findings in this study. Payne, Hawley [54] argues that meaningful activity is key to developing life satisfaction and a sense of contribution to society, and that future research should investigate the drive and motivation required to take part in productive, meaningful activity despite challenges resulting from a TBI.

Regarding personal factors, all the studies on personality variables included in this review show an influence on life satisfaction. Since there are few studies on each construct no conclusion can be drawn on their individual influence on life satisfaction, but the number of personality variables suggest that there is a relation. Personality factors, strengths, self-efficacy, sense of coherence and resilience were found in this literature search, and more knowledge about their influence on life satisfaction is welcomed. Older age is also a significant predictor of life satisfaction.

Limitations and directions for future research

A number of methodological issues were encountered during this review that warrant attention. The literature search and exclusion of titles was performed by one person only. Findings of the review should be interpreted with caution and serve as an overview of the

present literature on TBI and life satisfaction. The quality of the studies included has not been systematically assessed but included if they reported findings on possible influences on life satisfaction.

34 of the 42 studies chosen were US studies, and 14 of these were from the same database (TBIMS). The remaining 8 studies were from countries in Europe. Caution has to be paid when translating findings to other healthcare systems.

The variety of predictor and outcome variables used in the different studies is notable. Life satisfaction, severity and functional outcomes were measured by a variety of instruments. Regarding life satisfaction, the majority of studies (81%) uses the Satisfaction With Life Scale (SWLS) which has been found to be a venerable measure of life satisfaction [61].

This literature review adds knowledge regarding the individual level characteristics that promote or prevent life satisfaction. More research is needed focusing on how promoting factors can be enhanced and preventing factors can be avoided, and on who benefits from which factor. The heterogeneity of TBI and the myriad of factors influencing life satisfaction also suggest that qualitative studies might add knowledge to the complexity of life after TBI.

Conclusion

This literature review shows that life satisfaction is negatively influenced by cognitive functioning and depression, and positively influenced by productivity, participation in leisure activities, social integration, higher age and personality. Two important findings are that work status after TBI influences life satisfaction while work status prior to TBI does not, and that motor functioning does not influence life satisfaction directly in the longer term. When planning interventions after TBI, rehabilitation professionals should acknowledge the importance of an approach exploring what is meaningful for the individual and targeting social participation to influence life satisfaction.

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Declaration of interest

No potential conflict of interest is reported by the author.

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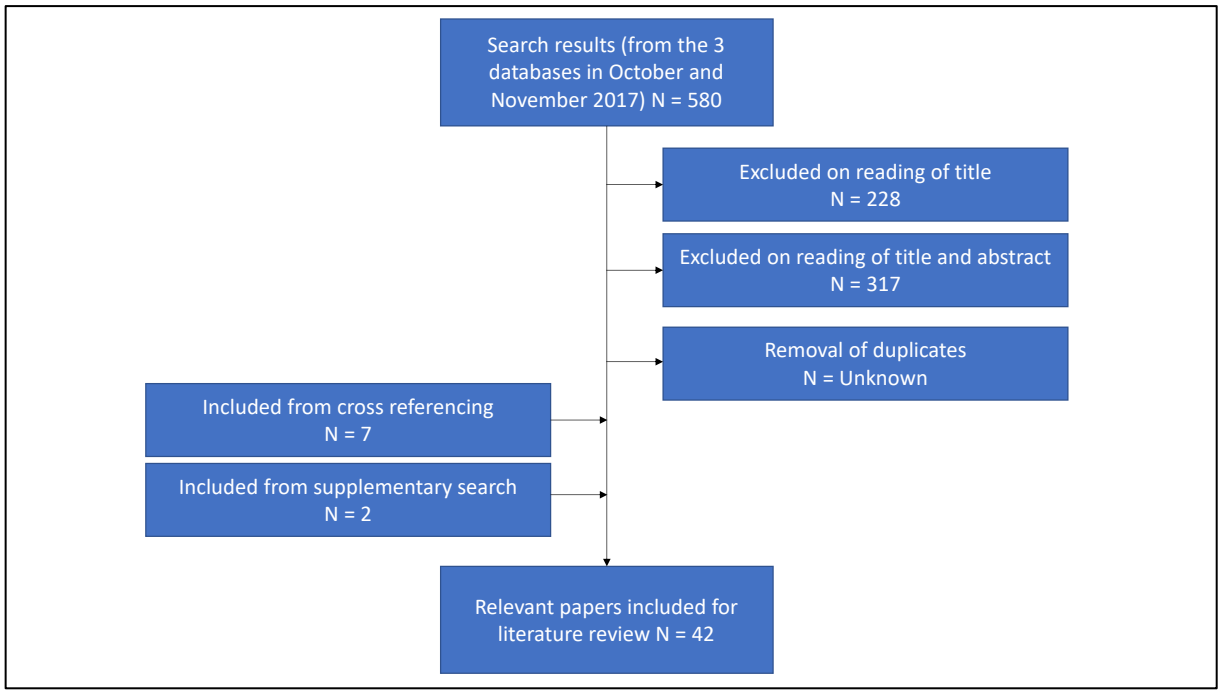
Appendix A: Flow chart for papers included

Figure 1: Flow chart for papers included



Appendix B: Studies on life satisfaction in moderate and severe TBI

Table 1: Studies on life satisfaction in moderate and severe TBI

Authors	**Year of publication**	**Participants**	**Design**	**Country**	**Life satisfaction measure**	**Other measures**	**Factors influencing life satisfaction**
Anke, Andelic et al.	2015	163 individuals in the first year after severe TBI	Prospective national multicentre study	Norway	SWLS	GOSE Rivermead HADS	Older age Low education Better functional outcome Absence of depressive and postconcussion symptoms
Arango-Lasprilla, Ketchum et al.	2009	3368 individuals with moderate to severe TBI	Retrospective study	US (TBIMS)	SWLS	GCS FIM DRS Length of PTA	African-Americans have poorer life satisfaction than Caucasians and Asians 1 year post TBI
Braden, Cuthbert et al.	2012	74 individuals with moderate to severe TBI one year or more post injury	Observational cohort study	US	SWLS	HLP-II SRAHP BHPAD SF-12 PRQ-a PWS PART-O	Frequency of engaging in health promoting behavior Self-efficacy Reducing barriers to health
Cicerone & Azulay	2007	97 individuals with mild, moderate or severe TBI 6 months or more post injury	Cross-sectional study	US	SWLS	CIQ QCIQ PQOL TBI-SE	Gender Time since injury Productivity Perceived self-efficacy (particularly for cognitive symptoms)

							Satisfaction with leisure activities
Corrigan, Bogner et al.	2001	218 patients 1 and 2 years post injury	Prospective, longitudinal	US	SWLS	FIM GCS MMSE CIQ	No history of substance abuse preinjury Having gainful employment at time of follow-up Motor independence Social integration Absence of depressed mood
Dahlberg, Hawley et al.	2006	60 individuals 1-21 years post mild, moderate or severe TBI	Cohort study	US	SWLS	SCSQ-A CHART-SF CIQ PFIC	Social communication skills deficits Decreased societal participation
Dahlberg, Cusick et al.	2007	52 individuals 1 year or more post TBI	Randomized control study	US (TBIMS)	SWLS	PFIC SCSQ-A GAS CHART-SF CIQ	Receiving social communication skills training leads to increased life satisfaction
Davis, Sherer et al.	2012	444 individuals 1 year post moderate or severe TBI	Secondary analysis of prospective, longitudinal registry	US (TBIMS)	SWLS	FIM	Preinjury functioning Preinjury condition Injury-related variables not significant Demographic variables not significant
Evans	2005	96 inpatients with TBI	Inception cohort	US	SWLS	ISA DRS	Depression inversely correlated with depression
Gause, Finn et al.	2017	278 individuals (veterans) 1 year or more post	Prospective observational cohort study	US (TBIMS)	SWLS	GCS FIM Substance misuse	Age Marital status Preinjury employment status

		mild, moderate or severe TBI				Mental health history	Preinjury mental health history Active duty status at time of injury
Goverover & Chiaravalloti	2014	30 individuals 1 year or more post mild, moderate or severe TBI	Cross-sectional survey	US	SWLS	AQ SF-12 MFQ CMDI	Depressive symptomatology Self-awareness not significant
Hanks, Rapport et al.	2014	65 individuals with mild, moderate or severe TBI	Prospective study with consecutive enrollment	US	SWLS	CIQ DRS MCIRS PANAS VIA-IS WTAR	Positive attributes (hope, zest, future orientation, optimism, perseverance, humor)
Hart, Brenner et al.	2011	1570 individuals 1 year post injury	Observational prospective study with a 2-wave longitudinal component	US (TBIMS)	SWLS	FIM PHQ-9 PARTO GCS-E	Life satisfaction progressively and significantly worse from no depression, to minor depression, to major depression
Hart	2005	94 individuals with moderate or severe TBI	Prospective, 2 group longitudinal study	US	SWLS	CIQ NFI-R	1 year post-TBI African-Americans and Whites did not differ in life satisfaction
Jacobsson & Lexell	2013	67 individuals 6-15 years post mild, moderate or severe TBI	Cross-sectional, compared with reference sample	Sweden	LiSat-11	Demographic factors	Marriage/cohabiting Being productive
Jacobsson , Westerberg et al.	2010	67 individuals 6-15 years post	Cross-sectional, compared with reference sample	Sweden	SWLS	SF-36	Own appraisal of the impact of the TBI Being productive

		mild, moderate or severe TBI					
Jacobsson, Westerberg et al.	2011	66 individuals 6-15 years post mild, moderate or severe TBI	Cross-sectional, compared with reference sample	Sweden	SWLS	MPAI-4 SOC-13	A strong sense of coherence Emotional factors Social participation Time since injury
Johnson, Resch et al.	2010	609 individuals the first 5 years post moderate, serious severe or severe TBI	Analysis of longitudinal data	US	LSI	FSS FIM	Higher family satisfaction for individuals with less functional impairment Marital status not significant
Johnston, Goverover et al.	2005	162 individuals the 1st year after mild, moderate or severe TBI	Interview study with follow-up	US	SWLS	CIQ-2	Instrumental activities (preparing family meals, shopping for necessities, housework, independence etc.).
Juengst, Adams et al.	2015	3012 individuals the first 5 years post moderate or severe TBI	Analysis of longitudinal data	US (TBIMS)	SWLS	PHQ-9 FIM PART-O	Participation in life roles Depressive symptoms
Kalpinski, Williamson et al.	2013	312 individuals the first 5 years after moderate or severe TBI	Prospective cohort study	US	LSI	AIS FIM CHART Health status	Participation in meaningful, productive activities
Kelley, Sullivan et al.	2014	62 individuals 5 years or more after moderate to severe TBI and significant their informants	Interview study 5-16 years after inpatient rehabilitation	US	SWLS	CIQ CBI	Own perception of TBI outcomes: Better self-reported neurologic functioning

Ketchum, Almaz et al.	2012	291 Hispanic individuals 1 year post TBI	Retrospective study	US (TBIMS)	SWLS	GCS DRS FIM	Higher age, no spinal cord injury, not being unemployed 1 year post TBI and very high or very low FIM cog scores associated with life satisfaction
Machamer, Temkin et al.	2013	374 individuals 6 months post moderate or severe TBI	Cross-sectional study	US	LSS	GCS GOS-E FSE	Ability to think and remember Work/receive adequate income Participation in leisure and recreational activities
Mailhan, Azouvi & Dazord	2005	75 individuals with mild, moderate or severe TBI	Cross-sectional study	France	SQLP	GOS NRS-R DRS Barthel index EBIS	Lowest satisfaction among the moderate disability group, compared to severe disability or good recovery group
Marwitz, Sima et al.	2017	195 individuals the first year post TBI	Longitudinal analysis of observational cohort	US (TBIMS)	SWLS	CD-RISC DRS PART-O TBI-QOL Anxiety and Depression	Higher levels of resilience related to greater life satisfaction
Payne, Hawley et al.	2018	74 individuals with low satisfaction 1-10 years post TBI	Part of RCT	US	SWLS FS SPANE	NIH TBI Common Elements Project WAIS-III TMT RAVLT MSVT	Low life satisfaction associated with impairments in cognition and psychological well-being (mood, affect, purpose and meaning in life)

						BSI-18 Rivermead Purpose in Life subscale of the Ryff Scale of Psychological Well-Being-54	
Philippus, Mellick et al.	2016	5573 interviews with individuals with moderate or severe TBI	Retrospective, cross-sectional cohort study	US (TBIMS)	SWLS	GAD-7 PHQ-9 PART-O FIM	Religious attendance is a significant predictor of life satisfaction
Pierce & Hanks	2006	180 individuals 1-5 years post mild, moderate or severe TBI	Prospective evaluation	US (TBIMS)	SWLS	FIM CIQ Physical exam score	Level of participation
Powell, Ekin-Wood & Collin	2006	61 individuals 1-3 years post TBI and 65 individuals 10-12 years post TBI	Cross-sectional, between-group design	UK	LiSat	PTGI HADS + questions	Negatively correlated with anxiety and depression
Resch, Villarreal et al.	2009	609 individuals the first 5 years after mild, moderate or severe TBI	Longitudinal	US	LSI	FIM	Greater cognitive impairments Greater motor impairments
Rutterford & Wood	2006	131 individuals with mild, moderate or severe TBI	Cross-sectional study	UK	SWLS	HISDS EPQ-R RLCQ SOS-SF PCRS	Personality (low neuroticism), better self-concept, self-efficacy

Saban, Smith et al.	2011	297 individuals 1 year after severe TBI	Cross-sectional	US (TBIMS)	SWLS	FIM GCS	Gender does not influence life satisfaction 1 year after severe TBI
Snekkevik, Anke et al.	2003	26 traumat patients with median injury severity score of 25 (range 9 – 50)	Prospective study	Norway	LiSat	SOC GHQ-20 HAD	SOC associated with life satisfaction
Underhill, Lobello et al.	2003	324 individuals the first 5 years post TBI	Longitudinal 2-group study	US (TBIMS)	LSI-A	AIS	Depression group had lower life satisfaction than no depression group 2, 4 and 5 years post TBI
Vangel Jr, Rapport & Hanks	2011	109 pairs of adults, a caregiver and an individual with TBI	Cross-sectional	US	SWLS	BSI-18 DRS SPS FAD DRS	Social support perceived by caregivers moderates the adverse effects of TBI on life satisfaction
Whiteneck, Cuthbert et al.	2016	2701 individuals with mild, moderate or severe TBI or no TBI at all	Statewide population-based survey	US	SWLS	Computer-assisted, modified Ohio state University TBI identification Method	TBI causes disability TBI exacerbates influence of other etiologies
Whiteneck, Cuthbert et al.	2016	2701 individuals with mild, moderate or severe TBI or no TBI at all	Statewide population-based survey	US	SWLS	Computer-assisted, modified Ohio state University TBI identification Method	Injury severity Hospitalization

Whiteneck, Gerhart & Cusick	2004	73 individuals with TBI	Cross-sectional study	US (TBIMS)	SWLS	CHIEF CHART FIM	Those reporting greater impact from environmental barriers also reported lower life satisfaction
Williams, Rapport et al.	2014	253 individuals with mild, moderate or severe TBI	Archival study of a longitudinal data set	US	SWLS	PANAS CHART-SF CIM BSI-18	Community involvement Emotional distress
Williamson, Ellliott et al.	2016	3157 individuals the first 10 years after mild, moderate or severe TBI	Hierarchical linear modeling analyses to examine the trajectories of life satisfaction	US (TBIMS)	SWLS	FIM GCS	Greater motor functioning Greater cognitive functioning Gender does not influence satisfaction

Appendix C: Life satisfaction measurements

Table 2: Life satisfaction measurements

Measure	Domains	Reliability/Validity	Rating	No. of studies
LiSat (The Life Satisfaction Checklist) 9 or 11	1 global and 10 domain-specific items.	Valid for the general population. Shorter Dutch version (Lisat-9) shows moderate reliability for patients with acquired brain injury, and good discriminant validity.	Scores range on a 6-point Likert scale from 1 (very dissatisfying) to 6 (very satisfying)	3
SWLS	Five items expressing life as a whole.	Valid in populations with moderate or severe TBI.	7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree).	33
LSI-A	20 items expressing passion for life, mood, and congruence between desired and achieved goals.	Reliable and valid for TBI populations.	20 items, each item scored 0 or 1.	4
SQLP	Functional life, social life, material life, mental/spiritual life.	High internal consistency and moderate-to-fair test-re-test reliability.	5-point Likert scale from -2 (very unsatisfied) to +2 (very satisfied).	1
LSS	17 different areas of life such as working or ability to walk or travel	Not known.	Scores range from 0 (not satisfied at all) to 100 (extremely satisfied).	1

Appendix D: Implications for Rehabilitation

- Life satisfaction is negatively influenced by cognitive functioning and depression, and positively influenced by productivity, participation in leisure activities, social integration, higher age and personality factors.
- Works status after TBI influences life satisfaction while work status prior to TBI does not.
- Motor functioning does not influence life satisfaction directly.
- Rehabilitation professionals should acknowledge the importance of an individual approach exploring meaningful activities and targeting social participation to influence life satisfaction.

ARTICLE II

Research Paper

What makes life worth living? A Phenomenological study of satisfied individuals 5-7 years after Traumatic Brain Injury.

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Abstract

Purpose: Life satisfaction is considered an important indicator of successful rehabilitation following traumatic brain injury (TBI). However, knowledge of why individuals are satisfied after TBI is limited. This paper describes a study exploring the meaning of being satisfied with life after TBI and discusses if the findings can be understood through the "sense of coherence".

Method: This phenomenological study interviewed 7 Norwegian adults who were satisfied with life 5-7 years after moderate or severe TBI. Interview data was analysed for themes which the individuals related to satisfaction with life.

Results: Being satisfied with life is *accepting life as it is.* This involves *being able to appreciate what one has* and *being optimistic about the future.* A relationship between SOC and life satisfaction is probable.

Conclusion: This research suggests that professionals should investigate the specific factors that may contribute to life satisfaction of the person they care for.

Keywords: Traumatic brain injury, head injury, TBI, life satisfaction, satisfaction with life, phenomenology, sense of coherence.

Introduction

Individuals with TBI may exhibit ongoing cognitive, emotional, physical or behavioural sequelae that can impact their life satisfaction [1, 2]. Life satisfaction refers to an individual´s cognitive appraisal of his or her overall life [3], and is considered a long-term endpoint after TBI [4]. In a review on long term consequences of TBI, Wilson, Stewart [5] state that disability or limitations to activity, limitations to societal participation, cognitive deficits, emotional problems, behaviour change, increased risk of comorbidities and shorter life expectancy are long term consequences of TBI. These outcomes are not fixed, but improvement and deterioration may occur many years after injury [5].

Compared to the general population and other comparison groups, individuals with TBI typically report lower life satisfaction [6, 7, 8]. Also, significantly lower life satisfaction regarding vocation, ADL and psychological health has been found for moderate to severe TBI compared to mild TBI [7]. Studies on life satisfaction trajectories show a decrease early after TBI [6, 9, 10] an increase from year 1 to approximately year 10, and from year 10 a decrease below the initial year 1 measure 20 years after injury [11]. Williamson, Elliott [12] argue that time is no longer a significant predictor of life satisfaction 10 years after TBI. The different studies all report high variability in life satisfaction scores among the participants [6, 7, 9, 10, 11, 12]. Four life satisfaction trajectory groups have been suggested; stable high satisfaction, stable dissatisfaction, initial satisfaction declining and initial dissatisfaction improving [13], showing that life satisfaction can both be stable, decrease or increase in the years after TBI. Among people in general life satisfaction trajectories are relatively stable throughout adulthood until late in life (ages 65 – 70) [14, 15]. The major difference between people in general and individuals with TBI seems to be a substantial drop in life satisfaction initially after injury, and a significant lower life satisfaction in the years after TBI. Diener [16] states that adaptation after a major life event (such as TBI) is more intricate than individuals quickly adapting back to their baseline levels, suggesting that environmental factors and individual

circumstances existing prior to the major life event continues to influence life satisfaction also in the years after the event. In a metasynthesis of qualitative research, Levack, Kayes [17] reviewed 23 studies representing the lived experience of 263 people with TBI. They found eight interrelated themes that people go through after TBI. The time perspective in this process is not set, but it is emphasized that recovery from TBI is not a linear path from loss and suffering to recovery and reconstruction but a lengthy, non-linear, iterative process. The experience of loss is divided into three; 1) disconnect with pre-injury self, 2) mind/body disconnect, and 3) social disconnect. These experiences lead to 4) emotional sequelae. In coping with their situation, people with TBI draw on 5) internal and external resources to progress from their losses. 6) Reconstruction of identity includes acceptance of their new self and 7) reconstruction of their place in the world includes the support by family and friends. Through this they get to a 8) reconstruction of personhood where they feel like a complete individual, and is also accepted as one by other people [17].

Aaron Antonovsky argued that health rather than disease should be the base of understanding and constructed the sense of coherence (SOC) as one of his key concepts [18, 19]. According to Antonovsky, health is movement on a continuum between ease and disease [20]. The major question is “What creates health?” (salutogenesis) [18] while medicine traditionally is concerned with the causes of disease (pathogenesis) [21]. The two perspectives are not contradictory but work together with a common goal of improving health [22].

Antonovsky defined SOC as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); and (3) these demands are challenges, worthy of investment and engagement (meaningfulness)" [19].

Antonovsky also coined another term called Generalized Resistance Resources (GRRs) [18, 19]. GRRs comprises the characteristics of a person, a group, or a community that facilitate the individual's abilities to cope effectively with stressors and contribute to the development of the individual's level of (SOC)» [23]. To facilitate the development of a strong SOC, at least four of the GRRs have to be at one´s disposal; meaningful activities, existential thoughts, contact with one's inner feelings, and social relations [19, 22]. The key is to use these resources in a health promoting way [22]. Research has found a strong association between SOC and life satisfaction in individuals with TBI [24] and in individuals after multiple trauma [25].

Research on life satisfaction in individuals with TBI is limited and has historically focused on how to explain different factors´ negative impact on life satisfaction. Knowledge of both factors that arise as a result of the TBI, and factors that existed prior to the TBI but continues to influence life satisfaction for the individual after TBI would advance our understanding of the phenomenon. Because of the heterogeneity of TBI, and the heterogeneity of life satisfaction, qualitative research methods might add value to the field of research. Because of the implications of a strong correlation between SOC and life satisfaction after TBI and because of the salutogenic angulation of the SOC, viewing life satisfaction through the lens of the SOC might deepen our understanding of factors promoting life satisfaction. This phenomenological study will elucidate why individuals report being satisfied with life 5-7 years after moderate or severe TBI.

Method

Design

The aim of this study is to elucidate meaning, and therefore a qualitative research approach is used [26]. The hermeneutic field of knowledge involves interpretation to try to understand and describe the individual´s life and world as they experience it themselves. This knowledge of another person´s life and world is always filtered through the lens of our own experience. It is a description of a phenomenon, but also a process in which the researcher makes an interpretation of the meaning of the lived experiences [26]. The study was conducted in the light of the author´s preunderstanding as an occupational therapist with experience of TBI rehabilitation and as a researcher in the field. The author was careful that this preunderstanding did not lead to bias. One pilot interview was conducted to enhance the awareness of the interviewer´s role in the interviews and to get feedback on the interview as a whole.

Participants and procedure

All individuals were recruited from the "Head Injury Project", a longitudinal (from the scene of accident and up to five years after injury) research project on moderate and severe traumatic brain injury in Norway. The individuals were recruited from the "Head Injury Project" if they had lived with the TBI for more than 5 years, and if they had responded to the assertion "Life as a whole is" with "satisfying" or "very satisfying" in LiSat-9[2] [27].

The research assistant in the "Head Injury Project" sent 15 individuals a letter including information about the current study and a reply form on which they could give their informed consent. After receiving permission, they were contacted by the author to find time

[2] LiSat-9 is a life satisfaction measurement showing moderate reliability and good discriminant validity for patients after acquired brain injury.

and place for an interview. 5 men and 2 women, aged 29-71 years, chose to participate in the study (see table 1).

[Insert table 1 here: Characteristics of study participants]

Ethical considerations

Approval for the study was given by the Regional Committee for Medical and Health Research Ethics in Mid-Norway. All individuals were given a guarantee of anonymity and confidentiality in reporting of the findings.

Data collection

Six of the seven interviews were conducted in the individuals` homes, and the last interview was done in a rehabilitation institution upon request by the interviewee. The interviews lasted 35 - 90 minutes. The interviews were semi structured and followed an interview guide, and all were audio recorded and later transcribed by the same researcher. One individual had been a former patient of the interviewer but was included because it was considered that the former relation would not significantly affect content of the former patient´s answers. The focus of the interviews was why the individuals were satisfied with life, and a list of topics provided a structure of the interview. The topics were 1) Relevant background information, 2) Life satisfaction now, 3) Life satisfaction today compared with life before injury, and 4) Life satisfaction in the future. These topics intended to be broad to enable participants to raise issues which they felt were of importance. Follow-up questions allowed elaboration and clarification of the individuals´ responses. After 7 interviews, collection of information ended according to the principle of saturation [28].

Data analysis

The data were analysed using a phenomenological hermeneutic interpretation inspired by Moustakas [29] and van Manen [30] and developed by Creswell [26]; Horizontalization, development of clusters of meaning, textural description, structural description and the essential structure.

The interviews were transcribed fully and were read and re-read to find the major themes. During the analysis the author kept a close eye on the transcripts to ensure that the themes were representative for the individual´s story. All interviewees were asked if they wanted a transcript of their own interview. As a consequence, 3 individuals received transcripts and as a result minor details in one of the transcripts was changed. Emergent themes described in the individual´s own words were grouped according to the content to identify any of the views and experiences shared among the individuals. Particular attention was given to the themes that the individuals had validated at the time of interview when their views had been summarised and reflected by the interviewer. Next, the description of the themes was written trying to capture the essence of the theme, but also describing the diversity of the individuals within that theme. The search for a possible underlying structure focused on finding the essence of being satisfied. The process of analysis was a dynamic interplay finally ending with writing the essence. The quotations were translated from Norwegian to English after writing the essence, to ensure that the meaning of the translated quotations were as similar as possible to the original quotations. The themes are presented here supported by the quotations, so readers can assess the trustworthiness of the interpretations.

Results

Accepting myself as I am

The personal experiences in this study suggest that life satisfaction involves an element of acceptance. The individuals have different everyday challenges such as memory difficulties, communication challenges, decreased motor function and fatigue. They express awareness of their challenges, and that they have accepted the challenges to be a part of who they are now.

> *"I consider life to be satisfying, and I´ve learnt to live with the limitations I have. Maybe I focused more on the differences straight after the accident, but I think (us) humans adapt quickly to new situations" (Nicole).*

Being able to appreciate what I have

A major contributing factor to acceptance and to life satisfaction is their ability to appreciate what they have. The diversity of factors they appreciate is considerable, but 4 subthemes emerged during the analyses: Income, avoiding illness, relations and meaningful activities. For the majority, appreciation had changed in a way that they were able to appreciate both bigger and smaller experiences to a greater extent.

> *"The biggest joy for me after my injury was getting my trailer and bus driver´s licence back. Driving trailer is the best thing I know. But not just that, I was even happier the day I had my car driver´s license back" (Mike).*

Sufficient income

Of those interviewed, four reported income as important for life satisfaction. These four were either retired from work or working part-time involuntarily as a result of sequelae from their injury.

"I won´t say that income makes life satisfying, but it is important to have a high enough income to do what you want to do" (Mike).

All of the individuals that mentioned income as important highlighted that they do not need a high income, but an income high enough so that they don´t need to worry about financial difficulties. They appreciate what they have rather than striving for more.

Staying well/avoiding illness

Three of the individuals reported staying well/avoiding illness as an important factor for life satisfaction. These were the three older ones. Despite challenges resulting from their TBI, none of them characterized themselves as being ill.

"It´s important that my wife and my children and my grandchildren stay well, and that my wife doesn´t get any worse than she is now, that everything is going well with my close ones" (Frank).

For some, the importance of their closest ones staying well/avoiding illness is said to be equally important to their life satisfaction as staying well/avoiding illness themselves. The awareness of staying well/avoiding illness comes as a result of battling sickness or disease in the past, resulting in an awareness that one should appreciate being well.

Relations

Being satisfied with life is closely connected to spending time being together with a spouse, a child, a grandchild or parents. The individuals experience safety, joy, understanding and practical or emotional support as a result of their close relations with their families. Some also explain that they have learnt to appreciate the importance of their family members to life satisfaction.

"My girlfriend is important for me. And I´ve learnt that my mother is important as well. Those are the ones I feel closest to and I can talk about anything with them. I think they are the ones who can understand me the most" (Mike).

"I have a small field where I plant potatoes. Every year my grandchildren are competing by putting one potato in the ground with their name on it. When we harvest the potatoes, we count how many potatoes each plant has yielded. The record is twenty-four potatoes. It´s so fun watching my grandchildren compete" (Frank).

Friends are also important for life satisfaction. Interestingly, the older individuals consider friends to be less important now than they used to be and individuals not in a relationship consider friends as just as important or more important than their family. The relation to friends are appreciated because of joint interests, giving and receiving help, honest feedback and because they understand the situation of the individuals.

"They are important because we meet often; I help them, they´re helping me. One of my friends is my own personal janitor; When I´m at work for some weeks, he stops by to water my plants" (Dan).

Meaningful activities

Being satisfied with life is about being able to contribute in a meaningful way. Independent of current working status, all individuals consider work as important for their life satisfaction. They appreciate the togetherness of working towards the same goal, the relations and feedback from their colleagues or others at work, and the possibility of working with something they love.

"Working together towards developing new therapies with better effect than existing therapies and less bi-effects compared to existing medicine is satisfying in itself, and a very strong driving force. As a consequence, leisure time is of less importance" (Laura).

Being satisfied with life is also about participating in leisure activities. The interest and engagement in the activity itself and/or the relation to other participants are why leisure activities are appreciated among the individuals.

"What is good about being outdoors is to get away from my routines, not having phone coverage and hearing about what happens elsewhere in the world, but just living then and there" (Nicole).

Being optimistic about the future

All individuals are optimistic about the future. Being optimistic is about knowing that prior challenges have been overcome and having a sense of being able to handle what awaits in the future. Some describe being optimistic as a trait they´ve always had while others refer to their TBI as an explanation of choosing to be optimistic.

"Positive thinking and having hopes and dreams about the future motivates me and drives me forward. I think it´s the same for others too" (Mike).

Discussion

This study suggests that being satisfied with life for an individual 5-7 years after TBI is about *acceptance of life as it is*. This involves *appreciation of what one has* and *being optimistic about the future*. *Appreciation of what one has* involves numerous individual factors of whom may have existed prior to TBI, but awareness of the factors´ contribution to life satisfaction is

more pronounced after TBI. Being satisfied is also about *being optimistic about the future* despite of increased difficulties resulting from the TBI.

[Insert figure 1 here: Essence of the experience of life satisfaction]

In a metasynthesis of qualitative research representing the lived experience of 263 individuals after TBI, Levack, Kayes [17] found that after an initial phase of coping with loss and emotional sequale individuals draw on internal and external resources to progress, before their new self is accepted by both themselves and other people. This suggests a similarity between individuals in this study and other individuals after TBI.

Acceptance of life as it is

In SOC, *acceptance of life as it is* is a GRR, in other words a cognitive characteristic of an individual that is effective in combating a wide variety of stressors (i.e. activity limitations, stigmatisation etc.) and thus preventing tension from being transformed into stress. *Acceptance of life as it is* as a GRR would propose that the individuals in this study have developed a strong SOC through the successful application of acceptance, in such a way that acceptance has become chronic and built into the life situation of the individual [23]. Individuals with a strong sense of coherence are able to cognitively redefine stress factors to non-stress factors; they trust that things will work out in the end, like they usually do [19]. Acceptance is a resource related to both comprehensibility, manageability and meaningfulness. For the individuals in this study, acceptance is acknowledging that both you and the demands you are facing have changed (comprehensibility) and that you have the resources to meet the demands of your new situation (manageability), and that these demands are worthy of investment and engagement (meaningfulness).

Being able to appreciate what I have

The individuals report that *being able to appreciate what they have* is a part of the explanation of why they are satisfied with life. The importance of sufficient income, staying well/avoiding illness, relations and meaningful activities were clear to them, and they felt they appreciated these things more now than prior to their TBI. This is very similar to a study by Jumisko, Lexell [31,p.22278] where "Individuals felt well when they were fairly healthy and lived as ordinary a life as possible. They valued deeply and enjoyed their body, certain moments and the people they had taken for granted when they were healthy". *Being able to appreciate what they have* is strongly related to the meaningfulness and manageability components of the SOC. Close relations to children, family and friends and being able to perform activities that they rate as important themselves are of great emotional importance and give meaning to life, while sufficient income is about manageability and staying well/avoiding illness is showing the importance of including pathogenic factors for life satisfaction.

The individuals who considered income to be important for life satisfaction in this study were the ones not working full time. In non-disabled individuals it has been found that the economic prosperity of a nation contributes to a person´s life satisfaction level [32], and that psychological perceptions about economic resources are strongly associated with life satisfaction [33]. This is in line with the individuals in this study, where sufficient income (not high income) is important for life satisfaction. For individuals with TBI, not receiving adequate income has been found to decrease life satisfaction [34]. Antonovsky [19] consider income to be a GRR [23], and related to the construct of manageability where increases towards the higher end of an income continuum would increase one´s view that things are manageable and within control.

Among the older individuals, staying well (avoiding illness) in the years to come is important to life satisfaction. The Shifting Perspectives Model of Chronic Illness consider illness as an ongoing and continually shifting process with either illness or wellness in the

foreground [35]. When wellness is in the foreground the focus is on being as well as possible, but when illness is in the foreground the focus is on the sickness, suffering, loss and burden associated with living with a chronic illness [35]. The participants in this study might be vary of the positive or negative consequences of illness and therefore consider avoiding illness to be of importance to life satisfaction. Typically, the participants who emphasize staying well as important to life satisfaction are older and in addition to their own illness history have experienced illness among their close ones. Avoiding illness is an example of a pathogenic factor (causes of disease) that is important to life satisfaction among these individuals, working together with other salutogenic factors (what creates health?) presented here. In the same way as fostering health through the coexistence of pathogenic and salutogenic factors, fostering life satisfaction can be a combination of both angulations too.

All individuals in this study consider relations to influence life satisfaction. Through positive relations they feel safe, experience joy, understanding and practical support, and continuing these relations in the same manner is important for future life satisfaction. Johnson, Resch [10] found that higher family satisfaction was associated with increases in life satisfaction for individuals with less functional impairments the first 5 years after TBI. The participants express that satisfaction among their close ones is very important for their own life satisfaction. In SOC, social support is an important GRR [18, 19]. Psychoemotional resources like quality of relationship with partner and social support have been found to contribute to the level of SOC in both men and women [36]. Lindström and Eriksson [22] state that social relations is one of four GRRs that has to be at one's disposal in order to facilitate the development of a strong SOC. The key is not only having resources at disposal but having the ability to use them in a health promoting manner. As an example, some of the individuals in this study use social relations to experience understanding, which in turn is important for life satisfaction. Experiencing understanding from your loved ones increases

comprehensibility (they are more aware of your challenges), it increases manageability (they can be resources when facing difficulties) and it can increase meaningfulness (they can give you feedback that the demands you face are worthy of investment and engagement).

Participants emphasized that having a sense of meaning in life is important for satisfaction. What they find meaning in differ, but close relationships with family and friends and doing activities they love are universal among the participants. These findings are in line with studies on meaning among nondisabled, where the most common sources of meaning are relationships and the types of activities we engage in [37, 38]. One longitudinal non-TBI study has found a positive correlation between meaning and life satisfaction over one year´s time [39]. In SOC, someone who experiences meaningfulness has a pervasive, enduring though dynamic feeling of confidence that the demands they are facing are challenges worthy of investment and engagement [19]. Lindström and Eriksson [22] argue that it is not the content of what gives meaning to one´s life that matters, but the fact that there is a strong belief that one´s life as such does have meaning. For the seven individuals in this study, activities are considered meaningful because of working towards a common goal, having close relations, doing something you love or engagement in the activity. In SOC, the knowledge why something is meaningful is not as important as actually having a feeling of meaningfulness.

Being optimistic about the future

The individuals in this study consider optimism about the future as important to life satisfaction. Optimism is related to positive thinking, and for some it is a choice of attitude that they have learned from experience. In a study on individuals with TBI, hope and dispositional optimism negatively correlated with depression while showing positive correlations with each other [40]. Ramanathan, Wardecker [41] found that higher levels of dispositional optimism in individuals with moderate or severe TBI is related to better

psychological functioning which in turn predicts improved cognitive and functional outcomes. In light of these findings, optimism may partly explain the individuals in this study´s evaluation of life as satisfying or very satisfying. In SOC, optimism is a GRR that contributes to the development of the individual´s level of SOC. It is highly related to manageability; optimism is a feeling of confidence that the resources are available to meet the demands posed by one´s internal and external environments.

Life satisfaction and the sense of coherence

Acceptance of life as it is, *being able to appreciate what I have* and *being optimistic about the future* can be explained as if the individuals have a strong sense of coherence. SOC is a personal way of thinking, being and acting, with an inner trust, which leads people to identify, benefit, use, and re-use the resources at their disposal (Eriksson & Lindström, 2006). High SOC is an attitude that in itself is the essential tool for coping [42, 43]. For the individuals in this study the determinants of a strong SOC are present; they experience meaningful activities (work, leisure activities, family), they have existential thoughts (appreciation of what they have), they´re in contact with their inner feelings (acceptance of life as it is) and social relations (appreciation of relations to their close ones). This supports the idea that a major life event like a TBI can reduce health temporarily but in the longer term it can also strengthen us in a way that makes it possible for us to manage stress [44]. A correlation between life satisfaction and SOC is probable, in the same manner that Antonovsky hypothesized that positive correlations are probable between SOC and well-being but causality is not [19]. This is in line with previous studies on individuals with TBI who have found a strong association between SOC and life satisfaction [24, 25]. Hypothetically, elements of life satisfaction do not necessarily help individuals towards the ease end of the health continuum, i.e. an individual with a TBI who regularly chooses to nurture relationships with friends and family instead of maintaining motor functions through physiotherapy might be satisfied with life because of it,

but his/her health would not improve. More studies are warranted to investigate the association between life satisfaction and SOC further.

Study limitations

The findings are limited as the sample consists of seven individuals living in a well-developed country, although the findings are similar to previous qualitative research on life after TBI [17]. The findings of the study can be used as consideration of individual cases. Although this study is relatively small, and the group interviewed heterogenous, data saturation was achieved. More men than women participated, which is in line with the prevalence of TBI [45]. Self-awareness was not formally assessed, with potential participants being approached on the basis of being satisfied with life; A greater or lesser degree of lack of awareness does not invalidate an individual´s subjective evaluation of life satisfaction, but it raises important methodological questions concerning the co-construction of meaning and whether or not the individual´s answers are reflecting their opinions.

Conclusion

Individuals consider being satisfied with life after TBI as *acceptance of life as it is.* This involves *being able to appreciate what I have,* which is about having sufficient income, staying well/avoiding illness, having close relations and doing meaningful activities, and *being optimistic about the future*. Professionals should investigate if these factors contribute to life satisfaction of the person they care for when planning rehabilitation interventions. More research is needed on the relationship between SOC and life satisfaction to optimize outcomes for individuals with TBI.

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Declaration of interest

No potential conflict of interest is reported by the author.

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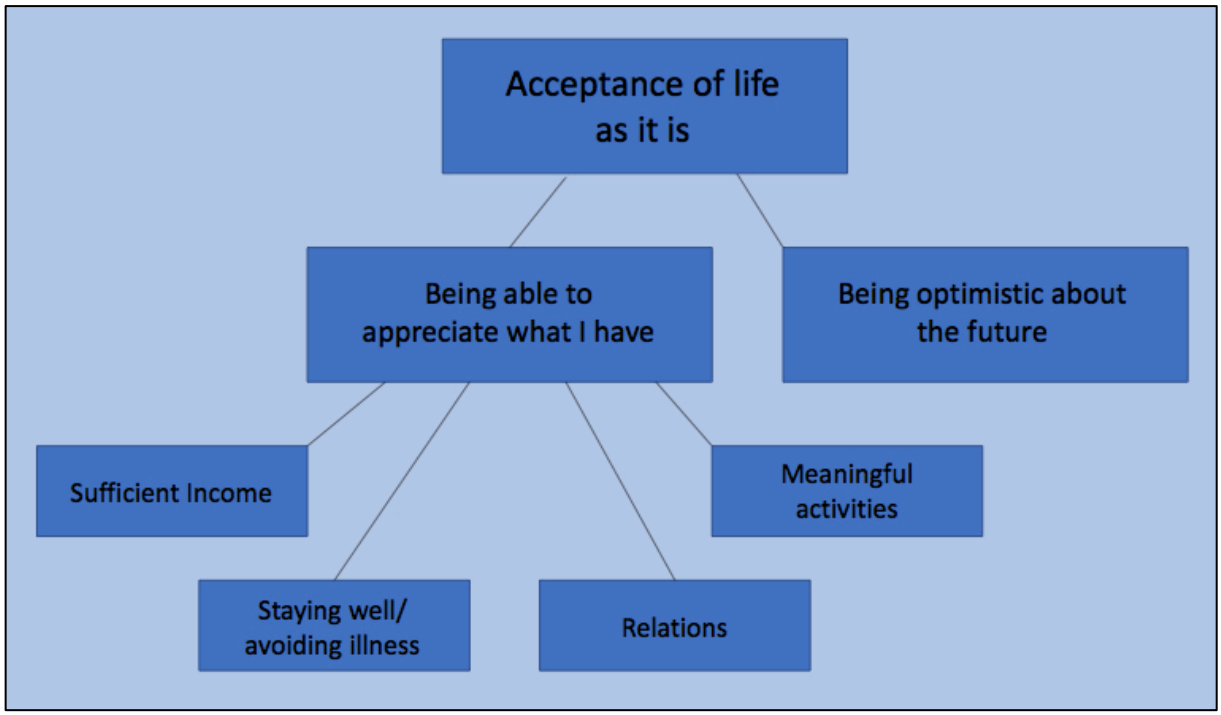
Appendix E: Characteristics of study participants

Table 1: Characteristics of participants

Participant	**Sex**	**Age**	**Marital status**	**Children**	**Type of trauma**	**Work status**
Adam	M	69	Married	Yes	Fall accident	Retired
Simon	M	29	Single	No	Road traffic accident	Sheltered employment
Frank	M	71	Married	Yes	Fall accident	Retired
Laura	F	60	Married	Yes	Road traffic accident	Full time
Dan	M	48	Single	No	Fall accident	Full time
Mike	M	32	Cohabitant	No	Road traffic accident	Part time
Nicole	F	36	Cohabitant	Yes	Fall accident	Part time

Appendix F: Essence of the experience of life satisfaction

Figure 1: Essence of the experience of life satisfaction



Appendix G: Implications for rehabilitation

Implications for Rehabilitation

- In a small sample this study shows that being satisfied with life after TBI is about acceptance of life as it is. This involves being able to appreciate what one has and being optimistic about the future.
- Interventions after TBI targeting life satisfaction should investigate if these factors contribute to life satisfaction of the person they care for when planning rehabilitation interventions.
- More research is needed on the relationship between life satisfaction and sense of coherence.

Appendix H: Approval by the Regional Ethical Committee

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Marit Hovdal Moan	73597504	12.12.2017	2017/1205/REK midt
			Deres dato:	**Deres referanse:**
			01.12.2017	

Vår referanse må oppgis ved alle henvendelser

Rune Kalland
NTNU

2017/1205 Hva er det som gjør at livet er godt å leve for personer med traumatisk hjerneskade? En studie med fokus på de gode sidene av et endret liv

Forskningsansvarlig: Norges teknisk-naturvitenskapelige universitet
Prosjektleder: Geir Arild Espnes

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK midt) i møtet 25.08.2017. Komiteen hadde noen merknader knyttet til identifisering av utvalget, rekruttering, og analysestrategi. Komiteen hadde også noen kommentarer til informasjonsskrivet. Komiteen ba derfor om en tilbakemelding og utsatte endelig vedtak. Tilbakemeldingen ble mottatt 01.12.2017. Tilbakemeldingen ble vurdert av komiteens leder på fullmakt med hjemmel i forskrift om behandling av etikk og redelighet i forskning §10. Vurderingen er gjort med hjemmel i helseforskningsloven §10, jf. forskningsetikkloven §4.

Komiteens prosjektomtale
Hensikten med prosjektet er å undersøke hva som gjør at livet oppleves som meget tilfredsstillende fem år eller mer etter en moderat eller alvorlig traumatisk hjerneskade (TBI). Studien er en kvalitativ studie, data innhentes gjennom individuelle, semi-strukturerte intervju. Deltakere: Personer som har levd med en traumatisk hjerneskade i fem år eller mer (både tidligere pasienter, og personer som ikke har vært innlagt ved sykehus). Inklusjon inntil metning er oppnådd. Potensielle deltakere identifiseres ved hjelp av allerede utfylte spørreskjema i Hodeskadeprosjektet (2009/2328(REK midt). Kunnskap om tilfredshet med livet for denne pasientgruppen tenkes å kunne bidra til utvikling av bedre behandlingstilbud til personer med TBI. Studien er samtykkebasert. Deltakere i Hodeskadeprosjektet har samtykket til at de kan forespørres om deltakelse i andre, liknende studier.

Vurdering av tilbakemelding datert 01.12.2017
Identifisering av utvalget
Komiteen tar informasjon om identifisering av utvalget til orientering,uten ytterligere merknader.

Rekrutteringsprosedyre
Reservasjon mot deltakelse er ikke en aktiv viljeserklæring, og slikt sett ikke i tråd med kravet i hfl. §13 om at samtykke skal være "uttrykkelig", dvs, en aktiv viljeserklæring. Komitteen ber om at potensielle deltakere gis anledning til å samtykke aktivt til å delta i studien. Kun de som svarer at de ønsker å delta skal inkluderes i studien; de som ikke svarer skal ikke inkluderes.

Forbedring av informasjonsskrivet
Komiteen ber om at informasjonsskrivet revideres i tråd med krav til endring av rekrutteringsprosedyre som beskrevet ovenfor.

Besøksadresse:
Fakultet for medisin og helsevitenskap Mauritz Hansens gate 2, Øya helsehus

Telefon: 73597511
E-post: rek-midt@mh.ntnu.no
Web: http://helseforskning.etikkom.no/

Analysestrategi
Komiteen tar informasjon om analysestrategi til orientering,uten ytterligere merknader.

Forsvarlighet
Komiteen har vurdert søknad, forskningsprotokoll, målsetting og plan for gjennomføring. Under forutsetning av at vilkårene nedenfor tas til følge, framstår prosjektet som forsvarlig og hensynet til deltakernes velferd og integritet er ivaretatt.

Vilkår for godkjenning

1. Revidert informasjonsskriv skal sendes komiteen til orientering. Vennligst benytt e-postadressen post@helseforskning.etikkom.no og "REK midt 2017/1205" i emnefeltet. Prosjektet kan ikke igangsettes før REK midt bekrefter at informasjonsskrivet er endret i henhold til komiteens merknader.
2. Komiteen forutsetter at forespurte potensielle deltakere kun blir inkludert i studien dersom de sender inn svar om at de ønsker å delta studien.
3. Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen. Prosjektet må også gjennomføres i henhold til REKs vilkår i saken og de bestemmelser som følger av helseforskningsloven (hfl.) med forskrifter.
4. Komiteen forutsetter at ingen personidentifiserbare opplysninger kan framkomme ved publisering eller annen offentliggjøring.
5. Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren». Av kontrollhensyn skal prosjektdata oppbevares i fem år etter sluttmelding er sendt REK. Data skal derfor oppbevares til denne datoen, for deretter å slettes eller anonymiseres, jf. hfl. § 38.
6. Prosjektleder skal sende sluttmelding til REK midt når forskningsprosjektet avsluttes. I sluttmeldingen skal resultatene presenteres på en objektiv og etterrettelig måte, som sikrer at både positive og negative funn fremgår, jf. hfl. § 12.

Vedtak
Regional komité for medisinsk og helsefaglig forskningsetikk Midt-Norge godkjenner prosjektet med de vilkår som er gitt.

Merknad
Helseforskningsloven stiller krav til prosjektleders faglige kompetanse. En student kan ikke være prosjektleder. Derfor er det naturlig at veileder har rollen som prosjektleder. Hun/han er ansvarlig for at endelig protokoll er kvalitetssikret og forankret hos ledelsen på det instituttet studenten er tilknyttet.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK midt på eget skjema senest 01.12.2018, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK midt dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningsloven § 28 flg. Klagen sendes til REK midt. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK midt, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Med vennlig hilsen

Vibeke Videm
dr. med.
leder, REK midt

Marit Hovdal Moan
seniorrådgiver

Kopi til: rek-ism@mh.ntnu.no; runekall@hotmail.com