Editor: Siw Tone Innstrand

# **Health Promotion – Theory and Practice**



# Health PromotionTheory and Practice

Editor: Siw Tone Innstrand

Research Centre for Health Promotion and Resources HiST/NTNU Trondheim, Norway, 2012

ISBN 978-82-93158-11-0 (trykk utg.) ISBN 978-82-93158-12-7 (elektr. Utg.) ISSN 1892-6207

Print and layout: NTNU-trykk

#### Introduction

With roots from a PsychoSomatic research group established in 2005, the Research Centre for Health Promotion and Resources HiST/NTNU (RCHPR) was founded in 2010 in Trondheim, Norway. RCHPR is a research unit coowned by the Norwegian University of Science and Technology NTNU and The Sør-Trøndelag University College HiST and aim to develop and translate new knowledge in health promotion work. The Centre will take part in the scientific exploration of what promotes, maintains and restores good health – both in healthy, vulnerable and diseased populations. The research group consists researchers with background as nurses, ergo therapists, physiotherapists, medical doctors, psychologists, and social scientists – all with a higher research degree and with a bio-psycho-social- existential health understanding. In line with the World Health Organization's view that health is more than the absence of infirmity health is understood as a positive resource which every person has more or less of.

What we have observed for the last years, is that the kinds of health problems now facing us have shifted, but our thinking about how to respond to them has not shifted accordingly. We feel that traditional bio-medical disease research is too limited in terms of facing the health challenges of the new millennium, which includes enormous increases in obesity in many populations, psychological distress, inactivity, musculoskeletal disorders, and self-perceived negative health outcomes. In Europe and many other regions around the world, the size of the senior citizen population is growing. This constitutes new challenges for authorities and researchers in terms of forming good health promotion strategies to handle the myriad of future health issues. Norway has the dubious position as a leader in the world in terms of money spent on the health care system. A growing number of people are receiving successful medical treatments, but many are returned home with adverse, late-stage effects from the disease and/or the treatment. Better health outcomes could be achieved with increased knowledge on how to promote health in these populations. Interdisciplinary research is needed to produce new knowledge and understanding about the diverse relationships required for the success of an efficient health promotion strategy.

The Centre will contribute to new knowledge about factors that promote, sustain, and restore good health in healthy people, vulnerable or exposed groups, and those with health deficiencies. The focus is on factors that promote health (i.e., salutogenesis) as opposed to the focus on factors that generate illness and disease (i.e., pathogenesis). As a central guideline for the centre's activity Positive Health Research (PHR) is defined "...as the

scientific study of factors leading to and determinants of health risk, and of the interventions which modify these factors and determinants, so as to have a positive impact on health maintenance and development."

Research Centre for Health Promotion and Resources HiST/NTNU comprises four research groups – all with a focus on health promotion in different settings. These are "Positive occupational health", "Health promotion among the ill", "The global health initiative", and "Health promotion in the life course." The Centre also have a Unit for Best Practice in health promotion and prevention to help organizations gather and systemize research/knowledge on actual health promotional interventions, to translate knowledge to practical use, and to evaluate health promotional and preventive interventions and practice.

The main aim with this booklet is to communicate what kind of research is carried through in this research group, together with our collaboraters, and the practical implications of a positive focus in health promotion research. The five sections in this book refer to each of the fields of interest in the Centre. We hope that this booklet can inspire researchers who have the same research interest as we do, to take contact. For more information of the centre see <a href="http://www.rchpr.org/about/backgroundandvision.aspx">http://www.rchpr.org/about/backgroundandvision.aspx</a>.

Geir Arild Espnes

Centre leader

## **Contents**

I. Positive Occupational Health	7
Positive and negative work-home interaction: An integrative model  SIW TONE INNSTRAND	9
Building engagement and healthy organisations. A test of the Nordic questionnaire on Positive Organizational Psychology (N-POP)	25
Challenges among health care workers when changes are introduced	
Leadership and health promotion workplaces  PÅL GJERSTAD & FRODE LYSBERG	49 49
II. Health Promotion among the Ill	59
Health promotion among the ill	61
Health related quality of life among elderly Polish and Norwegian MI survivors: in search of positive bases for secondary health promotion	
Resilience mechanisms as factors to sustain activity participation in home and leisure	
Perceived benefits of support groups for cancer victims and family members	
Rehabilitation in patients with Chronic Obstructive Pulmonary Disease (COPD) OLA BRATÅS	111 111
Children and Adolescents Surviving Cancer: Psychosocial Health and Quality of Life MARY-ELIZABETH BRADLEY EILERTSEN	125
III. Global Health Promotion Initiative	143
A theoretical assessment of the state of preparedness for Non Communicable Diseases (NCD) in Uganda and a suggestion for health promotion research to guide positive heapolicy and action	alth 145
Comparison of self-rated health, well-being, anxiety and depression in young female populations in Port Moresby, Papua New Guinea and Nord-Trøndelag, Norway	)
IV. Health Promotion in the Life Course	175
The role of resources and protective factors in relation to stress and health outcomes in adolescence.  UNNI KARIN MOKSNES	177

Knowledge based health promotion in Public Health, the HUNT Study, Norway.	
Opportunities for health promotion research STEINAR KROKSTAD	
Self-transcendence, well-being, and nurse-patient-interaction in cognitively intact nursi home patients	.205
Religion and mental health in the elderly: An exploration of possible associations  MARIANNE NILSEN KVANDE & TORGEIR SØRENSEN	
School wellbeing among children: The dialogue and possibilities	
V. Best Practice in Health Promotion	.253
Evidence-based health promotion — getting evidence into practice. Experiences from a Norwegian study	.255
A journey to the Center of Health - some views and reflections on concepts for health promotion practice – plotting a roadmap towards New Health and the Salutogenic Soci	-
BENGT LINDSTRÖM	267
Cultural activities as health promotional strategy.	.283

### I. Positive Occupational Health

Recently, more and more occupational health psychology researchers and practitioners have recognized that, in order to improve working conditions, simply identifying and preventing work factors related to worker's impaired health is not enough. Positive Occupational Health Psychology (POHP) is the study and application of optimal functioning in the workplace. It promotes occupational health and flourishing, and examines how positive phenomena (contexts, personal resources) can be used to protect against occupational risks.

This section provides both theoretical and practical examples within the field of Positive Occupational Health. In Chapter 1, Innstrand presents an integrative model on positive and negative work-home interaction building upon COR theory. Although COR theory is one of the leading theories in explaining job stress and burnout, its focus on different resources as a part of a greater dynamic process provides a comprehensive theoretical framework for an active, positive psychological perspective in occupational and organizational psychology. For the development of both theory and method in this area, Christensen and colleagues has developed a questionnaire – the Nordic Questionnaire on Positive Organizational Psychology (N-POP) – that provides a full measure of organizational health by focusing on six dimensions of organizational life: Individual resources, Job demands, Job resources, Work-related experiences and attitudes, Individual wellbeing, and Organizational performance. In Chapter 2 they present the results from the reliability and validity analyses of the questionnaire which was tested in two samples from Sweden and Norway.

In Chapter 3, André argues for the need for the presence of skilled and motivated key personnel in the unit within the health care field in times of change if implementation of these changes is to be successful. Similarly, in Chapter 4, Gjerstad and Lysberg discuss leadership and its impact on various aspects of work-related health. Health promotion leadership is concerned with creating a culture for health-promoting workplaces. This requires that the leaders are engaged in the systematic development of both the physical and psychosocial work environment.

We hope that this section about positive occupational health encourages scholars in occupational and organizational psychology to conduct more positive and resource-oriented research on questions within the area of occupational health.

# Positive and negative work-home interaction: An integrative model

#### SIW TONE INNSTRAND

Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Social Work and Health Science, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Building upon Hobfoll's Conservation of Resources (COR) theory (1989, 2001), this paper aims to provide a theoretical framework aiding work-home researchers to predict, explain and understand the work-home nexus and its associates. With its focus on both loss and gain of resources, COR theory encompasses the pros and cons of the work-family interaction. In order to prove its applicability, some practical examples and ways of reasoning about hypothesized relationships are illustrated.

#### Introduction

Changes in family structure, work context, and the composition of the work force mean a host of new challenges for both men and women as they struggle to cope with the often competing pressures of work demands and personal responsibilities. However, multiple roles might also provide arenas for joy and personal growth. There is a growing agreement in the work-home literature that work-home balance should be regarded as more than lack of conflict i.e., it may also indicate "the extent to which an individual is equally engaged in – and equally satisfied with- his or her work role and family role" (Greenhaus, Collins, & Shaw, 2003). Hence, a comprehensive understanding of the work-home interaction (WHI) should include components of both conflict and facilitation, and these components should be regarded as bidirectional (Byron, 2005; Carlson & Frone, 2003; Carlson et al., 2006; Eby, Casper, Lockwood, Bordeaux, & Brinley, 2005; Ford, Heinen, & Langkamer, 2007; Frone, 2003; Greenhaus & Powell, 2006). Work/home conflict occurs when the demands associated with one domain are incompatible with the demands associated with the other domain (Perrewé, Hochwarter, & Kiewitz, 1999), whereas work/home facilitation refers to how participation in one role is made better or easier due to participation in the other role (Wayne, Musisca, & Fleeson, 2004).

However, few attempts have been made in proposing a comprehensive model of antecedents and outcomes of WHI in which both conflict and facilitation are integrated. Conservation of resources (COR) theory is a stress and motivational theory which provides a framework to understand, predict, and examine this transactional relationship that can then be used to shape settings towards more optimal balance of resource cost and benefit (Hobfoll, 2011). The aim of this paper is to introduce a conceptual model of work-home interaction and show how the COR theory may illuminate this area of research. The model is an elaboration of Hobfoll and Shirom's (2001) COR model of the interplay between home and work stressors and is graphically depicted in Figure 1. First, I outline the theory and its general application. Second, I turn to the WHI literature and findings from our own studies to examine how COR theory illuminate this area of research. The results from our own study are based on data from a longitudinal study among eight different occupational groups in Norway: lawyers, physicians, nurses, teachers, church ministers, bus drivers, and people working in advertising and information technology (for more information, see Innstrand, 2009). Implications of the findings are discussed in the paper.

#### The Conservation of resources (COR) theory

The basic tenet of the COR theory is that people have a deeply rooted motivation to obtain, retain, and protect what they value, labeled resources. Both work and home life comprise a range of resources which are valued and sought after (i.e. see Hobfoll, 2001). The COR theory integrates work and home life through the concept of resources that join these different domains in a common economy in which resources are exchanged (Hobfoll & Freedy, 1993). As indicated by the two separate arrows between work resources and home resources in Figure 1, empirical evidence shows that this exchange is bidirectional but unique in how it operates in each direction (Byron, 2005; Carlson et al., 2006; Grzywacz & Marks, 2000; Kinnunen & Mauno, 1998; Montgomery, Peeters, Schaufeli, & Den Ouden, 2003; Peeters, Montgomery, Bakker, & Schaufeli, 2005). Stress or conflict occurs because resources are lost, threatened, or fail to give anticipated return in the process of juggling both work and home life (Grandey & Cropanzano, 1999). On the other hand, facilitation follows when resources contribute to the exchange of gains between the domains (Hobfoll, 1989; Wayne et al., 2007).

Resources are defined as "...those objects, personal characteristics, conditions, or energies that are valued by the individual or that serve as a means for attainment of these objects, personal characteristics, conditions, or energies" (Hobfoll, 1989, p. 516). These

resources may be rooted both in the work domain and the home domain. Hobfoll (1998, 2001) has identified 74 work-related and nonwork-related resources. Examples of work-related resources are "time for work," "stable employment," and "support from co-workers". Nonwork-related resources are, for example, "good marriage," "free time," or "time with loved ones". Losses and gains of these resources are important, because in addition to an instrumental value they also have a symbolic value by defining social identity (Hobfoll, 1989).

The COR theory expands previous stress theories in that it not only describes what individuals do when confronted with stress, but also in the absence of threats. Specifically, when confronted with stress, individuals are predicted by the model to strive to minimize net loss of resources. Significant and ongoing drains on resources may provide a state of chronic stress such as burnout (Hobfoll & Shirom, 2001). Conversely, when not currently confronted with threats, people strive to develop resource surpluses to offset the possibility of future loss. When people develop resource surpluses, they are likely to experience positive well-being and health.

Resources are not distributed equally, however, and the COR theory postulates that those with the most resources are less vulnerable to resource loss and more capable of resource gain. For example, a strong social network (partner, friends) provides social support and a safety net when strain occurs. This implies that those who lack strong resource pools are more likely to experience spirals of resource loss; initial losses beget further losses. Similarly, those with a strong resource pool are more likely to experience spirals of resource gain. Initial resource gain begets further resource gain (Hobfoll, 1998).

#### Theoretical model

COR theory has been applied as a theoretical framework to work-home conflict (Grandey & Cropanzano, 1999) and facilitation (Hakanen, Peeters, & Perhoniemi, 2011; Wayne, Grzywacz, Carlson, & Kacmar, 2007) separately. However, this is the first attempt to provide a resource based, integrative model of both positive and negative work-home interaction and some of its core relations. In the following sections, I demonstrate how the COR theory can be applied to WHI research.

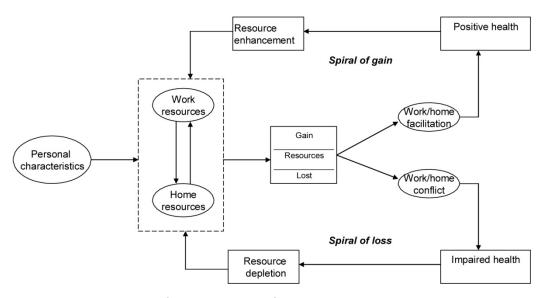


Figure 1. The conservation of resources model of work-home interaction.

#### Personal Characteristics and WHI

The COR theory proposes that threat or loss of highly valued personal characteristics may ensue stress and work/home conflict. For example, prior research indicates that role identification is positively related to time investment in that role (Rothbard & Edwards, 2003), and that highly identified roles are related to more work-home conflict (Adams, King, & King, 1996; Byron, 2005; Frone, Russell, & Cooper, 1992; Olson-Buchanan & Boswell, 2006). Conversely, as demonstrated by the COR theory, personal characteristics are also regarded as resources to the extent that they aid stress resistance (Hobfoll, 1989). Job self-efficacy is considered to be such a resource (Bandura, 1997; Wood & Bandura, 1989).

Another personal characteristic which may relate to one's resources is gender. Despite the increase of women in the work force, women still take the main responsibility at home (Kitterød, 2005; Kristiansen & Sandnes, 2006). This implies a conservation of resource such as time and energy for the women. Moreover, whereas a strong work related identity accords with the male breadwinner role, it is not consistent with the female homemaker role (Simon, 1995), thus possibly producing more guilt and conflict in women (Elvin-Nowak, 1999; Livingston & Judge, 2008). Inside the COR framework this means that salient gender roles or social identities may be threatened in the juggling of work and home life. On the other hand, Simon (1997) demonstrated that parenthood simultaneously involved benefits and costs and was a source of both positive and negative emotions, especially among mothers. Thus, it could be argued that despite the cost of juggling work and home life in women, multiple roles imply that more resources are disposed of, with positive consequences –

particularly for women. This confer with the COR theory's propositions of resource caravans and that initial resource gain begets further resource gain (Hobfoll, 1998).

#### Job characteristics and WHI

According to the COR model, as more strain is experienced in one domain, fewer resources are available to fulfill one's role in another domain. Thus, the experience of workload may leave fewer resources available for family demands. Conversely, the COR model posits that those with greater resources are less vulnerable to resource loss and more capable of resource gain (Hobfoll, 1989, 2001). Workload and autonomy are examples of energy resources that may aid the acquisition of other resources, such as time for work and family.

#### Home characteristics and WHI

In terms of COR theory, marriage or cohabitation are examples of condition resources that are valued and sought after by many people. If this valued condition is threatened or lost in the juggling of work and home, or through a resource depletion associated with increased responsibility, the theory may be related with resulting conflict. However, people living with a partner may also have more resources to draw from (i.e. their spouse, more finances). Thus, being married or cohabiting may also enable facilitation instrumentally (more resources to draw on or by) or affectively (i.e. positive moods and emotions), as suggested by Greenhaus and Powell (2006).

#### Impaired health and WHI

One corollary of the COR theory is that individuals must invest resources to limit loss of resources, to protect resources, or to gain resources. For example, individuals experiencing stress or conflict in their interaction between work and family may need to increase their investment of time, energy, and trust in those relationships. As illustrated in Figure 1, enduring investments of resources may promote burnout. The COR theory describes burnout as a state of extreme resource depletion (Hobfoll & Freedy, 1993), a conception that was recently supported empirically in a study by Neveu (2007). Leiter (1990) found that loss of resources related to both work and family predicted burnout six months later.

However, whereas it has previously been assumed that work/home conflict may have adverse effects on health (for a review see Allen et al., 2000), recent research indicates that impaired health may also exacerbate work/home conflict. For example, in a study among police officers in Norway, burnout was a strong predictor of work-family conflict (Mikkelsen & Burke, 2004). This relates to another corollary of the COR theory, suggesting that those

who lack resources are not only more vulnerable to resource loss, but initial loss also begets future loss, creating loss spirals (Hobfoll, 1989,1998, 2001).

#### Positive health and WHI

The COR theory posits that people strive to develop resource surpluses to offset the possibility of future loss. When people develop resource surpluses, they are likely to experience positive well-being and health. Although, a systematic research on potential outcomes of facilitation is still lacking (O'Driscoll, Brough, & Kalliath, 2009) recent studies have found work-home facilitation to be related to favourable outcomes like improved well-being, affective commitment, less depression and turnover intentions, motivation and productivity (Allis & O'Driscoll, 2008; Hammer et al., 2005; Hill, et al., 2007; Wayne et al., 2006). The COR theory further anticipates that positive experiences or resources are likely to accumulate, creating a positive spiral of resources, which, in turn, is likely to have positive health-promoting effects. In a 3-year cross-lagged panel study Hakanen and colleagues (Hakanen et al., 2011), found work-family enrichment and engagement to be reciprocally related supporting the COR theory.

#### Results

Building upon data from a longitudinal study among eight different occupational groups in Norway (Innstrand, 2009) we found support for most of the hypothesized relationship illustrated in Figure 1.

Personal Characteristics and WHI: In line with the COR theory's proposal that threat or loss of highly valued personal characteristics may ensue stress and work/home conflict we found individual vulnerability (job performance-based self-esteem) to contribute significantly to the explanation of work-home interactions, and in particular work-to-home conflict (Innstrand, Langballe, Espenes, Aasland, & Falkum, 2010). This implies that when self-esteem strongly depends upon performance at work, time and energy available for home life tends to be depleted, increasing the risk for work/home conflict. Moreover, in line with the COR theory, these variables were reciprocally related, thus ensuing spirals of loss. However, job performance-based self-esteem and work/home facilitation were only weakly associated. Another personal characteristic which may relate to one's resources is gender. By means of latent mean analysis we found women overall reported more conflict and facilitation in both direction as compared to men (Innstrand, Langballe, Falkum, Espnes, Aasland, 2009). Thus, even though the gap between the genders in Norway is among the

smallest in the world when it comes to economic participation and opportunities, educational attainments, and political empowerment, our study indicate that gender differences in the experience of work-home interaction are prevalent

Job characteristics and WHI: Workload and autonomy are examples of energy resources that may aid the acquisition of other resources, such as time for work and family. Examining work/home conflict and facilitation across four different family structures in Norway (Innstrand, Langballe, Falkum, Espnes, & Aasland, 2010) we found workload to be positively related to work/home conflict suggesting that initial losses beget further losses. Conversely, a positive association between autonomy and work/home facilitation supported the COR proposition that those with a strong resource pool are more likely to experience spirals of resource gain. Similarly, exploring occupational differences in WFI (Innstrand, Langballe, & Falkum, 2010) we found that those occupational groups experiencing the least conflict are also among those experiencing the least facilitation. Similarly, with few exceptions, those experiencing the most conflict are also among those experiencing the most facilitation. Subsequent analyses indicates that this apply for both men and women. These results empirically support the orthogonal nature of WFI and suggest that the interaction between work and family may be more permeable in some occupations than others.

Home characteristics and WHI: In terms of COR theory, marriage or cohabitation are examples of condition resources that are valued and sought after by many people. Examining work/home conflict and facilitation across four different family structures in Norway (Innstrand, Langballe, Falkum et al., 2010) we found that work/home conflict was more profound among those living in two-parent families and among single parents than among childless couples and singles. However, work-to-home facilitation did not vary by family structure, whereas the childless couples reported more home-to-work facilitation.

Impaired/positive health and WHI: One corollary of the COR theory is that individuals must invest resources to limit loss of resources, to protect resources, or to gain resources. Enduring investments of resources may promote burnout. In a longitudinal study of reciprocal relations we found work-home interaction and burnout may act as both a predictor and consequence of each other (Innstrand, Langballe, Espnes, Falkum, & Aasland, 2008). Bidirectional work/home was significant associated with both exhaustion and disengagement two years later. Moreover, initial experience of emotional exhaustion was associated with increased work/home conflict two years later supporting the COR proposition of loss spirals. In a recent study among male and female physicians, we even

found that work-home interaction plays a role above and beyond both individual factors and work-related factors in determining the level of experienced burnout (Langballe, Innstrand, Aasland, & Falkum, 2011).

Conversely, significant lagged negative effects from work-to-family facilitation to burnout, suggested that high levels of work-to-family facilitation at Time 1 caused low levels of exhaustion and disengagement at Time 2. Moreover, a high level of family-to-work facilitation at Time 1 predicted a low level of disengagement at Time 2 (Innstrand et al., 2008). Thus, in line with the COR theory's assumptions, a positive interaction between work and home may be regarded as a resource surplus as a high initial level of work/home facilitation seems to buffer against burnout.

#### Discussion

Researchers have explicitly called for greater attention to the positive side of the work-home interaction and the need of a theoretical model integrating both the positive and negative aspects and the mechanisms that underlie work-home interaction (i.e. Geurts & Demerouti, 2003). The aim of this paper is to introduce a conceptual model of work-home interaction and show how the COR theory may illuminate this area of research. Clearly, if this model's proportions of gain and loss of spiral are replicated in future empirical research, the practical utility to organizations would be significant. Empirical evidence indicates that different processes may underlie these components and highlights the importance of exploring the whole WHI nexus to understand the work-home balance. For example, our understanding of work-home interaction is incomplete without consideration of facilitation, since facilitation contributes to an understanding of work-home dynamics above and beyond conflict. As suggested by van Steenbergen and colleagues (2007) this implies that organizations should carefully examine the outcomes they want to address and tailor their interventions accordingly. For example, interventions aim to reduce impaired health such as burnout should mainly focus on reducing the experience of work-home conflict. Conversely, the aim of interventions is to increase positive health outcomes which might bolster job performance and work satisfaction, should, in addition to the reduction of conflict, find actions to stimulate the experience of work-home facilitation.

Although the COR theory provides a heuristic framework of WHI, the empirical evidence of the model depicted on Figure 1 has to be considered with some limitations in mind. It should be noted that although positive and impaired health is suggested as outcomes

in the present figure, other outcomes like job performance, affective commitment, and work satisfaction is also plausible. Similarly, other precursors could be included like home commitment, home satisfaction, and global satisfaction just to mention a few. Although the model takes both the direction and the effect of the interaction into consideration, the nature of conflict and facilitation can differ as well. For instance, work-home conflict has been proposed to have different dimensions in which conflict can be time-based, behavior-based, or strain-based (Greenhaus & Beutell, 1985). The level of resource drain might differ along these dimensions as well. Moreover, in the COR theoretical framework WHI is proposed to be caused by the exchange of valued resources. However, the exact values of these resources are only assumed. More research is needed on the value or meaning individuals attach to different roles. Similarly, as resource priorities are assumed to be largely culturally determined (Hobfoll, 1998) and the present model proposed originates from a Scandinavian point of view, cross-cultural studies on the viability of the model are warranted. Finally, the COR theory may in itself contain some limitations and biases (for a discussion see Hobfoll, 2001). Nevertheless, the COR is found to be a valid and robust contribution to the stream of stress scholarship (Quick & Gavin, 2001), providing a new standard in the field (Schwarzer, 2001) and enhancing contemporary understanding of stress and coping (Thompson & Cooper, 2001). The present paper has proved its applicability to the four dimensions of work-home interaction as well.

As long as work and family/home are the two most important life domains in contemporary societies, a more profound understanding of the factors that affect health and well-being needs to be found in the companion areas of work and home. Clearly more research is needed before firm conclusion can be made, especially concerning the facilitation aspect. It is hoped that the proposed model will guide and stimulate future research in this field and encourage more theory-driven innovative research.

#### References

- Adams, G. A., King, L. A., & King, D. W. (1996). Relationships of job and family involvement, family social support, and work-family conflict with job and life satisfaction. *Journal of Applied Psychology*, 81, 411-420.
- Allen, T. D., Herst, D. E. L., Bruck, C. S., & Sutton, M. (2000). Consequences associated with work-to-family conflict: A review and agenda for future research. *Journal of Occupational Health Psychology*, *5*, 278-308.
- Allis, P., & O'Driscoll, M. (2008). Positive effects of nonwork-to-work facilitation on well-being in work, family and personal domains. *Journal of Managerial Psychology*, 23, 273–291.
- Bandura, A. (1997). *Self-efficacy. The exercise of control*. New York: W. H. Freman and Company.
- Byron, K. (2005). A meta-analytic review of work-family conflict and its antecedents. *Journal of Vocational Behavior*, 67, 169-198.
- Carlson, D. S., & Frone, M. R. (2003). Relation of behavioral and psychological involvement to a new four-factor conceptualization of work-family interference. *Journal of Business and Psychology*, 17, 515-535.
- Carlson, D. C., Kacmar, K. M., Wayne, J. H., & Grzywacz, J. G. (2006). Measuring the positive side of the work-family interface: Development and validation of a work-family enrichment scale. *Journal of Vocational Behavior*, 68, 131-164.
- Clark, S. C. (2000). Work/family border theory: A new theory of work/family balance. *Human Relations*, *53*, 747–770.
- Demerouti, E., Bakker, A. B., Nachreiner, F., & Schaufeli, W. B. (2001). The job demands—resources model of burnout. *Journal of Applied Psychology*, 86, 499–512.
- Eby, L. T., Casper, W. J., Lockwood, A., Bordeaux, C., & Brinley, A. (2005). Work and family research in IO/OB: Content analysis and review of the literature (1980-2002). *Journal of Vocational Behavior*, 66, 124-197.
- Elvin-Nowak, Y. 1999. The meaning of guilt: A phenomenological description of employed mother's experiences of guilt. *Scandinavian Journal of Psychology*, 40, 73-83.

- Ford, M. T., Heinen, B. A., & Langkamer, K. L. (2007). Work and family satisfaction and conflict: a meta-analysis of cross-domain relations. *Journal of Applied Psychology*, 92, 57-80.
- Freund, A. M., & Riediger, M. (2001). What I have and what I do The role of resource loss and gain through life. *Applied Psychology: An International Review, 50*, 370-380.
- Frone, M. R. (2003). Work-family balance. In J. Campbel Quick & L. E. Tetrick (Eds.), *Occupational Health Psychology*. (pp.143-162). Washington, DC: American Psychological Association.
- Frone, M. R., Russell, M., & Cooper, M. L. (1992). Antecedents and outcomes of work-family conflict: Testing a model of the work-family interface. *Journal of Applied Psychology*, 77, 65-78.
- Geurts, S. A. E., & Demerouti, E. (2003). Work/non-work interface: A review of theories and findings. In M. J. Schabracq, J. A. M. Winnubst & C. L. Cooper (Eds.), *The handbook of work and health psychology*. (pp. 279-312). New York: John Wiley & Sons.
- Grandey, A. A., & Cropanzano, R. (1999). The conservation of resources mode applied to work-family conflict and strain. *Journal of Vocational Behavior*, *54*, 350-370.
- Greenhaus, J. H., & Beutell, N. J. (1985). Sources of conflict between work and family roles. *Academy of Management Review*, 10, 76-88.
- Greenhaus, J. H., Collins, K. M., & Shaw, J. D. (2003). The relation between work-family balance and quality of life. *Journal of Vocational Behavior*, *6*, 510-531.
- Greenhaus, J. H., & Powell, G. N. (2006). When work and family are allies: A theory of work-family enrichment. *Academy of Management Review*, 31, 72-92.
- Grzywacz, J. G., & Marks, N. F. (2000). Reconceptualising the work-family interface: an ecological perspective on the correlates of positive and negative spillover between work and family. *Journal of Occupational Health Psychology*, *5*, 111-126.
- Hakanen, J. J., Peeters, M. C. W., & Perhoniemi, R. (2011). *Journal of Occupational and Organizational Psychology*, 84, 8-30.
- Hakanen, J. J., Perhoniemi, R., & Toppinen-Tanner, S. (2008). Positive gain spirals at work: from job resources to work engagement, personal initiatives and work-unit innovativeness. *Journal of Vocational Behavior*, 73, 78 91.

- Hammer, L. B., Cullen, J. C., Neal, M. B., Sinclair, R. R., & Shafiro, M. V. (2005). The longitudinal effects of work-family conflict and positive spillover on depressive symptoms among dual-earner couples. *Journal of Occupational Health Psychology*, *5*, 138 154.
- Hill, E. J., Allen, S., Jacob, J., Bair, A. F., Bikhazi, S. L., Van Langeveld, A.,
  Martinengo, G., Parker, T. T., & Walker, E. (2007). Work-family facilitation:
  Expanding theoretical understanding through qualitative exploration. *Advances in Developing Human Resources*, 9, 507–526.
- Hobfoll, S. E. (2011). Conservation of resource caravans and engaged settings. *Journal of Occupational and Organizational Psychology*, 84, 116 122.
- Hobfoll, S. E. (1989). Conservation of resources. A new attempt at conceptualizing stress. *American Psychologist*, *44*, 513-52.
- Hobfoll, S. E. (1998). *Stress, culture, and community. The psychology and philosophy of stress.* New York: Plenum Press.
- Hobfoll, S. E. (2001). The influence of culture, community, and the nested-self in the stress process: Advancing conservation of resources. *Applied Psychology*, *50*, 337-421.
- Hobfoll, S. E., & Freedy, J. (1993). Conservation of resources: A general stress theory applied to burnout. In W. B. Schaufeli, M. Maslach & T. Marek (Eds.), *Professional burnout: Recent developments in theory and research.* (pp. 115-129). USA: Taylor & Francis.
- Hobfoll, S. E., & Shirom, A. (2001). Conservation of resources theory. Applications to stress and management in the workplace. In R. T. Golembiewski (Edt.), *Handbook of organizational behavior*. (2<sup>nd</sup> Ed) (pp. 57-80), *revised and expanded*. New York: Marcel Dekker.
- Innstrand, S. T. (2009). Work/home conflict and facilitation: COR(e) relations. A longitudinal study on work-home interaction in different occupational groups in Norway. Trondheim: NTNU 2009 (ISBN 978-82-471-1876-4).
- Innstrand, S. T., Langballe, E. M., Espnes, G. A., Falkum, E., & Aasland, O. G. (2008). Positive and negative work-family interaction and burnout: A longitudinal study of reciprocal relations. *Work & Stress*, 22, 1-15.

- Innstrand, S. T., Langballe, E. M., Espnes, G. A., Aasland, O. G., & Falkum, E. (2010). Personal vulnerability and work-home interaction: The effect of job performance- based self-esteem on work-home conflict and facilitation. *Scandinavian Journal of Psychology*, *51*, 480 -487.
- Innstrand, S. T., Langballe, E. M., & Falkum, E. (2010). Exploring occupational differences in work-family interaction: Who is at a risk? *International Journal of Stress Management*, 17, 38 55.
- Innstrand, S. T., Langballe, E. M., Falkum, E., Espnes, G. A., & Aasland, O. G. (2009). Gender specific perceptions of four dimensions of the work/family interaction. *Journal of Career Assessment, 17*, 402-416.
- Innstrand, S. T., Langballe, E. M., Falkum, E., Espnes, G. A., & Aasland, O. G. (2010).
  Work/Home Conflict and Facilitation across Four Different Family Structures in
  Norway. Community, Work & Family, 13, 231-249
- Kinnunen, U., & Mauno, S. (1998). Antecedents and outcomes of work-family conflict among employed women and men in Finland. *Human Relations*, *51*, 157-177.
- Kitterød, R. H. (2005). Han jobber, hun jobber, de jobber. Arbeidstid blant par av småbarnsforeldre [He works, she works, they works. Work hours among couples with small children] Oslo: Statistics Norway.
- Kristiansen, J. E., & Sandnes, T. (2006). Women and men in Norway. What the figures say. Oslo: Statistics Norway.
- Langballe, E.M., Innstrand, S.T., Aasland, O.G., & Falkum, E. (2011). The predictive value of individual factors, work-related factors, and work-home interaction on burnout in female and male physicians: a longitudinal study. *Stress & Health*, 27, 73–87.
- Lazarus, R. S. (2001). Conservation of resource theory (COR): Little more than words masquerading as a new theory. *Applied Psychology: An International Review*, 50, 381-391.
- Lee, R. T., & Ashforth, B. E. (1996). A meta-analytic examination of the correlates of the three dimensions of job burnout. *Journal of Applied Psychology*, 81, 123-133.
- Leiter, M. P. (1990). The impact of family resources, control coping, and skill utilization on the development of burnout: A longitudinal study. *Human Relations*, *43*, 1067–1083.

- Livingston, B. A., & Judge, T. A. (2008). Emotional responses to work-family conflict:

  An examination of gender role orientation among working men and women. *Journal of Applied Psychology*, 93, 207-216.
- Mikkelsen, A., & Burke, R. J. (2004). Work-family concerns of Norwegian police officers: Antecedents and consequences. *International Journal of Stress Management*, 11, 429-444.
- Montgomery, A. J., Peeters, M. C. W., Schaufeli, W. B., & Den Ouden, M. (2003). Work- home interference among newspaper managers: its relationship with burnout and engagement. *Anxiety, Stress, and Coping, 16*, 195-211.
- Neveu, J-P. (2007). Jailed resources: Conservation of resources theory as applied to burnout among prison guards. *Journal of Organizational Behaviour*, 28, 21-42.
- O'Driscoll, M., Brough, P., & Kalliath, T. (2009). Work-Family Conflict and Facilitation. Chapter 6 prepared for F. Jones, R. Burke & M. Westman (Eds.), *Managing the work-home interface*. Hove, Sussex, UK: Psychology Press.
- Olson-Buchanan, J. B., & Boswell, W. R. (2006). Blurring boundaries: Correlates of integration and segmentation between work and nonwork. *Journal of Vocational Behavior*, 68, 432-445.
- Peeters, M. C. W., Montgomery, A. J., Bakker, A. B., & Schaufeli, W. B. (2005). Balancing work and home: How job and home demands are related to burnout. *International Journal of Stress Management*, 12, 43-61.
- Perrewé, P., Hochwarter, W. & Kiewitz, C. (1999). Value Attainment: An explanation for the negative effects of work-family conflict on job and life satisfaction. *Journal of Occupational Health Psychology*, 4, 318-326.
- Premeaux, S. F., Adkins, C. L., & Mossholder, K. W. (2007). Balancing work and family: A field study of multi-dimensional, multi-role work-family conflict. *Journal of Organizational Behavior*, 28, 705-727.
- Quick, J. C., & Gavin, J. H. (2001). Four perspectives on conservation of resources theory: A commentary. *Applied Psychology: An International Review, 50*, 392-400.
- Rothbard, N. P., & Edwards, J. R. (2003). Investment in work and family roles: A test of identity and utilitarian motives, *Personnel Psychology*, *56*, 699-730.
- Schwarzer, R. (2001). Stress, resources, and proactive coping. *Applied Psychology: An International Review, 50*, 400-407.

- Simon, R. W. (1995). Gender, multiple roles, role meaning, and mental health. *Journal of Health and Social Behavior*, *36*, 182-194.
- Simon, R. W. (1997). The meaning individuals attach to role identities and their implications for mental health. *Journal of Health and Social Behavior*, *38*, 256-274.
- Thompson, M. S., & Cooper, C. L. (2001). A rose by another name...: A commentary on Hobfoll's conservation of resources theory. *Applied Psychology: An International Review, 50*, 408-418.
- van Steenbergen, E. F., Ellemers, N., & Mooijaart, A. (2007). How work and family can facilitate each other: Distinct types of work-family facilitation and outcomes for women and men. *Journal of Occupational Health Psychology*, 12, 279–300.
- Wayne, J. H., Grzywacz, J. G., Carlson, D. S., & Kacmar, K. M. (2007). Work-family facilitation: A theoretical explanation and model of primary antecedents and consequences. *Human Resource Management Review*, 17, 63-76.
- Wayne, J. H., Musisca, N., & Fleeson, W. (2004). Considering the role of personality in the work-family experience: Relationships of the big five to work-family conflict and facilitation. *Journal of Vocational Behavior*, 64, 108-130.
- Wayne, J. H., Randel, A. E., & Stevens, J. (2006). The role of identity and work-family support in work-family enrichment and its work-related consequences. *Journal of Vocational Behavior*, 69, 445–461.
- Wood, R., & Bandura, A. (1989). Impact of conceptions of ability on self-regulatory mechanisms and complex decision making. *Journal of Personality and Social Psychology*, *56*, 407-415.

#### 2. Building engagement and healthy organisations

## A test of the Nordic questionnaire on Positive Organizational Psychology (N-POP)

MARIT CHRISTENSEN<sup>1</sup>, GUNNAR ARONSSON<sup>2</sup>, THOMAS CLAUSEN<sup>3</sup>, JARI HAKANEN<sup>4</sup>, & LISA VIVOLL STRAUME<sup>4</sup>

Norwegian University of Science and Technology, Department of Psychology, Trondheim, Norway
<sup>2</sup> Stockholm University, Department of Psychology, Sweden
<sup>3</sup>National Research Centre for the Working Environment (NRCWE) Copehagen, Denmark
<sup>4</sup>Finnish Insitute of Occupational Health, Helsinki, Finland

#### Abstract

The main aim of this project was to investigate the predictors of positive work related states and attitudes, e.g. work engagement, meaning at work and personal growth, and healthy organisations. A questionnaire was developed and a pilot study was conducted in 2011 in Sweden (N=180) and Norway (N=202). The results of these studies were used as a background for a first validation of the Nordic Questionnaire on Positive Organizational Psychology (N-POP). The results of the analyses of the reliability (internal consistency) and the construct validity of the scales in N-POP reveals a reliable and valid instrument for assessing the psychosocial work environment, positive work-related states and attitudes and a series of organizational and individual outcomes in modern work organizations. Finally, the conclusion summarizes that the concepts of work environment, health and productivity seem to be able to flow together in an 'optimum' point where well-being at the individual level is coexistent with efficient and productive work organizations.

#### Aims and background of the project

The Nordic research project "Building engagement and healthy organisations" has aimed upon developing theory and methods on positive factors at work and healthy organisations. The main idea is that a healthy organisation assumes that the concepts of work environment, health, and productivity seem to flow together in an 'optimum' point where well-being at the individual level is coexistent with efficient and productive work organizations. For the development of both theory and method in this area the project group has developed a questionnaire – the Nordic Questionnaire on Positive Organizational Psychology (N-POP) –

that provides a full measure of organizational health by focusing on six dimensions of organizational life:

- Individual resources
- Job demands
- Job resources
- Work-related experiences and attitudes
- Individual well-being
- Organizational performance

The questionnaire was tested in two samples from Sweden (N=180) and Norway (N=202), and the results from reliability and validity analyses of these pilot studies are presented in this paper.

This report is the product of research undertaken by a project group on positive work and organizational psychology that has been supported by the Nordic Council of Ministers since 2006. The project group has since then published two reports on Nordic research on positive work and organizational psychology in Sweden, Norway, Finland and Denmark (Christensen et al., 2008; 2009). In the first two reports from this project, the project group proposed and investigated a model on the relationship between job resources and individual resources on the one hand and work-related experiences and attitudes and organizational and individual outcomes on the other (Christensen et al., 2008; 2009). The working model posits that job demands, job resources and individual resources have an impact on a series of workrelated experiences and attitudes that again are of importance for a variety of individual and organizational outcomes, such as sickness absence, well-being and productivity. In this respect, the working model links factors in the psychosocial work environment with a series of positive psychological states and outcomes that are of simultaneous importance at the individual the organizational and the societal level. The working model reflects the concepts that we measure in the Nordic Questionnaire on Positive Organizational Psychology (N-POP). Figure 1 presents the working model and the concepts that are measured in the N-POP.

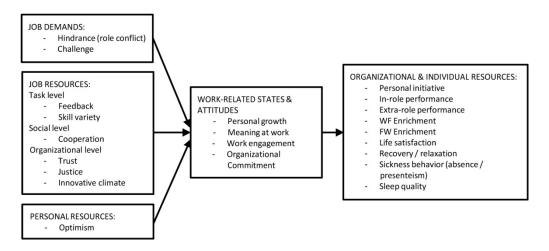


Figure 1. Conceptual framework of the Nordic Questionnaire on Positive Organizational Psychology (N-POP)

#### Theoretical background

The Nordic welfare societies are currently facing two main challenges. The first challenge stems from changes in the demographic composition of the Nordic countries (Nordic Council of Ministers, 2006). These demographic changes may, in combination with widespread early retirement from the labour market (Nordic Council of Ministers, 2006), will result in a shortage of labour in the Nordic countries in the coming decades. The field of positive work and organizational psychology appears to offer some interesting insights in response to this challenge, as the knowledge generated within the field of positive work and organizational psychology may contribute to increasing the labour supply through its emphasis of building on factors related to intrinsic job motivation (Turner, Barling, & Zacharatos, 2002). The issue of labour supply is traditionally approached in terms of establishing economic incentives but an alternative strategy towards increasing labour supply is offered by the field of positive work and organizational psychology (Clausen, 2009).

Another challenge that confronts the Nordic countries is related to the consequences of the terms of competition in an increasingly globalized economy. The dynamics of a globalized economy have contributed towards increasing the work-related demands experienced by large segments of the labour force. Firstly, the pace of skill change and the frequency of organizational reorganizations have increased job insecurity. Secondly, the competitive pressure of a globalized economy and a tendency towards increased worker autonomy in the production process entails an increased pressure on the employees to perform (Esping Andersen, 2002; Wrzesniewski & Dutton, 2001). Certainly, these developmental tendencies will have an impact on the well-being of employees in the contemporary labour market. Thus, in order to counter the increasingly stressful nature of

contemporary work life (Ferrie et al., 2001) it appears crucial to focus on the development of a series of positive work-life resources that may increase employees' abilities to cope with work-related demands.

Positive psychology, however, may provide some interesting responses to the challenges confronting Nordic welfare societies. The school of positive psychology represents a critique of mainstream psychology; the focus of positive psychology is to create a body of knowledge that focuses on human well-being and growth (e.g. Seligman & Csikszentmihalyi, 2000).

From the perspective of positive psychology, concurrent experiences of positive affect are viewed as the fuel in processes that enhance individual and collective experiences of wellbeing, engagement and human growth (Frederickson & Losada, 2005; Gable & Haidt, 2005). According to Meyer and Allen (1997), experiences of positive affect are positively correlated with job performance whereas experiences of positive affect have been found to be negatively correlated with turnover intentions (see also Clausen and Borg, 2010). Furthermore, research into the implications of positive experiences shows that experiences of positive affect are associated with creativity (Isen, Daubman, & Nowicki, 1987) and intuition (Bolte, Goschkey, & Kuhl, 2003). Also, Frederickson and her colleagues have found that concurrent experiences of positive affects result in increases in individual resilience (Frederickson, Tugade, Waugh, & Larkin, 2003). Experiences of positive affect at work have furthermore been found to increase an individual's capacity to cope with stress (Glazer & Kruse, 2008), reduce the risk of long-term sickness absence (Clausen et al., 2010) and increase the possibilities for returning to work after long-term sickness absence (Clausen et al., 2011). In addition, studies of Finnish teachers and dentists show that various energizing job resources not only mitigate the negative impacts of job demands and work-life changes on work engagement but also they seem to boost work engagement, particularly when the job demands are high (Hakanen, Bakker, & Demerouti, 2005; Bakker, Hakanen, Demerouti, & Xanthopoulou, 2007).

Thus, creating a working environment that draws upon the knowledge generated within the field of positive work and organizational psychology may contribute to the ability of the Nordic welfare societies to meet the aforementioned labour market challenges, both now and in the future. However, in order to reap these rewards it is important to study antecedents and consequences of experiences of positive affect in a variety of work settings.

The conceptual framework presented in the model appears to be closely related to the concept of organizational health as it focuses on psychosocial work environment factors,

individual well-being and indicators of organizational performance. According to Kivimäki and Lindström (2006) a healthy organization has a dual focus, as the well-being of employees and organizational performance are simultaneously at the centre of attention. Accordingly, organizational health is construed as the capability of the organization to function effectively in relation to various environmental factors and to respond to various environmental changes (Kivimäki & Lindström, 2006, p. 811). The concept of organizational health thus constitutes a nexus that allows the concepts of work environment, health and productivity to flow together in an 'optimum' point where well-being at the individual level is coexistent with efficient and productive work organizations. In the optic angle of positive psychology the concept of organizational health thus appears to have an interesting potential.

By drawing on Schaufeli and Bakker's Job Demands-Resources model (JD-R) (Schaufeli & Bakker, 2004), we see that the individually experienced balance between job demands and job resources in the psychosocial work environment has an impact on the well-being of the individual. Schaufeli and Bakker describe job demands as the things that have to be done and job resources as the aspects of the job that either/or (1) reduce job demands and the associated physiological and psychological costs; (2) are functional in achieving work goals; (3) stimulate personal growth, learning and development (Schaufeli & Bakker, 2004, pp. 296). It furthermore follows from the job demands and resource model that the presence of resources in a work organization predicts employee health and well-being whereas excessive demands predict burnout and ill health.

Furthermore, Harter, Schmidt, and Hayes (2002) shows that employee engagement are positively correlated with a series of organizational outcomes such as customer satisfaction, profits, turnover, and productivity. Thus, taken together, the findings of Harter et al. (2002) and Schaufeli and Bakker (2004) lend credence to the dynamics inherent to the notion of organizational health as they establish a link from factors in the psychosocial work environment to positive organizational outcomes via work-related well-being at the individual level.

#### Methods

The N-POP questionnaire was pilot tested through a data collection in some chosen companies in Norway and Sweden. The Swedish participants were employed in a medium-sized bank and worked within financial service and within departments such as private market, development and administration (N=180). The Norwegian questionnaire was

distributed to eight different workplaces. These eight workplaces were categorised into three different categories: Accounting/revision (n = 44), hospitals (n = 69), and university college (n = 89). The total Norwegian sample consisted of 202 respondents. The results of these studies were used as a background for a first validation of the Nordic Questionnaire on Positive Organizational Psychology (N-POP). In this paper, we present results on the reliability and the construct validity of the scales that we included in the N-POP questionnaire.

#### Results and Discussion

In this paper we report our testing of the reliability and construct validity of the concepts within the working model (Christensen, 2008; Christensen, 2009) (See Figure 1). The model reflects the concepts that we measure in the Nordic Questionnaire on Positive Organizational Psychology (N-POP). In the working model we accord theoretical primacy to job demands, job resources and individual resources. Accordingly, these entities are expected to have an impact on the work- related states and attitudes that are placed at the center of the working model, and these work- related states and attitudes are then expected to be important in the framing of a variety of organizational and individual outcomes. However, the positioning of the concepts is large done for analytical purposes and it can easily be imagined that some reversed causality may also be at play. For instance, the outcomes at the individual or organizational level could be expected to have an impact on both work-related states and attitudes of individual employees and on the psychosocial work environment in the work organization. However, for analytical purposes we hold to the working model, when analyzing associations between job demands, job resources, work-related states and various outcomes. However, in the real world it is important to be aware that the empirical phenomena that we investigate are intertwined.

In this paper we have evaluated the psychometric properties of the scales we included in the Nordic questionnaire on Positive Organizational Psychology – N-POP. We assessed the internal consistency of the scales by calculating Cronbach's alpha coefficients for all scales including three items or more. By and large, all scales exhibited satisfactory level for this measure of the internal consistency as 17 of 19 scales that included three or more items. When looking at the two samples the results showed that there were some differences in the internal consistencies of the scales in the two samples. However, these differences were relatively small which leads us to conclude that the scales must be considered as relatively robust measures of the empirical phenomena that they are supposed to measure, as the

internal consistency measures are similar in the Swedish and the Norwegian study populations. In assessing the construct validity of the measures included in the N-POP, we conducted a correlation analysis of the included measures. We conducted the tests of the construct validity of the included measures in three steps. In the first step we correlated scales measuring job resources, personal resources and job demands with the scales measuring work-related states and attitudes. These analyses showed that job resources are by and large correlated positively and significantly with the four scales measuring work-related states and attitudes. The results therefore affirm the construct validity of the measures of job resources and work-related states and attitudes as these measures are statistically associated while still being empirically distinguishable. This conclusion also holds validity in the assessment of the construct validity of our one measure for personal resources (optimism) vis-á-vis the four measures of work-related states and attitudes, as these scales also exhibit moderate to strong correlations. Finally, in the first step the analysis we examined the construct validity of the scales measuring job demands with reference to our four scales measuring work-related states and attitudes. This analysis showed that three of our four measures of work-related states and attitudes correlated negatively with experiences of role conflicts whereas one measure of work-related states and attitudes correlated positively with role conflicts. Surprisingly, our more general measures of job demands correlated positively with the four scales measuring work-related states and attitudes. These findings leads us to conclude that some job demands, as for instance role conflicts, may be considered occupational hindrances that may prevent employees from doing their job properly thereby clashing with professional identities, whereas other types of job demands may be considered challenges that, if dealt with successfully, may affirm the professional identities of employees (cf. Podsakoff, LePine, & LePine, 2007).

In the second step of the analysis, we investigated the construct validity of job resources, personal resources and job demands vis-á-vis the scales measuring organizational and individual outcomes. The correlation analysis showed that job resources by and large correlated positively with the scales measuring organizational and individual outcomes, which supports the construct validity of the included measures. No significant correlations were found between job resources and sickness absence, which is surprising as other studies have demonstrated robust associations between job resources and risk for sickness absence (e.g. Clausen et al. 2012). The correlation analyses furthermore showed that trust and justice were negatively associated with instances of sickness presenteeism which indicates that

employees who experience organizational trust and justice may be confident in the abilities of their colleagues to do the job properly which reduces their propensity to go to work in spite of illness. The personal resource of optimism also showed moderate to strong positive correlations with most of the scales measuring organizational and individual outcomes and optimism was furthermore negatively correlated with both sickness absence and sickness presenteeism. The results regarding job demands and organizational and individual outcomes are in line with the findings observed above as role conflicts (hindrance demands) and are associated with reduced in-role performance, recovery, family-work enrichment and sleep quality and increased risk of sickness absence, whereas the general job demands (challenge demands) are associated with increased personal initiative, extra-role performance, work-family enrichment and sleep quality.

In the third step of the analysis of the construct validity of the scales in the N-POP, we correlated the scales measuring work-related states and attitudes with the scales measuring organizational and individual outcomes. The results of these analyses showed that all four measures of work- related states and attitudes are positive and significantly correlated with personal initiative, role- performance, work-family/family-work enrichment and life satisfaction. The scales measuring work engagement, meaning at work and organizational commitment are furthermore significantly positively associated with the sleep quality and recovery of the respondents. The results of the third step of the analysis of the construct validity of the scales in the N-POP thereby supports the construct validity of the included scales since the analysis shows that the scales are statistically associated according to our expectations while still being empirically distinguishable.

All in all the analyses of the reliability (internal consistency) and the construct validity of the scales included in the Nordic questionnaire on Positive Organizational Psychology lead us to conclude that the N-POP constitutes a reliable and valid instrument for assessing the psychosocial work environment, work-related states and attitudes and a series of organizational and individual outcomes in modern work organizations. The fact that the N-POP was tested and yielded similar results in two countries furthermore lends credence to the robustness of the measures in the questionnaire.

It must be considered a major strength of the Nordic questionnaire on Positive Organizational Psychology that it is a part of a long-standing Nordic collaboration looking into positive factors at work. The research group that consists of researchers from Norway,

Sweden, Finland and Denmark has collaborated since 2006 and the N-POP can therefore be considered a product of the accumulated experiences of the research group.

Secondly, it can be considered a strength of the N-POP that it is informed by two of the most dominant theories within the field of positive organizational psychology – namely the Job Demands-Resource model (Schaufeli and Bakker, 2004) and the conservation of resources theory (Hobfoll, 2001). The questionnaire is therefore solidly anchored within the research traditions of positive organizational psychology, which emphasizes that work must be considered a creative activity that, potentially, contributes to enhancing well-being and personal growth. Thirdly, the measures that have been included in the N-POP have been validated and used in other research. However, many of the applied measures have been abbreviated in the N-POP, which enhances the feasibility of using these measures in the practical assessment of the work climate in modern work organizations.

It can, however, be considered a limitation of the validation of the N-POP that the validation procedure is based on relatively small samples. It is furthermore important to stress that the data have been collected in one Swedish company and four Norwegian companies and that the results therefore cannot be considered representative for the Swedish and Norwegian working populations. Finally, the results are based on cross-sectional data and it is therefore not possible to draw causal inferences from the results presented in the present report. Furthermore, the fact that all data are collected at one time-point also means that in cannot be ruled out that some of the observed correlations may be ascribed to common methods biases (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003).

#### Conclusion

In the present paper we have presented results on the reliability and validity of a new Nordic questionnaire on Positive Organizational Psychology – N-POP. The analyses indicate that the N-POP has satisfactory reliability and construct validity. The questionnaire contributes with a new perspective on organizational psychology as it is anchored within the research traditions of positive organizational psychology, which emphasizes that work must be considered a creative activity that, potentially, contributes to enhancing well-being and personal growth. Finally, the results of the analyses lend credence to the notion of organizational health as the concepts of work environment, health and productivity indeed do seem to flow together in an 'optimum' point where well-being at the individual level is coexistent with efficient and productive work organizations.

#### References

- Bakker, A., Hakanen, J., Demerouti, E., & Xanthopoulou, D. (2007). Job resources boost work engagement, particularly when job demands are high. *Journal of Educational Psychology*, 99, 274-284.
- Bolte, A., Goschkey, T., & Kuhl, J. (2003). Emotion and intuition: Effects of positive and negative mood on implicit judgements of semantic coherence. *Psychological Science*, *14*, 416-421.
- Christensen, M. (2008). *Positive Factors at Work. The First Report of the Nordic Project.* Copenhagen: Nordic Council of Ministers.
- Christensen, M. (2009). Validations and test of central concepts in positive work and organizational psychology. The second report from the Nordic Project 'Positive factors at work'. Copenhagen: Nordic Council of Ministers.
- Clausen, T. (2009). Psychosocial work characteristics, positive work-related states, and labour market outcomes. A study on the antecedents and consequences of affective organizational commitment and experience of meaning at work.

  (Doctoral dissertation, The Danish Research School of Psychology Copenhagen).
- Clausen, T. & Borg, V. (2010). Do positive work-related states mediate the association between psychosocial work characteristics and turnover? A longitudinal analysis. *International Journal of Stress Management*, 17, 308-324.
- Clausen, T., Christensen, K. B., & Borg, V. (2010). Positive work-related states and long-term sickness absence: A study of register-based outcomes. *Scandinavian Journal of Public Health*, *38(Suppl 3)*, 51-58.
- Clausen, T., Friis Andersen, M., Bang Christensen, K., & Lund, T. (2011). Return to work among long-term sickness absent employees in eldercare a prospective analysis of register- based outcomes. *International Journal of Rehabilitation Research*, 34, 249-254.
- Clausen T, Nielsen K, Caneiro IG & Borg V (2012) Job demands, job resources and long-term sickness absence in the Danish eldercare services: a study of register based outcomes. *Journal of Advanced Nursing* 68, 127-136.
- Esping Andersen, G. (2002). *Why we need a new welfare state*. Oxford: Oxford University Press.

- Ferrie, J. E., Shipley, M. J., Marmot, M. G., Martikainen, P., Stansfeld, S. A., & Smith, G. D. (2001). Job insecurity in white-collar workers: Toward an explanation of association with health. *Journal of Occupational Health Psychology*, 6, 26-42.
- Fredrickson, B. L., & Losada, M. F. (2005). Positive affect and the complex dynamics of human flourishing. *American Psychologist*, 60, 678-686.
- Fredrickson, B. L., Tugade, M. M., Waugh, C. E., & Larkin, G. R. (2003). What are good emotions in crisis? A prospective study of resilience and emotions following the terrorist attacks on the United States on September 11th, 2001. *Journal of Personality and Social Psychology*, 84, 365-376.
- Gable, S. L., & Haidt, J. (2005). What (and why) is positive psychology? *Review of General Psychology*, *9*, 103-110.
- Glazer, S. & Kruse, B. (2008). The role of organizational commitment in occupational stress models. *International Journal of Stress Management*, 15, 329-344.
- Hakanen, J. J., Bakker, A. B., & Demerouti, E., 2005. How dentists cope with their job demands and stay engaged: The moderating role of job resources. *European Journal of Oral Sciences*, 113, 479-487.
- Harter JK., Schmidt, LF., & Hayes, TL (2002) Business-Unit-Level Relationship Between Employee Satisfaction, Employee Engagement, and Business Outcomes: A Meta- Analysis. *Journal of Applied Psychology.* 87, 268-279.
- Hobfoll, S. E. (2001), "The influence of culture, community, and the nested-self in the stress process: Advancing Conservation of Resources theory", *Applied Psychology: An International Review*, *50*, 337-370.
- Isen, A. M., Daubman, K. A., & Nowicki, G. P. (1987). Positive affect facilitates creative problem solving. *Journal of Personality and Social Psychology*, *52*, 1122-1131.
- Kivimäki, M. & Lindström, K. (2006). Psychosocial approach to occupational health. In: G.Salvendy (Ed.), Handbook of Human Factors and Ergonomics (pp. 801-817). New Jersey: John Wiley & Sons.
- Meyer, J.P., & Allen, N. J. (1997). Commitment in the workplace. Theory, research and application. Thousand Oaks, CA: Sage.
- Nordic Council of Ministers (2006). *Nordic statistical yearbook 2006*. Copenhagen: Nordic Council of Ministers.

- Podsakoff, N. P., LePine, J. A., and LePine, M. A. (2007), "Differential challenge stressor-hindrance stressor relationships with job attitudes, turnover intentions, turnover, and withdrawal behavior: A meta-analysis", *Journal of Applied Psychology*, *92*, 438-454.
- Podsakoff, P. M., MacKenzie, S. B., Lee, J. Y., and Podsakoff, N. P. (2003), "Common method biases in behavioral research: a critical review of the literature and recommended remedies", *Journal of Applied Psychology*, 88, 879-903.
- Schaufeli, W. & Bakker, A. (2004). Job demands, job resources, and their relationship with burnout and engagement: a multi-sample study. *Journal of Organizational Behavior*, 25, 293-315.
- Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist*, *55*, 5-14.
- Turner, N., Barling, J., & Zacharatos, A. (2002). Positive psychology at work. In: Snyder & Lopez (Eds.). *Handbook of positive psychology*. Oxford: Oxford University Press.
- Wrzesniewski, A. & Dutton, J. E. (2001). Crafting a job: Revisioning employees as active crafters of their work. *Academy of Management Review*, 26, 179-201.

# 3. Challenges among health care workers when changes are introduced

### **BEATE ANDRÉ**

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

### Abstract

Organizational changes in the social work environment will challenge both the structure of health care organizations and the more deeply rooted organizational climate and culture in health care systems. When changes are made in health care, theories and models for change processes that have emerged from various organizations/business companies are often used for explanations. These models or theories will not, however, take into consideration the nature of the different units and department in health care and their responsibility and purpose. As an example, it is obvious that the values in an organization that cares for patients in their last phase of life are different when compared with companies that are directed towards trade and the market. We have found that if the when computerized tools are introduced in a health care organization, and if this is going to succeed, an adequate training program is imperative. In palliative care, conflicts between the "high-tech" and "high-touch" are acutely visible and it is important that the implementation process is conducted in such a manner that the health care personnel are involved; if this occurs, the benefits of the tool can be realized. There is also a need for skilled and motivated key personnel to be present in the unit if implementation is to be successful.

# The challenge of introducing changes in organizations

The increased use of technology in an organization may challenge basic institutional assumptions, disturb traditional patterns of conduct and force people to modify established routine practices (Anderson, 2002; Ash et al., 2000; Herbert, 1998; Massaro, 1993; Patel, Arocha, Diermeier, Greenes, & Shortliffe, 2001). Models from health psychology can describe connections and causes concerning how people tend to react. These models assume that perceived behavioral control indirectly affects behavior by affecting underlying intentions (Strobe, 2008). Under certain conditions, perceived behavioral control can also directly affect behavior that is not originally mediated by intentions, such as when health care workers are busy with clinical work most of the day and have little or no time for

working at the computer. Thus, although health care workers may intend to use the computer, the actual lack of control over their workday may casually and directly influence their behavior. Health workers' motivation to help patients, their ability to improve the quality of patient care with or without changing routines (Ash et al., 2003; Friedman, 1999), and their perceived behavioral control in situations in which they experience changes are all important factors in a changing process. For instance, a change can be incorrectly interpreted as a threat or a personal loss (Brown & Coney, 1994; Friedman, 1999; Lorenzi & Riley, 2000). It is said that the heart and the soul of every organization can be found in the knowledge, the skills and the value systems of its people (Andrew, 1996). Accordingly, the leadership of an organization should take care in introducing innovations that are not consistent with the organization's existing values (Anderson & Aydin, 1997; Friedman, 1999). The subjective norms in every single person as well as in different groups of people must be acknowledged (Shefter, 2006).

The effect that changes and implementations has on the culture, on behavior and in the organization has been described (Massaro, 1993). The cultural and behavioral problems seem to be more important problems than the user-friendliness of the new technology. Further, Massaro finds that "it is widely appreciated that the introduction of a major new technology can be a destabilizing event" (Massaro, 1993). This fact has been accepted by parts of the business world, but it has been given little attention in health care where new technologies are introduced frequently. An information technology system is not culturally neutral; the values of the organization and their responses to this cultural assault are predictable, and cannot fix problems that it did not create (Massaro, 1993). However, Massaro found that such technology can accentuate existing problems by diverting attention from the underlying causes and fundamental issues involved. Cross-functional innovation in an institution structured along functional lines requires active and constant support from the top management team (Massaro, 1993).

The culture and values in an organization may expect to be of importance when changes are introduced. One basic idea is that mastering the process of polarization and unification is the most important aspect of successful change in organizations (Sjøvold, 1998).

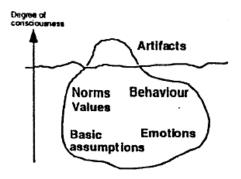


Figure 1 The Elements of Group and Organizational Culture (Sjøvold, 1998).

One way of describing organizational culture is by its elements, as shown in Figure 1 (Sjøvold, 1998). A polarization always exists between groups or individuals acting on different "Basic Assumptions". While norms represent rules of behavior which connect the personality of individuals to the roles required for maintaining group culture, and values legitimate the sanctions administered to those who break the norms, the "Basic Assumptions" govern the way group members should think (Sjøvold, 1998).

# Reactions to change

When people are presented with innovations that require changes in their behavior, such as the introduction of new technology to health care units, they may react in a variety of ways (Ash, et al., 2000). A common reaction by many may be to resist these changes (Friedman, 1999). Different categories of resistance have been identified: resistance to environmental changes, resistance to general organizational or systems changes, general resistance to changes, and resistance to specific changes (Ash, et al., 2000; Lorenzi, Riley, & Dewan, 2001). These reactions may represent a psychological and educational challenge (Andrew, 1996; Friedman, 1999). In addition, people are more likely to resist technology that they perceive as imposed on them than technology that is voluntary (Lorenzi & Riley, 2000). Requiring workers to use new technologies may well be perceived by the workers as behavior regulation and, as has been known for some time (Brehm, 1989), people generally resist the introduction of new technology that may require change of work habits. Furthermore, people have a tendency to react negatively when their freedom of action is limited or restricted. The theory of psychological reactance posits that one habitual response to change is the desire to restore threatened behavior regulation (Brehm, 1989).

# Intentions and goal achievement

Implementation research is the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and, hence, to improve the quality and effectiveness of services (Eccles & Mittman, 2006). There is a substantial gap between people's goal intentions and their goal achievement, because forming a goal intention does not prepare people sufficiently for dealing with self-regulatory problems in initiating, maintaining, disengaging from, or overextending oneself in goal striving. Goal striving should be regulated effectively, and goal achievement should thereby be facilitated. Even with goal intention it does not guarantee goal achievement.

Understanding which factors determine whether people succeed or fail in achieving desired outcomes is a fundamental concern in both basic and applied psychology (Gollwitzer & Sheeran, 2006).

It is proposed that successful goal achievement is facilitated by a second act of willing that furnishes the goal intention with an if-then plan specifying when, where, and how the person will investigate responses that promote goal realization. These plans are termed implementation intentions (Gollwitzer & Sheeran, 2006). However, correlations between goal intentions and future behavior may overestimate the strength of intentionbehavior relations because it is possible that future behavior and goal intentions are both determined by self-perceptions of past behavior (Bem, 1972). The implication is that analyses should control for previous performance in order to determine to what extent goal intentions are associated with behavior change (Sheeran, Trafimow, & Armitage, 2003). Producing significant changes in goal intention strength only generates a modest change in goal achievement which can led to a substantial "gap" between people's goal intentions and their subsequent attainment (Gollwitzer & Sheeran, 2006). One can conclude that the single act of willing involved in forming a goal intention is not sufficient to ensure goal achievement; some additional psychological concepts are needed. People often become inclined opponents rather than inclined actors. Developing self-regulatory strategies to help and understand how people "bridge" the gap between their intentions and their behavior will be important (Gollwitzer & Sheeran, 2006).

# Barriers and resistance

Computer implementation may lead to occupational stress, both directly and indirectly (Smith, Conway, & Karsh, 1999). Also the strategies used to implement computer technology may effect the level of employee stress (Smith, et al., 1999). How specific job

factors produce stress will probably vary according to type of job. Computer users in less skilled jobs have greater amounts of stress than those in higher skilled jobs (Smith, et al., 1999). Understanding a work group's culture is essential to facilitate the change process (Coeling & Wilcox, 1990). Different health care professions will demand different approaches in the introduction programs, because they emcompass different cultures as well as different work tasks. Different work task may lead to different approaches to the same problem.

Negative attitude, resistance and behavior problems can be viewed as barriers to implementation (Brown & Coney, 1994; Lee, Teich, Spurr, & Bates, 1996; Massaro, 1993; Mikulich, Liu, Steinfeldt, & Schriger, 2001; Newton, 1995; Paré & Elam, 1999). Studies suggest that attitude is a stable factor that is not influenced by the implementation process. Attitude, anxiety, resistance or other behavioral problems are difficult to identify, establish and to measure and they can be perceived and handled in different ways.

Barriers can be seen as underlying intentions that may have indirect effect on behavior. If the underlying intention is a negative attitude toward the use of computers in the hospital ward, health care personnel will most likely avoid using them and/or focus mainly on negative implications of computer use. Changing underlying intentions may then produce more positive behavior. Perceived behavioral control is mostly connected to knowledge through the concept of self-efficacy (Bandura, 1977, 1986). Lack of knowledge can make people perceive less self-efficacy, which again can lead to feelings of lack of control and resistance to change. Self-efficacy relates to the individual's confidence that he or she can perform a certain task and is a sense of being competent and effective.

Efficacy is an important factor in determining individual decisions to use a computer. Efficacy beliefs may be more important than direct experience (Henderson, Deane, & Ward, 1995; Hill, Smith, & Mann, 1987). The assumptions are that attitudes and beliefs are major determinants of behavior; these models are rational reasoning models which assume that individuals consciously deliberate about the likely consequences of behavioral alternatives that are available to them before engaging in action. The theory of planned behavior (Ajzen, 1991) describes the components in an process of changing behavior.

In this case the wanted behavior is use of CT. Perceived behavioral control with a direct effect on behavior not meditated by intentions may be exemplified by available computers or lack of available computers (Laerum, Ellingsen, & Faxvaag, 2001). Such a direct effect can be easier to change than an indirect effect, because one can change the

factors that cause the effect. Problems such as lack of available computers or discontent with the software can be remedied. Furthermore, self–reported skills are an important predictor of baseline computer anxiety and computer attitude. When people state that they have few skills, this can be an expression of low expectations with respect to the use of new technology. Low expectations constitute a central component in the social learning theory of computer aversion (Brown & Coney, 1994). Thus, low expectations can indirectly lead to resistance to computer technology. The role or behavior patterns may be closely related to attitude, behavioral intention, subjective norms and perceived behavioral control (Ajzen & Fishbein, 1975). To achieve successful implementation of CT, it is important to investigate the attitudes of health care personnel (Lorenzi & Riley, 2000). Newton found that the introduction of CT leads to a shift of power from those with professional knowledge, to those with technological skills (Newton, 1995). Health care personnel, whose power is rooted in their professional skills, may feel their power eclipsed by the need for new technological skills. The relationship between technology, professional skills and caring roles must be illuminated to overcome this problem, where the goal must be that computers should be viewed as support tools rather than replacements for humans.

# Implementation of computerized tools in health care

Demands for improved patient care as well as improved efficiency in the delivery of health care have increased dramatically in recent years. New technologies, including computers, are expected to play an important role in meeting these demands. The dual needs to both assess and change attitudes were identified as crucial factors in allowing for the successful implementation of these new technologies (B. André et al., 2008). The challenges for future clinical work and research will be to influence the behavior and intentions of health care personnel, to focus on the benefits of introducing computerized tools in health care units, and to make certain that the institution's leadership is fully supportive of the change. Furthermore, if the introduction of computerized tools is going to succeed, an adequate training program is imperative (B. André, et al., 2008).

# Implementation of computerized technology in palliative care units

Symptom assessment is important in palliative care. Computerized technology (CT) is available for use in such assessment, but barriers against implementation of CT in health care in general are well known, but less is known about how such technology is perceived by palliative health care personnel. It has been found that the health condition of the patient is

important in their perception of whether the tool is useful or not. Conflicts between the "high-tech" and "high-touch" were reported in both units. When the implementation process is conducted in such a manner that the health care personnel are involved, benefits of the tool can be realized. Thus, effective implementation and use of "high-tech" can lead to more time release for "high-touch" (Andre, Ringdal, Loge, Rannestad, & Kaasa, 2009). The desire for a resource person was reported and the expectations regarding this person differed but included that this person had to be present at the unit, should provide quick help, should be a driving force and responsible for training and teaching. There is a need for skilled and motivated key personnel in the unit if implementation is to be successful (Beate André, Ringdal, Loge, Rannestad, & Kaasa, 2008).

# Conclusion

Innovations in information technology must actually be deployed to have a positive impact on quality and productivity. Yet, innovation researchers have known for some time that a new technology may be introduced with great enthusiasm and enjoy widespread initial acquisition, but will nevertheless still fail to be thoroughly deployed among many acquiring firms. Even if the health services are increasingly in need of the benefits that information technology can promise, the capability to bring about these benefits is being severely compromised by inability to adequately address the problems that organizations present. So, even if the organizations need the benefit that a new information system can bring, lack of people and organizational skills can hamper the implementation (Lorenzi, 2004). An implementation strategy, used in several organizations to implement information technology, may not be fully applicable in health care organizations due to their complexity. The nature of the organization and its interaction with the implementation strategy also brings out special issues in health care organizations (Southon, Sauer, & Dampney, 1999). Further on, the focus on technologies-in-practice also allows an examination of the extent to which users realize the designer's intention for a technology, or if it is actually user governed. It has long been recognized that technologies are often not used as designed or intended, but generating an adequate understanding of how, where and why the slippage between design and use occurs in practice has been difficult (Orlikowski, 2000). There are several challenges in health care organizations concerning introduction of changes and new tools. The professions working in health care are not engaged in development and implementation of the tools or the models for organizational changes. Both the usefulness of these tools and how to develop an ownership to them are important issues in the introduction of changes in health care

organizations. If this introduction is going to succeed, it is important that health care workers' experiences are included in the research of developing and implementation of new tools and models for change in health care and that the social working environment is a focus when changing processes to ensure quality of patient care.

# References

- Ajzen, I. (1991). The Theory of Planned Behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179-211.
- Ajzen, I., & Fishbein, M. (1975). A Bayesian Analysis of Attribution Processes. *Psychological Bulletin*, 82(2), 261-277.
- Anderson, J. G. (2002). Evaluation in health informatics: social network analysis. *Comput.Biol.Med.*, *32*(3), 179-193.
- Anderson, J. G., & Aydin, C. E. (1997). Evaluating the impact of health care information systems. *Int.J.Technol.Assess.Health Care*, *13*(2), 380-393.
- Andre, B., Ringdal, G. I., Loge, J. H., Rannestad, T., & Kaasa, S. (2009).

  Implementation of computerized technology in a palliative care unit. *Palliat Support Care*, 7(1), 57-63.
- André, B., Ringdal, G. I., Loge, J. H., Rannestad, T., & Kaasa, S. (2008). The importance of key personnel and active management for successful implementation of computer-based technology in palliative care result from a qualitative study. *CIN: Computer, Informatics, Nursing, 26*(4).
- André, B., Ringdal.G.I, Loge, J. H., Rannestad, T., Laerum, H., & Kaasa, S. (2008).
   Experiences with Implementation of Computerized Tools in Health Care Units A review article *International Journal of Human-Computer Interaction*, 7(24).
- Andrew, C. G. (1996). The peopleware paradigm. *Hosp.Mater.Manage Q., 18*(1), 47-60.
- Ash, J. S., Anderson, J. G., Gorman, P. N., Zielstorff, R. D., Norcross, N., Pettit, J., & Yao, P. (2000). Managing change: analysis of a hypothetical case. *J.Am.Med.Inform.Assoc.*, 7(2), 125-134.
- Ash, J. S., Gorman, P. N., Lavelle, M., Payne, T. H., Massaro, T. A., Frantz, G. L., & Lyman, J. A. (2003). A cross-site qualitative study of physician order entry. *J.Am.Med.Inform.Assoc.*, 10(2), 188-200.
- Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychol.Rev.*, 84(2), 191-215.
- Bandura, A. (1986). Fearful Expectations and Avoidant Actions As Coeffects of Perceived Self-Inefficacy. *American Psychologist*, *41*(12), 1389-1391.
- Bem, D. J. (1972). Self-perception theory. *Advances in Experimental Social Psychology*, 6, 1-62.

- Brehm, J. W. (1989). Psychological reactance theory and applications. *Advances in Consumer Research*, 16 72-75.
- Brown, S. H., & Coney, R. D. (1994). Changes in physicians' computer anxiety and attitudes related to clinical information system use. *J.Am.Med.Inform.Assoc.*, *I*(5), 381-394.
- Coeling, H. V., & Wilcox, J. R. (1990). Using Organizational Culture to Facilitate the Change Process. *ANNA Journal*, *17*(3), 231-241.
- Eccles, M. P., & Mittman, B. S. (2006). Welcome to Implementation Science. *Implementation Science*, 2006(1), 1-1.
- Friedman, C. P. (1999). Information technology leadership in academic medical centers: a tale of four cultures. *Acad.Med.*, 74(7), 795-799.
- Gollwitzer, P. M., & Sheeran, P. (2006). Implementation intentions and goal achivements: a meta-analysis of effects and processes. *Advances in Experimental Social Psychology*, *38*, 69-119.
- Henderson, R. D., Deane, F. P., & Ward, M. J. (1995). Occupatinal differences in computer-related anxiety:implications for the implementation of a computerized patient management information system. *Behaviour & information technology*, 14 (1), 23-31.
- Herbert, M. A. (1998). Impact of IT on health care professionals: changes in work and the productivity paradox. *Health Services Management Research*, 11(2), 69-79.
- Hill, T., Smith, N., & Mann, M. (1987). Role of efficacy expectations in predicting the decision to use advanced technologies:the case of computers. *Journal of Applied Psychology*, 72, 307-313.
- Laerum, H., Ellingsen, G., & Faxvaag, A. (2001). Doctors' use of electronic medical records systems in hospitals: cross sectional survey. *BMJ*, *323*(7325), 1344-1348.
- Lee, F., Teich, J. M., Spurr, C. D., & Bates, D. W. (1996). Implementation of physician order entry: user satisfaction and self-reported usage patterns. *J.Am.Med.Inform.Assoc.*, 3(1), 42-55.
- Lorenzi, N. M. (2004). Beyond the gadgets Non-technological barriers to information systems need to be overcome too. *British Medical Journal*, *328*(7449), 1146-1147.
- Lorenzi, N. M., & Riley, R. T. (2000). Managing change: an overview. *J.Am.Med.Inform.Assoc.*, 7(2), 116-124.

- Lorenzi, N. M., Riley, R. T., & Dewan, N. A. (2001). Barriers and resistance to informatics in behavioral health. *Medinfo.*, *10*(Pt 2), 1301-1304.
- Massaro, T. A. (1993). Introducing physician order entry at a major academic medical center: I. Impact on organizational culture and behavior. *Acad.Med.*, *68*(1), 20-25.
- Mikulich, V. J., Liu, Y. C., Steinfeldt, J., & Schriger, D. L. (2001). Implementation of clinical guidelines through an electronic medical record: physician usage, satisfaction and assessment. *Int.J.Med.Inf.*, *63*(3), 169-178.
- Newton, C. (1995). A study of nursesïattitudes and quality of documents in computer care planning. *Nursing Standard*, *9*(38), 35-39.
- Orlikowski, W. J. (2000). Using technology and constituting structures: A practice lens for studying technology in organizations. *Organization Science*, 11(4), 404-428.
- Paré, G., & Elam, J. J. (1999). Physicians'acceptance of clinical information systems:an empirical look at attitudes, expectations and skills. *Int.J.Healtcare Technology and Management*, 1(1-2), 46-61.
- Patel, V. L., Arocha, J. F., Diermeier, M., Greenes, R. A., & Shortliffe, E. H. (2001). Methods of cognitive analysis to support the design and evaluation of biomedical systems: the case of clinical practice guidelines. *J.Biomed.Inform.*, *34*(1), 52-66.
- Sheeran, P., Trafimow, D., & Armitage, C. J. (2003). Predicting behaviour from perceived behavioural control: Tests of the accuracy assumption of the theory of planned behaviour. *British Journal of Social Psychology*, *42*, 393-410.
- Shefter, S. M. (2006). Workflow technology: the new frontier. How to overcome the barriers and join the future. *Lippincotts.Case.Manag.*, 11(1), 25-34.
- Sjøvold, E. (1998, 1998). Group and Organizational Culture from the Viewpoint of Polarization.
- Smith, M. J., Conway, F. T., & Karsh, B. T. (1999). Occupational stress in human computer interaction. *Ind.Health*, *37*(2), 157-173.
- Southon, G., Sauer, C., & Dampney, K. (1999). Lessons from a failed information systems initiative: issues for complex organisations. *International Journal of Medical Informatics*, *55*(1), 33-46.
- Strobe, W. (2008). *Social psychology and health*. (Vol. Third Edition). Buckingham Philadelphia: Open University Press.

# 4. Leadership and health promotion workplaces

# PÅL GJERSTAD & FRODE LYSBERG

Norwegian University of Science and Technology, Department of Social Work and Health Sciences,

Trondheim, Norway

University of Agder, Faculty of Health and Sport Sciences, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

# Abstract

The discussion regarding leadership and its impact on various aspects of work-related health, as well as in which ways leaders influence the health of employees, is ongoing.

In recent years, health promotion leadership has received increasing attention, especially in the Nordic countries. Some authors have attempted to develop a definition of health promotion leadership; however, there is presently no consensus. Further studies are needed to explore the concept of leadership and health promotion workplaces.

# Health promotion workplaces

Health promotion programmes were first introduced in the workplace in the 1960s as part of occupational health schemes, primarily for safety and product quality reasons. They have since then evolved into a wide range of approaches to improve employees' health (Rootman et al., 2001).

In recent decades there has been an increased focus on workplace health promotion, both internationally and nationally. This is furthermore authorized by the legislation, declarations and charters of some countries. Health Promotion is defined in the Ottawa Charter as: "Health promotion is the process of enabling people to increase control over, and to improve, their health" (WHO, 1986). "According to this definition, health is not merely an absence of disease but also a resource for everyday life, including physical, mental and social well-being" (Eriksson, 2011). In Norway, the Norwegian Trade Unions, the Confederation of Norwegian Business and Industry, the Ministry of Labour and Government Administration and the Ministry of Health, worked up in The Lillestrøm Declaration (2002) that health-promoting workplaces are characterised by the following:

 workplaces which give everyone the opportunity to make use of his or her resources and in this way contribute to sustainable economic growth and healthy, viable enterprises

- leaders who are present and act as facilitators
- leaders who promote broad-mindedness, tolerance, and freedom to think differently
- common, visible basic values which create identity and pride
- openness for diversity and our human differences
- ensuring that everyone feel they master their jobs and contribute to the results through feedback from customers and users
- consideration for the whole person based on individual needs and life situations
- physical surroundings which inspire us, make us happy, and create arenas where we can be together
- opportunities for personal and professional development and learning at the workplace

(The Lillestrøm Declaration on Workplace Health Promotion, 2002).

"Scandinavian work environment research, by tradition, has emphasized the importance of employee job control and participation. Furthermore, trade unions have fought for better working conditions on behalf of their members, realizing that a positive work climate will not only reduce employee strain but also contribute to a more motivated workforce and, in the long run, greater organizational effectiveness" (Sverke, 2009). In Norway, health promotion in the workplace is also warranted in the Working Environment Act as: a) to secure a working environment that provides a basis for a healthy and meaningful working situation, which affords full safety from harmful physical and mental influences and that has a standard of welfare at all times consistent with the level of technological and social development of society, b) to ensure sound conditions of employment and equality of treatment at work, c) to facilitate adaptations of the individual employee's working situation in relation to his or her capabilities and circumstances of life, d) to provide a basis whereby the employer and the employees of undertakings may themselves safeguard and develop their working environment in cooperation with the employers' and employees' organizations and with the requisite guidance and supervision of the public authorities, e) to foster inclusive working conditions (The working Environment Act, 2005).

The salutogenic approach developed by Antonovsky (1987) views health as a psychosocial concept and focuses on factors that promote and maintain health. In recent decades, the pathogenic approach has been the dominating perspective, this view having more focus on the biomedical aspects of health. On the contrary, health promotion focuses

more on socioeconomic conditions and shifting resources in order to prevent problems before they occur (Rootman et al., 2001). In Antonovsky's article, The salutogenic model as a theory to guide health promotion, he clarifies his theory of sense of coherence (SOC): "These strands of thought led to the emergence of the sense of coherence (SOC) construct, a generalized orientation toward the world which perceives it, on a continuum, as comprehensible, manageable and meaningful" (Antonovsky, 1996). Hanson (2007) builds on Antonovsky's theories of SOC, and claims that employees who experience work as meaningful, manageable and comprehensible, will experience work as a coping and health promotion workplace. He has operationalised these perspectives and relationships with examples from the workplace. Elements which contribute to the achievement of meaningfulness are those pertaining to conditions such as goals and rewards, human relationships, positive experiences, accomplishing something that gives value, being included, and the concept of fighting for and experiencing success. Conditions including knowing each other, having communication, knowledge and overview, give comprehensibility. Cooperation, proper knowledge, influence in the workplace, and appropriate tools to solve the tasks, provide manageability in the daily work. Hanson (2007) believes that these dimensions must be managed, included and accepted individually, within the group and in the organization, in order to provide positive synergy effects.

In recent years there has been some interesting research on health promotion workplaces in the Nordic countries, especially in relation to studying the importance of psychosocial work conditions for employee health and well-being. Sverke (2009) states: "It is by now well-known that factors such as too high job demands, role conflict, job insecurity, time pressure, violence at work, poor leadership, and excessive work hours may negatively affect the individual employee. On the other hand, several beneficial factors have also been identified, including control at work, participation in decision-making, social support, clear goals, relevant feedback, and skill utilization". In 2008, a Swedish study examined the recovery factors in companies, and what should be done in order to reduce sickness absence. Based on their assessment, there are "healthy" companies in all industries (Ahlberg, 2008). This indicates that the perception of some industries having higher sickness absence than others is not necessarily correct. Additional findings in the study were: clear leadership and involved employees provide greater health benefits. Sick leave is lower in firms that recruit their managers internally. Companies that have routines for rehabilitation have healthier employees.

In summary, research on workplace health promotion is in a state of dynamic change. As Rootman et al., (2001) emphasised, the ways of measuring the processes and outcomes of health promotion programmes in the work place are in their infancy. They also point out that much can be learned from evaluations undertaken in non-health areas with similar complex issues, such as management approach and evaluation methods from other disciplines.

# Health Promotion Leadership

Many definitions of leadership have been introduced over the years, although the majority of these definitions possess less research approval (Yukl, 2006). Management literature and research on the topic has mainly been linked to a western industrialized culture. Bass (2004) points out that there are almost as many definitions of leadership as there are people whom have tried defining the term. However, he believes that there are some similarities and characteristics corresponding to the term. These characteristics include leadership focus on group processes, an actualised influence, persuasion skills, and relationships, the attainment of goals, and interactions and implementation of structure. A clear and simple definition of management is therefore a challenge. The concept of leadership is often used as a binary concept - "either or neither thinking" (Wittek & Kvernbekk, 2009), either a good leader or a bad leader. Such categorisation can be difficult, since there often are some overlapping similarities between them. There are many descriptive definitions of leadership, and they have been introduced throughout hundreds of years, often being related to each other. Even Machiavelli's book "The Prince", written in 1513, deals with management. His description of leadership is still relevant today, although many would argue that it is raw and unmasked. He portrays certainly not leadership as it should be, but as it actually occurs (Bjartveit, Eikeset, 2008).

From a historical perspective, numerous leadership theories have been launched. In the early twentieth century, managers' personality traits were in focus, and different personality traits were promoted as part of good leadership (Northouse, 2004; Yukl, 2006). Within the last decades, the visionary and charismatic leadership has gained increasing attention. (Avolio, Yammarino, 2002; Bass, 1990; Bass, Riggio, 2006). In this period the "Five-factor" model (Costa, McCrae, 1985) has focused on managers' personality traits. The Five-factor model has also been used to investigate the importance of personality in connection with transformational leadership. Today there are several models and leadership theories that are used. One is the situational leadership theory developed by Hersey & Blanchard (1969). According to this model, effective leadership varies, depending on the

task, job or function that needs to be accomplished, and the employees' maturity. Another is the leader – member exchange (LMX) model. This theory describes the role-making processes between a leader and each individual subordinate, and explains how those relationships with various members can develop in unique ways and over time (Dansereau et al., 1975). Today the transformational leadership model has gained an increase in research focus (Martinsen, 2004; Yukl, 2006).

The model of transformational and transactional leaderships was first introduced by Burns (1978) and later developed by Bass (1985). "The two types of leadership were defined in terms of the component behaviours' used to influence followers and the effects of the leader on followers" (Yukl, 2006). Transformational leadership increases follower motivation and performance, and generate enthusiasm and commitment to task objectives more than transactional leadership. Transformational leadership is perceived to be the form of management that integrates parts of earlier leadership theories (Bass, Riggio, 2006). Bass (1985) argued that transactional leadership was an inefficient way to lead compared to transformational leadership. Several studies have shown that the two leadership styles are complementary, and can be used by the same manager, depending on the situation and task. But there are a couple of crucial differences between the two. A number of studies indicate that transformational leadership is related to effectiveness, satisfaction and commitment of employees (Bass, 1990; Bass, Riggio, 2006; Hetland, Sandal, 2003; Judge, Bono, 2002). Transformational leaders are often seen as good and efficient, and the organizations they manage more often achieve positive economic results (Bass, Riggio, 2006).

In addition, transformational leadership has a positive and motivating effect on subordinates (Yukl, 2006). The followers feel trust, loyalty, admiration and respect towards the transformational leader, and they achieve more than they were originally expected to do. Bass (1999) summarizes the research on the effects of transactional versus transformational leadership. He indicates that the transformational leadership is more efficient on job satisfaction among employees, and empowers followers to take more initiative in their work. Despite a large number of studies regarding transformational leadership, researchers have not found the specific leader characteristics that give these positive effects. However, they suggest that leadership charisma, motivation, support, recognition, empowerment, and the consultation of employees are included in this leadership style (Yukl, 2006; Yukl, Lepsinger, 2004). Bass (1990) points out some personality traits such as determination, self-confidence, and understanding of subordinate needs that characterize transformational leaders. In

addition, there are four various types of transformational leadership behaviours: *Idealized Leadership* is the behaviour that arouses employees to feel a powerful identification toward the leader. *Inspirational Motivation* is the leader behaviour that includes communication of an inspiring vision and promotes for the followers powerful symbols to arouse greater effort and a feeling of belonging. *Individualized Consideration* is the behaviour that provides coaching, support and encouragement. *Intellectual Stimulation* influences the employees to view problems from another perspective and with a new awareness. There are today several studies indicating that part of transformational leadership can be learned (Bass, Avolio, 1994; Bass, Riggio, 2006). Yukl (2006) indicates that transformational leaders influence employees' cognitions of empowerment. The degree of empowerment is dependent on the leaders' degree of delegation and cooperation with their employees. Other benefits of empowerment are improved decision-making, increased sense of responsibility, initiative and skills amongst employees (Yukl, 2006). Empowerment is closely related to Sense of Coherence (SOC) and healthy workplaces (Hanson, 2010).

Health promoting leadership has gained an increase in attention. Frick (2004) indicates that organisational work environment, management style and organisation of work tasks are important for employee health. In Norway, The Lillestrøm Declaration (2002) emphasises that the management plays a role in building health promoting workplaces. The declaration states: the management takes responsibility for building up commitment and understanding of the importance of health promotion in the organisation, the management in collaboration with the employees creates social and professional meeting places and settings with a view to developing a health-promoting culture, and the management in collaboration with the employees paves the way for a culture that uses creativity and humour.

Some authors have tried to define what health promotion leadership is, but there is currently no common consensus on the concept and therefore no clear definition (Shain, Kramer, 2004). Eriksson (2011) is one who has tried to define health promotion leadership as: "leadership that works to create a culture for health promoting workplaces and values, to inspire and motivate employee participation in such a development. Health promoting leadership can also be viewed as a critical part of organisational capacity for health promotion, including managerial knowledge and skills as well as organisational policies and structures that support a health promoting workplace. Therefore, leadership involvement in the systematic development of both the physical and psychosocial work environment is important". Nyberg et al., (2005) point out several aspects of health promoting factors in

leadership. A health promoting leader shows consideration towards subordinates, initiates structure when needed –especially in stressful situations, allows employees to control their work environment, gives access to empowerment structures, provides opportunities for participation, inspires employees to see a higher meaning in their work and provides intellectual stimulation. In addition, a good leader is often charismatic. A bad leader does not show consideration, uses only a transactional approach towards employees, does not respond to subordinates, does not monitor performance, and deprives employees of participation, autonomy, and control. The authors thus indicate that health promoting leadership corresponds to different aspects of transformational behaviour and characteristics. Hanson (2010) builds on Antonovsky's theory of Sense of Coherence, and he indicates that people who experience their work as meaningful, manageable and comprehensible will experience a health promotion workplace. A health promotion leader must therefore concentrate on building an environment that focuses on comprehensibility, manageability, and meaningfulness in the subordinates' daily work.

Health promotion leadership is concerned with creating a culture for health promoting workplaces, and that the leaders are engaged in the systematic development of both the physical and psychosocial work environment. However, there are few studies that have examined the influence processes that account for the positive relationship found between leader behaviour and follower performance and health promotion work places. In addition, Eriksson (2011) points out that future research should emphasize the evaluation of the effects of a health promotion leadership. More research is needed to determine these relationships.

# References

- Ahlberg, G., Bergman, P., Ekenvall, L., Parmsund, M., Stoetzer, U., Waldenström, M., & Svartengren, M. (2008). *Hälsa och framtid*. Karolinska Institutet: Stockholm.
- Antonovsky, A. (1996). *The salutogenic modell as a theory to guide health promotion.*Health promotion International, Oxford University Press.
- Antonovsky, A. (1987). *Unraveling the mystery of health; how people manage stress and stay well.* (1<sup>st</sup> Ed), Jossey-Bass, San Francisco: Calif.
- Avolio, B. J., & Yammarino, F. J. (2002). *Transformational and charismatic leadership: The road ahead*. Boston: JAI.
- Bass, B.M. (1985). Leadership: Good, better, best. Organizational Dynamics, 13, 26-40.
- Bass, B. M. (1990). Bass and Stogdill's handbook of leadership: Theory, research and managerial applications (Vol. 3). New York: Free Press.
- Bass, B. M. (1990). From transactional to transformational leadership: Learning to share the vision. Organizational Dynamics, 18, 19-31.
- Bass, B. M., Avolio, B. J. (1990). Training and development of transformational leadership: Looking to 1992 and beyond. *European Journal of Industrial Training*, *14*, 21-27.
- Bass, B. M., Avolio, B. J. (1994). *Improving organizational effectiveness through transformational leadership*. Thousand Oaks, CA: Sage.
- Bass, B. M. (1999). Two decades of research and development in transformational leadership. *European Journal of Work and Organizational Psychology*, 8, 9-32.
- Bass, B. M. (2004). Fra transaksjonsledelse til transformasjonsledelse: Å lære å dele en visjon. In: Ø.L. Martinsen. *Perspektiver på ledelse*, Gyldendal akademiske: 191-201.
- Bass, B. M., & Riggio, R. E. (2006). *Transformational leadership, Lawerence Erlbaum assiciates*. *Mahwah*, New Jersey: London.
- Bjartveit, S., & Eikeset, K. (2008). *Makt og verdighet Perspektiver på Ledelse*. Cappelen Akademisk forlag: Oslo.
- Burns, J.M. (1978). Leadership. New York: Harper and Row.
- Costa, P. T., & McCrae, R. R. (1985). *The NEO personality Inventory Manual*. Odessa, FL:Psychology Assessment Resources.

- Danserueau, F., Jr., Graen, G., Haga, W.J. (1975). A vertical dyad linkage approach to leadership within formal organisations: A longitudinal investigation of the role making process. *Organizational Behavior and Human Performance*, 13, 46-78.
- Eriksson, A. (2011). *Health-Promoting Leadership: A study of the concept and critical conditions for implementation and evaluation*. (Doctoral dissertation, Nordic School of Public, Gothenburg, Sweden).
- Frick, K. (2004). Organisational Development for Occupational Health and Safety Management. In *OHS Regulation for a Changing World of Work* (Bluff, Gunningham and Johnstone Eds) (pp. 43-67) Federation Press: Sydney.
- Hanson, A. (2010). *Salutogent ledarskap för hälsosam framgång*. Fortbildning i Stockholm.
- Hersey, P., & Blanchard, K. H. (1969). *Management of Organizational Behavior Utilizing Human Resources*. Prentice Hall: New Jersey.
- Hetland, H., & Sandal, G.M. (2003). Transformational leadership in Norway: Outcomes and personality correlates. *European Journal of Work and Organizational Psychology* 12, 147–170.
- Judge, T.A., Bono, J.E., Ilies, R., & Gerhardt, M.W. (2002). Personality and leadership: A qualitative and quantitative review. *Journal of Applied Psychology*.
- Martinsen, Ø.L. (2004). Perspektiver på ledelse. Oslo: Gyldendal Akademisk
- Northouse, P.G. (2001). *Leadership: Theory and practice* (2<sup>nd</sup> Ed). London: Sage Publications.
- Northouse, P.G. (2004). Betydning av lederens trekk og lederstil: In: Ø.L. Martinsen. *Perspektiver på ledelse*. Oslo, Gyldendal Akademiske.
- Nyberg, A., Bernin, P., & Theorell, T. (2005). *The impact of leadership on the health of subordinates*, National Institute for Woriking Life, Stockholm.
- Rootman, M., Goodstadt, B., Hyndman, D., McQueen, L., Potvin, J., & Springett, E.Z. (2001). *Evaluation in health promotion: principles and perspectives*. WHO Regional Publications, European Series, No 92. Denmark.
- Shain, M., & Kramer, D.M. (2004). Health promotion in the workplace: framing the concept: reviewing the evidence. *Ocuppational and Environmental Medicine*, 61, 643 648.

- Sverke, M. (2009). The importance of the psychosocial work environment for employee well-being and work motivation. *Scandinavian Journal of Work and Environmental Health 35*, 241-243.
- The working Environment Act of 17, 2005, Norway.
- National Institute of Occupational Health. (2002). The Lillestrøm Declaration on Workplace Health Promotion. Norway.
- Wittek, L., & Kvernbekk, T. (2009). *On the problems of asking for a definition of quality in higher education*. Paper presented at the EARLI, Amsterdam.
- World Health Organization. (1986). Ottawa Charter for Health PromotionFirst International Conference on Health Promotion.
- Yukl, G.A.(2006). *Leadership in Organizations*.(6<sup>th</sup> Ed.) Upper Saddle River, NJ: Prentice-Hall.
- Yukl, G., & Lepsinger, R. (2004). Flexible leadership: creating value by balancing multiple challenges and choices. San Francisco Calif.

# II. Health Promotion among the Ill

Health promotion is often associated with strategies to help the healthy people stay healthy. However, more people survive former lethal diseases, often with long-term side-effects from the disease or the medical treatment, and a growing number of people are diagnosed with a chronic condition. Promoting health should therefore be regarded as a reasonable strategy, also for the many defined as ill. Since 'health' implies a bio-psycho-social-spiritual entity, 'health promotion' resembles well-being and quality of life. In this section, some parts of the phenomenon 'health promotion' and related concepts are investigated in different patient populations. In chapter 5, a theoretical presentation of health promotion among the ill is given. In chapter 6, quality of life and health promotion among survivors of myocardial infarct is investigated. In chapter, 7, resilience as a factor to sustain activity participation is discussed. In chapter 8, benefits from support groups for cancer victims are investigated. In chapter 9, benefits from rehabilitation for patients with COPD are shown. And finally, in chapter 10, results from a study on psychosocial health and quality of life among children/adolescents surviving cancer are given.

# 5. Health promotion among the ill

### **TORIL RANNESTAD**

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

### Abstract

Health promotion is also a sensible strategy for the ill. Health comprises all aspects of life; physical, psychological, social and existential aspects. Health promotion should therefore be directed towards actualizing the health potential in all these interconnected aspects, whether a person is ill or not. Health promotion is further closely linked to well-being and quality of life, with a potential positive impact on health. Most of our health is created in what can be called society, but health and ill-health is persistently unequally distributed. Equity becomes a highly relevant factor for health promotion strategies and salutogenic societies. Health services must move beyond their disease orientation and be re-oriented towards health promotion, not only for the healthy but also for the ill.

# Introduction

Recently, a growing emphasis has been paid to health promotion. There is a desire for more knowledge about the sources of health (salutogenesis) in addition to all the knowledge we have from the medical discipline about the sources of disease (pathogenesis). How can health be promoted, improved, and strengthened? In the public health perspective, health promotion is mainly viewed as activities directed at helping healthy people stay healthy. A legitimate question is whether health promotion can be regarded as a plausible strategy also for people who are ill. In this introductory Chapter I will argue that health promotion among the ill is important and valuable.

# Health and illness

In modern societies public health has improved throughout the last century. In Norway, infant mortality has decreased to literally zero at the same time as longevity has increased substantially. In contrast to earlier times, almost all babies will survive and can face a prospect of living long lives. As such, the public itself can be regarded as healthy. Nevertheless, more people than ever consult doctors and more people than ever are on sick leave or have a disability pension. Are Norwegians, after all, more ill than before?

Illness can be explained by individual lifestyle factors such as tobacco use, poor diet, and physical inactivity. Disease prevention aims at changing the unhealthy behavior of individuals. Due to demographic changes in most countries, the number of elderly people will grow, indicating a higher prevalence of illness in the future. Thanks to - among others - the advances in medical development more people will survive former lethal diseases, living long lives with a chronic condition or long-term side-effects from certain types of medical treatment. A disease prevention approach will not have any significant effect on this trend.

Illness can also be explained by society-related factors. According to Krokstad et al (2002), an increase in sick leave is for the most caused by new and strenuous requirements at work, rather than a higher incidence of diseases. Many employed people get ill and fall out of the post-industrial working force because they cannot cope with the high speed and multiple changes with a growing demand for communicative skills and social intelligence (Mæland, 2010). The main reason for sick leave and disability pension in Norway is not well-known diagnosable diseases, but rather pain conditions and minor mental disorders. A bio-medical approach will not have any significant effect on these matters.

Further, there is strong evidence that the strongest and most dominant effects on health are determined by social inequality and inequity (Mackenbach and Kunst, 1997; Mittelmark et al, 2012). Health promotion views health as created in society, in the everyday arenas of homes, work, schools, and local communities, demanding political action.

Although disease, illness and health comprise concepts embedded in different scientific paradigms, a distinct discrimination between them is, perhaps not, a fruitful approach in health promotion. As human beings, as long as there is breath in us, we have some level of health (Antonovsky, 1988). At the same time all of us will fall ill during our lifetime, some with long-lasting/chronic disorders. To be ill is so common that it actually should be regarded as a natural part of life (Ihlebæk et al, 2002). Health and illness are intertwined and related phenomena in life rather than opposite entities. A strict line between the healthy and the ill is arbitrary and not based in reality.

# Health

If health is understood in bio-statistical terms as the absence of disease (Boorse, 1977), health will be attributed to the elimination of diseases. Health promotion will then have a negative focus, defined as disease prevention. Health is, however, more often understood in a broader, bio-psycho-social-existential sense (Espenes and Smedslund, 2009). This holistic

perspective on health views these dimensions as a whole, where the elements are interconnected and one element affects the other (Glaister, 2001; Quinn, 2005). When asking lay Norwegians about their comprehension of health (Fugelli and Ingstad, 2009), it becomes obvious that most people regard health in such a multidimensional, holistic way. And most people are rather pragmatic about what they consider being healthy - they proclaim that they can have a good health despite having a disease and do not expect a utopian, perfect health or complete well-being. "Good is good enough".

Holistic health (Nordenfelt, 1987) is a good thing, meaning that the person is healthy if he/she feels well and can function in his/her social context (Mæland, 2010). Health promotion in this tradition will go beyond elimination of "the holy trinity of risk" (Raphael, 2010), and have a positive focus, aiming at the promotion of well-being and actualizing the health potential in all aspects of life (WHO, 1986, Pender et al, 2005). Then a distinction between the healthy and the ill becomes subsidiary and rather uninteresting.

# Health promotion

If holistic health is to be promoted, health promoting activities must be regarded as more than nutrition and fitness. Further, if holistic health is to be promoted among the ill, health promoting activities must be more than a bio-medical focus on the management of the disease. Whether or not people are healthy or ill (as arbitrary as that distinction may be), health promoting activities should not be merely directed towards strengthening the physical health (by nutrition and fitness), but also towards strengthening the psychological (by stress management and career achievement), the social (by friends and family), and the existential (by love and hope) (Hodgkinson et al, 2007; Keyes, 2007; Lim and Zebrack, 2008).

Since all these dimensions are interconnected and one dimension affects the other (Glaister, 2001; Quinn, 2005), more attention should be paid on promoting the psychosocial-existential parts of our health when the physical health is impaired by disease and illness. The total "sum" may thus be good health, in spite of having an illness.

A strong link between mind and body (psyche and soma) has been postulated in different cultures at all times. As far as almost 3000 years ago, scholars wrote that "a joyful heart helps healing, but a broken spirit dries up the bones" (Proverbs, 17:22). Current research gives evidence that supports such relationships (Hodgkinson et al, 2007; Keyes, 2007; Lim and Zebrack, 2008; Seligmann, 2008). Improving the psychological, social and existential health and well-being may be good for its own worth, but may also have a

positive effect on the physical health, by improving the immune, neuroendocrine and cardiovascular systems (Ryff et al, 2004; Nelson et al, 2008) as well as being a salutogenic buffer against potential pathogenic processes. Maybe the optimal health promoting actions are to teach the children to be happy (Byrne, 2011) and to help people live flourishing lives (Keyes, 2002)?

As indicated in Figure 1, the medical discipline concentrates on diagnosing, treating and preventing physical and mental disease. This is fine – we need experts on diseases. In contrast to this, health promotion is directed towards promoting physical and mental *health*. Interesting enough, regardless where a person finds her-/himself on the disease-health-continuum, she/he may experience a good quality of life (QoL) (Ringdal and Ringdal, 2000). Since "a joyful heart helps healing" (Proverbs, 17:22), health promotion is also directed towards promotion of QoL, and that people can have flourishing and meaningful lives. The term "health promotion" is in this sense more equivalent to "life-promotion" (Lindström and Eriksson, 2010).

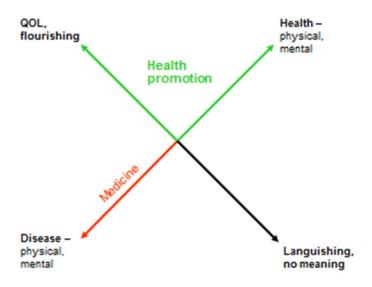


Figure 1: Relationships between health, disease, quality of life (QoL) and health promotion.

# Health and quality of life (QoL)

A broad, holistic comprehension of health is related to well-being (WHO, 1946; 2006), which again is related to QoL (Nordenfelt, 1991). Whereas "happiness" has been described and defined throughout history from the time of the early philosophers (Tatarkiewicz, 1976), QoL is a rather new concept, emerging from the economic and political discussions in the USA in the 1960s. The medical, nursing and health sciences have used the concept since the 1980s, mainly for research, but also for practical/clinical reasons, and comprising an

understanding of a multidimensional and subjective comprehension of the good life (Wahl and Hanestad, 2004).

More than holistic health theories, QoL encompasses values and meaning in life – questioning 'what is important to you?' Although the concept of QoL emerges from philosophical descriptions of happiness, the definitions often used nowadays comprise a notion of satisfaction. QoL is thus manifested as *satisfaction with the domains of importance to you* (Oleson, 1990; Ferrans and Powers, 1992). Although inflicted with a disease, an individual may be satisfied with other areas of life that are important to him/her.

Values and expectations vary from person to person, during the course of life and after illness. Health (life) promoting activities should be directed towards acting together with people with a chronic illness to re-orient their values (Sprangers and Schwartz, 1999) in such a way that a good QoL and a meaningful, flourishing life may be reestablished and achieved.

# Responsible for health

Who is responsible for health – the individual or society? It is inevitable that the person's lifestyle has an immense impact on his/her health. Accordingly, health promotion is therefore "the process of enabling people to increase control over, and to improve, their health" (WHO, 1986).

Studies show, however, that health is persistently associated with higher socioeconomic strata, and also in socio-democratic countries (Mackenbach and Kunst, 1997).

Such social inequalities in health could be explained by determinants of social position.

Although this relationship has been found for some marginalized groups, there is limited scientific evidence for such associations (Elstad, 2005). On the contrary, components of social position have been found to increasingly determine health outcomes. The psychosocial perspective proposes that ill-health is a consequence of long-term stress. Lack of control (Syme, 1996) and relative deprivation (Wilkinson, 1996) may represent the key elements of this association, as both phenomena are related to the lower levels of the social hierarchy in modern societies. According to The Ottawa Charter (WHO, 1986), health promotion focuses on:

"- achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to

information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men."

Health promotion demands coordinated action by all concerned; by governments, by health and other social and economic sectors, by nongovernmental and voluntary organization, by local authorities, by industry and by the media. Consequently, health promoting strategies aim at creating salutogenic societies with environments that support good health practices (Eriksson and Lindström, 2008).

# Health services

Health is not created mainly in the health sector, but rather in all sectors that constitute a society. Therefore, the prerequisites and prospects for health cannot be ensured by the health sector alone (WHO, 1986). Recently, new White Papers have been passed in Norway to ensure more attention to health promotion and public health. Also, the health services must be re-oriented to move increasingly in a health promotion direction, beyond their responsibility for providing only clinical and curative services. Patients will be transferred earlier from specialized hospitals to health services in municipalities, where the main focus will be on health (despite the disease), health promotion in a broad sense, functioning, coping with the illness, and QoL.

# Conclusion

Health promotion is a sensible strategy also for the ill. Health comprises all aspects of life; physical, psychological, social and existential aspects. Health promotion should therefore be directed towards actualizing the health potential in all these interconnected aspects, regardless whether a person is ill or not. Further, health promotion is closely linked to well-being and QoL, with potential positive impacts on health. Most of our health is created in what can be called society, but health and ill-health are persistently unequally distributed. Equity becomes a highly relevant factor for health promotion strategies and salutogenic societies. Health services must move beyond their disease orientation and be re-oriented towards health promotion, which includes health promotion for the ill.

# References

- Antonovsky, A. (1988). *Unraveling the mystery of health. How people manage stress and stay well.* Jossey-Bass Publishers.
- Boorse, C. (1977). Health as a Theoretical Concept. Philosophy of Science, 44, 542-573.
- Byrne, D. From Evidence to Practice: The Role of Research in Delivering Effective

  Psychological Interventions in Health Care. Lecture at PhD-seminar at NTNU,

  Norway, spring 2011.
- Elstad, J.I. (2005). Sosioøkonomiske ulikheter i helse teorier og forklaringer [Socioeconomic inequalities in health theories and explanations]. Sosial- og helsedirektoratet, Oslo.
- Eriksson, M., & Lindström, B. A. (2008). Salutogenic interpretation of the Ottawa Charter. *Health Promotion International*, *23*, 190-199.
- Espnes, G.A., & Smedslund, G. (2009). *Helsepsykologi* [Health psychology]. Gyldendal Norsk Forlag.
- Ferrans, C.E., & Powers, M.J. (1992). Psychometric Assessment of the Quality of Life Index. *Research in Nursing and Health*, *15*, 29-38.
- Fugelli, P., & Ingstad, B. (2009). *Helse på norsk. God helse slik folk ser det* [Health in Norwegian. Good health as people see it]. Gyldendal Norsk Forlag.
- Glaister, J.A. (2001). Healing: Analysis of the concept. *International Journal of Nursing Practice*, 7, 63-68.
- Hodgkinson, K., Butow, P., & Fuchs, A. et al. (2007). Long-term survival from gynaecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology*, *104*, 381-389.
- Ihlebæk, C., Eriksen, H.R., & Ursin, H. (2002). Prevalence of subjective health complaints (SHC) in Norway. *Scandinavian journal of Public Health*, *30*, 20-29.
- Keyes, C.L.M. (2002). The mental health continuum: from languishing to flourishing in life. *Journal of Health and Behavior Research*, 43, 207-222.
- Keyes, C.L.M. (2007). Promoting and protecting mental health as flourishing. *American Psychologists*, 62, 95-108.

- Krokstad, S., Johnsen, R., & Westin, S. (2002). Social determinants of disability pension: a 10-year follow-up of 62 000 people in a Norwegian county population. *International Journal of Epidemiology, 31*, 1183-1191.
- Lim, J.W., & Zebrack, B. (2008). Different pathways in social support and quality of life between Korean American and Korean breast and gynaecological cancer survivors. *Quality of Life Research*, 17, 679-689.
- Lindström, B., & Eriksson, M. (2010). *The hitchhiker's guide to salutogenesis*. *Salutogenic pathways to health promotion*. Folkhälsan Research Center, Research report 2.
- Mackenbach, J.P., & Kunst, A.E. (1997). Measuring the magnitude of socio-economic inequalities in health: An overview of available measures illustrated with two examples from Europe. *Social Science & Medicine*, *44*, 757-771.
- Mittelmark, M.B., Kickbusch, I., Rootman, I., Scriven, A., & Tones, K. (2012).

  Helsefremmende arbeid ideologier og begreper [Health promotion practice ideologies and concepts]. In: Å. Gammersvik & T. Larsen (Eds).

  Helsefremmende sykepleie i teori og praksis [Health promoting nursing in theory and action]. Fagbokforlaget.
- Mæland, J.G. (2010). Forebyggende helsearbeid folkehelsearbeid i teori og praksis [Preventive health care public health care in theory and practice]. Universitetsforlaget.
- Nelson, E.L., Wenzel, L.B., & Osann, K. et al. (2008). Stress, immunity, and cervical cancer: biobehavioral outcomes of a randomized clinical trial. *Clinical Cancer Research*, *14*, 2111-2118.
- Nordenfelt, L. (1987). *On the Nature of Health. An Action-Theoretical Approach*. D. Reidel Publishing Company.
- Nordenfelt, L. (1991). Hälsa och värde [Health and value]. Thales: Stockholm.
- Oleson, M. (1990). Subjectively Perceived Quality of Life. IMAGE: *Journal of Nursing Scholarship*, *22*, 187-90.
- Pender, N., Murdaugh, C., & Parsons, M. (2005). *Health promotion in nursing practice*. Lavoisier.
- Proverbs, *The Bible*.

- Quinn, J. (2005). Transpersonal Human Caring and Healing. In: B. Dossey, L. Keegan,& C. Guzzetta (Eds.) *Holistic Nursing*. A Handbook for Practice. Jones andBartlett Publishers.
- Raphael, D. (2010). *Health Promotion and Quality of Life in Canada*. Essential Readings. Canadian Scholars' Press.
- Ringdal, G.I., & Ringdal, K. (2000). A follow-up study of the quality of life in cancer patients with different diagnoses. *Quality of life Research*, *9*, 65-73.
- Ryff, C.D., Singer, B.H., & Love, G.D. (2004). *Positive health: connecting well-being with biology*. Philosophical Transactions of the Royal Society of London Series B: Biological Sciences.
- Seligman, M.E.P. (2008). Positive Health. Applied Psychology: An International Review. *57*, 3-18.
- Sprangers, M.A.G., & Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: a theoretical model. *Social Science & Medicine*, 48, 1507-1515.
- Syme, S.L. (1996). To prevent disease the need for a new approach. In Blane D, Brunner E, Wilkinson R (Eds). *Health and social organization*. London and New York: Routledge.
- Tatarkiewicz, W. (2004). Analysis of Happiness. Martinus Nijhoff, The Hague.
- Wahl, A.K., & Hanestad, B.R. (2004). Måling av livskvalitet i klinisk praksis. En innføring. [Measuring quality of life in clinical practice. An introduction]. Fagbokforlaget: Bergen.
- WHO, 1946. http://www.who.int/bulletin/archives/
- WHO, 1986: http://www.who.int/healthpromotion/conferences/previous/ottawa/en/
- WHO. Constitution of the World Health Organization Basic Documents, Forty-fifth edition, Supplement, October, 2006.
- Wilkinson, R. Unhealthy societies. London: Routledge. 1996.

# 6. Health related quality of life among elderly Polish and Norwegian MI survivors: in search of positive bases for secondary health promotion.

MAGDALENA ANNA LAZAREWICZ<sup>1,2</sup>, EVA SLIND<sup>3</sup>, LINDA ERNSTSEN<sup>2,4</sup>, DOROTA WLODARCZYK<sup>1</sup> & GEIR

ARILD ESPNES<sup>2,5</sup>

<sup>1</sup> Medical University of Warsaw, Department of Medical Psychology, Warsaw, Poland

### Abstract

Regardless of the vast progress in cardiovascular diseases' treatment, health outcomes remain poor for patients with heart diseases: morbidity rates are still high, while quality of life (QoL) of those who survive is diminished. Therefore, an increased emphasis is being placed on QoL improvement. However, many prevention, health promotion and rehabilitation programmes remain inaccurate and ineffective. Due to the gradual aging of societies, followed by an increasing number of persons at high risk of myocardial infarction (MI), research on the QoL in somatic disease and creating it as a coherent multivariable theoretical concept seems crucial for both the individual welfare of patients and finances within the health sector. The following paper presents a Polish-Norwegian research project whose main goal is to investigate mechanisms that connect chosen positive personality characteristics and social support with health-related QoL in elderly male and female MI survivors and, in addition, to compare those factors and their interactions in Polish and Norwegian patients. We believe that providing empirical data on those relations and differences will help in planning more efficient, gender-and culturally- sensitive interventions aimed at improving the MI survivors' health and QoL. The research is in the implementation phase, therefore the purpose of this paper is only to present the project itself: its theoretical background and methodology.

<sup>&</sup>lt;sup>2</sup> Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

<sup>&</sup>lt;sup>3</sup> St. Olavs Hospital, Outpatient Clinic at the Department of Cardiology, Trondheim, Norway

<sup>4</sup> Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

<sup>&</sup>lt;sup>5</sup> Norwegian University of Science and Technology, Faculty of Social Sciences and Technology Management, Department of Social Work and Health Science, Trondheim, Norway

#### Introduction

Multi-annual medical and psychological research on coronary disease patients has allowed researchers to recognise a variety of heart disease risk factors and to develop a number of accurate and successful medical therapies. However, little is known about factors having the biggest influence on the level of patients' adaptation to life after cardiac events. It is known, though, that their quality of life (QoL) is diminished (e.g. Bosworth et al., 2000). Therefore, much emphasis is recently being placed on its increase. For example, The European Society of Cardiology has included maintenance and improvement of QoL as treatment goals in their guidelines for patients with different heart diseases (Fox et al., 2006; Swedberg et al., 2006). It has become an underlying goal of many rehabilitation and health promotion programs (Bennett et al., 2001). Nevertheless, QoL is a multi-dimensional and complex construct with a great variety of environmental and individual characteristics that influence it (Wilson & Cleary, 1995). This may be one of the reasons why many interventions appear to be ineffective in regard to QoL (Bennett et al., 2001). Nowadays, when - due to a dynamic medical development - we work with a growing number of somatic disease survivors (Tunstall-Pedoe et al., 2000), conducting research in the area of post-disease, it seems that QoL is even more crucial and important. Especially in countries where a gradual aging of society (WHO, 2007), accompanied by an increasing number of persons being at high risk of having an acute myocardial infarction (MI) (Aboderin et al., 2002), is observed.

A majority of previous psychosocial studies in the MI area have mainly provided knowledge on biological, psychological and social limitations experienced by working-age male MI survivors and on their correlation with QoL (Emery et al, 2004; Rankin, 2002; Wickholm & Fridlung, 2003). Little is known, however, about older adults and women's post-MI recovery period (Norekvål et al., 2007), whilst a gradual increase in MI incidence in older women has been observed and a decline in cardiovascular diseases (CVD) death in women of a lesser magnitude has been observed when compared with men (Rosamond et al., 1998; Tunstall-Pedoe et al., 2000). Moreover, longitudinal studies on the mechanisms underlying changes in QoL after MI are needed. Additionally, latest studies indicate that in order to fully understand the processes of change in QoL after MI, we need to look beyond a pathological approach, turn more attention to positive psychology and investigate positive aspects of life such as patients' resources and strengths in relation to adapting to cardiac disorders (Bennett et al., 2001). Among these aspects are the so-called "positive" personality traits and characteristics, as well as social resources.

#### Positive personality characteristics and QoL

Personality factors, as one of a group of potential human resources, can influence the way people approach life circumstances or the outcomes they experience, which in turn may have a favourable or unfavourable impact on their QoL. Thus, we may improve our understanding of pathways to QoL by conceptualizing personality as part of its post-disease theoretical model (Wrosch & Scheier, 2003). Such an approach is in line with the recent studies mentioned above, as well as is broadly discussed in the literature, including the Lazarus and Folkman's (1984) cognitive and transactional model of stress, which is a general, conceptual framework for the project.

When incorporating ideas of positive psychology into a project concentrating on health, the following three personality dispositions will be of a special interest: (1) Antonovsky's concept of sense of coherence (1987), (2) Bandura's self-efficacy (1977; 1997), and (3) Scheier and Carver's dispositional optimism (1985). Sense of coherence (SOC) is defined as a "global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence" (Antonovsky, 1987, p. 19), selfefficacy refers to assessment of personal abilities to overcome taxing situations in the future (Bandura, 1977), while dispositional optimism denotes positive expectancies even in the face of obstacles (Scheier & Carver, 1985). Recently, those dispositions were found to be associated with many aspects of health, wellbeing, functioning and QoL in a variety of somatic patients' samples (including cardiac and elderly patients) (e.g. Barlow, Wright & Cullen, 2002; Bandura, 1997; Caprara, 2002; Carver et al., 2005; Eid & Diener, 2004; Ekman, Fagerberg & Lundman, 2002; Gallagher, Parle & Cairns, 2002; Kashdan & Roberts, 2004; Kattainen, Merilainen & Sintonen, 2006; Lent et al., 2005; Luszczynska, Gutiérrez-Doña & Schwarzer, 2005). Even though these three concepts share some similarities, they also differ in many aspects and their potential overlaps have not been well investigated. Thus, it is suggested that the joint examination of those types of expectations is important in order to delimit their contribution and interrelationships (Karademas, Kafetsios & Sideridis, 2007). The post-disease stability in time of these concepts has also not been well investigated.

Although an increasing body of evidence indicates positive personality dispositions - QoL associations, the pathways through which they operate are still unclear. It is hypothesised that SOC, self-efficacy and optimism might be related to enhanced outcomes through regulating behaviour and emotions or through mediating other underlying cognitive

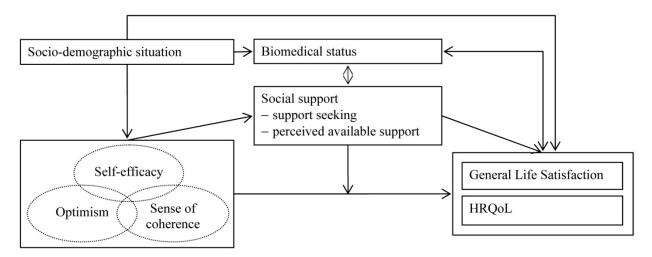
structures and processes (Karademas et al. 2007). There is some evidence supporting such a hypothesis (Pallant & Lae, 1999; Taylor & Armor, 1996; Bandura, 1997; Schwarzer, 1992). Recently, there is also a growing body of evidence indicating that they may be positively related to another important personal recourse - social support (e.g. Boland & Cappeliez, 1997; Kirenko & Byra, 2008; Park & Folkman, 1997; Brissette, Scheier & Carver, 2002).

The place of social support in the personality dispositions – QoL relation Similarly to the concept of QoL, social support also does not have one, coherent and commonly accepted definition. It is generally accepted, though, that it is multidimensional and complex. Thorough overviews of social support definitions, meanings, conceptualizations and classifications can be found in several publications (e.g. Cohen, Underwood & Gottlieb, 2000; Schwarzer & Leppin, 1991; Uchino, 2004).

In the context of the present paper it is worth mentioning that besides the above-mentioned positive relations between SOC, self-efficacy, optimism and social support, different dimensions of social support are also found to be significantly associated with QoL, also in the group of cardiac patients (Bennett et al., 2001; Emery et al., 2004). Moreover, different dimensions of social support reduce depression and anxiety during times of stress, and promote psychological adjustment to chronically stressful conditions, including coronary artery disease (Holahan et al., 1997). However, the exact way in which they operate on QoL and, especially, their role in the positive personality dispositions – QoL relation remains unclear. Moreover, the results on the level of influence of different aspects of social support on QoL are inconsistent, while being controlled for gender and age differences (e.g. Emery et al., 2004; Glebocka & Szarzynska, 2005). Many researchers express a need for more research on this topic (e.g. Schwarzer & Rieckmann, 2002).

#### Theoretical framework

A literature review, accompanied by identification of areas requiring further research, led to building a preliminary model of associations between three positive dispositions: SOC, optimism and self-efficacy, two dimensions of social support (support seeking and perceived available support) and HRQoL in elderly MI survivors. The model is presented in Figure 1.



**Figure 1.** A preliminary theoretical model of associations between positive personality predispositions, (self-efficacy, optimism, sense of coherence), social support and QoL in elderly MI survivors.

# Aims of the study

The main goal of this project is to investigate mechanisms connecting positive personality characteristics (SOC, self efficacy and optimism) and social support with HRQoL in elderly female and male MI survivors. Within the scope of that goal, the following detailed aims of the study are as follows:

- determining the relationship between the individual positive personality characteristics studied and MI survivors' HRQoL at different phases of treatment and rehabilitation;
- determining the relationship of individual positive personality characteristics studied with social support at different phases of treatment and rehabilitation;
- investigating a relationship between social support and MI survivors' HRQoL at different phases of treatment and rehabilitation;
- determining the role of social support in the study of the positive personality characteristics HRQoL relationship (mediation *versus* moderation);
- investigating time stability of the explored positive personality characteristics (after a stressful event such as MI) and investigating the interrelations of those characteristics;
- investigating the importance of other bio-psychosocial characteristics in the above mentioned relations (socio-demographics, subjective health status, health behaviours and medical data as moderators of the investigated relations);
- analysis of differences between patients over and under 60 years of age, within the scope of the above-mentioned relations;

- analysis of gender differences within the scope of the above-mentioned relations;
- analysis of differences within the scope of the above-mentioned relations between
   Polish and Norwegian subjects.

#### Methods

#### Ethics and licences

The study was approved by the Bioethical Committee of Medical University of Warsaw, Poland (KB/104/2010) and Local Bioethics Committee of the Institute of Cardiology, Warsaw, Poland. In Norway, The Norwegian Data Inspectorate and The Regional Committee for Medical and Health Research Ethics approvals will be obtained.

Questionnaires protected by copyrights are ordered from license holders. Statistical analysis are conducted in freeware (G\*Power 3.1.2.) or/and licensed software (Statistica 9, SPSS Statistics 17.0 and IBM®SPSS®Amos).

#### Sampling

Six hundred patients<sup>1</sup> after a first or subsequent acute MI are included in the study at baseline – 300 in Norway and 300 in Poland. Each national group consists of 150 patients over 60 years old (study group; "older people" according to UN standards, *WHO*, 2002) and 150 under this age (control group), preferable men and women in an equal distribution.

Primary inclusion criteria - diagnosis of acute MI - is based on international criteria introduced by *European Society of Cardiology* and *American College of Cardiology* in 2000 and updated in 2007 (Alpert et al., 2000; Thygesen et al., 2007). Information about patients who fulfil those criteria is given by doctors in charge or taken from the medical records. Exclusion criteria are a major psychiatric condition that would confound evaluation of measured variables, cognitive dysfunction, a serious hearing impairment disabling fluent communication, illiteracy and not being fluent in Polish or Norwegian, respectively.

All patients admitted to participating cardiology wards who meet inclusion criteria are invited to participate in the study (until the samples reach the desired size). Registration of those cases in which patients matched the criteria but finally did not participate in the study will be conducted in the form of general, anonymous notes on reasons for lack of

\_

<sup>&</sup>lt;sup>1</sup>Required sample size has been established on the basis of *a priori* power analysis, conducted with G\*Power 3.1.2. software (Faul et al., 2007). Occurrence of participants' dropout from the study at each wave has been taken into account and predicted at 50% level at 2<sup>nd</sup> and 3<sup>rd</sup> wave. The calculations were set for the following desired parameters: power (1-β)=.95; α=.05 and effect size f(V)=.27 (calculated for total score of MACNEW questionnaire, see: Höfer et al., 2004), within given statistical analysis design.

participation (e.g. lack of agreement or missing glasses). The number of patients meeting particular exclusion criteria is also controlled.

#### Procedure

A prospective longitudinal design with repeated measures is applied, patients being followed for 6 months after MI. In this period participants are asked to fill in sets of questionnaires three times: at the end of hospitalization (wave 1); three months (wave 2) and six months after discharge (wave 3).

Baseline/Wave 1. Patients are recruited in the hospital setting, shortly before discharge from hospital (1-2 days). They are informed (verbally and in writing) about the study's background, purpose, design, procedure, voluntary nature of participation and possibility to withdraw at any time. Those who agree to participate are asked to sign a written consent. This stage of a study is conducted by trained nurses, whom the patients know, and takes place in a separate room on the cardiac ward with the nurse being present throughout filling in the questionnaires.

Waves 2 & 3. Three and six months after discharge from the hospital participants receive letters containing information leaflet, instructions, a set of questionnaires and a preaddressed and stamped return envelope. Researchers make phone calls to check if the letters reached their recipients.

Data on patients' medical history includes MI severity (with complications - loss of consciousness, resuscitation; or without complications) and type (NSTEMI or STEMI), left ventricular ejection fraction (LVEF), treatment method (PTCA, CABG or pharmacological treatment), appearance of arrhythmic events during hospitalization, length of hospital stay and patients' gender; this information is obtained by researchers at baseline from the medical history. All other data is collected from patients on the bases of self-administered questionnaires.

#### Measures

Sociodemographics and Health Questionnaire. Three versions of a questionnaire are constructed to obtain data on socio-demographics (age, marital status, education level, professional activity, subjective socio-economic status, place and terms of permanent residence) and patient-reported health data (subjective health status, number and dates of previous MI's, comorbidity, health behaviours, rehabilitation process). Those versions vary accordingly to each wave (e.g. at waves 2 and 3 more specific questions on rehabilitation

process and current physical functioning are asked, while stable demographic questions from wave 1 are skipped). The first version consists of 19 items, version 2 and 3 – of 16 items.

Sense of coherence is measured with a 13-item Sense of Coherence scale (SOC-13) – based on the original SOC-29-scale. (Antonovsky, 1987; 1993). The instrument has a 7-point semantic differential scale response format with two opposite anchoring phrases (e.g. very seldom or never and very often). The scale consists of 4 items on meaningfulness (e.g. 'How often do you have the feeling that there's little meaning in the things you do in your daily life?'), 5 items on comprehensibility (e.g. 'Do you have the feeling that you are in an unfamiliar situation and don't know what to do?') and 4 items on manageability (e.g. 'Has it happened that people whom you counted on disappointed you?'). The answer key allows the calculation of a total SOC score as well as separate scores for the three above theoretical dimensions. However, as recommended initially by Antonovsky (1993) and more recently by other researchers (e.g. Bernabe et al., 2009; Feldt et al., 2006; Zwolinski, 2000), only a total SOC score is calculated in this study. After reversing the scores on five negatively worded items, a total sum score, ranging from 13 to 91, is obtained (with higher scores reflecting stronger SOC). Due to the ongoing debate on the structure of the SOC measures (e.g. Konttinen, Haukkala & Uutela, 2008) a confirmatory factor analysis will be conducted. In previous studies, SOC-13 internal consistency calculated with Cronbach's α coefficient ranks from .74 to .92 (Antonovsky, 1993; Feldt et al., 2006; Zwolinski, 2000).

For measuring *self-efficacy* a *General Perceived Self-Efficacy* scale (GSE) developed by Schwarzer & Jeruzalem (1993; 1995) is used. It consists of 10 items with a 4 point response scale ranging from *I=not at all true* to *4=exactly true*. A typical item is, 'Thanks to my resourcefulness, I can handle unforeseen situations'. Total score ranges from 10 to 40, with higher scores indicating higher self-efficacy. GSE scale has demonstrated high validity and reliability (Cronbach's α from .75 to .92) in many studies across various research contexts and ethnically diverse populations (e.g. Boehmer, Luszczynska & Schwarzer, 2007; Juczynski, 2009; Luszczynska, Gutierrez-Dona & Schwarzer, 2005; Scholz et al., 2002; Schwarzer & Jerusalem, 2000).

*Optimism*. The 10-item *Life Orientation Test - Revised* (LOT-R) (Scheier, Carver & Bridges, 1994) is used to assess dispositional optimism. The scale contains 3 questions concerning positive outcomes (e.g. 'In uncertain times, I usually expect the best'), 3 concerning negative outcomes (e.g. 'If something can go wrong for me, it will'), and 4 filler items. A 5-point Likert-type scale ranging from *0=strongly disagree* to *4=strongly agree* is

used for scoring. For calculating a total score, responses to negative outcomes' items are reversed so that high values imply optimism. Total scores range from 0 to 24, with higher scores reflecting higher level of optimism. LOT-R is internationally applicable and was found to be a valid and reliable instrument (Cronbach's  $\alpha$ =.78) in a number of previous studies (see: e.g. Juczynski, 2007; Scheier, Carver & Bridges, 1994).

Social support is measured by two subscales from the Berlin Social Support Scales, BSSS (Schwarzer & Schulz, 2000; Schulz & Schwarzer, 2003); an 8-item Perceived Available Support Scale (4 items measuring emotional social support, e.g. 'There are some people who truly like me', 4 measuring instrumental social support, e.g. 'I know some people upon whom I can always rely') and a 5-item Support Seeking Scale (e.g. 'Whenever I am down, I look for someone to cheer me up again'). In this questionnaire, patients rate their agreement with the statements on a 4-point scale, with anchoring responses ranging from I=strongly disagree to 4=strongly agree. Scales scores are obtained either by adding up items responses or by generating the scales' mean scores. The measure is found to be valid and reliable, with Cronbach's α for its subscales ranking from .77 to .90 in previous studies (Luszczynska et al., 2006; Schulz & Schwarzer, 2003).

Additionally, three items from The Nord-Trøndelag Health Study (HUNT 3) are used: two measuring *Perceived Available Support* ('Do you have friends that can help you when you need them?', 'Do you have friends that you can speak to confidentially?' with a *Yes/No* answer) and one measuring *Social Participation* ('How many times in the last 6 months have you participated in the following: association or club meeting/activity; music, singing, theatre; parish work; outdoor activities; dance; worked out, sports?' with answers on a 5-point scale for each activity, ranging from *more than once per week* to *never*). Those items are included in a Socio-demographics and Health Questionnaire (information on HUNT Study available at: www.huntbioscences.com).

Satisfaction with Life is measured with a Satisfaction With Life Scale (SWLS) created by Diener et al. (1985). It consists of 5 items with a 7-point Likert-type scale response format, ranging from *1=strongly disagree* to 7=strongly agree. A typical item is, 'In most ways my life is close to my ideal'. Total score ranges from 5 to 35, with higher scores indicating higher satisfaction with life. SWLS has been applied in many studies and found to be a valid and reliable instrument (Cronbach's α from .81 to .87) (Diener et al., 1985; Juczynski, 2009; Pavot & Diener, 1993; Pavot et al., 1991).

Health Related Quality of Life is measured with the MacNew Heart Disease Health-Related Quality of Life questionnaire (MacNew) (Dixon, Lim & Oldrige, 2002; Höfer et al., 2004). It has a 2-week timeframe, contains 27 items and provides three scales: a 13-item physical limitations scale (e.g. 'How much shortness of breath have you experienced while doing your day-to-day activities?'), a 14-item emotional function scale (e.g. 'How much of the time did you feel relaxed and free of tension?') and a 13-item social function scale (e.g. 'How often have you felt unable to do your usual social activities or social activities with your family?') (8 items belong to more than one scale). A 7-point Likert-type scale, e.g. ranging from l=none of the time to r=1 of the time, is used for scoring. Each scales' score is calculated as the average of the responses provided to items in that scale. If more than 50% of the items are missing, the score for that scale is not calculated. A global HRQoL score is calculated as the average of all scored items. MacNew is a valid and highly reliable instrument, with Cronbach's α for its subscales ranking from .87 to .97 in previous studies (Höfer et al., 2004; Wrzesniewski, 2006).

#### Statistics analysis

Application of the above procedure allows to collect data suitable for cross-sectional analysis (age, gender and national differences, correlations between particular variables within each wave), longitudinal analysis investigating predictors of HRQoL at further phases of treatment and rehabilitation (at wave 2 and 3) as well as for investigating main and mediation/moderation effects of social support. Correlation analysis, analysis of means or analysis of variance and regression analysis (including structural equation modelling), respectively, will be conducted to investigate the data.

# What we hope to learn from the study and how we are planning to use this knowledge

In this project, we try to connect the most recent theoretical trends in positive and health psychology. We hope that results of this study will contribute to a better understanding of the mechanisms underlying "positive personality dispositions—QoL" relations. Through this study we also aim at participating in synthesizing knowledge on those personality dispositions which we investigated , their mutual relations and stability after MI, as well as determining gender and cultural differences in the investigated QoL predictors in the studied sample.

Although the above primary goals of the study pertain mainly to fundamental research, we hope that the increase of knowledge on psychological mechanisms affecting HRQoL will contribute to creating new psycho-medical interventions for elderly cardiac patients who are undergoing rehabilitation in which these interventions display sensitivity to both gender and cultural differences. Moreover, results of the study may help in planning successful prevention programs and in increasing diagnostic accuracy for elderly patients with high risk of poor QoL on further phases of treatment and rehabilitation after MI. The above practical effects are crucial for the QoL, functioning and health of individuals. The results also have wider social and economical implications, as improvement of patients' QoL may have a significant indirect effect on social welfare and expenses in the health sector.

### Acknowledgements

The project was implemented with support from Iceland, Liechtenstein and Norway through the EEA Financial Mechanism of the European Economic Area and Norwegian Financial Mechanism under the Scholarship and Training Fund.

#### References

- Aboderin, I., Kalache, A., Ben-Shlomo, Y., Lynch, J.W., Yajnik, C.S., Kuh, D., & Yach, D. (2002) *Life Course Perspectives on Coronary Heart Disease, Stroke and Diabetes: Key Issues and Implications for Policy and Research*. Geneva, World Health Organization.
- Alpert, J. S., Thygesen, K., Antman, E., & Bassand, J. P., et al. (2000). Myocardial Infarction Redefined— A Consensus Document of the Joint European Society of Cardiology/American College of Cardiology Committee for the Redefinition of Myocardial Infarction. *Journal of American College Cardiology*, 36, 959–969.
- Antonovsky, A. (1987). Unraveling the mystery of health: how people manage stress and stay well. San Francisco: Jossey-Bass.
- Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science and Medicine*, *36*, 725–733.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, *84*, 191–215.
- Bandura, A. (1997). Self-efficacy: The exercise of control. New York: Freeman & Co.
- Barlow, J., Wright, C., & Cullen, L. (2002). A job-seeking self-efficacy scale for people with physical disabilities: Preliminary development and psychometric testing.

  \*British Journal of Guidance and Counselling, 30, 37–53.\*
- Bennett, S. J., Perkins, S. M., Lane, K. A., Deer, M., Brater, D. C., & Murray, M. D. (2001). Social support and health-related quality of life in chronic heart failure patients. *Quality of Life Research*, *10*, 671–682.
- Bernabe, E., Tsakos, G., Watt, R. G. Suominen-Taipale, A. L. Uutela, A., Vahtera, J., & Kivimaki, M. (2009). Structure of the sense of coherence scale in a nationally representative sample: the Finnish Health 2000 survey. *Quality of Life Research*, 18, 629-636.
- Boehmer, S., Luszczynska, A., & Schwarzer, R. (2007). Coping and quality of life after tumour surgery: Personal and social resources promote different domains of quality of life. *Anxiety, Stress, and Coping, 20,* 61-75.
- Boland, A., & Cappeliez, P. (1997). Optimism and neuroticism as predictors of coping and adaptation in older women. *Personality & Individual Differences*, 22, 909–919.
- Bosworth, H. B., Siegler, I. C., Olsen, M. K., Brummett, B. H., Barefoot, J. C.,

- Williams, R. B., Clapp-Channing, N. E., & Mark, D. B. (2000). Social support and quality of life in patients with coronary artery disease. *Quality of Life Research*, *9*, 829-839.
- Brissette, I., Scheier, M. F., & Carver, C. S. (2002). The role of optimism in social network development, coping, and psychological adjustment during a life transition. *Journal of Personality and Social Psychology*, 82, 102–111.
- Carver, C. S., Smith, R. G., Antoni, M. H., Petronis, V. M., Weiss, S., & Derhagopian, R. P. (2005). Optimistic personality and psychosocial well-being during treatment predict psychosocial well-being among long-term survivors of breast cancer. *Health Psychology*, 24, 508–516.
- Caprara, G. V. (2002). Personality psychology: Filling the gap between basic processes and molar functioning. In von C. Hofsten, & L. Backman (Eds). *Psychology at the turn of the millennium, Vol. 2: Social, developmental, and clinical perspectives* (pp. 201–224). Florence, KY: Taylor & Frances.
- Cohen, S., Underwood, L., & Gottlieb, B. (2000). Social Support Measurement and Intervention: A Guide for Health and Social Scientists. New York: Oxford University Press.
- Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment*, 49, 71-75.
- Dixon, T., Lim, L. L., & Oldrige, N.B. (2002). The MacNew heart disease health-related quality of life instrument: Reference data for users. *Quality of Life Research*, 11, 173-183.
- Eid, M., & Diener, E. (2004). Global judgments of subjective well-being: Situational variability and long-term stability. *Social Indicators Research*, *65*, 245–277.
- Ekman, I., Fagerberg, B., & Lundman, B. (2002). Health-related quality of life and sense of coherence among elderly patients with severe chronic heart failure in comparison with healthy controls. *Heart & Lung, 31*, 94-101.
- Emery, C. F., Frid, D. J., Engebretson, T. O., Alonzo, A. A., Fish, A., Ferketich, A. K., Reynolds, N. R., Dujardin, J. P., Homan, J. E., & Stern, S. L. (2004). Gender differences in quality of life among cardiac patients. *Psychosomatic Medicine*, 66, 190-197.

- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175-191.
- Feldt, T., Lintula, H., Suominen, S., Koskenvuo, M., Vahtera, J., & Kivimaki, M. (2006). Structural validity and temporal stability of the 13-item sense of coherence scale: prospective evidence from the population-based HeSSup study. *Quality of Life Research*, *16*, 483-493.
- Fox, K., Garcia, M. A., Ardissino, D., Buszman, P., Camici, *P. G.*, & Crea, F., et al. (2006). Guidelines on the management of stable angina pectoris: executive summary: the Task Force on the Management of Stable Angina Pectoris of the European Society of Cardiology. *European Heart Journal*, *27*, 1341-81.
- Gallagher, J., Parle, M., & Cairns, D. (2002). Appraisal and psychological distress six months after diagnosis of breast cancer. *British Journal of Health Psychology*, 7, 365–376.
- Glebocka, A., & Szarzynska, M. (2005). Wsparcie społeczne a jakość życia ludzi starszych [Older persons social support and QoL]. *Gerontologia Polska*, 13, 255-259 [in Polish].
- Holahan, C. J., Moos, R. H., Holahan, C. K., & Brennan, P. L. (1997). Social context, coping strategies, and depressive symptoms: An expanded model with cardiac patients. *Journal of Personality and Social Psychology*, 72, 918–928.
- Höfer, S., Lim, L., Guyatt, G., & Oldridge, N. (2004). The MacNew heart disease health-related quality of life instrument: a summary. *Health and Quality of Life Outcomes*, 2(3) [Open Access electronic version].
- Juczynski, Z. (2009). *Narzędzia Pomiaru w Promocji i Psychologii Zdrowia PTP*[Measurement Tools in Health Promotion and Health Psychology] (2<sup>nd</sup> Edit).

  Warsaw: Pracownia Testow Psychologicznych [in Polish]
- Karademas, E. C., Kafetsios, K., & Sideridis, G. D. (2007). Optimism, self-efficacy and information processing of threat- and well-being–related stimuli. *Stress and Health*, 23, 285–294.
- Kashdan, T. B., & Roberts, J. E. (2004). Social anxiety's impact on affect, curiosity, and social self-efficacy during a high self-focus social threat situation. *Cognitive Therapy and Research*, 28, 119–141.

- Kattainen, E., Merilainen, P., & Sintonen, H. (2006). Sense of coherence and health-related quality of life among patients undergoing coronary artery bypass grafting or angioplasty. *European Journal of Cardiovascular Nursing*, *5*, 21-30.
- Kirenko, J., & Byra, S. (2008). *Zasoby osobiste w chorobach somatycznych* [Personal resources in somatic disease] Lublin: Wydawnictwo UMCS [in Polish].
- Konttinen, H., Haukkala, A., & Uutela, A. (2008). Comparing Sense of Coherence, depressive symptoms and anxiety, and their relationships with health in a population-based. *Study Social Science & Medicine*; 66, 2401–2412.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lent, R. W., Singley, D., Sheu, H., Gainor, K. A., Brenner, B. R., Treistman, D., & Ades, L. (2005). Social cognitive predictors of domain and life satisfaction: Exploring the theoretical precursors of subjective well-being. *Journal of Counselling Psychology*, *52*, 429–442.
- Luszczynska, A., Gutiérrez-Doña, B., & Schwarzer, R. (2005). General self-efficacy in various domains of human functioning: Evidence from five countries. *Interpersonal Journal of Psychology*, 40, 80–89.
- Luszczynska, A., Kowalska, M., Mazurkiewicz, M., & Schwarzer, R. (2006). Berlinskie Skale Wsparcia Spolecznego (BSSS). Wyniki wstepnych badan nad adaptacja skal i ich wlasnosciami psychometrycznymi [Berlin Social Support Scales (BSSS): Polish adaptation and preliminary results on the scales psychometric properties]. *Studia Psychologiczne*, 44, 17-27 [in Polish].
- Norekvål, T. M., Wahl, A. K., Fridlund, B., Nordrehaug, J. E., Wentzel-Larsen, T., & Hanestad, B. R. (2007). Quality of life in female myocardial infarction survivors: a comparative study with a randomly selected general female population cohort. *Health and Quality of Life Outcomes*, 5(58)
- Pallant, J., & Lae, L. (2002). Sense of coherence, well-being, coping and personality factors: Further evaluation of the sense of coherence scale. *Personality and Individual Differences*, *33*, 39-48.
- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *Review of General Psychology*, *1*, 115–144.

- Pavot, W., & Diener, E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment*, *5*, 164-172.
- Pavot, W., Diener, E., Colvin, C., & Sandvik, E. (1991). Further validation of the Satisfaction With Life Scale: Evidence for the cross-method convergence of well-being measures. *Journal of Personality Assessment*, *57*, 149-161.
- Rankin, S. H (2002). Women recovering from acute myocardial infarction: psychosocial and physical functioning outcomes for 12 months after acute myocardial infarction. *Heart Lung*, 31, 399-410.
- Rosamond, W. D., Chambless, L. E, Folsom, A. R., Cooper, L. S., Conwill, D. E., & Clegg, L., et al. (1998). Trends in the incidence of myocardial infarction and in mortality due to coronary heart disease, 1987-1994. *New England Journal of Medicine*, 339, 861-867.
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, *4*, 219–247.
- Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994) Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): A re-evaluation of the Life Orientation Test. *Journal of Personality and Social Psychology*, 67, 1063-1078.
- Scholz, U., Gutiérrez Doña, B., Sud, S., & Schwarzer, R. (2002). Is General Self-Efficacy a Universal Construct? Psychometric Findings from 25 Countries. *European Journal of Psychological Assessment, 18*, 242–251.
- Schulz, U., & Schwarzer., R. (2003). Soziale Unterstützung bei der Krankheitsbewältigung. Die Berliner Social Support Skalen (BSSS) [Social support in coping with illness: The Berlin Social Support Scales (BSSS)]. *Diagnostica*, 49, 73-82 [in German]
- Schwarzer, R. & Leppin, A. (1991). Social support and health: A theoretical and empirical overview. *Journal of Personal and Social Relationships*, 8, 99-127.
- Schwarzer, R. (1992). Self-efficacy in the adoption and maintenance of health behaviors: Theoretical approaches and a new model. In: R. Schwarzer (Ed.), *Self-efficacy: Thought control on action* (pp. 217–243). Washington, DC: Hemisphere.

- Schwarzer, R. & Jerusalem, M. (1993). *English Version of the General Self-Efficacy Scale*. Retrieved on November 15, 2009 from http://userpage.fuberlin.de/~health/engscal.htm
- Schwarzer, R. & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In: J. Weinman, S. Wright, & M. Johnston (Eds.), *Measures in health psychology: A user's portfolio. Causal and control beliefs* (pp. 35-37). Windsor, UK: NFER-NELSON.
- Schwarzer, R., & Jerusalem M. (2000). *General Perceived Self-Efficacy*. Retrieved on March 22, 2011 from: http://web.fu-berlin.de/gesund/skalen/Language\_Selection/Turkish/General\_Perceived\_Self-Efficac/hauptteil general perceived self-efficac.htm
- Schwarzer, R., & Schulz, U. (2000). *Berlin Social-Support Scale (BSSS)*. Retrieved on November 15, 2009 from: http://www.ralfschwarzer.de/
- Schwarzer, R., & Rieckmann, N. (2002). Social support, cardiovascular disease, and mortality. In: G. Weidner, M. S. Kopp & M. Kristenson (Eds.), *Heart disease: Environment, stress, and gender. NATO Science Series, Series I: Life and Behavioural Sciences (Vol. 327, pp. 185-197*). Amsterdam: IOS Press.
- Swedberg, K., Cleland, J., Dargie, H., Drexler, H. Follath, F., & Komajda, M., et al. (2005). Guidelines for the diagnosis and treatment of chronic heart failure: executive summary (update 2005): The Task Force for the Diagnosis and Treatment of Chronic Heart Failure of the European Society of Cardiology. *European Heart Journal*, 26, 1115-1140.
- Taylor, S. E., & Armor, D. A. (1996). Positive illusions and coping with adversity. *Journal of Personality*, 64, 873–898.
- Thygesen, K., Alpert, J. S., & White, H. D. (2007). Joint ESC/ACCF/AHA/WHF Task Force for the Redefinition of Myocardial Infarction. *Journal of the American College of Cardiology*, *50*, 2173-2195.
- Tunstall-Pedoe, H., Vanuzzo, D., Hobbs, M., Mahonen, M., Cepaitis, Z., Kuulasmaa, K., & Keil, U. (2000). Estimation of contribution of changes in coronary care to improving survival, event rates, and coronary heart disease mortality across the WHO MONICA Project populations. *Lancet*, 26, 355(9205), 688-700.

- Uchino, D. (2004). Social Support and Physical Health: Understanding the Health Consequences of Relationships. New Haven, Connecticut: Yale University Press.
- WHO (2002). Definition of an older or elderly person. Downloaded 20.04.2011 from: http://www.who.int/healthinfo/survey/ageingdefnolder/en/index.html
- WHO (2007). 10 facts on ageing and the life course. Downloaded 20.04.2011 from: http://www.who.int/features/factfiles/ageing/en/index.html
- Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life. *JAMA*, 273, 59–65.
- Wrosch, C., & Scheier, M. F. (2003). Personality and quality of life: The importance of optimism and goal adjustment. *Quality of Life Research*, *12* (Suppl. 1), 59–72.
- Wickholm, M., & Fridlund, B. (2003). Women's health after a first myocardial infarction: a comprehensive perspective on recovery over a 4-year period. *European Journal of Cardiovascular Nursing*, 2, 19-25.
- Wrzesniewski, K. (2006). Wybrane zagadnienia teoretyczne i metodologiczne pojęcia jakości życia [Chosen theoretical and psychological aspects of QoL]. In: T. Pasikowski & H. Sek (Eds.), *Psychologia zdrowia: teoria, metodologia i empiria* [Health Psychology: theorie, methodology and practice] (pp.61-72). Poznan: Bogucki Wydawnictwo Naukowe [in polish].
- Zwolinski, M. (2000). Kontrowersje dotyczące struktury czynnikowej Kwestionariusza Orientacji Życiowej (skali SOC) A. Antonovsky'ego [Controversies around factor structure of A. Antonovsky's Sense of Coherence Scale]. *Przeglad Psychologiczny*, 43, 291-308 [in polish].

# 7. Resilience mechanisms as factors to sustain activity participation in home and leisure

#### LILLIAN REINSETH

Sør-Trøndelag University College, Department of Occupational Therapy,
School of Health Education and Social Work, Trondheim, Norway
Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

The knowledge of resilience mechanisms as factors to sustain the involvement in activities for home and leisure in chronic diseases is limited. This study aimed at examining the relationships associated with participation in committed activities (activities we are obliged to perform), discretionary activities (activities for recreation and pleasure), health related quality of life and self-efficacy in women with rheumatoid arthritis (RA).

The study included 233 women with RA. Their participation in activities was measured by the Interest checklist, efficacy-beliefs by Arthritis self-efficacy scales and health related quality of life by SF-36.

Related samples T-test showed a statistically significant decrease in the participation of activities during the last ten years. Multivariate analyses demonstrated that a high level of participation in committed activities were independently related to positive self-efficacy in coping with RA functions, psychological well-being and high educational level; in addition was good physical function a significant factor regarding discretionary activities.

#### Introduction

Rheumatoid arthritis (RA) is a progressive autoimmune disease with both articular- and systemic manifestations (Lee & Weinblatt, 2001). The prevalence of RA is in the region of 0.5-1% (Kvien, et al., 1997). RA occurs most often in women with a female/male proportion of 2.5/1 (Lee & Weinblatt, 2001). In a large multinational study, RA disease measures appear to be worse in women than in men (Sokka, et al., 2009). The burden of RA seems to be reduced during the last decade, due to better and more aggressive treatments (Uhlig, et al., 2008). In spite of better medications, remission of the most important clinical features like disease activity, pain and fatigue are only reached by 10-36% of early RA patients (Scott & Lempp, 2006) and work disability rates remain high among people with RA (Sokka, et al., 2010).

Occupational participation is a concept that refers to engaging in work, play, or activities of daily living that are part of an individual's social and cultural context and that are desired and /or necessary to the well-being of the individual (Kielhofner, 2008). A disabling chronic disease that causes performance limitations, may change occupational participation, but not necessarily prevent it (Kielhofner, 2008). Obligatory activities include necessary activities for survival, like activities of daily living (ADL) including eating, hygiene and dressing (Katz, et al., 2006). Committed activities contain our main social roles like household responsibilities, family care, studying or participating in paid work (Katz, et al., 2006). Discretionary activities are leisure activities like exercising, socializing, hobbies and other activities one might take on for recreation and pleasure (Katz, et al., 2006). Previous research showed a significant decrease in activity participation in women with RA over the last ten years (Reinseth & Espnes, 2007). A loss of leisure activities occurs early in RA and mainly in those who have low formal education (Wikstrom, et al., 2006).

Resilience means processes that lead to well-being despite of facing significant adversity like for instance a chronic disease (Ungar, 2008). Two processes explain resilience; navigation and negotiation (Ungar, 2008). The individual shows ability to navigate towards resources that can sustain their well-being and shows the capacity to negotiate for these resources to be provided in culturally meaningful ways (Ungar, 2008). In a comparison between a non-resilient and a resilient group of people with chronic pain, the resilient group reported significant higher levels of task persistence, control perceptions and lower levels of disability beliefs (Karoly & Ruehlman, 2006). In another study of persons with chronic pain, higher levels of positive affect predicted lower levels of pain (Zautra, et al., 2005). Positive reinterpretation, active coping and acceptance coping were strongly related to resilience factors in a study regarding people with RA (Smith & Zautra, 2008).

Health related quality of life (HRQoL) is a broad concept including physical, social and mental well-being and is often used to describe the impact a chronic disease will have at quality of life (Ware, et al., 2000). In a previous study, the results showed that performing a high number of activities for home and leisure, correlated with high scores on psychological well-being, while the participation in few activities correlated positively with scores on psychological distress (Reinseth & Espnes, 2007).

The concept of self-efficacy can be explained as an individuals' judgement of their capabilities to achieve given levels of performance and to exercise control over events (Bandura, 1997). The beliefs that persons can influence the course of events in their daily life

are strong motivators to achieve desired results (Kielhofner, 2008). This ability can be confronted by chronic disease and impairment, which often leads to feelings of being controlled by outside factors (Kielhofner, 2008). A recent study showed that partaking in a high amount of leisure-time physical activities was related to less fatigue and higher self-efficacy (Reinseth, et al., 2010).

The knowledge of resilience mechanisms as factors to sustain the partaking in activities for home and leisure in chronic diseases is limited. This study aims at exploring relationships associated with participation in committed and discretionary activities in RA and also to explore resilience mechanisms as factors to sustain the participation in such activities.

#### Materials and methods

#### Sample and study design

The study was performed using a cross-sectional and retrospective design. Participants were recruited during the autumn 2005 and spring 2006 from the files of patients examined from August 1999 until August 2005 at the Department of Rheumatology, St. Olav University Hospital in Trondheim, Norway. Inclusion criteria were RA according to the 1987 American College of Rheumatology (Arnett, et al., 1988), female sex, disease duration > 2yrs and age between 20 and 79. A manual search of the patient records was performed to document disease duration and rheumatoid factor (RF).

The study has been approved by the Regional Ethical Committee (REK).

#### Measures

The questionnaires comprised socio-demographic factors such as age, marital status, employment status and educational level. Marital status was recorded in five categories; widowed, divorced, single, cohabitant or married. Employment status was recorded as full-time or part-time work, not working or retired. Educational level was recorded in seven categories; from primary school to more than four years of university where the participants recorded their highest level of education.

Health status was measured with the Modified Health Assessment Questionnaire (MHAQ) (Pincus, et al., 1983) and Visual Analogue Scales (VAS) (Karoly & Jensen, 1987; Revill, et al., 1976). MHAQ is a self-reported instrument to measure the degree of difficulty in performing activities of daily living (Pincus, et al., 1983). The instrument comprises eight

questions of functional ability and are scored on four levels from 0 "with no difficulty" to 3 "unable to perform". MHAQ mean – values >0.5 are considered as the persons in question having moderate functional problems and MHAQ – values higher than 1 are understood as considerable functional problems (Kvien, 1996). Recent findings specify that MHAQ are valid as measure of physical function in RA patients (Uhlig, et al., 2006). Joint pain-, fatigue-, disease activity- and general pain last week were measured on 100-mm VAS with anchors of "no pain/ fatigue/disease activity" and "maximum pain/fatigue/disease activity". The VAS has been extensively tested for reliability, validity and sensitivity and was found to satisfy these aspects (Karoly & Jensen, 1987; Revill, et al., 1976).

The Interest Checklist is a self-report instrument that contains ordinary activities one might do on an everyday basis, including social and physical activities, household duties, handicrafts and other activities for home and leisure (Kielhofner, 2008). The Interest Checklist is used to show changes in activity choices over a time period and whether one currently participates in these activities (Kielhofner, 2008). Lee (Lee, 1996) has adjusted the Interest Checklist to the population of Norway's most common non-vocational activities according to "The Norwegian Central Agency for Statistics". The Norwegian version contains 55 non-vocational activities with additional space to fill in activities that are not already included in the list. The Interest Checklists include "activities performed in the past ten years", "activities performed last year" and "activities performed at present" and was applied in the current study. The scoring of the Interest Checklist is based on positive responses; participation/interest in an activity is scored by 1 and not participating is scored by 0.

The Arthritis Self-Efficacy Scale (ASES) is built upon Bandura's understanding on the concept of self (Bandura, 1997). ASES is a reliable and valid instrument that is developed to measure self-efficacy in persons with rheumatic diseases (Lorig, et al., 1989; Marks, 2001). The questionnaire contains five items regarding coping with pain, nine items about function and six items concerning other symptoms related to RA like fatigue and depression. Each item presents a statement in which the respondent may agree or disagree. The scores are expressed as values between 10 and 100, where a score of 10 represents the lowest possible self-efficacy level and a score of 100 represents the best possible level of self-efficacy.

The Short-Form-36 (SF-36) was originally constructed for use in health policy and general population surveys to evaluate health status. Lately, this instrument has been extensively used in clinical research and practise to investigate health-related quality of life in

people with different chronic diseases; also with RA (Scott & Garrood, 2000; Ware, et al., 2000). The instrument has previously been used for evaluation of health related quality of life in RA-patients in Norway (Kvien, et al., 1998b; Uhlig, et al., 2007). Thirty-six items covering eight domains of quality of life compose the SF-36; limitations in physical activities because of health problems, limitations in usual role activities because of physical health problems, bodily pain, limitations in social activities because of physical or emotional problems, general mental health, psychological distress and well-being, limitations in usual role activities because of emotional problems, vitality, energy and fatigue, and general health perceptions. For each subscale of the SF-36 a score is calculated with values from 0-100, and high scores indicate good health (Ware, et al., 2000). SF-36 is a self-administered questionnaire that is well suited for postal surveys (Bowling, 2001), has been translated into Norwegian and is validated (Kvien, et al., 1998a; Loge, et al, 1998).

#### Data analysis and statistics

Descriptive statistics for continuous data are presented as means with standard deviations (SD) and as percentages for counts. The application of parametric statistics was verified by testing variables with the Kolmogorov-Smirnov test.

The focus of the present study is at committed activities; for instance household responsibilities and discretionary activities; for instance leisure time activities. The Interest Checklist was for this purpose divided into committed and discretionary activities according to previous studies (Katz, et al., 2006; Verbrugge & Jette, 1994).

Related-samples *t* tests were applied to test if there were statistically significant differences between the mean amount of committed and discretionary activities performed during the last ten years, the last year and activities currently being performed. Cohen's *d* was calculated to find the strengths of these relationships (Cohen, 2001; Cohen, 1988). Cohen's *d* is the difference between two means divided by a pooled estimate of the standard deviation (Cohen, 2001).

To prepare for multiple linear regression analyses, Pearson's correlation coefficient were calculated between the two dependent variables committed activities and discretionary activities; and independent variables; health related quality of life (SF-36), and demographic variables (education, work participation, marital status, disease duration and age) to explore the material and eliminate irrelevant variables. Variables that were not significantly associated with the dependent variables were not included in the regression analysis. The

regression equations were found to satisfy the suppositions of multiple regressions normality, linearity, and equality of variance and the nonappearance of collinearity. The enter method of multiple linear regression analyses was applied to analyse the associations between the study variables SF-36 HRQoL as fixed factors - controlled for demographic factors, at first with "committed activities performed at present" and then with "discretionary activities performed at present" as dependent variables. Results for multiple linear regression analysis are presented as unstandardized coefficients B, standard error of the estimate (SE), standardized Beta coefficients ( $\beta$ ), and the t statistics with the significant value of the t added and R squared ( $R^2$ ).

Data analysis was carried out with the Statistical Package for the Social Sciences (SPSS) for Windows, version 19.0. Results were considered significant when *p*-values were equal to or below 0.05. The present analysis did not assess the causal relationships between independent and dependent variables. Instead, associations between variables were examined to explore our main research questions.

#### Results

Of the 258 females with RA that received the questionnaires, 238 (92.4%) answered within four weeks or after receiving a reminding letter. Due to incompleteness of the questionnaire responses, five questionnaires were excluded, leaving 233 for the analysis. Characteristics of the study subjects are shown in Table 1. Their mean age was 57.1 (SD 12.1) and the mean disease duration was 14.8 years (SD 10.1). A positive rheumatoid factor (RF+) was present in 177 persons (76%). A total of 164 (70.4%) were living with a spouse, and 90 persons (38.6%) were still in paid employment (See table 1). MHAQ mean was 0.54, 83 (35.6%) women with RA had moderate functional problems, while 34 (14.6%) had considerable functional problems. VAS fatigue in the previous week had the highest scores among the VAS scales with a mean of 44.8 (See table 1). The participation in committed and discretionary activities had a significant decrease over the ten-year period, with a decrease of approximately 25% of activities performed in the past ten years compared to present performance, for both committed and discretionary activities. (See Table 1).

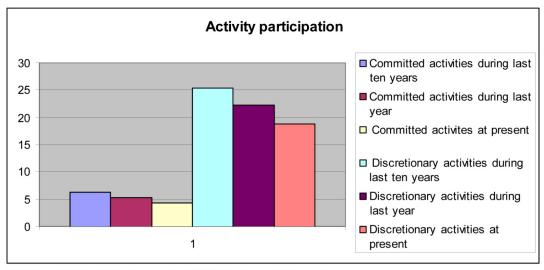
There were no significant differences between responders and non-responders concerning age, disease duration or proportions with RF+.

Table 1. Subject characteristics and differences between rheumatoid arthritis and controls

	RA Mean (SD) or n (%)
Age	57.1 (12.1)
Marital status: Living with a spouse	164 (70.4)
Educational level > 12yrs	70 (30.1)
Working	90 (38.6)
Disease duration	14.8 (10.1)
RF positive	177 (76)
MHAQ (0-3) ‡	0.54 (0.49)
SF-36, 1. Physical function (0-100) †	52.8 (24.5)
SF-36, 2. Role – physical (0-100) †	34.4 (37.5)
SF-36, 3. Bodily pain (0-100) †	45.6 (20.8)
SF-36, 4. Social function (0-100) †	70.2 (25.6)
SF-36, 5. Mental health (0-100) †	73.6 (17.9)
SF-36, 6. Role – emotional (0-100) †	62.8 (41.8)
SF-36, 7. Vitality (0-100) †	40.8 (20.5)
SF-36, 8. General health perception (0-100) †	51.3 (21)
VAS joint pain last week (0-100) ‡	34.0 (21.4)
VAS fatigue last week (0-100) ‡	44.8 (26.0)
VAS disease activity last week (0-100) ‡	37.7 (22.5)
VAS general pain last week (0-100) ‡	26.6 (24.2)
ASES pain (10-100) †	53.2 (18.3)
ASES function (10-100) †	68.9 (22.2)
ASES symptoms (10-100) †	67.2 (15.0)
Committed occupations last ten years	6.3 (2.3)
Committed occupations last year	5.3 (1.9)
Committed occupations at present	4.3(1.8)
Discretionary occupations last ten yrs.	25.4 (7.3)
Discretionary occupations last year	22.3 (6.9)
Discretionary occupations at present	18.8 (7.4)
N	233

Note. † = High value means good health status or high self-efficacy;‡=High value means low health status; RF=Rheumatoid factor; PCS = Physical Component Summary; MCS = Mental Component Summary; ASES = Arthritis Self-efficacy Scales; MHAQ = modified health assessment questionnaire; VAS = Visual Analogue Scales; MHAQ – values >0.50 are interpreted as moderate functional problems.

The result of the paired samples *t*-test showed significance beyond the 0.0001 level for all four pairs; between committed/discretionary activities during the last ten years/during last year and between committed/discretionary activities during last year and presently (See Figure 1). The Cohen's *d* was 0.6 in the difference between participation in committed activities during the last ten years compared to the last year and 0.9 between committed activities the last year and presently, which means medium and high effect size respectively. The Cohen's *d* was respectively 0.6 and 0.7 for the difference between discretionary activities during the last ten year compared to the last year and during the last year compared to presently, which was a medium effect size. In percentages, the mean participation in committed activities, as well as in discretionary activities, had decreased significantly from the last ten years to the last year and from the last year to the present, by 16% and 17.5% respectively for committed activities, and by 12% and 16% for discretionary activities (See figure 1).



Paired samples t-test showing p-value < 0.0001 between all four pairs

Figure 1. Differences between activity participation during the last ten years, the last year and at present

According to Table 2, multiple linear regression analysis showed significant associations between high participation in committed and discretionary activities and high efficacy beliefs in RA functions, high scores on SF-36 mental health, and a high educational level. In addition, SF-36 physical function was significantly associated with high participation in discretionary activities.

**Table 2.** Summaries of the two multiple regression analysis (enter method) associated with the 2 dependent variables; Committed and discretionary activities at present. The analysis was controlled for independent variables: demographics, health variables, self-efficacy (ASES) and SF-36 Health related quality of life.

Predictors	Committed activities at present (dependent 1)				
	B <sub>a</sub>	Standard	$\beta_{\rm a}$	$\mathbb{R}^2$	t-values a
		error <sub>a</sub>			
ASES function	0.27	0.01	0.31	0.17	4.76***
SF-36 Mental Health	0.19	0.01	0.18	0.21	2.93**
Educational level	0.18	0.06	0.19	0.24	2.94**

	Discretionary activities at present (dependent 2)					
	Ba	Standard	<b>β</b> <sub>a</sub>	$\mathbb{R}^2$	t-values	
		error <sub>a</sub>				
ASES function	0.06	0.03	017	0.19	2.13*	
SF-36 Physical function	0.05	0.02	0.17	0.21	2.09*	
SF-36 Mental Health	0.11	0.02	0.27	0.29	4.64***	
Educational level	1.0	0.23	0.26	0.35	4.42***	

*Note.*;  $_{\bf a}$  = B, Standard error,  $\beta$ , and t-values after the last model of the enter regression analysis; ASES = Arthritis Self-efficacy Scales; SF-36 = 36-item short-form health survey.

#### Discussion

This study explored relationships associated with participation in committed and discretionary activities and of particular interest were resilience mechanisms as factors to sustain the participation in activities for home and leisure.

One could have hoped for improved function and higher activity participation in RA because of improved medications during the last decade, but remission is only achieved by 10-36% of early RA patients (Scott & Lempp, 2006). In accordance with previous research (Reinseth & Espnes, 2007), the present study showed a decrease in the participation of committed and discretionary activities during the last ten years in women with RA.

The multivariate analysis in the present study showed significant associations between high participation in both committed and discretionary activities and psychological well-being, self-efficacy in functioning; i.e. efficacy beliefs about performing common activities of daily living, and a high educational level. In spite of facing significant adversity in the form of RA, those who have been able to keep up a high participation in activities, demonstrate a high score on mental health or psychological well-being, which can be seen as a part of resilience processes (Ungar, 2008). Coping was a significant factor in the present study, and a study by Smith (2008) also concerning people with RA, showed that coping was strongly related to resilience factors.

<sup>\* =</sup> p < 0.05. \*\* = p < 0.01. \*\*\* = p < 0.0001.

In addition, a high participation in discretionary activities was associated with a better physical function in the present study. Furthermore, those who participated in a lot of discretionary activities had a higher education and the opposite was true – those who participated in few leisure time activities had lower education. These results are consistent with the findings of Wikstrom (2006), who reported a reduction in the participation in discretionary activities early in RA, especially in those with low education.

A limitation of this study is the cross-sectional design that does not make it possible to conclude on cause and effect, only on associations. The Interest Checklist is used by many occupational therapists on a daily basis to provide information on activity participation and development (Kielhofner, 2008). The checklist has on several occasions been used in research. However, it should be further tested to ensure its reliability.

In conclusion, the present study highlighted the decrease in the participation of committed and discretionary activities in women with RA during the last ten years. Those who still participate in a greater number of committed and discretionary activities also experienced psychological well-being and high self-efficacy in functioning which are both factors that could be related to resilience mechanisms. In addition, a high educational level was significantly associated with participation in many committed and discretionary activities.

# Acknowledgements

Funding was provided by the author's employer, the Department of Occupational Therapy, the School of Health Education and Social Work, the Sør-Trøndelag University College, Trondheim and the Norwegian Women's Public Health Association. The author also appreciates that the St. Olav University Hospital of Trondheim allowed sending the questionnaires for this study to some of their patients. The author gratefully acknowledges the participants for thoroughly answering the questionnaires.

# References

- Arnett, F. C., Edworthy, S. M., Bloch, D. A., McShane, D. J., Fries, J. F., & Cooper, N. S., et al. (1988). The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis and rheumatism*, 31, 315-324.
- Bowling, A. (2001). *Measuring disease a review of disease specific quality of life measurement scales* (2nd ed.). Buckingham: Open University Press.
- Cohen, B. H. (2001). *Explaining psychological statistics* (2nd ed.). New York: Wiley. Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2<sup>nd</sup> Ed.). Hillsdale, N. J.: Laurence Erlbaum.
- Karoly, P., & Jensen, M. P. (1987). *Multimethod assessment of chronic pain*.

  \*Psychology practitioner guidebooks. Multimethod assessment of chronic pain. x, (155 pp). Elmsford, NY: Pergamon Press.
- Karoly, P., & Ruehlman, L. S. (2006). Psychological "resilience" and its correlates in chronic pain: findings from a national community sample. [Comparative Study Research Support, N.I.H., Extramural]. *Pain*, 123, 90-97.
- Katz, P. P., Morris, A., & Yelin, E. H. (2006). Prevalence and predictors of disability in valued life activities among individuals with rheumatoid arthritis. *Annals of the rheumatic diseases*, 65, 763-769.
- Kielhofner, G. (2008). *Model of human occupation theory and application* (4<sup>th</sup> Ed.). Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins.
- Kvien, T. K. (1996). *Specialized rehabilitation of patients with rheumatoid arthritis and related diseases*. Oslo: Statens helsetilsyn.
- Kvien, T. K., Glennas, A., Knudsrod, O. G., Smedstad, L. M., Mowinckel, P., & Forre,
  O. (1997). The prevalence and severity of rheumatoid arthritis in Oslo. Results
  from a county register and a population survey. [Research Support, Non-U.S.
  Gov't]. Scandinavian Journal of Rheumatology, 26, 412-418.
- Kvien, T. K., Kaasa, S., & Smedstad, L. M. (1998a). Performance of the Norwegian SF-36 Health Survey in patients with rheumatoid arthritis. II. A comparison of the SF-36 with disease-specific measures. *Journal of clinical epidemiology*, *51*, 1077-1086.

- Kvien, T. K., Kaasa, S., & Smedstad, L. M. (1998b). Performance of the Norwegian SF-36 Health Survey in patients with rheumatoid arthritis. II. A comparison of the SF-36 with disease-specific measures. *Journal of Clinical Epidemiology*, *51*, 1077-1086.
- Lee, D. (1996). The Interest Checklist for Norwegian conditions *Ergoterapeuten* 4, 12-15.
- Lee, D. M., & Weinblatt, M. E. (2001). Rheumatoid arthritis. Lancet, 358, 903-911.
- Loge, J. H., Kaasa, S., Hjermstad, M. J., & Kvien, T. K. (1998). Translation and performance of the Norwegian SF-36 Health Survey in patients with rheumatoid arthritis. I. Data quality, scaling assumptions, reliability, and construct validity. *Journal of Clinical Epidemiology*, *51*, 1069-1076.
- Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis and rheumatism*, *32*, 37-44.
- Marks, R. (2001). Efficacy theory and its utility in arthritis rehabilitation: review and recommendations. *Disability and Rehabilitation*, 23, 271-280.
- Pincus, T., Summey, J. A., Soraci, S. A., Jr., Wallston, K. A., & Hummon, N. P. (1983).
  Assessment of patient satisfaction in activities of daily living using a modified
  Stanford Health Assessment Questionnaire. *Arthritis and Rheumatism*, 26, 1346-1353.
- Reinseth, L., & Espnes, G. A. (2007). Women with rheumatoid arthritis: non-vocational activities and quality of life. *Scandinavian Journal of Occupational Therapy*, *14*, 108-115.
- Reinseth, L., Uhlig, T., Kjeken, I., Koksvik, H. S., Skomsvoll, J. F., & Espnes, G. A. (2010). Performance in leisure-time physical activities and self-efficacy in females with rheumatoid arthritis. *Scandinavian Journal of Occupational Therapy*.
- Revill, S. I., Robinson, J. O., Rosen, M., & Hogg, M. I. (1976). The reliability of a linear analogue for evaluating pain. *Anaesthesia*, *31*, 1191-1198.
- Scott, D. L., & Garrood, T. (2000). Quality of life measures: use and abuse. *Bailliáere's best practice & research. Clinical rheumatology, 14*, 663-687.

- Scott, D. L., & Lempp, H. (2006). Outcomes associated with early rheumatoid arthritis. *Expert Rev Pharmacoecon Outcomes Res*, 6, 495-508.
- Smith, B. W., & Zautra, A. J. (2008). Vulnerability and Resilience in Women With Arthritis: Test of a Two-Factor Model. *Journal of Consulting and Clinical Psychology*, 76, 799-810.
- Sokka, T., Kautiainen, H., Pincus, T., Verstappen, S. M., Aggarwal, A., & Alten, R., et al. (2010). Work disability remains a major problem in rheumatoid arthritis in the 2000s: data from 32 countries in the QUEST-RA study. [Multicenter Study]. *Arthritis Research & Therapy, 12*, R42.
- Uhlig, T., Haavardsholm, E. A., & Kvien, T. K. (2006). Comparison of the Health Assessment Questionnaire (HAQ) and the modified HAQ (MHAQ) in patients with rheumatoid arthritis. [Comparative Study]. *Rheumatology (Oxford)*, 45, 454-458.
- Uhlig, T., Heiberg, T., Mowinckel, P., & Kvien, T. K. (2008). Rheumatoid arthritis is milder in the new millennium: health status in patients with rheumatoid arthritis 1994-2004. [Research Support, Non-U.S. Gov't]. *Annals of the Rheumatic Diseases*, *67*, 1710-1715.
- Uhlig, T., Loge, J. H., Kristiansen, I. S., & Kvien, T. K. (2007). Quantification of reduced health-related quality of life in patients with rheumatoid arthritis compared to the general population. *The Journal of Rheumatology*, 34, 1241-1247.
- Ungar, M. (2008). Resilience across Cultures. [Research note]. *British Journal of Social Work*, *38*, 218–235.
- Verbrugge, L. M., & Jette, A. M. (1994). The disablement process. *Social Science & Medicine (1982)*, 38, 1-14.
- Ware, J. E., Kosinski, M., & Gandek, B. (2000). *SF-36 health survey manual & interpretation guide* (2<sup>nd</sup> Ed.). Lincoln, RI: QualityMetric Inc.
- Wikstrom, I., Book, C., & Jacobsson, L. T. (2006). Difficulties in performing leisure activities among persons with newly diagnosed rheumatoid arthritis: A prospective, controlled study. *Rheumatology (Oxford)*, 45, 1162-1166.
- Zautra, A. J., Johnson, L. M., & Davis, M. C. (2005). Positive affect as a source of resilience for women in chronic pain. [Research Support, Non-U.S. Gov't]. *Journal of Consulting & Clinical Psychology*, 73, 212-220.

# 8. Perceived benefits of support groups for cancer victims and family members

#### **GERD INGER RINGDAL**

Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Psychology, Trondheim, Norway

#### Abstract

In the last decades, there has been a strong growth in the number of voluntary support groups for cancer victims and family members, both in Norway and internationally. However, systematic evaluations of the benefits of these groups are under-reported in the literature. Therefore, the main aim was to study the effects of group participation on cancer victims and partners/family members. The following research questions were examined: Does the participation in a support group have any beneficial effects on cancer victims' and family members' health related quality of life (HRQOL) and on coping with stress? Does the participation in a support group have persisting effects? The existing literature reports about the extreme psychosocial strain of cancer victims and also of the strain for family members. Such support groups may therefore be an important contribution to cancer victims and their families. Prospective, randomized studies as well as a few non-randomized studies of voluntary support groups of cancer victims and family members have reported that participation in a support group contributes to increased quality of life and coping ability, and that such benefits also continued after a follow-up period of six months.

#### Introduction

The incidence of cancer is increasing and the number of individuals who live with the disease over a longer time period is increasing. Those who receive a cancer diagnosis today are expected to increase by 20 percent as we reach 2020 (Kreftregisteret, 2006). In the year 1955, the incidence of cancer was about the same for women and men. After the year 2000, the incidence has increased to double the amount for men and as much as 70 percent for women. The risk for getting a cancer diagnosis during one's life time increases with age. Thus, one reason for this increase is the longer life expectancy in the population. Four of ten individuals in Norway will get cancer once in his or her life. The four most common reported cancer diagnoses include prostate, breast, colon and lung cancer and constitute more than half of all cancer cases in Norway today. In total, one out of four persons in all age groups

will die of cancer or a cancer-related disease. About 170,000 individuals live with cancer in Norway, and the amount of family members are even higher. The huge increase in the incidence of cancer shows that in most families there will be members that sooner or later will be affected by cancer or a cancer-related disease.

In view of this background, both in terms of the severity and the increased incidence of cancer diseases, it is no surprise that support groups and a holistic approach as regards caring of cancer victims and family members, has been emphasized as a priority area in the last decades. Important tasks for such support groups are to contribute with information and knowledge both about the disease and treatment, and to give cancer victims and family members the opportunity to meet others in a similar life situation and to exchange experiences with each other. Group identification may be valuable in increasing self-confidence, coping ability and quality of life. Belonging to a group may also stimulate solidarity and social support among the participants.

Many find it very stressful to receive a cancer diagnosis and to have to go through demanding treatments. In addition, the uncertainty whether one will recover from the cancer disease and the worries about one's family members and one's future may be a strain in itself. In this new life situation, one's own earlier life experiences and coping strategies may not always be sufficient to understand and cope with what has happened. The existing literature has reported about the extreme psychosocial strain of cancer victims (Fawzy, & Fawzy., 1998; Ringdal, Ringdal, Jordhøy, & Kaasa, 2007; Rustøen, & Hanestad, 1998) and also of family members both before and after the death of the loved one (Ringdal, et al., 2004; Ringdal, et al., 2001b). Thus, such support groups may contribute to an increasing ability to 'learn to live with the cancer disease' and to adapt and cope with the situation.

# Support groups

Support groups for cancer victims are not of new date. As early as in the seventies, studies were published about social support groups for cancer victims. About the same point in time, quality of life research emerged in combination with the first prospective population studies about people's subjective well-being, satisfaction with life and quality of life (Andrews, & Whitey, 1976; Campbell, Converce, & Rodgers, 1976) and with the first published study focusing on the importance of psychosocial aspects of terminal (breast) cancer disease (Priestman, & Baum, 1976). At the same time the earliest prospective population studies

about the importance of social support for health and survival length were published (Berkman, & Syme, 1979). Replication studies 20 years later confirmed the findings that lack of social support may have a negative influence on both physical and psychological health, while access of social support may have a positive influence on health (House, Landis, & Umberson, 1988).

The development from the biomedical to the bio-psychosocial model meant an emphasis on an overall or holistic approach to health and disease. It obtained great importance based on the views of health care personnel and researchers that not only biological, but also psychosocial factors are important for people's health and survival (Engel, 1979; Suls, & Rothman, 2004). The importance of including psychosocial factors in the treatment of diseases and thereafter, in the follow-up both of patients and family members, resulted in a strong growth in research. This research focused on both in the area of quality of life and psychosocial interventions of cancer victims and family members. Prospective, randomized studies have reported that those who have participated in such groups have better psychosocial adaptation to the disease after the course of treatment ended, compared to those in control-groups without such support (Koopman, et al 1998; Fawzy, et al 1996, Goodwin, et al 2001). The most common kinds of treatment in such psychosocial intervention groups consist of psychotherapy, cognitive therapy, psycho- educative and supporting techniques, and relaxation training, often taking place in group conversation, chaired by a psychologist or psychiatrist.

Furthermore, this also involved a strong growth in the amount of support groups for cancer victims and family members as they function in their real lives, from the so-called voluntary support groups, both in Norway and internationally. It is, however, not easy to make exact conclusions about how valuable these groups are, neither as regards general benefits nor as to the content of the groups since there is, with the exception of a couple of studies (Cella, et al 1993; Ringdal, & Dulin, 2004), a scarcity of published studies with systematic data collection. The results from the non-randomized studies that evaluate such voluntary support groups for cancer victims in one American county (Cella, et al 1993) and in the counties in the middle part of Norway (Ringdal, & Dulin, 2004), were in agreement with those from randomized studies and showed improvement in adjustment and coping, connected with reciprocal support from others in a similar life situation in a trusting environment.

# The benefits of support groups

The Norwegian study (Ringdal, & Dulin, 2004) showed that participation in such a support group contributed to increased quality of life and coping ability, and that such benefits also continued according to a follow-up study six months later. Each of these groups was led by a female nurse with several years of work experience and further education within cancer care and group work. As many as 85-90% of both the cancer victims and the family members experienced their participation as useful and they also reported satisfaction with the support group they had participated in, both in terms of its content, composition of the participants, and with the group leaders' contribution. Almost no one (zero to one percent) reported to be 'very dissatisfied' with the group in which he or she had participated. This is also in agreement with earlier findings from the American study (Cella, et al 2003) showing that nearly all (90%) reported to be very satisfied with the support group in which he or she had participated. The results from both studies (Cella, et al 2003, Ringdal, & Dulin, 2004) showed that the possibilities to give and receive reciprocal support from other participants attributed significant importance. Furthermore, the leaders of the support groups also evaluated the participation in such groups as very high both for cancer victims and family members (Dulin, & Ringdal, 2004). The literature is, however, less convincing on the question of whether psychosocial treatment may contribute to longer survival time for cancer victims (Smedslund, & Ringdal, 2004).

# Shortcomings

The ideal design in examining the effects of participation in social support groups is a randomized trial with control groups. However, this was impossible to carry out in the voluntary support groups, due to both practical and ethical reasons. The only possibility for a 'control group in both the Norwegian study and in the American study was to let the participants be their own control through a pretest – posttest and follow-up design. Use of a control group of cancer victims not participating in a support group might only have a limited value because the participation in the groups was based on self-selection, and not on a random selection of cancer victims. Moreover, it would have been hard to succeed in establishing such a control group, since the participants in the support groups usually were decided just shortly before the first meeting. The strength of our non-randomized design was the examination of the support groups as they naturally function. This gave us the possibility to examine the situation as it is in real life.

### Conclusion

Participation in support groups contributes to an increased quality of life and coping ability. Such benefits also continue and are present after a follow-up period of six months. The number of individuals that get cancer or a cancer-related disease is increasing and the number of individuals living with cancer over a longer period of time is also increasing. On the other hand, the time a patient is in a hospital becomes shorter and shorter which means that the need for voluntary support groups of cancer victims and family members is increasing. Thus, this only underlines the support groups as an important priority area for the future.

#### References

- Andrews, F.M., & Withey, S.B. (1976). *Social indicators of Eell-Being*. New York: Plenum.
- Berkman, L.F., & Syme, L. (1979). Social network, host resistance, and mortality: A nine-year follow-up study of Alameda County Residents. *American Journal of Epidemiolgy*, 109, 186-204.
- Campbell. A., Converse, P.E., & Rogers, W.L. (1976). *The Quality of American Life*. New York: Russel Sage Foundation
- Cella, D., Sarafian, B., Snider, P.R., Yellen, S.B., & Winicour P. (1993). Evaluation of a community-based cancer support group. *Psycho-Oncology*, *2*, 123-132.
- Dulin, R., & Ringdal, G.I. (2004). Støttegrupper for kreftrammede og pårørende I Midt-Norge. Gruppeledernes evaluering av nytteverdien av støttegruppene har for deltakerne, og hvilke kompetansekrav som bør stilles til gruppelederne. Rapport II. Den Norske Kreftforening, kompetansesenteret i Sør-Trøndelag, Trondheim.
- Engel, G.L. (1977). The need for a New Medical Model: A Challenge for Biomedicine. *Science*, *196*, 129-136.
- Fawzy, F.I., Fawzy, N.W., & Wheeler, J.G. (1996). A post-hoc comparison of the efficiency versus individual formats: an analysis of data from two studies. *Psycho-Oncology*, *5*, 81-89.
- Fawzy, F. I., & Fawzy, N. W. (1998). Group therapy in the cancer setting. Review. *Journal of Psychosomatic Research*, 45, 191–200.
- Garlan, R.W., Butler, L.D., Rosenbaum, E., Siegel A., & Spiegel, D. (2010). Perceived benefits and psychosocial outcomes of a brief existential family intervention for cancer patients/survivors. *Omega-Journal of Death and Dying*, 62, 243-268.
- Goodwin, P.J., Leszcz M., & Ennis, M., et al. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *New England Journal of Medicine*, *345*, 1719-1726.
- Greer, S., Moorey, S., & Baruch, J. D. R. et al. (1992). Adjuvant psychological therapy for patients with cancer: a prospective, randomized trial. *British Medical Journal*, 304, 657–680.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science*, *241*, 540–545.
- Koopman, C., Hermanson, K., Diamond, S., Angell, K., & Spiegel, D. (1998). Social

- support, life stress, pain and emotional adjustment to advanced breast cancer. *Psycho-Oncology*, *7*, 101-111.
- Kreftregisteret (2006). Cancer in Norway 2005. Cancer incidence, mortality, survival and prevalence in Norway. Special issue: predictions of cancer incidence by Health Region 2010–2020.
- Priestman, T. J., & Baum, M. (1976). Evaluation of quality of life in patients receiving treatment for advanced breast cancer. *Lancet*, 24, 899–901.
- Ringdal, G. I., & Dulin, R. (2004). *Støttegrupper for kreftrammede og*partnere/pårørende i Midt-Norge. Rapport I. Den Norske Kreftforening,

  Kompetansesenteret i Sør-Trøndelag, Trondheim.
- Ringdal, G. I., Ringdal, K., Jordhøy, M. S., Ahlner-Almqvist, M., Magnus, J. & Kaasa, S. (2004). Health Related Quality of Life (HRQOL) in family members to cancer victims. Results from a longitudinal intervention study in Norway and Sweden. *Palliative Medicine*, 18, 108–120.
- Ringdal, G. I., Ringdal, K., Jordhøy, M. S., & Kaasa, S. (2007). Does social support from family and friends work as a buffer against reactions to stressful life events such as terminal cancer? *Palliative and Supportive Care*, *5*, 61–69.
- Ringdal, G. I., Jordhøy, M. S., Ringdal, K., & Kaasa, S. (2001a). The first year of grief and bereavement in close family members to individuals who have died of cancer. *Palliative Medicine*, *15*, 91-105.
- Ringdal, G. I., Jordhøy, M. S., Ringdal, K., & Kaasa S. (2001b). Factors affecting grief reactions in close family members to individuals who have died of cancer. *Journal of Pain and Symptom Management*, 22, 1016-1026.
- Rustøen, T., & Hanestad, B. R. (1998). Nursing intervention to increase hope in cancer patients. *Journal of Clinical Nursing*, 7, 19–27.
- Smedslund, G., & Ringdal, G.I. (2004). Meta-analysis of the effects of psychosocial interventions on survival time in cancer patients. *Journal of Psychosomatic Research*, *57*, 123-131.
- Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: Prospects and challenges for health psychology. *Health Psychology*, *23*, 119-125.

## 9. Rehabilitation in patients with Chronic Obstructive Pulmonary Disease (COPD)

#### OLA BRATÅS

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Chronic obstructive pulmonary disease (COPD) may lead to reduction of health related quality of life (HRQL) caused by impairments in physical, psychological and social functioning. Pulmonary rehabilitation is recommended as one of the main nondrug treatments for COPD. The aims of this study were to identify and compare objective and self-perceived characteristics in COPD patients who do and do not choose rehabilitation, and to evaluate short- and long-term outcomes of rehabilitation on HRQL, exercise capacity, anxiety and depression. COPD patients who choose rehabilitation had significant poorer HRQL and enhanced levels of anxiety and depression than medical outpatients. Four weeks after rehabilitation, improvements in HRQL, exercise capacity and depression level were found. Six months after discharge, however, short-term benefits from rehabilitation did not sustain. Maintenance of short-term effects may be enhanced through integrated care of the COPD patients and establishment of low-threshold rehabilitation services in primary health care.

#### Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality throughout the world. According to World Bank/World Health Organization (WHO), COPD is expected to rank fifth as cause of death in 2020 worldwide (Jeppesen et al, 2011). COPD is a local and systemic inflammatory disease involving airflow limitation, intrinsic airway narrowing and with potential damage of several other organs outside the respiratory track, e.g. heart failure, osteoporosis and skeletal muscle dysfunction (Monninkhof et al, 2002). In addition to physiological impairments and breathlessness, COPD patients may experience symptoms such as pain, fatigue and sleep problems (Andenaes, 2005; Rabe et al, 2007). It has also been found that they experience significantly more psychological distress, such as anxiety and depression, than the general population (Schneider et al, 2010; Wagena et al, 2005). Moreover, compared to patients with other chronic diseases such as epilepsy, angina

pectoris, and rheumatoid arthritis, COPD patients perceive larger impairments in health related quality of life (HRQL) areas of physical and social functioning (Stavem et al, 2000).

An established and well documented non-pharmacologic treatment for COPD patients is the rehabilitation regimen. Pulmonary rehabilitation is administrated in inpatient, outpatient or home settings, or a variety of combinations of these. The primary goals of pulmonary rehabilitation are to (1) alleviate symptoms, (2) restore functional capabilities as much as possible and (3) reduce handicap, thus enhancing overall quality of life (Hill, 2006).

All types of rehabilitation have proven to be effective treatments that enhance exercise capacity and quality of life and reduce psychological distress in COPD patients (Ergün et al, 2011; Hill, 2006; Lacasse et al, 2006; Pirraglia et al, 2011; Skumlien et al, 2007).

Despite favourable effects, not all COPD patients use rehabilitation services. This is thought to be caused by lack of motivation, significant cognitive impairment, inability to attend the program consistently, unstable medical condition that may pose risk or inadequate financial resources (Hill, 2006). However, characteristics of COPD patients who choose to participate in rehabilitation are less studied, with subsequently few comparisons on potential clinical, socio-demographical or psychosocial differences between those who use rehabilitation services and those who do not use these services.

Most studies of rehabilitation have been performed in outpatient settings (Derom, Marchand & Troosters, 2007; Lacasse et al, 2006), with only 10% of all pulmonary rehabilitation literature referring to effects obtained in inpatient settings (Clini & Romagnoli, 2005). Although maintenance of the short-term effects of pulmonary rehabilitation is essential (Hill, 2006; Nici et al, 2006), clinical studies on long-term effects of inpatient pulmonary rehabilitation programs in COPD patients are even more scarce. Hence, the overall aims of the present study were:

- To obtain knowledge about potential differences between COPD patients who use and do not use rehabilitation services.
- To obtain knowledge about short- and long-term effects of inpatient pulmonary rehabilitation in COPD patients.

This knowledge may be useful to further understand patients' incentives for choosing or not choosing rehabilitation, which in turn could help clinicians motivate and encourage their COPD patients to participate in rehabilitation programs. Further, new knowledge of

short and long-term effects may be useful in order to show potential benefits from inpatient pulmonary rehabilitation across all levels of COPD, and for rehabilitation centres to adjust their rehabilitation services where necessary.

#### Material and methods

#### Design

The present study has a prospective, quasi-experimental, and longitudinal design. Short and long-term effects of rehabilitation were assessed through a One-Group Pretest-Posttest design, with measurements at baseline (t1), 4 weeks (t2) and 6-month follow-up (t3).

#### **Participants**

Participants in the study sample consisted of 205 eligible COPD patients who were aged over 40 years with COPD stages I-IV and with no exacerbations. Prior to this study, they all have been encouraged to participate in a rehabilitation programme by their physician. Of their own accord, they selected inpatient rehabilitation (n=161) or ordinary outpatient consultations (n=44). Participants in the rehabilitation group were recruited from three rehabilitation centres in mid and eastern Norway comprising consecutive cases of COPD patients attending a four week inpatient rehabilitation program during the period from March 2007 till December 2007. Participants in the outpatient group, reviewed routinely as medical outpatients, were recruited by three pneumologists at two hospitals and one private practise centre in Mid-Norway comprising consecutive cases of outpatients with COPD during the period from April 2007 till April 2008. The response-rate was 67% in the rehabilitation group and 42 % in the outpatient group.

Between t1 and t2, 25 patients in the rehabilitation group dropped out from the study because of withdrawal, death, discontinued stay or an unknown reason, which left 136 eligible patients at t2, a response-rate of 84%. Between t2 and t3, 25 patients dropped out because of withdrawal, death or an unknown reason, which left 111 patients at t3, a response-rate of 82%.

#### Data collection procedure

The potential participants in the rehabilitation group were given oral and written information about the study a few days after attending the rehabilitation centre. The patients who wanted to participate returned the questionnaires and the signed written consent form in a postage-paid envelope to the researcher. The potential participants in the outpatient group were orally

informed about the study by the pneumologists during ordinary outpatient consultation. The information they were to give the patients was based on a written and oral presentation from the principal researcher to all three pneumologists. The patients who wanted to participate were also given written information about the study when they received the questionnaires.

#### Pulmonary rehabilitation program

In the present study, the duration and the vocational content of the rehabilitation program was in accordance with the European Respiratory Society (ERS) and The American Thoracic Society (ATS) requirements regarding pulmonary rehabilitation (Nici et al, 2006). The program timetable was structured as 7.5 hours a day, five days per week for four weeks, and participation was mandatory. After initial evaluation by a physician, a multidisciplinary team (consisting of physician, nurses, physiotherapists, assistant occupational therapists, social workers and ergonomists) assessed the patient and formulated an individualized rehabilitation plan, including training intensity based on patient's medical condition. The rehabilitation program comprised medical, physical, educational, psychosocial and practical/technical activities, which were organized both as group based treatment and individual counselling.

#### Classification of severity and stages of COPD

Lung function, expressed by post-bronchodilator forced expiratory volume in 1 second (FEV<sub>1</sub>), was assessed by spirometric tests carried out by trained personnel. Classification of severity and COPD stages (I-IV) was carried out in accordance with the Global Initiative for Chronic Obstructive Lung Disease (GOLD) Guidelines (Rabe et al, 2007).

#### Assessment of exercise capacity

Exercise capacity was measured at commencement of the rehabilitation program and at discharge by a six-minute walking distance test (6MWD). All tests were conducted indoors, on flat, straight corridors and performed in accordance with published guidelines (American Thoracic Society, 2002). The results on the 6MWD were reported in metres: higher 6MWD scores indicate a better result.

#### Assessment of health related quality of life (HRQL)

The St. George's Respiratory Questionnaire (SGRQ) is a disease-specific instrument designed to measure three domains of HRQL in patients with chronic lung disease: a symptom score that measures the frequency and severity of respiratory symptoms, an activity

score that measures activities that are limited by breathlessness, and an impact score that measures aspects of social functioning and psychosocial disturbances caused by airway disease (Jones, Quirk & Baveystock, 1991). The score ranges from 0 to 100 for each domain, and high values reflect decreased HRQL. The scores for the three domains can be added together for a total score. A change in score of four units is considered clinically significant (ibid.).

#### Assessment of anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) was used to assess symptoms of depression and general anxiety. Anxiety (HADS-A) and depression (HADS-D) are assessed as separate components, each with seven items that are rated on a four point scale: 0 (not present) to 3 (significant symptoms) (Zigmond & Snaith, 1983). The scores range from 0 to 21 for anxiety and 0 to 21 for depression. Scores for the two components can also be added together to give a composite anxiety-depression score with a maximum of 42 points (total score). Higher scores indicate more severe symptomatology.

#### Socio-demography and co-morbidity

The questionnaire also contained items about socio-demographic characteristics and on self-reported co-morbidity. Co-morbidity was defined as specific diseases and disorders in the past twelve months, with "yes/no" response to different diseases listed in the form, e.g. heart diseases, allergy, ulcer, diabetes, constipation, migraine, cancer, arthritis, kidney failure and metabolic diseases. Number of co-morbidities were categorised in no co-morbidity, 1-4 and 5-8 additional diseases.

#### Ethical considerations

The study was approved by the Regional Committee for Medical Research Ethics, Health Region IV, Norway and the Parliamentary Commissioner for privacy in research, supervised by the Norwegian Social Science Data Services. The participants were informed that participation in the study would not hinder their present or future medical treatment. Additionally, they were assured confidentiality.

#### Results

As shown in Table 1, the difference in mean age between the groups (65.0 in the rehabilitation group and 67.2 in the outpatient group) was not statistical significant. Men and women were nearly equally represented in the rehabilitation group (49% men vs. 51%

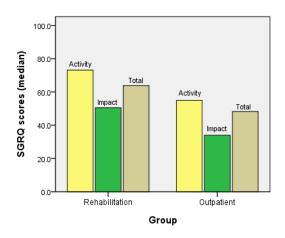
women), while the majority of patients in the outpatient group were men (70.5% men vs. 29.5% women). This observed gender difference between the total groups was significant (p=0.012). More patients in the rehabilitation group were diagnosed with very severe COPD (34.2% vs. 15.9%, p=0.020), whereas more outpatients were diagnosed with severe COPD (40.9% vs. 25.5%, p=0.045). The prevalence of co-morbidity was equally distributed in the groups (Table I). More patients in the outpatient group were married/partner (81.8%) compared to the rehabilitation group (63.4%) (p=0.021), while more patients in the rehabilitation group were divorced/separated (21.7%) than in the outpatient group (6.8%) (p=0.024). The outpatients received more psychological support from spouse/partner than patients in the rehabilitation group (70.5% vs. 49.1%, p=0.012).

**Table 1:** Socio-demographic characteristics and prevalence of COPD stages, and co-morbidity in patients self-selected to inpatient rehabilitation and outpatient clinics.

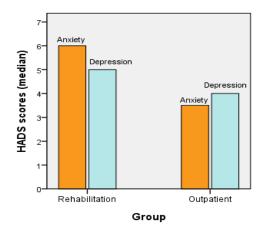
	Rehabilitation patients (n=161)	Outpatients (n=44)	<i>p</i> -value
Age (mean)	65.0 (9.1)	67.2 (10.2)	0.166
Gender (m/w)	79/82	31/13	0.012
Prevalence of COPD stages (%):			
I Mild	6.2	2.3	0.305
II Moderate	34.2	40.9	0.409
III Severe	25.5	40.9	0.045
IV Very severe	34.2	15.9	0.020
Prevalence in co-morbidity (%)			
No additional diseases	7.5	13.6	0.200
1-4 additional diseases	77.6	77.3	0.959
5-8 additional diseases	14.9	9.1	0.321

Patients in the rehabilitation group scored significantly higher on median SGRQ activity score, impact score and total score (73.3 vs. 55, p=0.000; 50.4 vs.34, p=0.000; 64 vs. 48, p=0.000, respectively) (Figure 1). The median anxiety and depression scores on HADS

were higher in the rehabilitation group than in the outpatient group, with a score of 6 versus 3.5 on anxiety (p=0.006) and 5 versus 4 on depression (p=0.031), respectively (Figure 2).



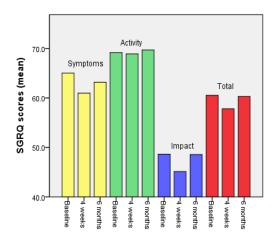
Figur 1. HRQL in COPD patients at rehabilitation and outpatient clinics (high scores indicate decreased HRQL).



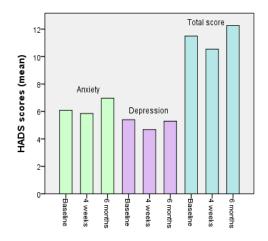
Figur 2. Psychological distress in COPD patients at rehabilitation and outpatient clinics

After rehabilitation exercise capacity was improved with a mean score difference of  $\pm$  44 metres (p =0.000) (Bratås et al, 2010 b). All scores on the SGRQ, except from the activity score, improved significantly from t1 to t2 with a change of -4.0 for the symptom score (p=0.012), -3.6 for the impact score (p=0.009) and -2.8 for the total score (p=0.012). Between t2 and t3, however, all SGRQ scores deteriorated, with significant differences for SGRQ impact score ( $\pm$ 3.5,  $\pm$ 9=0.016) and SGRQ total score ( $\pm$ 2.5,  $\pm$ 9=0.029) (Figure 3).

The anxiety score did not change significantly after rehabilitation (-0.2, p=0.381), though there was a significant reduction of the depression score (-0.7, p=0.011). Between t2 and t3 all HADS scores deteriorated, with significant differences for HADS anxiety score (+1.1, p=0.000), HADS depression score (+0.6, p=0.022) and HADS total score (+1.7, p=0.000) (Figure 4). There were no differences on SGRQ and HADS scores between t1 and t3, except for HADS anxiety score (+0.9, p=0.003) (Figures 3 and 4).



Figur 3. HRQL in COPD patients before and after rehabilitation (high scores indicate decreased HRQL).



Figur 4. Psychological distress in COPD patients before and after rehabilitation

Adjusted for gender, age, co-morbidity, anxiety and depression, patients with mild to moderate COPD (FEV<sub>1</sub>  $\geq$  50% predicted) were more likely to have a clinically significant improved HRQL at 4 weeks follow-up compared to patients with severe and very severe COPD (FEV<sub>1</sub>  $\leq$  50% predicted) (OR 4.2, 95% CI 1.7 – 10.3, p =0.002) (Bratås et al, 2010 b). After adjustment for gender, age, disease severity, co-morbidity, education and social participation, patients who lived alone were more likely to have an unaltered or improved HRQL 6 months after rehabilitation compared to patients who lived with someone (OR 2.9, 95% CI 1.1-7.8, p=0.039) (Bratås et al, 2011).

#### Clinical implications and future directions

The findings from the present study show that the incentives for choosing pulmonary rehabilitation may be determined by impaired HRQL, psychological distress, being divorced or separated and lack of psychological support from a significant other rather than disease severity alone. Hence, to identify physical and psychological health, as well as psychosocial factors are important when assessing the need for and encouraging participation in

rehabilitation. Despite the same level of disease severity and co-morbidity, COPD patients who did not choose to participate in a rehabilitation program had better HRQL and psychological health compared to those who were admitted, suggesting stronger resilience to COPD through protective socio-demographical and psychosocial factors. Our findings show that COPD patients admitted to inpatient pulmonary rehabilitation may have composite needs, which underpin the need for an overall inpatient rehabilitation model where physical, educational, practical, psychosocial and recreational activities are tailored to a variety of individual needs and goals of the COPD patients (Bratås et al, 2010 a).

The 4-week multidisciplinary inpatient rehabilitation program resulted in short-term benefits comprising improvements in HRQL and exercise capacity and reduced depression in COPD patients. Patients with mild or moderate COPD were more likely to achieve a clinically improved HRQL after rehabilitation than patients with severe or very severe COPD. Referral to pulmonary rehabilitation at an early stage of the disease may therefore be beneficial as it allows for greater emphasis on promoting health rather than regaining function. Our results showed that also patients with major disease severity achieved beneficial results from pulmonary rehabilitation, suggesting that inpatient programs should not be restricted only to a small fraction of relatively stable COPD patients with minor disease (Bratås et al, 2010 b).

The general decline in psychological health together with relapse of HRQL at 6 month follow-up calls for efforts in order to maintain short-term effects. One way to optimize maintenance of short-term effects may be by incorporating pulmonary rehabilitation into an *integrated care* of the COPD patients. In integrated care plans for COPD patients, maintaining effects from pulmonary rehabilitation may be provided by collaboration, communication and coordination among primary and speciality healthcare professionals, rehabilitation services, patients and their families (Nici et al, 2007; Nici et al, 2009). Relapse of HRQL and psychological health after rehabilitation may be related to decline in physical, as well as in social and recreational activities. In some COPD patients, follow-up intervention by primary care and community care professionals may therefore be necessary in order to motivate and facilitate for these kinds of activities after rehabilitation. An important assumption, however, is that domestic conditions and environmental resources of the patients should be detected by professionals in the rehabilitation services and communicated to the primary care, which requires close collaboration among professionals in rehabilitation services and primary care (Nici et al, 2009).

A target area in future health service in Norway is the establishment of low-threshold rehabilitation services in primary health care (Helse- og Omsorgsdepartementet, 2010). The purpose of this priority is to promote access to rehabilitation where people live; implying enhanced municipal responsibility for rehabilitation services. For COPD patients, decentralised rehabilitation services may be beneficial in order to prevent decline in physical and social activities after inpatient pulmonary rehabilitation. For instance, easily accessible training facilities in the local community may increase COPD patients' motivation and possibilities to continue with physical activities learned at rehabilitation, which in turn may enhance the likelihood of maintaining positive effects. In addition, access to rehabilitation facilities in proximity of patients' home community may lead to stronger integration of physical and social activities into everyday life of COPD patients, which may contribute to maintenance of positive changes. In order to succeed with future post rehabilitation care of COPD patients, enhanced co-ordination and collaboration between institutional and primary care based rehabilitation services is considered necessary (ibid.).

Our results indicate that patients living alone were more likely to maintain or improve their HRQL after discharge than patients living with someone, suggesting that living alone may enforce both self-care and self-responsibility, which is favourable for HRQL (Bratås et al, 2011). This finding may seem rather contradictory to the protective role of a spouse/partner through care, support and encouragement, leading to improved compliance with therapies and better disease self-management for the patient (Crockett et al, 2002). On the other hand, a life partner may also be too protective and careful in his or her care in such a way that necessary efforts to maintain or improve the positive effects of rehabilitation are hindered (Halding, Wahl & Heggdal, 2010). In other words, implementation of family participation in the rehabilitation program may enable spouse or partner to motivate and support activities that are considered necessary to maintain or improve effects obtained through rehabilitation.

#### Conclusions

Choosing pulmonary rehabilitation may be determined by the patient's perception of low HRQL together with enhanced levels of anxiety and depression. This study demonstrated that short-term benefits from inpatient rehabilitation across all levels of COPD did not sustain after 6 months. Maintenance of short-term effects may be enhanced through integrated care of the COPD patients, implementation of family participation in the

rehabilitation program, and establishment of low-threshold rehabilitation services in primary			
health care.			

#### References

- American Thoracic Society (2002). ATS Statement: Guidelines for the Six-Minute Walk Test. *American Journal of Respiratory and Critical Care Medicine*, 166, 111-117.
- Andenaes, R. (2005). Psychological distress, coping, and quality of life among patients with chronic obstructive pulmonary disease (COPD). (Doctoral dissertation, University of Oslo, Faculty of Medicine).
- Bratås, O., Espnes, G.A., Rannestad, T., & Walstad, R. (2010a). Characteristics of patients with chronic obstructive pulmonary disease choosing rehabilitation. *Journal of Rehabilitation Medicine*, 42, 362-367.
- Bratås, O., Espnes, G.A., Rannestad, T., & Walstad, R. (2010b). Pulmonary rehabilitation reduces depression and enhances health related quality of life in COPD patients especially in patients with mild or moderate disease. *Chronic Respiratory Disease*, 7, 229-237.
- Bratås, O., Espnes, G.A., Rannestad, T., & Walstad, R. (2011). Relapse of health related quality of life and psychological health in patients with chronic obstructive pulmonary disease 6 months after rehabilitation. *Scandinavian Journal of Caring Sciences*, doi:10.1111/j.1471-6712.2011.00921.
- Clini, E.M., & Romagnoli, M. (2005). Inpatient pulmonary rehabilitation: does it make sense? *Chronic Respiratory Disease*, 2, 1, 43-46.
- Crockett, A.J., Cranston, J.M., Moss, J.R., & Alpers, J.H. (2002). The impact of anxiety, depression and living alone in chronic obstructive pulmonary disease. *Quality of Life Research*, 11, 309-316.
- Derom, E., Marchand, E., & Troosters, T. (2007). Pulmonary rehabilitation in chronic obstructive pulmonary disease. Review. *Annales de Réadaptation et de Médecine Physique*, *50*, 615-626.
- Ergün, P., Kaymaz, D., Günay, E., Erdogan, Y., Turay, U.Y., & Demir, N. et al (2011). Comprehensive out-patient pulmonary rehabilitation: Treatment outcomes in early and late stages of chronic obstructive pulmonary disease. *Annals of Thoracic Medicine*, *6*, 70-76.
- Halding, A.G., Wahl, A., & Heggdal, K. (2010). 'Belonging'. Patients' experiences of social relationships during pulmonary rehabilitation. *Disability and Rehabilitation*, 32, 1272-1280.

- Helse- og Omsorgsdepartementet (2010). *Nasjonal helse- og omsorgsplan (2011-2015)*. *Utkast til lov om kommunale helse- og omsorgstjenester*. Oslo: Helse- og Omsorgsdepartementet (in Norwegian).
- Hill, N.S. (2006). Pulmonary rehabilitation. *Proceedings of the American Thoracic Society*, *3*, 66-74.
- Jeppesen, E., Brurberg, K.G., Lidal, I.B., Holte, H.H., & Vist, G.E. (2011). *Intermediære enheter og "hjemmesykehus" ved behandling av pasienter med akutt KOLS-forverring*. Rapport fra Kunnskapssenteret nr 08 Systematisk kunnskapsoversikt. ISBN 987-82-8121-402-6, ISSN 1890-1298 (in Norwegian).
- Jones, P.W., Quirk, F.H., & Baveystock, C.M. (1991). The St George's Respiratory Questionnaire. *Respiratory Medicine*, 85, Suppl. B, 25-31, discussion 3-7.
- Lacasse, Y., Goldstein, R., Lasserson, T., & Martin, S. (2006). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cohrane Database of Systematic Reviews*, 4, doi:10.1002/14651858. CD003793.
- Monninkhof, E.M., van der Valk, P.D.L.P.M., van der Palen, J., van Herwaarden, C.L.A, Partidge, M.R., Walters, E.H., & Zielhuis, G.A. (2002). Self-management education for chronic obstructive pulmonary disease. Cochrane Database *of Systematic Reviews*, 4: doi: 10.1002/14651858. CD002990.
- Nici, L., Donner, C., Wouters, E., Zuwallack, R., Ambrosino, N., & Bourbeau, J. et al (2006). American Thoracic Society/European Respiratory Society statement on pulmonary rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, 173, 1390-1413.
- Nici, L., Raskin, J., Rochester, C.L., Bourbeau, J.C., Carlin, B.W., & Casaburi, R. et al. (2009). Pulmonary rehabilitation: WHAT WE KNOW AND WHAT WE NEED TO KNOW. *Journal of Cardiopulmonary Rehabilitation and Prevention*, *29*, 141-151.
- Pirraglia, P.A., Casserly, B., Velasco, R., Borgia, M.L., & Nici, L. (2011). Association of change in depression and anxiety symptoms with functional outcomes in pulmonary rehabilitation patients. *Journal of Psychosomatic Research*, 71, 45-49.

- Rabe, K.F., Hurd, S., Anzueto, A., Barnes, P.J., Buist, S.A., & Calverley, P. et al (2007). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: GOLD executive summary. *American Journal of Respiratory and Critical Care Medicine*, 176, 532-555.
- Schneider, C., Jick, S.S., Bothner, U., & Meier, C.R. (2010). COPD and the Risk of Depression. *Chest*, *137*, 341-347.
- Stavem, K., Lossius, M.I., Kvien, T.K., & Guldvog, B. (2000). The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. *Quality of Life Research*, *9*, 865-871.
- Skumlien, S., Skogedal, E.A., Bjortuft, O., & Ryg, M.S. (2007). Four weeks' intensive rehabilitation generates significant health effects in COPD patients. *Chronic Respiratory Disease*, *4*, 5-13.
- Wagena, E.J., Arrindell, W.A., Wouters, E.F., & van Schayck, C.P. (2005). Are patients with COPD psychologically distressed? *European Respiratory Journal*, 26, 242-248.
- Zigmond A.S., & Snaith R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*, 361-370..

### 10. Children and Adolescents Surviving Cancer: Psychosocial Health and Quality of Life

#### MARY-ELIZABETH BRADLEY EILERTSEN

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

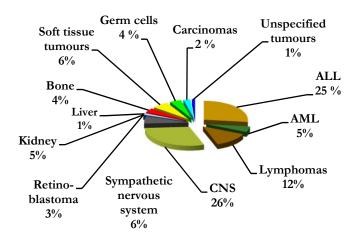
Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Childhood cancer involves a crisis for the child and their family where they face many challenges to achieve normality after diagnosis, even after successful treatment. The present chapter focuses on psychosocial health and QoL for children and adolescents surviving cancer at least 3 years after their cancer diagnosis, compared with a healthy control group. This was a case-control study including 50 children and adolescents diagnosed with cancer between 1993–2003. To improve the child's psychosocial health and QoL our results indicate the need to develop pertinent and adequate supportive interventions and programs when planning and implementing long-term follow-up care and rehabilitation of children and adolescents surviving cancer, especially for survivors with brain tumours, and those with late effects. Our results also indicate the need to take into account subjectively perceived and proxy reported psychosocial health and QoL for children surviving cancer.

#### General Introduction

In Norway, approximately 120-150 children and adolescents under the age of 15 are diagnosed with cancer each year (annual incidence 16.2/100,000) and approximately 40 children die yearly of their cancer illness (Cancer Registry, 2009). The most common type of malignancy in children is leukaemia; acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML), accounting for approximately 1/3 of childhood cancers (Bringager et al., 2003). The second most frequent malignancy in children is tumours of the central nervous system (CNS) (figure 1).



**Figure 1**: Distribution of childhood cancer in the Nordic countries (NOPHO Annual Report, 2009) (Used with kind permission from the author, B. Lund from a lecture 14.12.2010).

Generally, cancer is one of the most common diseases in both genders and in all age groups in the Western world (Baider et al., 1996). Nevertheless, childhood cancer is rare and accounts for less than one percent of all cancer in industrialized countries (Stiller et al., 2005). Since childhood cancer is uncommon, professionals are dependent upon collaboration both nationally and internationally to gain the necessary knowledge for diagnosis, treatment and rehabilitation (Bringager et al., 2003).

Survival rates for childhood cancer have improved dramatically through the past years, resulting in a growing population of childhood cancer survivors. With the help of cancer treatment such as chemotherapy, radiation, surgery and improved supportive care (both somatic and psychosocial) nearly 80 % of children currently treated for cancer will become long-term survivors (Meadows, 2006; Oeffinger et al., 2006; Landier, 2007; Shepherd, 2010).

Even though childhood cancer today is no longer considered a terminal illness, but viewed as a chronic, life-threatening illness (Hoekstra-Weebers, 1996; Stiller & Eatock, 1999; Last et al., 2005; Robinson et al., 2007), the diagnosis of childhood cancer is still a crisis for both the child and its family (Hagedoorn et al., 2011). Intensive medical treatment together with its side effects and prolonged periods of uncertainty about the outcome can result in psychosocial problems for parents and child, and affect their QoL several years after diagnosis and treatment (Koocher & O'Malley, 1981; Spinetta, 1984; Van Dongen-Melman et al., 1995; Dyregrov & Raundalen 1996; NOU 1997:20 (§ 8.10.4.2.); Eiser, 1998; Eiser et al., 2000; Koot & Wallander, 2001; Patenaude & Kupst, 2005). As survival rates for childhood cancer have increased, research has therefore focused on QoL issues (Koot &

Wallander, 2001) as well as on psychological adjustment and late effects (Patenaude & Kupst, 2005) among survivors.

#### Aim

The present chapter focuses on psychosocial health and QoL for children and adolescents surviving cancer at least three years after their cancer diagnosis, compared with a healthy control group, including a multi-informant perspective.

#### Material and methods

This population-based, case-control study was carried out between April 2007 and May 2008 and included children and adolescents in Central Norway from the ages of six to 20 years who were diagnosed with cancer between 1.1.1993 and 1.1.2003. Eligible for participation were children who had completed their cancer treatment at the Department of Pediatrics, St. Olavs University Hospital, Trondheim, and survived at least three years after diagnosis. Data was collected by using questionnaires mailed to the respective families and the invited child's teacher, and by reviewing the child's medical records. A control group was recruited by asking children and adolescents in the study group to invite one friend of the same gender and age (± one year) to participate, as well as one of the friend's parents and teacher. Questionnaires were sent to these invited families and teachers. One reminder was sent to those who did not answer the first invitation.

For *children surviving cancer* there were a total of 50 (46%) children (of 109 eligible children) who participated, as well as one of their parents. Of these 50 children, 29 (58%) were males and 21 (42%) females, aged 6-20 years and born in the period of 1987 to 2001. The median age was 12.5 years (interquartile range: 10.0-16.0), with 29 (58%) being adolescents (12-20 years). The children took part in this study 4-16 years (median: 7.5; interquartile range: 6.0-10.2) after their cancer diagnosis and 1-13 years (median: 6.0; interquartile range: 4.0-7.2) after completion of treatment. The group included children with leukaemia (n=20), malignant brain tumours (n=13), lymphoma (n=5) and other cancer tumours (n=12) (paper III and IV). Of the 50 parents, 45 consented to further contact the child's teacher, whereof 36 teachers responded.

Control children were recruited by asking the 50 families in the study group to give written consent to contact one friend to participate as a control in the study, 40 families gave written consent, and 29 (73%) peers (friend) and one of their parents agreed to participate. Of these 29 peers, were 15 (52%) males and 14 (48%) females, aged 6-20 years and born in the

period between 1987 to 2001. The median age was 12.0 years (10-14.5), with 21 of the 29 (73 %) being adolescents. Of the 29 parents, 24 gave written consent to further contact the child's teacher and 19 teachers responded.

There were no significant differences between children surviving cancer and the control group regarding the children's age and gender or in the parents' educational and economical status. Mean sosioeconomic status (SES) score was 3.8 (SD: 1.1) for parents of children with cancer, compared to 3.7 (SD: 1.2) in the control group (p = 0.8). Twelve (24%) children with cancer lived with single parents compared to two (7%) children in the control group (p = 0.07).

Standardized questionnaires for data collection were used and administered to children and adolescents, their parents, and teachers (Psychosocial health and academic performance: Strengths and Difficulties Questionnaire (SDQ) (Goodman & Goodman, 2009) and The Achenbach System of Empirically Based Assessment (ASEBA) (Achenbach & Rescorla, 2001); Quality of Life (QoL): The Inventory of Life Quality in Children and Adolescents (ILC) (Mattejat & Remschmidt, 2006) and The Kinder Lebensqualität Fragebogen (KINDL) (Ravens-Sieberer & Bullinger, 2000) questionnaires). In addition, diverse background data was recorded, parents were asked to give information about demographic data (where and whom they lived with, number of children and marital status), and for children surviving cancer, their child's diagnosis, as well as their child's health status and late effects at the time of this study. Based upon these questions we defined a variable called late effects which included somatic health problems that could probably be related to the cancer diagnosis or its treatment. Somatic diagnoses and any psychological problems were collected from the child's medical records. Parents' socioeconomic status (SES) were calculated according to Hollingshead's two factor index of social position scaled one (low) to five (high), based on a combination of parents' education and occupation (Hollingshead, 1958). Parents also evaluated their economical situation as "poor", "average" or "good".

When comparing the control group with an extensive representative sample of children and parents from the general population in the same geographical area there were no significant differences shown in the total sum scores of the parent report for either the ILC (N=1777) or KINDL (N=1742). Furthermore, no significant differences were shown in the adolescent report for the ILC questionnaire (N=1032). However, a significant difference was found in the child report for the KINDL *Total quality of life* (N=1966), when comparing our

control group with the general population (Mean (SD): 75.3 (8.2) and 70.6 (12.4) respectively; p=0.011).

#### Ethical considerations

Ethical approval was obtained from the Regional Committee for Medical and Health Research Ethics in Central Norway (Ref.nr. 4.2006.2610), ensuring that the project did not violate the UN Convention of the Rights of the Child (CRC) (1991). Approval was given for a single written reminder, whereas permission was not given to get in touch with the individual families by telephone. Written consent to participate in the study, as well as access to the medical records of children surviving cancer, was given by the participant or by one of the child's parents, if the child was younger than 16 years of age. Families also gave written consent to contact the child's teacher and a friend of the same gender and age. Approval by the Norwegian Social Science Data Services (Ref.nr. 15372/JE) was obtained for a license to maintain a register containing personal data.

#### Results and discussion of psychosocial health and quality of life for children and adolescents surviving cancer

In this study, children surviving cancer had more emotional symptoms, higher total problem scores and poorer academic performance, than healthy controls. Emotional problems were consistently reported by parents, teachers and adolescents themselves, in particular for childhood survivors with brain tumours and late effects. Yet we found that adolescents surviving cancer on the whole reported equal QoL compared with healthy controls, while only adolescents surviving brain tumours and survivors with late effects reported a lower QoL and an increased number of QoL domains perceived as problematic, when assessed with the ILC. Parents however, reported an overall lower QoL and a greater number of QoL domains perceived as problematic for their children surviving cancer. Our findings of lower QoL and higher emotional problem scores are consistent with a number of previous studies and reviews of psychosocial functioning and QoL studies in childhood cancer survivors (Upton & Eiser, 2006; Hudson et al., 2003; Oeffinger et al., 2008; Reinfjell et al., 2009; Grant et al., 2006; Speechley et al., 2006; Zeltzer et al., 2009). Results are discussed in detail in Eilertsen et al. (2011 a & b).

#### Parent proxy and teacher proxy reports on psychosocial health

There were some notable differences in our findings between the parent and teacher report in the SDQ findings. While parents reported no difference in pro-social behaviour for survivors compared with controls, teachers suggested an abnormal pro-social behaviour for all survivors as well as survivors of brain tumours and leukaemia. Parent and teacher ratings in the present study are somewhat in contrast to the study by Upton & Eiser (2006) where parent ratings showed a significant difference in pro-social behaviour, while teacher ratings showed no significant difference. Upton & Eiser (2006) studied children with brain tumours exclusively and used British norms for comparison. The lower mean score on the pro-social scale in our study may reflect being less helpful and more unwilling to share with others, a possible and understandable consequence following the intense and long-term cancer treatment, which might be emphasized more by teachers than parents. In addition, cancer treatment can contribute to long absences from normal social and school activities, and consequently impair interaction with others. An adverse psychosocial development could have more impact and thus be more evident in a school setting than at home. Psychosocial support is therefore essential to promote optimal adjustment for the child and its family both at home and at school (Eilertsen et al., 2009).

# Child, adolescent and parent proxy reports on psychosocial health and QoL In general and when compared to the parent and adolescent control group, adolescents surviving cancer in our study reported fewer psychosocial problems when assessed by the

surviving cancer in our study reported fewer psychosocial problems when assessed by the SDQ than their parents did. These results are consistent with other studies of childhood cancer comparing parent and child ratings on the same measures (Eiser et al., 2000; Reinfjell et al., 2009).

There was a strong correlation between the ILC (total) QoL scores reported by parents and by their adolescent child, which was also consistent with other studies (Eiser et al., 1995; Sawyer et al., 1999; De Clercq et al., 2004; Russell et al., 2006; Upton et al., 2008), possibly suggesting that in the case of cancer, parents and adolescents share much of the same perspective. Moreover, our finding of lower QoL among children with brain tumours and late effects compared with controls were found for both parent proxy report and adolescent self-report. These results emphasize the need for addressing the issue of diagnosis and presence of late effects in QoL studies in childhood cancer survivors. Our results are consistent with other studies of reduced QoL among children surviving brain tumours (Upton et al., 2005; Cardarelli et al., 2006; Varni et al., 2007; Penn et al., 2009; Yoo et al., 2010), as well as with studies and reviews of late effects and QoL of childhood cancer (Pemberger et al., 2005; Calaminus et al., 2007; Eiser et al., 2007; Ishida et al., 2010, 2010).

Nevertheless, there were some considerable differences between the results obtained from parents and adolescents when compared with healthy controls, especially when assessed by the ILC. In general in this study, and in keeping with other QoL studies of childhood cancer comparing parent and child ratings with controls (Sawyer et al., 1999; Russell et al., 2006; Varni et al., 2007), adolescents as a group reported a QoL similar to controls, while parents reported an overall poorer QoL for both their children and adolescents surviving cancer compared to controls.

The subjective and objective perspectives of QoL has been the source for discussions, suggesting that parents and other adults can provide relevant and valid information on behalf of their children's emotional and behavioural problems and other aspects such as QoL. Earlier, were younger children seen as unreliable respondents, lacking both cognitive and linguistic skills to answer questionnaires (Jozefiak et al., 2009a; Eiser & Morse, 2001) however, the child and adolescent's subjective perception on QoL has been emphasized in the later years (Eiser & Morse, 2001).

The discrepancy on psychosocial health and QoL between the child and parent report for children surviving cancer compared with controls is most likely a consequence of the different perspectives about the child's health and well-being and not a question of which perspective is right or wrong (Varni et al., 2005; Upton et al., 2008; Jozefiak et al., 2008). Parents may vary in their awareness, sensitivity and tolerance of children's health concerns (Upton et al., 2008). In addition, the impact of the child's disease and actual problems may have an influence on the total burden of their parents' experience of stress (Angold et al., 1998; Jozefiak, 2004; Davies et al., 2008) and thus, their perception of the child's psychosocial health and QoL. On the other hand, children living with a chronic illness may assess their own psychosocial health, QoL and possible problems differently, dependent upon their subjective experience of how they feel mentally and physically. Findings of good QoL in some survivors with late effects could be related to changes in the survivors' outlook on life resulting from the cancer experience (Apajasalo et al., 1996; Gray et al., 1992), a negative coping style resulting in compensating and overcompensating existing late effects (Apajasalo et al., 1996) or the existence of repressive coping in children (Phipps et al., 2001). Furthermore, younger children have a limited cognitive capacity (Eiser & Morse, 2001) and tend to live more in the present on a "here and now" level, not having the same sense of time as adults, consequently effecting their experience of how they feel mentally and physically. Many children may respond to stressors by repressing their own issues as an important

defence mechanism for coping and possibly resulting in poorer psychosocial health and QoL, whereas other children and adolescents may show resilience and positive coping strategies (Woodgate, 1999a,b; Borge, 2010), which can result in increased growth and the potential for enhanced psychosocial health and QoL for children surviving cancer (Haase, 1997; Woodgate, 1999a,b). Sequentially, can improved psychosocial health and QoL lead to improved resilience to stressors (Woodgate, 1999a,b; Haase, 2004).

Therefore as stated by both Parsons (1999) and Upton et al. (2008), the main question is not essentially, "most important question may be "how then can the information we receive from both the parent proxy and self-report about psychosocial health and QoL be used to guide and improve interventions enhancing the child's total functioning and well-being?" (Rosenbaum, 2009).

Thus, the difference in children and adolescent's perspectives in this study also support emphasizing the need for obtaining information from both parents and children (Eiser & Morse, 2001; Klassen et al., 2006; Wilson-Genderson et al., 2007). Obtaining information about psychosocial health and QoL provided by children and their parents is therefore important in contributing to a comprehensive understanding from different informant perspectives. Our results are in accordance with other studies reporting a discrepancy between the self-report and proxy-report in different clinical and general population studies (Theunissen et al., 1998; Chang & Yeh, 2005; Yeh & Chang, 2005; Jozefiak et al., 2008, 2009a,b & 2010). However, our study showed that comparing both psychosocial health and QoL child vs. proxy report *directly* in studies of children surviving cancer could be misleading without including a control group because of the discrepancies found between the different perspectives. With the use of both the child self-report and parent proxy report our results suggest that especially adolescents surviving brain tumours and survivors of late effects have more psychosocial problems and an overall poorer QoL compared with a healthy control group.

More psychosocial problems, poorer academic performance and a lower QoL score and an increased number of domains perceived as problematic, were found among almost all survivors *with* physical late effects than healthy controls. We can therefore not disregard the physical and psychological consequences of the cancer disease and its treatment. In various other studies suggesting that childhood cancer survivors function well psychologically (Zeltzer et al., 2009; Gray et al., 1992; Langeveld et al., 2002) despite a seemingly traumatic childhood experience, it was uncertain if these survivors suffered from late effects or not.

#### Implications for clinical practice and further research

To improve the child's psychosocial health and QoL our results indicate the need to develop pertinent and adequate supportive interventions and programs when planning and implementing long-term follow-up care and rehabilitation (Rosenbaum, 2009) of children and adolescents surviving cancer, especially for survivors with brain tumours, and those with late effects. Our results also indicate the need to particularly take into account subjectively perceived and proxy reported QoL, in addition to children and adolescents' psychological problems and psychosocial functioning.

Further research is needed to obtain an even more comprehensive understanding of psychosocial health and QoL in survivors of childhood cancer. Based on our results we suggest that focus be given to potential factors in health promotion, such as resilience that can contribute to the experience of good psychosocial health and QoL, as well as more indepth studies using both self and proxy reports in addition to quantitative and qualitative methods. Results can therefore be used to guide interventions and improve strategies to enhance the child's total functioning and well-being.

#### Conclusion

In conclusion, our study shows that adolescents surviving cancer on the whole reported equal QoL compared with healthy controls. However, adolescents surviving brain tumours and survivors with late effects reported a lower QoL and an increased number of QoL domains perceived as problematic, as well as more emotional symptoms and higher total problem scores when compared with healthy controls, even many years after diagnosis and treatment. To gain a richer understanding our results show the need to particularly take into account subjectively perceived and proxy reported QoL, in addition to children and adolescents' psychological problems and psychosocial functioning.

#### References

- Achenbach, T., & Rescorla, L.A. (2001). *Manual for the ASEBA School-Age Forms & Profiles*. University of Vermont, Research Center for Children, Youth, & Families, Burlington.
- Angold, A., Messer, S.C., Stangl, D., Farmer, E.M.Z., Costello, E.J., & Burns, B.J. (1998). Perceived Parental Burden and Service Use for Child and Adolescent Psychiatric Disorders. *American Journal of Public Health*, 88, 1, 75-80.
- Apajasalo, M., Sintonen, H., Siimes, M.A., Hovi, L., Holmberg, C., Boyd, H., Mäkelä, A., & Rautonen, J. (1996). Health-related QoL of adults surviving malignancies in childhood. *European Journal of Cancer*, *32*, 1354-58.
- Baider, L., Cooper, C.L., & De-Nour, A.K. (1996). *Cancer and the family*, Wiley: New York.
- Borge, A.I.H. (2010). *Resiliens- risiko og sunn utvikling* (Resilience- risk and healthy developement). Gyldendal Norsk Forlag AS: Oslo.
- Bringager, H., Hellebostad, M., & Sæter, R. (2003). *Barn med Kreft en medisinsk og sykepleiefaglig utfordring* (Children with Cancer a medical and nursing care challenge), Gyldendal adademisk: Oslo.
- Calaminus, G., Weinspach, S., Teske, C., & Gobel, U. (2007). Quality of survival in children and adolescents after treatment for childhood cancer: the influence of reported late effects on health related quality of life. *Klinische Padiatrie*, 219, 152-157.
- Cancer Registry of Norway (2009). Cancer in Norway 2008 Cancer incidence, mortality, survival and prevalence in Norway, Oslo.
- Cardarelli, C., Cereda, C., Masiero, L., Viscardi, E., Faggin, R., Laverda, A., Bisogno, G., & Perilongo, G. (2006). Evaluation of Health Status and Health-Related Quality of Life in a Cohort of Italian Children Following Treatment for a Primary Brain Tumor. *Pediatric Blood & Cancer*, 46, 637-44.
- Chang, P.C., & Yeh, C.H. (2005). Agreement between child Self-Report and Parent-Proxy report to Evaluate Quality of Life in Children with Cancer.

  \*Psycho-Oncology, 14, 125-34.
- Davies, B., Waters, E., & Priest, N. (2008). The relationship between proxy reported health-related quality of life and parental distress: gender differences. *Child: care, health and development, 34,* 830-7.

- De Clercq, B., Fruyt, F., Koot, H.M., & Benoit, Y. (2004). Quality of Life in Children Surviving Cancer: A Personality and Multi-Informant Perspective. *Journal of Pediatric Psychology*, *29*, 579-90.
- Dyregrov, A., & Raundalen, M. (1996). Children and Grief, part 1 short and longterm reactions (Sorg hos barn, del 1 kort og langtidsreaksjoner). *Journal of the Norwegian Psychologist Association*, *33*, 510-20.
- Eilertsen, M.E., Kristiansen, K., Reinfjell, T., Rannestad, T., Indredavik, M., & Vik, T. (2009). Professional collaboration support for children with cancer and their families focus group interview a source of information and knowledge professionals' perspectives. *Journal of Interprofessional Care*, *23*, 355-68.
- Eilertsen, M.E., Rannestad, T., Indredavik, M., & Vik, T. (2011). Psychosocial health in children and adolescents surviving cancer. *Scandinavian Journal of Caring Sciences*, *25*, 725-34.
- Eilertsen, M.E., Jozefiak, T., Rannestad, T., Indredavik, M., & Vik, T. (2011). Quality of Life in Children and Adolescents Surviving Cancer. *European Journal of Oncology Nursing*, doi:10.1016/j.ejon.2011.08.001.
- Eiser, C., Havermans, T., Craft, A., & Kernahan, J.A. (1995). Development of a measure to assess the perceived illness experience after treatment for cancer. *Archives of Disease in Childhood*, 72, 302-7.
- Eiser, C. (1998). Practitioner review: Long term consequences of childhood cancer. *Journal of Child Psychology and Psychiatry*, *39*, 621-633.
- Eiser, C., Hill, J., & Vance, Y. (2000). Examining the psychological consequences of surviving childhood cancer: systematic review as a research method in pediatric psychology. *Journal of Pediatric Psychology*, 25, 449-60.
- Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research*, 10, 347-57.
- Eiser, C., Absolom, K., Greenfield, D., Snowden, J., Coleman, R., Hancock, B., & Davies, H. On behalf of the Late Effects Group, Sheffield (2007). Follow-up care for young adult survivors of cancer: lessons from pediatrics. *Cancer Survival*, 1, 75-86.

- Goodman, A., & Goodman, R. (2009). Strengths and Difficulties Questionnaire as a Dimensional Measure of Child Mental Health. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48, 400-3.
- Grant, J., Cranston, A., Horsman, J., Furlong, W., Barr, N., Findlay, S., & Barr, R. (2006). Health status and health-related quality of life in adolescent survivors of cancer in childhood. *Journal of Adolescent Health*, *38*, 504-10.
- Gray, R., Doan, B., Shermer, P., FitzGerald, A.V., Berry, M.P., Jenkin, D., & Doherty,M.A. (1992). Psychological Adaptation of Survivors of Childhood Cancer.Cancer, 70, 2713-21.
- Haase, J. (1997). Hopeful teenagers with cancer: Living courage. *Reflections*, 23, 20.
- Haase, J. (2004). The Adolescent Resilience Model as a Guide to Interventions. *Journal of Pediatric Oncology Nursing*, 21, 289-99.
- Hagedoorn, M. Kreichbergs, U., & Appel, C. (2011). Coping with cancer: The perspective of patients' relatives. *Acta Oncologica*, *50*, 205-11.
- Hoekstra-Weebers, J. (1996). Social support and psychological distress of parents of pediatric cancer patients. In: Baider (Ed.), *Cancer and the family*, 93-108, Wiley, New York.
- Hollingshead, A.B. (1958). *Two factor index of social position*. Yale University: New Haven.
- Hudson, M., Mertens, A., Yasui, Y., Hobbie, W., Chen, H., Gurney, J., Yeazel, M.,Recklitis, C., Marina, N., Robison, L., & Oeffinger, K. (2003). Health Status ofAdult Long-term Survivors of Childhood Cancer. *JAMA*, 290, 1583-92.
- Ishida, Y., Honda, M., Ozono, S., Okamura, J., Asami, K., Maeda, N., Sakamoto, N., Inada, H., Iwai. T., Kamibeppu, K., Kakee. M. & Horibe, K. (2010). Late effects and quality of life of childhood cancer survivors: Part 1. Impact of stem cell transplantation. *International Journal of Hematology*, *91*, 865-76.
- Ishida, Y., Sakamoto, N., Kamibeppu, K., Kakee. M. Iwai. T., Ozono, S., Maeda, N., Okamura, J., Asami, K., Inada, H., Honda, M., & Horibe, K. (2010). Late effects and quality of life of childhood cancer survivors: Part 2. Impact of radiotherapy. *International Journal of Hematology*, 92, 95-104.

- Jozefiak, T. (2004). Quality of life among children and adolescents in a psychiatric outpatient sample. In: H. Remschmidt, & M. Belfer (Eds.), *Book of abstracts of the 16<sup>th</sup> World congress of the international association for child and adolescent psychiatry and allied professions.* (pp. 177). Darmstadt: Steinkopf, Berlin, Germany.
- Jozefiak, T., Larsson, B., Wichstrøm, L., Mattejat, F., & Ravens-Sieberer, U. (2008). Quality of life as reported by school-aged children and their parents: a cross-sectional survey. *Health and Quality of Life Outcomes*, 6, 34.
- Jozefiak, T., Larsson, B., & Wichstrøm, L. (2009a). Changes in quality of life among Norwegian school children: a six-month follow-up study. *Health and Quality of Life Outcomes*, 7,7.
- Jozefiak, T. (2009b). Quality of life and mental health in children and adolescents:

  Child and parent perspectives. (Doctoral dissertation, Norwegian University of Science and Technology, Trondheim, Norway).
- Jozefiak, T., Larsson, B., Wichstrøm, L., Wallander, J., & Mattejat, F. (2010). Quality of Life as reported by children and their parents: a comparison between students and child psychiatric outpatients. *Health and Quality of Life Outcomes*, 8, 136.
- Klassen, A.F., Miller, A., & Fine, S. (2006). Agreement between parent and child report of quality of life in children with attention deficit/hyperactivity disorder. *Child: Care, Health & Development, 32,* 397-406.
- Koocher, G.P., & O'Malley, J.E. (1981). *The Damocles syndrome*. Mcgraw-Hill: New York.
- Koot, H.M., & Wallander, J.L. (2001). *Quality of Life in Child and Adolescent Illness*. Brunner-Routledge: East Sussex.
- Landier, W. (2007). Long-term follow-up program, resource guide. Children's Oncology Group Nursing Discipline Clinical Practice Subcommittee/Survivorship in collaboration with the Late Effects Committee. Children's Oncology Group, California.
- Langeveld, N.E., Stam, H., Grootenhuis, M.A., & Last, B.F. (2002). Quality of life in young adult survivors of childhood cancer. *Support Care Cancer*, *10*, 579-600.
- Last, B.R., Grootenhuis, M.A., & Eiser, C. (2005). International comparison of contributions to psychosocial research on survivors of childhood cancer: Past and future considerations. *Journal of Pediatric Psychology*, *30*, 99-113.

- Mattejat, F., & Remschimidt, H. (2006). The inventory of life quality in children and adolescents ILC (in German) (Das Inventar sur Erfassung der Lebensqualität bei Kindern und Jugendlichen ILK). *Hans Huber Verlag*, Bern.
- Meadows, A.T. (2006). Pediatric cancer survivorship: Research and clinical care. *Journal of Clinical Oncology*, *24*, 5160-5165.
- NOPHO, Nordic Society for Pediatric Hematology and Oncology, *Childhood Cancer in the Nordic Countries*. Report on Epidemiologic and Therapeutic Results From Registries and Working Groups. Annual report, Århus (2009) and Turku (2011).
- NOU 1997:20 (§ 8.10.4.2.) Official Norwegian Reports (Norges offentlig utredning) Social care and knowledge! Norwegian Cancer Plan. Children's cancer care (Omsorg og kunnskap! Norsk kreftplan. Barnekreft omsorgen).
- Oeffinger, K., Mertens, A.C., Sklar, C.A., Kawashima, T., Hudson, M., & Meadows, A., et al. (2006). Chronic health conditions in adult survivors of childhood cancer. New England *Journal of Medicine*, *355*, 172-82.
- Oeffinger, K.C., Nathan, P.C., & Kremer, L.C. (2008). Challenges after curative treatment for childhood cancer and long-term follow up of survivors. *Pediatric Clinics of North America*, *55*, 251-73.
- Parsons, S.K., Barlow, S.E., Levy, S.L., Supran, S.E., & Kaplan, S.H. (1999). Health-related quality of life in pediatric bone marrow transplant survivors: according to whom? *International Journal of Cancer*, Suppl., *12*, 46-51.
- Patenaude, A.F., & Kupst, M.J. (2005). Psychosocial functioning in pediatric cancer. *Journal of Pediatric Psychology*, *30*, 41-45.
- Pemberger, S., Reinhold, J., Frey, E., Felder-Puig, R., Gadner, H., Kryspin-Exner, I., & Reinhard, T. (2005). Quality of life in long-term childhood cancer survivors and the relation of late effects and subjective well-being. *Support Cancer Care*, *13*, 49-56.
- Penn, A., Lowis, S.P., Stevens, M.C., Hunt L.P., Shortman, R.I., McCarter, R.J., Curran, A.L., & Sharples P.M. (2009). Family, Demographic and Illness-Related Determinants of HRQL in Children With Brain Tumours in the First Year After Diagnosis. *Pediatric Blood & Cancer*, 53, 1092-1099.
- Phipps, S., Steele, R.G., Hall, K., & Leigh, L. (2001). Repressive Adaptation in Children with Cancer: A Replication and Extension. *Health Psychology*, 20, 445-51.

- Ravens-Sieberer, U., & Bullinger, M. (2000). KINDL-R *Questionnaire for measuring health-related quality of life in children and adolescents-* revised version. (http://www.kindl.org).
- Reinfjell, T., Lofstad, G.E., Nordahl, H.M, Vikan, A., & Diseth, T.H. (2009). Children in remission from acute lymphoblastic leukaemia: mental health, psychosocial adjustment parental functioning. *European Journal of Cancer Care*, *18*, 364-70.
- Robinson, K., Gerhardt, C., Vannatta, K., & Noll, R. (2007). Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology*, *32*, 400-10.
- Rosenbaum, P. (2009). The quality of life for the young adult with neurodisability: overview and reprise. *Developmental Medicine & Child Neurology*, *51*, 679-82.
- Russell, K., Hudson, M., Long, A., & Phipps, S. (2006). Assessment of Health-related Quality of life in children with cancer. *Cancer*, *106*, 10.
- Sawyer, M., Antoniou, G., Toogood, I., & Rice M. (1999). A Comparison of Parent and Adolescent Reports Describing the Health-related Quality of Life of Adolescents Treated for Cancer. *International Journal of Cancer*, Suppl., *12*, 39-45.
- Shepherd, E., & Woodgate, R. (2010). Cancer Survivorship in Children and Young Adults: A Concept Analysis. *Journal of Pediatric Oncology Nursing*, 27, 109-18.
- Speechley, K.N., Barrera, M., Shaw, A.K., Morrison, H.I., & Maunsell, E. (2006). Health-related quality of life among child and adolescent survivors of childhood cancer. *Journal of Clinical Oncology*, *24*, 2536-43.
- Spinetta, J.J. (1984). Methodology in behavioral and psychosocial cancer research.

  Measurement of family function, communication, and cultural effects. *Cancer*, 53, 2330-2338.
- Stiller, C.A., & Eatock, E.M. (1999). Patterns of care and survival for children with acute lymphoblastic leukaemia diagnosed between 1980 and 1994. *Archives of Disease in Childhood*, 81, 202-8.
- Stiller, C.A., & Draper, G.J. (2005). *The epidemiology of cancer in children*, in Vôute et al. (Eds.), Cancer in Children- clinical management, 1-16. Oxford University Press, Oxford.

- Theunissen, N.C.M., Vogels, T.G.C., Koopman, H.M., Verrips, G.H.W., Zwinderman, K.A.H., Verloove-Vanhorick, S.P., & Wit, J.M. (1998). The proxy problem: child report versus parent report in Health-related quality of Life research. *Quality of Life research*, 7, 387-97.
- Upton, P., Maddocks, A., Eiser, C., Barnes, P.M., & Williams, J. (2005). Development of a measure of the health-related quality of life of children in public care. *Child Care Health Dev*, *31*, 409-415.
- Upton, P., & Eiser, C. (2006). School experiences after treatment for a brain tumour. *Child Care Health Dev*, *32*, 9-17.
- Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of Life Research*, 17, 895-913.
- Van Dongen-Melman, J.E.W., Pruyn, J.F.A., de Groot, A., Koot, H.M., Halren, K., & Verhulst, F.C. (1995). Late psychosocial consequences for parents of children who survived cancer. *Journal of Pediatric Cancer*, 20, 567-586.
- Varni, J.W., Burwinkle, T.M., & Lane, M.M. (2005). Health-related quality of life measurement in pediatric clinical practice: An appraisal and precept for future research and application. *Health and Quality of Life Outcomes*, *3*, 34.
- Varni, J.W., Limbers, C.A., & Burwinkle, T.M. (2007). Impaired health-related quality of life in children and adolescents with chronic conditions: a comparative analysis of 10 disease clusters and 33 disease categories/severities utilizing the PedsQL 4.0 Generic Core Scales. *Health and Quality of Life Outcomes*, 5, 43-57.
- Wilson-Genderson, M., Broder, H.L., & Phillips, C. (2007). Concordance between caregiver and child reports of child's oral health-related quality of life. *Community Dentistry and Oral Epidemiology*, *35*, Suppl. 1, 32-40.
- Woodgate, R.L. (1999a). Conceptual Understanding of Resilience in the Adolescent With Cancer: Part I. *Journal of Pediatric Oncology Nursing*, *16*, 35-43.
- Woodgate, R.L. (1999b). A Review of the Literature on Resilience in the Adolescent With Cancer: Part II. *Journal of Pediatric Oncology Nursing*, *16*, 78-89.
- Yeh, C.H., & Chang, P.C. (2005). Evaluating Quality of Life in Children with Cancer Using Children's Self-Reports and Parent-Proxy report. *Nursing Research*, *54*, 354-362.

- Yoo, H-J., Ra, Y-S., Park, H-J., Lai, J-S., Cella, D., Shin, H-Y., & Kim, D-S. (2010).

  Agreement Between Pediatric Brain Tumor Patients and Parent Proxy Reports

  Regarding the Pediatric Functional Assessment of Cancer Therapy-Childhood

  Brain Tumor Survivors Questionnaire, Version 2. *Cancer*, 3674-3682.
- Zeltzer, L.K., Recklitis, C., Buchbinder, D., Zebrack, B., Casillas, J., Tsao, J., Lu, Q., & Krull, K. (2009). Psychological status in childhood cancer survivors: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*, 10, 2396-404.

#### III. Global Health Promotion Initiative

Health development is a concept that goes beyond borders. Increasing numbers of researchers around the world are reacting toward a single sided concentration on disease avoidance in health work and health research. The Research Centre for Health Promotion and Resources, together with our partners, are working at global, regional and country levels to improve the effectiveness and preciseness of health promotion action.

In the Global Health Research Initiative we work to strengthen an individual's health resources, collective capacities and assets, and also to give results that can impact national systems and strategies for health promoting action. The challenges and possibilities in health promotion show similarities but also important differences in all settings and ecological environments.

At all levels we and our partners jointly assess and analyse information, prioritize the interventions, build an evidence-based action plan, monitor the health situation and the health sector response. Thus, we work within a number of countries and regions.

In this book we present two such research initiatives. The first example is from Papua, New Guinea. The example is a research initiative which is carried through to get information on female health in the capital – Port Moresby. The research is planned to be the first part of a long lasting engagement for health promotion in Papua, New Guinea.

The second example, which is research in Uganda is still on the planning stage – but in the phase just before the project is expected to begin. The project describes how both the teaching institutions and the authorities in Uganda can have direct access to information from research that can direct better health promotion strategies and action.

# 11. A theoretical assessment of the state of preparedness for Non Communicable Diseases (NCD) in Uganda and a suggestion for health promotion research to guide positive health policy and action

JAMES MUGISHA 1 & GEIR ARILD ESPNES 2,3

<sup>1</sup>Principle Behavioral Scientists Uganda Ministry of Health and Makerere University Kampala, Uganda

<sup>2</sup> Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

<sup>3</sup> Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Social Work and Health Science, Trondheim, Norway

#### Abstract

The intention of this paper is twofold. First, we shall theoretically assess the level of preparedness of Uganda to deal with lifestyle related diseases, NCDs, and second, we shall assess how to introduce health promotion research as a knowledge basis for developing a positive national health policy and health practice. These assessments indicate that there is a lack of both political and technical preparedness in Uganda. The political preparedness largely stems from the lack of policy direction, and this affects the country's ability to plan and mobilize resources required to address the burden of lifestyle diseases in the country. In addition to the above, the paper focuses on the level of technical capacity in the country. There seems to be lack of adequate human resources in terms of skills and competencies to respond to the burden of lifestyle diseases in the country and this comes with a number of dilemmas. In the second part of the paper we argue for the need to introduce health promotion research in order to guide positive health policy and practice.

#### Introduction

In Africa, the state of preparedness with which countries have to address life style diseases can best be described as in both a political and technical *slumber*. It is in a political slumber because most countries in Africa, Uganda inclusive, lack documented policies about how to address life style diseases, despite the fact that politicians are supposed to lead the country in the policy making process (Jasson, 2011). And, this slumber is technical because the government departments responsible for leading the struggle against life style diseases lack technical capacity and other forms of preparedness to address the increasing magnitude of

life style diseases, now more often known under the term Non Communicable Diseases (NCDs,) in Uganda.

There are several statements within Uganda Ministry of Health Reports that seem to indicate that the country has a great deal of concern about the links between ill-health and impoverishment, and this has placed *health* at the center of development (Russell, 2004). Despite the pronouncements in these reports, much of the attention in Africa has been put on malaria and HIV/AIDS and how these two conditions (malaria and HIV/AIDS) have contributed to poverty in Uganda. This means that the country has a narrow definition of illhealth which is largely limited only to the two conditions (malaria and HIV/AIDS). Though the two diseases are given priority because they are the major sources of morbidity and mortality in developing countries, the drastic rise of NCDs cannot be ignored anymore. The life style diseases under focus include hypertension, diabetes mellitus, bronchial asthma, stroke, cardiovascular diseases, sickle cell disease, cancer and HIV/AIDS. In addition to this narrow focus in defining ill-health, the focus has to be framed in such a way that good health is the end product instead of seeing the absence of disease as the sole outcome variable (Brundtland 2002). Because of this lacuna, there are no strategic/systematic programs geared towards enhancing health. Hence, Public Health practice in Uganda lacks efforts aimed at improving welfare and quality-of-life and disease prevention. The main focus within the public health domain is promoting curative options/interventions. Yet, there is a need for people to change their focus, as well as have more control of their own health and therefore find themselves enabled to do more with their life-style diseases: this is a strong and growing concern today.

Due to the biased focus on malaria and HIV/AIDS, Uganda projected to spend \$35 million for the FY 2011(USAID, 2010) on malaria treatment and management and US \$ 75 million per year is spent on HIV and AIDS subsector annually. Despite this resource commitment to malaria and HIV/AIDS, there seems to be no direct resource allotment to NCDs as a subsector. However, the resources available are those that are routinely allocated to heath facilities for management of ailments (including those related to lifestyle). In addition, there are no direct allocations within the health facility budgets that are meant for prevention of life style diseases.

Even without reliable statistics on the magnitude of NCDs in the country, there seems to be growing consensus that this problem has assumed the status of a public health concern. One of the largest studies that have ever been conducted in Uganda that is known to the

authors is that of Parkin et al. (2006) which focused on cancer incidence in the period 1991-2006. This study indicated that there was an overall increase in the risk of cancer in both sexes in Kyadondo County. Among other cancers, this study revealed that the incidence rates of cancers of the breast and prostate increased 4.5% annually within the study period. The study concluded that overall, there was an increase in the cases of cancer in the review period in both men and women particularly those common in the "Western" world (lung, prostate, large bowel and breast). Despite its limitations - since the study methodology was a review of records at the Uganda cancer registry and not a population based study - this study indicates that cancer is a growing problem in the country. In terms of diabetes, in 2003, at Mulago hospital (the country's national referral hospital) there were 300,000 recorded cases of diabetic patients alone (Adome, 2007). Just as in the first study, this study was also a hospital-based study. However, despite its limitations, the study provides some evidence that diabetes is currently a public health issue in the country. With respect to cardiovascular diseases, a prevalence rate of 23.7 of cardiovascular diseases among the patients attending the Out Patient Department (OPD) was also established (ibid). The same report indicates a prevalence rate of 10.6 % of heart related problems among secondary school children in Kampala, the capital city of Uganda. Adome (2007) also noted that over a period of 6 years, the cases of hypertension in Mulago hospital increased from 2,777 in 2001 to 4,780 in 2006. And, in 2005, 109 patients were admitted to Mulago hospital with a clinical stroke as compared to only 60 admitted in the same period in 1999 (Adome, 2007).

#### Discussion

# Political and Policy inadequacies and the possible dilemmas

Midgley et al. (2009) argues that governments should be in a position to enact policies that enhance people's welfare and health, and this includes medical care. This implies that policy formulation is largely the responsibility of government. While Uganda has been credited for having quite extensive HIV/ AIDS and malaria control policies, there is apparently no policy on NCDs in the country. Jansson (2011) argues that policies should help to define problems and show the extent of the problem. Without any policy in place as regards this problem, it is not surprising that the extent and magnitude of life styles diseases in Uganda is unknown. The country relies on the few statistics from hospital-based studies but these cannot be relied upon to understand the magnitude and complexity connected to the increasing development of lifestyle diseases in the country.

The second dilemma is how to plan and respond to the increase of life style diseases in the Uganda. Is it possible to plan without policy? Such an approach to a challenge is normally defined as *muddling through* (Parsons, 2002). Service programs should be created and based on a well-defined need and methodologies which address them should be done so on a clearly defined goal found in the policy documents (Midgley, 2009). So, in the absence of clear policies, the country cannot claim that it has either clear service programs or clear methodologies to address life style diseases in the country.

Policies normally define resources needed for service delivery in any particular field. In the absence of a policy on life style diseases, Uganda cannot know the cost of this burden to the population and neither can the country know the amount of funds and other resources required to respond to the challenge posed by life style diseases - not today, not in the short term, and not in the long term. And, it is possible that by the time Uganda hears the wakeup call and eventually arises from its slumber, this subsector (life style diseases) will have become a *bottomless pit*.

#### Technical

The key issues here are, a) having the rights skills to handle the emerging challenges across relevant disciplines and, b) having the right number of people to address the burden of life style diseases.

- *Skills gap:* Just as in all other developing countries, Uganda still lacks staff in the specialized fields in medicine and public health. This also applies to the work with life style diseases. The cancer and heart institutes in Mulago (the only specialized units in the country) are not only underfunded but also lack key personnel and competences. Other regional referral hospitals face the same challenge.
- Number of relevant cadres to handle lifestyle related conditions: Based on the Annual Health Sector Performance Report 2010/2011, the doctor- patient ratio in Uganda is 0.036/1000 people in the population. The same report indicates that there are 1.49 core health workers per 1,000 people in the population. This is far below the WHO recommended minimum of 2.3 per 1,000. In addition to the above, other relevant cadres in the field are lacking at both national, regional and district levels. For example, even the cancer and heart institute, which are specialized units, do not have psychologists. They depend on psychologists who also are employed elsewhere, primarily at Makerere University. In addition to this, public health

training at both the diploma and degree levels has not been extended to improving knowledge on prevention of life style diseases at the community level.

A review of the Ministry of Health Strategic Plan 2005/6 – 2009/10 indicates that non-communicable diseases appear in that strategic plan. The main focus of this strategic plan includes a) establishing the financial, medical, and human burden of disease and main risk factors for Non-Communicable Disease conditions (NCDs) in Uganda by the end 2005, b) increasing the level of awareness in the population by 80 %, c) social mobilization in 100% of districts implementing the prevention and control of NCD/conditions, d) integration of NCD prevention and management within the functions of 100% of Health Centre IVs Core interventions, e) formulation of the national policy and medium-term strategic plan for NCD (by the end of 2006), f) building community awareness on prevention and control of NCDs using a multi-sectoral approach, g) development and implementation of an information and advocacy strategy on the public health importance of NCD, and finally h) strengthening the capacity at all HC IVs to correctly manage NCDs so as to prevent avoidable complications. Despite the pronouncements above in the National Health strategic Plan, most of the items listed in the National Health strategic Plan are still lying on the table of both the technical staff and other policy implementers. And, this strategic plan has now expired without even beginning to formulate a policy on how to fight NCDs. As a consequence, resources (both financial and human) are largely not within reach to respond to health threat of life style diseases represented in the country - which mostly would have to be accomplished in terms of health promotion.

#### Building a case for a Life Style Change Research Project

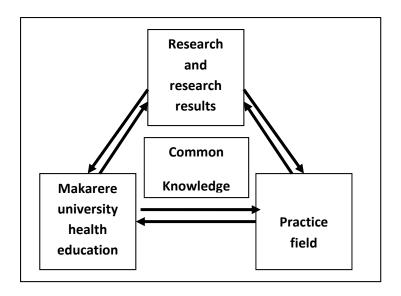
As noted earlier, almost all attention has been given to HIV- and AIDS prevention and little has been accorded to life style diseases, which is the fastest growing group of diseases in the poorer countries in Africa. This has been necessary given the number of and threats from communicable diseases to countries in Mid-and Southern Africa. But in the shadow of this, new health problems and challenges have emerged. If we focus on what has happened throughout the last years it has become increasingly evident that third world countries are facing, and will continue to face, other health threats of great magnitude in the years to come (life style diseases largely due to change in life style).

Given the "threat" from life style diseases, there is a need - through research and health promotion efforts - to seek options that enable people take charge of their own health.

This implies that there is a need for more health promotion research in Uganda in the years to come in order to face not only general health challenges but also challenges connected to a growing incidence of life style diseases. We need this focus in order to identify options through which people could strengthen their health, to build on what is good and works in the society (best practices). It is of importance to investigate what are effective healthpromoting behaviors on a societal level, as well as how to build societies that act in accordance with this. In summary, it is now of great importance to begin a project in three areas. These areas are (1) to map the knowledge about the causes of diseases/and causes of good health in the populations in the country, and (2) thereafter, to map the health situation in these populations, not only by death statistics, or statistics from general practitioners or health authorities, but through factual knowledge via epidemiological data on health, since most health statistics are on disease incidence and prevalence rather than on health, and through studies on both negative and positive health factors. The third part of the project is to educate health workers and to build and test interventions for life style changes and evaluate both the interventions and their success in terms of how the implementations that the project tried actually responded to poor health and non-communicable diseases. The following is a description of the factual organization and plan for such a project.

# The Project

This project will be the African Chapter for the Research Centre for Health Promotion and Resources HiST/NTNU. Research Centre for Health Promotion and Resources HiST/NTNU is a research unit co-owned by the Norwegian University of Science and Technology, NTNU and The Sør-Trøndelag University College, HiST.



**Figure 1:** A model showing how the knowledge in the project among the different partners will become shared knowledge and become a part of the common knowledge base.

The scope of the project is to establish both new knowledge on health status and health promotion indicators through research and to establish strong links aiming at bringing new knowledge from the research field faster to the practitioners and thus, directly into use. This will be achieved by establishing research that is directly linked to the Makarere University health education units and to the practice field (see Figure 1). The practice field will also be a critical mass by first bringing knowledge about the experience in the practice field as background for formulating accurate and adequate research questions and second, by bringing the newly accumulated knowledge directly into use. The project will therefore make both the researchers and the practitioners experts about the health situation and how to deal with the challenges. The international involvement also ensures quality control since the research results will be published in international research journals and these will be reviewed in the publication process.

The implementation will be done in four steps:

- Research on life style health status and health promotion is conducted.
- The research results are fed directly into the health education system at Makarere University.
- The students go to different practise fields and apply the new research-based
   practise and the new results then immediately become a part of the practise field
- Evaluations of the new practise and new research questions that are fed into the research team.

# References

- Adome, O. (2007). *Lifestyle disease in Uganda*. Presentation at the CPF workshop, Kampala, Uganda.
- Brundtland, G. H. (2002). From the World Health Organization. Reducing risks to health, promoting healthy life. *JAMA*, *288*, 23-30.
- Jansson, B.S. (2011). Becoming an Effective Policy Advocate: From Policy Practice to Social Justice. Brooks/Cole/Cengage.
- Midgley, J., & Livermore, M. (2009). *Handbook of Social Policy*. Thousand Oaks, CA: Sage Publications.
- Parkin, D.M., Nambooze S., Wabwire-Mangen. F., Wabinga., H.R. (2006). Changing cancer incidence in Kampala, Uganda, (1991-2006). International *Journal of Cancer*, *126*, 1187-95.
- Parsons, W. (2002). From muddling through to muddling up Evidence based policy making and the modernisation of British Government. *Public Policy and Administration*, 17, 43-60.
- Russel, S. (2004). The economic burden of illness for households in developing countries: a review of studies focusing on malaria, tuberculosis, and human immunodeficiency virus/acquired immunodeficiency syndrome. *American Journal of Tropical Medicine and Hygiene, 71,* 147–155.
- Uganda Ministry of Health strategic Plan 2005/6-2009/10. Kampala Uganda.
- Uganda Ministry of Health. (2011). Uganda Ministry of Health Sector Performance Report: Financial Year 2010/2011. Kampala, Uganda.

# 12. Comparison of self-rated health, well-being, anxiety and depression in young female populations in Port Moresby, Papua New Guinea and Nord-Trøndelag, Norway

VICTORIA BJØRO<sup>1</sup>, INGVILD BALSTAD PEDERSEN<sup>1</sup>, STEINAR KROKSTAD<sup>2</sup> & GEIR ARILD ESPNES<sup>3, 4</sup>

#### Abstract

The objective of this pilot study was twofold; (1) to assess self-rated health, well-being, anxiety and depression and compare two samples of women from Papua New Guinea (PNG) and Norway and (2) to investigate the applicability of the North-Trøndelag Health Survey (HUNT) Questionnaire, including the Hospital Anxiety and Depression Scale (HADS), in the PNG-sample. Respondents in the PNG sample reported better health, but poorer well-being compared to the HUNT sample. Adjusted for various health measures, we found that site have an effect on self-reported health and well-being. The structure of self-rated health did not to differ significantly, whereas the structure of well-being did show differences. As for the HADS, the study demonstrated considerately higher scores for both anxiety and depression in the PNG sample compared to HUNT. There were slight discrepancies in the psychometric properties of the HADS between the two samples as well as slight differences in the symptom pattern of anxiety and depression. In total, the HADS demonstrated satisfactory psychometric properties in both countries, and shows promise as a valid instrument for assessing anxiety and depression in PNG.

#### Introduction

Promotion of women's health has been on the health policy agenda for several years (WHO, 2003). Still, outcomes and access to care for women have been found to vary widely both within and between countries (WHO, 2008b). By comparing the health situation in two countries with great socio-economical differences such as Norway and Papua New Guinea

<sup>&</sup>lt;sup>1</sup>Norwegian University of Science and Technology, Faculty of Medicine, Trondheim, Norway

<sup>2</sup> HUNT Research Centre, Faculty of Medicine, Norwegian University of Science and Technology,

Norway

<sup>&</sup>lt;sup>3</sup> Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

<sup>4</sup> Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Trondheim, Norway

(PNG), the areas in need of attention for improving health promotion may be brought to a head

Norway and PNG differ widely in health challenges as well as in demographic and socio-economic conditions. In the 2009 Human Development Report the two countries ranked 1 and 148, respectively, on the Human Development Index (HDI) (UNDP/UN, 2009). Communicable diseases dominate the burden of disease in PNG, and there are great challenges in women's health including reproductive health and domestic violence (Amnesty International, 2006; UNAIDS/WHO, 2008; WPRO/WHO, 2009). In Norway, however, the disease panorama is characterized by non-communicable diseases, many of which are influenced by unhealthy lifestyle, and neuropsychiatric and stress-related psychosomatic disorders have come to dominate the burden of disease, accounting for most disability-adjusted life-years (DALYs) (WHO/Europe, 2006).

Self-rated health has been used as a predictor for health for many decades and is found to be a strong predictor of mortality, independent of objective health status (Idler, Russell, & Davis, 2000; Mossey & Shapiro, 1982). More dimensions are included in a subjective health assessment than in objective health measures such as chronic diseases and impairments (Miilunpalo, Vuori, Oja, Pasanen, & Urponen, 1997), making it a more stable, more sensitive and therefore a better indicator of health and health development (Manderbacka, 1998). Self-rated health measures have shown good test-retest reliability, content and construct validity across ethnic groups (Chandola & Jenkinson, 2000; Fillenbaum, 1979; Jylha, Guralnik, Ferrucci, Jokela, & Heikkinen, 1998; Kartal & Inci, 2010; Krause & Jay, 1994; Lundberg & Manderbacka, 1996). General well-being and quality of life, are culturally constructed experiences influenced by culture due to differences in perceptions of health and illness, different understandings of symptoms and expectations of care (Kagawa-Singer, Padilla, & Ashing-Giwa, 2010). Four dimensions have been included into the concept of health-related quality of life: physical, mental and social health and global perceptions of function and well-being (Berzon, Hays, & Shumaker, 1993).

As for negative health experiences, anxiety and depression are two major public health challenges worldwide with high incidence in the Western Pacific region (PIMHNet/WHO, 2010). PNG is one of the Western Pacific countries struggling with acute challenges in the mental health sector (WHO, 2008a). Mental health research conducted in PNG is very limited and there are no official statistics on the prevalence of mental illness in the country. However, the few studies to date indicate that women in PNG are worse off than

men and have poor psychosocial health (Hinton & Earnest, 2010a; McManus, 2006). PNG women may be particularly vulnerable to anxiety and depression due to high rates of domestic violence, incest and rape (Amnesty International, 2006). Psychosocial health problems, such as anxiety and depression, reflect the powerlessness and challenges women encounter (Hinton & Earnest, 2010a). Outcomes of anxiety and depression include increased morbidity and disability (WHO, 2010), and reduced quality of life (Pedersen, 2010).

In order to tackle the major challenges of mental health it is important to have good instruments for screening mental illness and identifying individuals in need of treatment. The Hospital Anxiety and Depression Scale (HADS) is widely used as a self-administered instrument to measure presence and severity of symptoms of anxiety and depression in somatic and psychiatric patients as well as in general populations. The HADS has been extensively validated in a variety of populations including clinical and community samples (Bjelland, Dahl, Haug, & Neckelmann, 2002; Herrmann, 1997). The good validity of the HADS has been demonstrated across culturally diverse groups in versions including Arabic, Chinese, Iranian and Japanese (Bjelland, et al., 2002; Matsudaira et al., 2009; Montazeri, Vahdaninia, Ebrahimi, & Jarvandi, 2003).

The objective of this pilot study was to investigate how two samples of women in Norway and PNG report their self-perception of health, general well-being, anxiety and depression, and to what extent the questions in the HUNT data collection instrument, including the HADS, are appropriate for international comparative studies.

#### Methods

# Study design and participants.

This study is a cross-sectional survey. Data from two independent samples were compared: (1) PNG and (2) HUNT. We used a sample from the most recent HUNT3 in this study. In PNG, the data was collected in 2007 as part of collaboration between the University of Papua New Guinea, Port Moresby (UPNG), the HUNT-study and the Centre for Health Promotion and Resources Research HiST/NTN. A two-way translation according to standards for both semantic and conceptual equivalence of the translations was carried out (Fumimoto et al., 2001; Prince, 2008; Zinke, Lam, Harden, & Fogg, 2010). Basic data in the PNG sample consists of results from a general health questionnaire completed by women associated with UPNG. Respondents were recruited using a snowball strategy. Inclusion criteria for both samples were: (a) female gender and (b) age 20 to 29. In PNG a third criterion was (c)

resided in PNG at one year of age. For the analyses of self-rated health and general well-being we applied a fourth criterion (d) being a student. The level of English proficiency in academic circles in PNG is high and an English version was therefore used. The study was approved by the Regional Committee for Research Ethics in Norway.

#### Measures

Demographic variables include age, occupation, civil status and having had at least one child. Living with a spouse or partner was added to examine the possible correlation with well-being in PNG. The self-rated health measure consisted of the question "How is your health at the moment?" with the categories 1) poor to 4) excellent. The measure of general well-being consisted of the question "Thinking about your life at the moment, would you say that you by and large are happy/satisfied with life, or are you generally unhappy/unsatisfied?" and the categories were 1) extremely happy/satisfied to 7) extremely unhappy/unsatisfied. Other health measures included self-reports on long-term illness (at least one year), pain or stiffness in the last year (at least three consecutive months), general feeling, physical activity, anxiety, depression and ever seeking help for mental problems. The variables meeting criteria for confounding (e.g. significantly associated with self-rated health or general wellbeing in both samples) were included in the initial analysis.

The HADS includes an anxiety sub-scale (HADS-A) and a depression sub-scale (HADS-D), each containing seven intermingled items (Table 1). Items are scored from 0 to 3 (0= absence of symptoms, 3= maximum symptom intensity). Item scores are summed resulting in maximum scores of 21 on each of the respective sub-scales. In the majority of studies ≥8 is considered optimal cut-off for caseness on both sub-scales, providing satisfactory levels of sensitivity and specificity of anxiety and depressive disorders (Bjelland, et al., 2002), and was also applied in this study.

**Table 1:** The Hospital Anxiety and Depression Scale

ltem number	Item text
Anxiety sub-scale	
Item 1	I feel tense or 'wound up
Item 3	I get a sort of frightened feeling as if something awful is about to happen
Item 5	Worrying thoughts go through my mind
Item 7	I can sit at ease and feel relaxed
Item 9	I get a sort of frightened feeling like 'butterflies' in the stomach
Item 11	I feel restless as if I have to be on the move
Item 13	I get sudden feelings of panic
Depression sub-scale	
Item 2	I still enjoy the things I used to enjoy
Item 4	I can laugh and see the funny side of things
Item 6	I feel cheerful
Item 8	I feel as if I'm slowed down
Item 10	I have lost interest in my appearance
Item 12	I look forward with enjoyment to things
Item 14	I can enjoy a good book or radio or TV program

#### Statistical analyses

Analyses were conducted with SPSS/PASW Version 18. Demographic variables were analyzed for each sample using frequency distributions and sample means were calculated and tested for significance with independent-samples t-test and Chi-square independence test, respectively. Fisher's test of significance was performed to sort out the variables that had significant associations with the outcome variables. These were then included in the logistical regression analysis. Bivariate logistic regression was conducted to evaluate the correlational structure of self-rated health and general wellbeing in both cultures. Breslow-Day Test for Homogenicity of Odds Ratios was applied to analyze whether the odds ratios of the dependent variables were significantly different between the samples. Mean scores on each HAD sub-scale were calculated and compared using independent-samples t-test. A cut-

off of ≥8 was applied to dichotomize the anxiety and depression subscales and to calculate the prevalence of both disorders. The samples were then compared with Chi-square test of independence. The factor structure of the HADS was investigated with Principal Components Analysis (PCA). The relationship between the sub-scales was investigated using Pearson product-moment correlation coefficient. Shared variances were estimated by square-rooting the correlation coefficients. The internal consistency of the HADS and HAD subscales was measured with Cronbach coefficient alpha.

## Results

## Demographics

The HUNT sample consisted of 2501 respondents. In PNG the questionnaire was completed by 489 women aged 18 to 56. 390 respondents met inclusion criteria for the current study, out of which 359 were students. As seen in Table 2 there were evident demographic differences between the groups. In the PNG sample, the mean age was 2.2 years lower, the proportion of students was higher and the numbers of respondents living with a partner or having had at least one child was lower compared to the HUNT sample.

Table 2: Demographics for the total sample

	PNG (n=390)		HUNT3 (n=390)		
	Whole sample	Students	Whole sample	Students	
Age	23.5	22.4	24.7	23.0	<0.000
Students	92.1% (359)	100.0% (359)	34.9% (912)	100% (912)	<0.000
Live with partner	5.4% (21)	4.2% (15)	43.8% (1096)	29.3% (267)	<0.000
Have had children	5.9% (23)	4.5% (16)	36.7% (917)	13.7% (125)	<0.000

**Table 3**: Number of participants and percentages in the different groups of self-reported health and general wellbeing in PNG (2007) and HUNT 3 (2006-2008).

		PNG	HUNT
		Students	Students
Self-rated health	Poor	0.3% (1)	0,4% (4)
	Not very good	4.0% (14)	9.1% (81)
	Good	59.6% (208)	55.4% (494)
	Excellent	36.1% (126)	35.1% (313)
General well-being	Extremely happy	18.5% (66)	23.1% (209)
	Very happy	27.5% (98)	36.8% (332)
	Fairly happy	33.7% (120)	26.5% (239)
	Undecided	12.1% (43)	10.7% (97)
	Fairly unhappy	5.1% (18)	2.2% (20)
	Very unhappy	1.4% (5)	0.6% (5)
	Extremely unhappy	1.7% (6)	0.1% (1)

#### Distribution of answers on self-rated health and general well-being

Students in PNG had the highest prevalence of excellent health (Table 3). In spite of this, they reported being less happy with life than students in HUNT. The majority of students in PNG reported being fairly happy with life, as opposed to the majority in HUNT, who stated they were very happy with life. There was statistical significance between the samples in self-ratings of health (p=0,014) and general well-being (p=0,000) as well as the other variables used in the analyses (p=0,000), except for long-term illness (p=0,197).

#### Comparison of the structure of self-rated health in PNG and HUNT

Of the odds ratios of the outcome variable adjusted for predictor variables, the only one that differed significantly between the samples was "general feeling" (Table 4). OR of poor health for female PNG students compared to HUNT students were adjusted for all covariates. Before adjustment, PNG students were less likely to report poor self-rated health (OR=0.43; CI 0,24-0,75) compared to HUNT (OR=1). The adjusted odds-ratio was even lower (OR=0.21; CI 0.09-0.53). The models that mostly affected the likelihood of poor health for students in PNG, were anxiety (OR=0.20; CI 0,11-0,38) and low physical activity (OR=0.23; 0,11-0,45).

**Table 4:** Bivariate logistic regression models showing the unadjusted odds of poor self-rated health with major predictor variables among female students in Port Moresby and Nord-Trøndelag

		PNG		HUNT		Sig. <sup>b</sup>	
		OR	95% CI	OR	95% CI		
Presence of long-term illness	No	1.00	-	1.00	-		
	Yes	6.78*	2.59-22.35	6.90*	4.28-11.13	0.872	
Presence of pain or stiffness	No	1.00	-	1.00	-		
	Yes	4.75*	1.60-14.08	3.10*	1.81-5.29	0.485	
General wellbeing	Нарру	1.00	-	1.00	-		
	Neutral	1.675**	0.34-8.17	8.16*	3.66-198.44		
	Unhappy	7.28*	2.20-24.08	24.85*	10.72-57.60	0.073	
General feeling	Strong/alert	1.00	-	1.00	-		
	Both	1.33**	0.34-5.12	6.46*	3.05-13.69		
	Tired/worn out	2.53**	0.54-11.76	18.50*	8.64-39.63	0.010	
Vigorous physical activity	None	0.90**	0.12-6.59	4.11*	1.35-12.50	0.203	
	Less than 1 h a week	1.32**	0.26-6.76	5.35*	2.30-12.41		
	1-2 hs a week	1.03**	0.18-5.82	2.16**	0.92-5.07		
	3 or more h/week	1.00	-	1.00	-		
Low physical activity	None	1.26**	0.14-11.41	9.23*	1.47-57.79	0.139	
	Less than 1 h a week	1.36**	0.38-4.85	7.25*	3.15-16.71		
	1-2 h/week	0.77**	0.18-3.32	1.87**	0.99-3.55		
	3 or more h/week	1.00	-	1.00	-		
Mental health problems	No	1.00	-	-	1.00		
	Yes	5.45*	1.38-21.52	5.28*	3.21-8.68	0.966	
Anxiety <sup>a</sup>	No	1.00	-	1.00	-		
	Yes	1.15E8***	0.00-	4.63*	2.65-8.10	0.174	
Depression <sup>a</sup>	No	1.00	-	1.00	-		
	Yes	4.17*	1.45-11.97	7.59*	3.48-16.59	0.366	

<sup>\*</sup> p<0.05 \*\*\* p>0.05 \*\*\* p>0.05 \*\*\*All respondents in PNG reporting poor health, scored 8 or more on the anxiety part of the HADS, resulting in the value 1.15E8.

a. Scores 8 or more on the Hospital Anxiety and Depression Scale

b. Breslow-Day Test of Homogenicity of Odds Ratio

# Comparison of the structure of well-being in PNG and HUNT

Table 4 shows that several of the odds ratios of the outcome variable adjusted for predictor variables differed significantly between the samples; including long-term illness, feeling tired or worn out, low physical activity and living with a spouse or partner. Respondents in PNG were more likely to report being unhappy than in HUNT (OR=1,61; CI 1,17-2,22). This changed when adjusted for all variables (OR=0,84; CI 0,45-1,58), but the results were not significant. The model which best explained the difference was anxiety, i.e. had the greatest positive effect on the OR, by solely reducing the OR to 0,81 (CI 0,53-1,24).

**Table 4**: Bivariate logistic regression models showing the unadjusted odds of reduced well-being with major predictor variables among female students in PNG and HUNT.

		PNG		HUNT		Sig. <sup>b</sup>	
		OR	95% CI	OR	95% CI		
Self-rated health	Poor	8.56E9***	0.00	6.19**	0.61-62.86	0.073	
	Not very good	3.98*	1.24-12.70	22.07*	11.34-42.99		
	Good	1.41**	0.78-2.52	2.66*	1.51-4.71		
	Excellent	1.00	-	1.00	-		
Presence of long-term illness	No	1.00	-	1.00	-		
	Yes	1.19**	0.54-2.64	3.91*	2.54-5.10	0.009	
Presence of pain or stiffness	No	1.00	-	1.00	-		
	Yes	1.32**	0.63-2.76	2.38*	1.47-3.86	0.189	
Mental health problems	No	1.00	-	1.00	-		
	Yes	3.57*	1.35-9.42	6.38*	4.12-9.88	0.282	
General feeling	Strong/alert	1.00	-	1.00	-		
	Both	2.15*	1.02-4.51	6.41*	3.38-12.16		
	Tired/exhausted	6.09*	2.58-14.39	17.32*	8.85-33.91	0.007	
	None	1.48**	0.53-4.13	2.61*	1.35-5.99	0.616	
Physical activity – vigorous	Less than 1 h a week	1.90**	0.77-4.66	1.99*	1.06-3.71		
	1-2 hs a week	1.84**	0.74-4.63	0.90**	0.48-1.67		
	3 or more h/week	1.00	-	1.00	-		
Physical activity – low	None	0.68**	0.19-2.49	6.61*	1.07-40.93	0.032	
	Less than 1 h a week	1.08**	0.56-2.06	4.13*	1.82-9.36		
	1-2 h/week	0.93**	0.48-1.79	1.73**	0.98-3.04		
i							

	3 or more h/week	1.00		1.00	-	
Lives with spouse/partner	No	1.00	-	1.00	-	
	Yes	2.28**	0.74-7.03	0.51*	0.31-0.82	0.010
Anxiety <sup>a</sup>	No	1.00	-	1.00	-	
	Yes	4.63*	2.13-10.07	6.00*	3.62-9.95	0.568
Depression <sup>a</sup>	No	1.00	-	1.00	-	
	Yes	5.14*	2.82-9.37	13.14*	6.13-28.16	0.054

<sup>\*</sup> p<0.05 \*\*\* p>0.05 \*\*\*None of the respondents in PNG who reported being happy also reported poor health, resulting in the value 8.56E9.

#### HADS scores

Table 5 displays the calculated prevalence of anxiety and depression. As we see there were striking differences between the samples, with anxiety being more than three times as prevalent and depression close to four times as prevalent in PNG as in HUNT. The mean score on both HADS-A and HADS-D was approximately twice as high in PNG.

**Table 5** Prevalence of anxiety and depression defined by cut-off score ≥8

	PNG	(n=390)	HUNT	(n=2501)	р
Anxiety	69.9%	(245)	19.2%	(338)	<0.000
Depressive	19.0%	(69)	4.9%	(86)	<0.000
		, ,	4.9%	, ,	<0.000
Mean score	g	0.0		4.9	

#### Factor structure of the HADS

The factor structure of the HADS was first investigated in the PNG sample. When performing PCA a two-factor solution emerged in which eleven of fourteen items loaded highest on their respective sub-scales. Item 7, however, loaded on the depression scale and item 8 on the anxiety scale. Item 10 did not load on either sub-scale. In the HUNT sample PCA produced a three-factor solution. The first factor, representing anxiety, contained items 1, 3, 5, 9 and 13. The second factor contained items 2, 4, 6, 10 and 12, which are depression items. The third factor comprised the mixed items 7, 11 and 14. Item 8 did not load on either sub-scale. The study findings showed that two of the items did not load on any factor, namely item 10 in PNG and item 8 in HUNT.

a. Scores 8 or more on the Hospital Anxiety and Depression Scale

b. Breslow-Day Test of Homogeneity of Odds Ratio

# Inter-correlation of the sub-scales and internal consistency

There was a strong, positive correlation between the two subscales, 0.565 and 0.570, in PNG and HUNT respectively, producing shared variances of 31.9% in PNG and 32.5% in HUNT. The internal consistency of the HADS was satisfactory for both samples (values of 0.66-0.83), although slightly lower in PNG compared to HUNT.

Table 6 Pattern Matrix for PCA of the HADS

		PNG		HUN	Т
-	F1	F2	F1	F2	F3
Anxiety sub-scale				_	
Item 1	.647	002	.708	172	001
Item 3	.597	056	.692	109	081
Item 5	.500	285	.566	286	.099
Item 7	.170	666	.214	243	.563
Item 9	.663	.143	.700	.214	.075
Item 11	.589	035	.263	.264	.711
Item 13	.667	.068	.695	035	.038
Depression sub- scale					
Item 2	071	600	.063	693	.132
Item 4	147	743	.024	662	.108
Item 6	.187	626	.137	573	.108
Item 8	.580	088	.394	274	040
Item 10	.233	284	.056	531	217
Item 12	.006	614	.025	723	.128
Item 14	.002	548	197	288	.694

# Discussion

In Papua New Guinea, the country with the highest burden of diseases and the lowest HDI rating, more female students aged 20-29 rated their health as excellent, fewer respondents reported suffering from a long-term illness and half as many reported pain or stiffness in muscles and joints. Still these students reported less satisfaction with life. Adjusted for

various health measures and effects of size, we found that site had a significant effect on self-reported health and well-being. Students in PNG were less likely to report being unhappy than students in HUNT. Anxiety was the factor that most affected the odds ratio of poor health and reduced well-being when comparing the two samples. The correlation between the objective health measures and self-rated health did not differ significantly between the two samples, strengthening the construct validity in PNG. The construct validity of general well-being, however, was weaker.

The results of our study are consistent with previous findings in terms of linking poor self-rated health to the presence of reduced objective health (Jylha, et al., 1998), long-term illness (Goldstein, Siegel, & Boyer, 1984; Pope, 1988), pain or stiffness in muscles or joints (Fylkesnes & Forde, 1991), reduced quality of life (Zubaran, Persch, Tarso, Ioppi, & Mezzich, 2008), physical activity (Miilunpalo, et al., 1997) and negative feelings (Shetterly, Baxter, Mason, & Hamman, 1996). In line with other studies, we found that well-being is associated with long-term illness (Alonso et al., 2004; Caldwell, Baxter, Mitchell, Shetterly, & Hamman, 1998), chronic pain (Gureje, Von Korff, Simon, & Gater, 1998), mental health symptoms (Bowling, 2010), and physical activity (Ekeland, Heian, Hagen, Abbott, & Nordheim, 2004; Netz, Wu, Becker, & Tenenbaum, 2005; Stathopoulou, Powers, Berry, Smits, & Otto, 2006). The contrast of lower self-rated health but higher quality of life ratings in one group compared to another has been found in other cross-cultural studies as well (Caldwell, et al., 1998; Shetterly, et al., 1996). In these studies, the less privileged group report poorer health but better well-being.

One of the key elements concerning the findings on self-rated health and well-being was to determine whether the results could represent objective differences in health status. According to Shetterly et al. (1996), it is necessary to fully examine the disparities in self-rated health between ethnic groups before it is assumed that the findings reflect differences in objective health status. The comparability of self-rated health across cultures is considered challenged if differences in the correlational structure of self-rated health are found (Jylha, et al., 1998). For our study, this implies that the measure of self-rated health is applicable in PNG, but raises a question to whether general well-being is.

Although PNG is considered less developed that Norway, our sample from PNG consists of a group of women that are more privileged than the rest of PNG's female population, perhaps even more than the sample from HUNT. Socio-economic status was unfortunately not assessed in this study due to methodological difficulties with the variables.

Young women's experiences of health in PNG are highly based on social and cultural experiences, such as social support, workload demands, economic constraints, gender roles, responsibility, independence and education (Hinton & Earnest, 2009, 2010a). Students in PNG may be more independent, experience more modern gender roles, have less economic constraints and less (physical) workload than the general PNG woman. The discrepancy between the sample and the general population is greater in PNG than in HUNT. This could have a positive effect on self-rated health for the social group in our PNG sample. This view is supported by an earlier study (Espnes & Mellam, 1999) and could explain why PNG students, despite a higher burden of disease in their country, reported better health. It could also be that Norwegian students rate their health as poorer than one would expect.

In the PNG sample the mean scores of both HADS-A and HADS-D were approximately twice as high as in the sample from HUNT. When applying cut-off score ≥8 in both samples levels of anxiety were more than 3 times as high and levels of depression close to 4 times as high in PNG as in HUNT. As for the factor analysis, results indicated that the HADS had satisfactory psychometric properties with adequate internal consistency and moderate sub-scale intercorrelation in both samples.

Considering the lack of research and concurrent statistics on mental health in PNG, the results need to be taken with caution. However, several other studies have found relatively high mean scores in general populations, especially with HADS-A (Caci et al., 2003; Chan, Leung, Fong, Leung, & Lee, 2010; Matsudaira, et al., 2009). As for cut-off scores, these values differ widely (Bjelland, et al., 2002). In Norway, ≥8 is considered the optimal cut-off on both HADS (A and D) sub-scales (Bjelland, et al., 2002), and it is likely that further research on the HADS in Papua New Guinea will provide cut-off values slightly higher than the ones applied in Norway.

In the PNG sample we obtained a two-factor structure of the HADS supported by Zigmond and Snaith's original presentation as well as a serious of studies over the last decades (Herrmann, 1997). The three-dimensional structure obtained in the HUNT sample is in accordance with a long list of previous studies (Caci, et al., 2003; Dunbar, Ford, Hunt, & Der, 2000; Martin, Thompson, & Barth, 2008; Mykletun, Stordal, & Dahl, 2001; White, Leach, Sims, Atkinson, & Cottrell, 1999) with the third factor involving "restlessness" (Caci, et al., 2003), "psychomotor agitation" (Barth & Martin, 2005; Friedman, Samuelian, Lancrenon, Even, & Chiarelli, 2001) or "negative affectivity" (Dunbar, et al., 2000).

In PNG item 8 ("I feel as if I'm slowed down"), originally belonging to the depression sub-scale, loads on the anxiety component. In HUNT, however, item 8 does not load on either sub-scale. This suggests that in PNG the item might be interpreted differently than in HUNT. Aspects of time are often culturally based and might be distinct in the two countries. In PNG the item might be interpreted as the external environmental factors slowing them down and not an intrinsic factor, as was the original intention with this question. As for the results in HUNT, psychomotor retardation is a symptom of severe depression (Association, 2000). In a general population sample prevalence of severe depression is marginal and could be a plausible reason for why this item does not load on the depression component in the HUNT sample and is in accordance with a tendency seen in several other studies where this item 8 has reached only borderline values (Chan, et al., 2010; Matsudaira, et al., 2009). Item 10 ("I have lost interest in my appearance") did not load on either sub-scale in PNG. In previous studies this item has shown high variability. In most studies it loads on the depression sub-scale (Bjelland, et al., 2002), however, it has shown to be the one item contributing the least and some studies have even proposed it be discarded in future revisions (Caci, et al., 2003; Chan, et al., 2010; Herrmann, 1997; Matsudaira, et al., 2009; Montazeri, et al., 2003). As for cultural differences, image consciousness might be less important in PNG than in Norway, where studies have shown strong loadings of this item on the depression component (Mykletun, et al., 2001).

The satisfactory internal consistency and the strength of the factor components should leave little doubt that the HADS shows promise as a reliable and valid instrument in PNG, and that it does measure the two components intended, depression and anxiety. The results of this study showed disturbingly high prevalence of anxiety and depression symptoms in PNG compared to HUNT. The findings could very well be a credible indicator of the level of symptoms in women in accordance with their own perception of their lives with relatively high levels of stressors.

In addition to showing very high prevalence in PNG, anxiety turned out being the single most associated factor with low well-being and one of the most important factors to influence self-rated health. Port Moresby is a city with high degree of social disturbance, crime and violence (Goddard, 2005). Female PNG students have been found to report more fear of assault or rape than Norwegian students, whose worst fear is losing a family member (Espnes & Mellam, 1999). According to Amnesty International women and girls in PNG are victims of widespread and pervasive violence both in the home and in the community

(Amnesty International, 2006). Women in PNG are marginalized and impoverished (Hinton & Earnest, 2010a, 2010b). They have little control of their own lives and few opportunities to achieve personal and economic independence (Hinton & Earnest, 2009, 2010b). For many university students the years away from home offer relief from abuse at home, but preoccupation with family members who are still suffering act as a major stressor (McManus, 2006). Female students might also live under insecure conditions being away from their closest family and supportive networks.

# Generalizability and limitations.

It is important to bear in mind that PNG is a culturally diverse country with approximately 1000 different languages and dialects. Developing universal instruments for screening under these circumstances is close to impossible. Hence, the results cannot without further research be generalized to the broader female population. As for the limitations, the study included only female respondents' ages of 20 through 29. In addition, in PNG the questionnaire was only distributed among women currently residing in Port Moresby and only among women associated with the university. These women are not necessarily representative of the general female population. Respondents were recruited with the "snowball-strategy" which could represent a bias.

## Conclusion

This study analyzed the structures and validity of self-rated health, well-being and the HADS among women aged 20 to 29 in Port Moresby, Papua New Guinea and the HUNT-study. Students in the PNG sample reported better health, but poorer well-being than the students in the HUNT sample. Adjusted for various health measures, we found that site had an effect on self-reported health and well-being. The *structure* of self-related health was found not to differ significantly, whereas the structure of well-being did. This indicates that the self-rated health measure is applicable in PNG, while well-being needs more research before being considered a valid instrument in PNG. As for the HADS, the level of anxiety and depression symptoms was considerately higher in the sample from PNG compared to HUNT. There were slight discrepancies in the psychometric properties of the scale as well as in the symptom pattern of anxiety and depression. However, the HADS did demonstrate satisfactory psychometric properties in both countries, and shows promise as a valid instrument for assessing anxiety and depression in PNG. Ultimately, it is warranted to conduct further qualitative research to verify how many respondents fill criteria for

depression and anxiety diagnoses, before appropriate cut-off scores can be secured and the HADS completely validated for use in PNG.

# Acknowledgements

Professor Albert Mellam at the University of Papua New Guinea arranged the data collection in Port Moresby. The Nord-Trøndelag Health Study (The HUNT Study) is a collaboration between HUNT Research Centre (Faculty of Medicine, Norwegian University of Science and Technology NTNU), Nord-Trøndelag County Council and The Norwegian Institute of Public Health.

# References

- Alonso, J., Ferrer, M., Gandek, B., Ware, J. E., Jr., Aaronson, N. K., Mosconi, P., . . . Leplege, A. (2004). Health-related quality of life associated with chronic conditions in eight countries: results from the International Quality of Life Assessment (IQOLA) Project. *Quality of Life Research*, *13*(2), 283-298.
- Amnesty International. (2006). Papua New Guinea: Violence against women; not inevitable, never acceptable! In I. Secretariat (Ed.), *AI index: ASA 34/003/2006*. London: Amnesty International.
- Association, A. P. (2000). Diagnostic and statistical manual of mental disorders: DSM-IV-TR. Washington, DC
- Barth, J., & Martin, C. R. (2005). Factor structure of the Hospital Anxiety and Depression Scale (HADS) in German coronary heart disease patients. *Health Qual Life Outcomes*, *3*, 15. doi: 10.1186/1477-7525-3-15
- Berzon, R., Hays, R. D., & Shumaker, S. A. (1993). International use, application and performance of health-related quality of life instruments. *Quality of Life Research*, *2*(6), 367-368.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *Journal of Psychosomatic Research*, *52*(2), 69-77. doi: S0022399901002963 [pii]
- Bowling, A. (2010). Do older and younger people differ in their reported well-being? A national survey of adults in Britain. *Family Practice*. doi: cmq082 [pii]
- 10.1093/fampra/cmq082 [doi]
- Caci, H., Bayle, F. J., Mattei, V., Dossios, C., Robert, P., & Boyer, P. (2003). How does the Hospital and Anxiety and Depression Scale measure anxiety and depression in healthy subjects? *Psychiatry Research*, *118*(1), 89-99.
- Caldwell, E. M., Baxter, J., Mitchell, C. M., Shetterly, S. M., & Hamman, R. F. (1998). The association of non-insulin-dependent diabetes mellitus with perceived quality of life in a biethnic population: the San Luis Valley Diabetes Study. *American Journal of Public Health*, 88(8), 1225-1229.
- Chan, Y. F., Leung, D. Y., Fong, D. Y., Leung, C. M., & Lee, A. M. (2010).

  Psychometric evaluation of the Hospital Anxiety and Depression Scale in a large community sample of adolescents in Hong Kong. *Quality of Life Research*, 19(6), 865-873. doi: 10.1007/s11136-010-9645-1

- Chandola, T., & Jenkinson, C. (2000). Validating self-rated health in different ethnic groups. *Ethnicity and Health*, *5*(2), 151-159.
- Dunbar, M., Ford, G., Hunt, K., & Der, G. (2000). A confirmatory factor analysis of the Hospital Anxiety and Depression scale: comparing empirically and theoretically derived structures. *British Journal of Clinical Psychology*, 39 (Pt 1), 79-94.
- Ekeland, E., Heian, F., Hagen, K. B., Abbott, J., & Nordheim, L. (2004). Exercise to improve self-esteem in children and young people. *Cochrane Database Syst Rev*(1), CD003683. doi: 10.1002/14651858.CD003683.pub2
- Espnes, G. A., & Mellam, A. C. (1999). *Perceived health in Papua New Guinean and Norwegian female students*. Studies in Cross-cultural Health Psychology; Selected papers from studies in Papua New Guinea, Norway and Australia. The University of Science and Technology and The University of Papua New Guinea. Trondheim.
- Fillenbaum, G. G. (1979). Social Context and Self-Assessments of Health among the Elderly. *J Health Soc Behav.*, 20(1), 45-51.
- Friedman, S., Samuelian, J. C., Lancrenon, S., Even, C., & Chiarelli, P. (2001). Three-dimensional structure of the Hospital Anxiety and Depression Scale in a large French primary care population suffering from major depression. *Psychiatry Research*, 104(3), 247-257.
- Fumimoto, H., Kobayashi, K., Chang, C. H., Eremenco, S., Fujiki, Y., Uemura, S., . . . Kudoh, S. (2001). Cross-cultural validation of an international questionnaire, the General Measure of the Functional Assessment of Cancer Therapy scale (FACT-G), for Japanese. *Quality of Life Research*, 10(8), 701-709.
- Fylkesnes, K., & Forde, O. H. (1991). The Tromso Study: predictors of self-evaluated health--has society adopted the expanded health concept? *Social Science and Medicine*, 32(2), 141-146.
- Goddard, M. (2005). *The Unseen City. Anthropological perspectives on Port Moresby,*Papua New Guinea. Canberra, Australia: Panadus Books, Research School of
  Pacific and Asian Studies, The Australian National University.
- Goldstein, M. S., Siegel, J. M., & Boyer, R. (1984). Predicting changes in perceived health status. *American Journal of Public Health*, 74(6), 611-614.
- Gureje, O., Von Korff, M., Simon, G. E., & Gater, R. (1998). Persistent pain and wellbeing: a World Health Organization Study in Primary Care. *JAMA*, *280*(2), 147-151. doi: joc72070 [pii]

- Herrmann, C. (1997). International experiences with the Hospital Anxiety and Depression Scale--a review of validation data and clinical results. *Journal of Psychosomatic Research*, 42(1), 17-41.
- Hinton, R., & Earnest, J. (2009). Beyond risk factors to lived experiences: young women's experiences of health in Papua New Guinea. *Rural Remote Health*, *9*(4), 1257. doi: 1257 [pii]
- Hinton, R., & Earnest, J. (2010a). 'I worry so much I think it will kill me': Psychosocial health and the links to the conditions of women's lives in Papua New Guinea. *Health Sociology Review, 19*(1), 5-19.
- Hinton, R., & Earnest, J. (2010b). Stressors, coping, and social support among women in Papua New Guinea. *Qualitative Health Research*, 20(2), 224-238. doi: 20/2/224 [pii] 10.1177/1049732309357572 [doi]
- Idler, E. L., Russell, L. B., & Davis, D. (2000). Survival, functional limitations, and self-rated health in the NHANES I Epidemiologic Follow-up Study, 1992. First National Health and Nutrition Examination Survey. *American Journal of Epidemiology*, 152(9), 874-883.
- Jylha, M., Guralnik, J. M., Ferrucci, L., Jokela, J., & Heikkinen, E. (1998). Is self-rated health comparable across cultures and genders? *Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, *53*(3), S144-152.
- Kagawa-Singer, M., Padilla, G. V., & Ashing-Giwa, K. (2010). Health-related quality of life and culture. *Seminars in Oncology Nursing*, *26*(1), 59-67. doi: S0749-2081(09)00115-6 [pii] 10.1016/j.soncn.2009.11.008 [doi]
- Kartal, A., & Inci, F. H. (2010). A cross-sectional survey of self-perceived health status and metabolic control values in patients with type 2 diabetes. *International Journal of Nursing Studies*. doi: S0020-7489(10)00215-4 [pii] 10.1016/j.ijnurstu.2010.07.004 [doi]
- Krause, N. M., & Jay, G. M. (1994). What do global self-rated health items measure? *Med Care*, 32(9), 930-942.
- Lundberg, O., & Manderbacka, K. (1996). Assessing reliability of a measure of self-rated health. *Scandinavian Journal of Social Medicine*, *24*(3), 218-224.
- Manderbacka, K. (1998). Examining what self-rated health question is understood to mean by respondents. *Scandinavian Journal of Social Medicine*, *26*(2), 145-153.

- Martin, C. R., Thompson, D. R., & Barth, J. (2008). Factor structure of the Hospital Anxiety and Depression Scale in coronary heart disease patients in three countries. *Journal of Evaluation in Clinical Practice*, *14*(2), 281-287. doi: 10.1111/j.1365-2753.2007.00850.x
- Matsudaira, T., Igarashi, H., Kikuchi, H., Kano, R., Mitoma, H., Ohuchi, K., & Kitamura, T. (2009). Factor structure of the Hospital Anxiety and Depression Scale in Japanese psychiatric outpatient and student populations. *Health Qual Life Outcomes*, 7, 42. doi: 10.1186/1477-7525-7-42
- McManus, M. (2006). Domestic and sexual violence, youth and media reporting in Papua New Guinea.
- Miilunpalo, S., Vuori, I., Oja, P., Pasanen, M., & Urponen, H. (1997). Self-rated health status as a health measure: the predictive value of self-reported health status on the use of physician services and on mortality in the working-age population. *Journal of Clinical Epidemiology*, 50(5), 517-528. doi: S0895-4356(97)00045-0 [pii]
- Montazeri, A., Vahdaninia, M., Ebrahimi, M., & Jarvandi, S. (2003). The Hospital Anxiety and Depression Scale (HADS): translation and validation study of the Iranian version. *Health Qual Life Outcomes*, 1, 14. doi: 10.1186/1477-7525-1-14
- Mossey, J. M., & Shapiro, E. (1982). Self-rated health: a predictor of mortality among the elderly. *American Journal of Public Health*, 72(8), 800-808.
- Mykletun, A., Stordal, E., & Dahl, A. A. (2001). Hospital Anxiety and Depression (HAD) scale: factor structure, item analyses and internal consistency in a large population. *British Journal of Psychiatry*, *179*, 540-544.
- Netz, Y., Wu, M. J., Becker, B. J., & Tenenbaum, G. (2005). Physical activity and psychological well-being in advanced age: a meta-analysis of intervention studies. *Psychol Aging*, 20(2), 272-284. doi: 10.1037/0882-7974.20.2.272
- Pedersen. (2010). Self-perceived health, general well-being and longstanding limiting illness among young women in Port Moresby, Papua New Guinea and Nord-Trøndelag, Norway.
- PIMHNet/WHO. (2010). The WHO Pacific Islands Mental Health Network (PIMHNet), from <a href="http://www.who.int/mental">http://www.who.int/mental</a> health/policy/pimhnet/en/index.html
- Pope, G. C. (1988). Medical conditions, health status, and health services utilization. *Health Services Research*, 22(6), 857-877.

- Prince, M. (2008). Measurement validity in cross-cultural comparative research. *Epidemiologia e Psichiatria Sociale, 17*(3), 211-220.
- Shetterly, S. M., Baxter, J., Mason, L. D., & Hamman, R. F. (1996). Self-rated health among Hispanic vs non-Hispanic white adults: the San Luis Valley Health and Aging Study. *American Journal of Public Health*, 86(12), 1798-1801.
- Stathopoulou, G., Powers, M. B., Berry, A. C., Smits, J. A. J., & Otto, M. W. (2006). Exercise Interventions for Mental Health: A Quantitative and Qualitative Review. *Clinical Psychology: Science and Practice*, *13*(2), 179-193.
- UNAIDS/WHO. (2008). Epidemiological fact sheet on HIV and AIDS core data on epidemiology and response. Papua New Guinea 2008 update. Geneva: UNAIDS/WHO Working group on Global HIV/AIDS and STI Surveillance.
- UNDP/UN. (2009). United Nations Development Report 2009.
- White, D., Leach, C., Sims, R., Atkinson, M., & Cottrell, D. (1999). Validation of the Hospital Anxiety and Depression Scale for use with adolescents. *British Journal of Psychiatry*, 175, 452-454.
- WHO. (2003). Gender sensitivity and gender-based analysis in women's health development. Historical outlines and case studies of best practice. Kobe, Japan: Women and health Program, Centre for Health Development.
- WHO. (2008a). Reproductive health, child and adolescent health, nutrition, and health for older persons Retrieved 28.12, 2010, from <a href="http://www.wpro.who.int/NR/rdonlyres/D37ABCE4-A9C0-4CA2-A4CE-FC7815ADC55E/0/14a">http://www.wpro.who.int/NR/rdonlyres/D37ABCE4-A9C0-4CA2-A4CE-FC7815ADC55E/0/14a</a> Chapter9Reproductivehealth.pdf
- WHO. (2008b). World Health Report 2008. Geneva: World Health Organization.
- WHO. (2010). Mental Health; Depression Retrieved December 22, 2010, from <a href="http://www.who.int/mental">http://www.who.int/mental</a> health/management/depression/definition/en/
- WHO/Europe. (2006). Highlights on health in Norway. Copenhagen.
- WPRO/WHO. (2009). Country Health Information Profile, Papua New Guinea. Geneva: World Health Organization/Western Pacific Regional Office.
- Zinke, J. L., Lam, C. S., Harden, R. N., & Fogg, L. (2010). Examining the cross-cultural validity of the english short-form McGill Pain Questionnaire using the matched moderated regression methodology. *Clinical Journal of Pain, 26*(2), 153-162. doi: 10.1097/AJP.0b013e3181b99f56 [doi] 00002508-201002000-00012 [pii]

Zubaran, C., Persch, K., Tarso, D., Ioppi, A., & Mezzich, J. (2008). The correlation between health status and quality of life in southern Brazil. *Sao Paulo Med J*, 126(5), 257-261. doi: S1516-31802008000500003 [pii]

# IV. Health Promotion in the Life Course

Health is not created and lived in isolation. It results from an on-going process and interaction with the individuals' socio-ecological environment throughout the whole life course. In this context, we all have to function as active participating subjects in our own life, making use of resources in order to maintain and improve health. Thus, health can be seen as a lifelong learning process where we reflect on what will create health and what are the options for life and quality of life.

Health is perceived and evaluated differently by the individual across the age span, and highly depends on factors within the individual, but also on factors in the individuals' close and distant environment. Health and well-being is significantly influenced by the circumstances of our lives, access to services, work and income and by the communities where we live as well as our own lives. Therefore, the knowledge base of health promotion, as well as strategies to promote health, must be seen in a life course perspective.

The five following chapters focus on different aspects relevant to the life course perspective. Chapters 13 and 17 focuses on the role of health promoting resources in relation to stress, health and school well-being in children and adolescents. Chapter 14 presents opportunities for health promotion research and knowledge based on public health through the HUNT Study Norway. In Chapter 15, focus is devoted to the role of self-transcendence, well-being and nurse-patient-interaction in cognitively intact nursing home patients. And finally, Chapter 16 focuses on religion and mental health in the elderly.

# 13. The role of resources and protective factors in relation to stress and health outcomes in adolescence

#### **UNNI KARIN MOKSNES**

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Adolescence is a developmental period characterized by multiple changes in virtually every aspect of an individual's life, calling for new psychological adaptations. Exposure to different stressors caused by these changes represents a central and normal part of the process of growth and development during adolescence. The present chapter focuses on the role and nature of adolescent stressors and the association between stress and psychological health outcomes. Meanwhile, when faced with identical stressors, the stress process and the health outcomes of stress vary individually; the outcome depends on the role of different vulnerabilities and protective factors, in the individual as well as in the environment. The chapter considers the role of three potential protective factors with importance for stress and coping processes, as well as for health and well-being during adolescence; leisure time physical activity, self-esteem and sense of coherence (SOC).

Adolescence is conceptualized as a life phase, which begins with the onset of puberty and ends with the acceptance of adult roles and responsibilities. Of all life-stages, except childhood, adolescence is the one most marked by rapid and potentially tumultuous transition (Steinberg, 2008). This is to be seen in the domain of biological development where the changes are physically externally manifest as well as in the progression of both cognitive and psychosocial maturity from that of childhood to that of the fully functioning adult (Byrne, Davenport, & Mazanov, 2007; Moksnes, Byrne, Mazanov, & Espnes, 2010). While the transition through adolescence is inevitable the speed and magnitude of these changes may overtax the capacity of many young people to cope and the resulting phenomenon of adolescent stress is now well recognized (Byrne, et al., 2007).

Adolescence has historically been a life stage of relative neglect with respect to research on both mental and physical health interventions and outcomes, although research on growth and development during adolescence has expanded during the past years (Compas

& Reeslund, 2009). Perhaps such neglect has occurred because most adolescents compared with other developmental periods are healthy when assessed by traditional medical markers such as the presence or absence of chronic disease, use of health care services and hospitalization (Ozer, & Irwin, 2009). However, adolescence is a pivotal period of development with respect to health and illness. Most adolescents transverse this developmental period successfully resolving the challenges they face to become competent, productive adult members of society. Meanwhile, adolescence also marks the increase in the incidence of a number of mental health problems and threats to physical health (Compas & Reeslund, 2009, pp. 561). Many health habits and behaviours are consolidated, and important health risk behaviours are first evident during this life stage. These patterns affect not only the immediate health of adolescents, but lay the foundation for health throughout the lifespan (Ozer, & Irwin, 2009).

Understanding the role and nature of stressors in the lives of adolescents, how experience of stress is associated with different health outcomes, as well as identifying potential protective factors in this context is crucial for helping adolescents capitalize on the many changes taking place in their lives, and equip them with tools to make their journey through adolescence a positive growth-oriented experience (Grant et al., 2006). Understanding the role of stress is also important to the identification of those adolescents most in need of early intervention, whereas clarification of factors that promotes health and well-being and moderate the negative health effects of stress can be used to form interventions to strengthen adolescent development in general, as well as to support those with potential risk (Compas & Reeslund, 2009).

# Conceptualization of stress and stressors

Stress has traditionally been conceptualized in three ways; as a stimulus (an event or accumulation of events); as a response (a psychophysiological reaction); or as a transactional process, in which a person and the environment interact to produce an appraisal of threat or loss (Caltabiano, Sarafino, & Byrne, 2008). The present chapter has focus on *perceived stress*. Thus, "stress" is used to describe the subjective experience of pressure, implying an evaluation of the outcome of a process. This is in line with the transactional view of stress as a relationship between environmental events or conditions, and the individual's cognitive appraisals of the degree and type of challenge, threat, harm or loss (Lazarus & Folkman, 1984). The most widely accepted definition of stress is the transactional definition offered by Lazarus and Folkman (1984): "Psychological stress involves a particular relationship

between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). According to this definition, stress is subjective by nature, since it involves an appraisal of individual experiences.

Exposure to stressful events (stressors) represents significant sources of risk to the healthy development of adolescents, and stressors are experienced in different intensities and durations of arousal in adolescence (Compas & Reeslund, 2009; Moksnes & Espnes, 2011). Stressors of both an acute and chronic nature are important in the course of normal as well as disrupted development during adolescence. Stressors are defined according to Grant et al. (2003, p. 449) as: "Environmental events or chronic conditions that objectively threaten the physical and/or psychological health or well-being of individuals of a particular age in a particular society."

#### Stress and health in adolescence

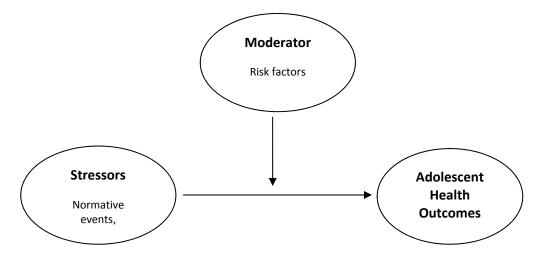
A number of models may be relevant in explaining the association between stress and different negative psychological outcomes through the life span (Graber & Sontag, 2009). Models of cumulative and simultaneous events posit that when individuals experience major stressful events or transitions given the nature of adolescent development (e.g. academical demands or change in social relationships) either in close sequence (cumulatively) or simultaneously, they are more likely to have negative behavioural and emotional outcomes as a result of the confluence of events (Graber & Sontag, 2009). Cumulative events may also be characterized by increasing numbers of stressful events that occur for adolescents commensurate with changes in peer groups, friendships, parental relationships, and school demands. Coping resources may be overwhelmed by the experience of multiple changes in close proximity, which lead to negative health outcomes. In essence, the individual's assessments of the importance of the stressful events and their timing, and whether the event is controllable or not are all factors affecting whether stressful events are associated with negative health outcomes in this model (Graber & Sontag, 2009).

Research has established that the overall number of stressors tend to increase from preadolescence to adolescence (Compas & Reeslund, 2009). Girls tend to perceive higher levels of stress than boys, especially in relation to interpersonal stressors, e.g. peers, romantic partners, and family relationship (Charbonneau Mezulis, & Hyde, 2009; Hankin, Mermelstein, & Roesch, 2007; Shih, Eberhart, Hammen, & Brennan, 2006).

Relations between stressors, especially those in an interpersonal context (e.g. peers, family, romantic relationships) and symptoms of depression and anxiety in childhood and adolescence have been well established in cross-sectional and prospective longitudinal studies (Bouma, Ormel, Verhulst, & Oldehinkel, 2008; Hankin, et al., 2007; McLaughlin, Hatzenbuehler, & Phil, 2009; McLaughlin & Hatzenbuehler, 2009; Moksnes, Moljord, Espnes, & Byrne, 2010a, Moksnes, Moljord, Espnes, & Byrne 2010b). In this regard, girls appear to be more vulnerable to the negative psychological effects of interpersonal stress, than boys (Bouma et al., 2008; Charbonneau et al., 2009; Hankin et al., 2007; Shih et al., 2006).

### The role of potential stress moderators

Stress alone is not sufficient to explain individual differences in people's health. When faced with the same stressor(s), the stress process and the impact from stress vary individually and lead to different health outcomes; this depends on individual and environmental vulnerabilities and resources, as well as the ability to cope effectively with the stressors (Compas & Reeslund, 2009).



#### Physical activity

Previous studies have shown that daily physical activity, regular exercise and a sufficient level of physical fitness protect against a variety of negative physical (Sundblad et al., 2008) and psychological conditions (Hallal, Victoria, Azevedo, & Wells, 2006; Piko & Keresztes, 2006), and promote positive perceived health, and well-being during adolescence (Edwards, 2006). Physical activity has shown to be beneficial in relation to depression (Jerstad, Boutelle, Ness, & Stice, 2010), anxiety (Salmon, 2001), and self-esteem (Ekeland, Heian, & Hagen, 2005; Schmalz, Deane, Birch, & Davison, 2007). In the review of Gerber & Pühse

(2009) which summarizes the literature from 1982 to 2008, 16 studies fully supported the validity of an exercise-based stress-buffer hypothesis, where six studies were based on adolescent samples. In contrast, 15 investigations (five in adolescent samples) did not support the stress-buffering hypothesis. Gerber & Pühse (2009) suggest several mechanisms that may explain how physical activity alleviates the effects of stress. First, it can be assumed that physical activity results in reduced arousal (mood enhancement due to cognitive distraction or biochemical changes) or more positive health behaviours during periods of high stress (i.e. decreased smoking, healthier eating habits). Second, physical activity may bring about higher levels of fitness and – as an indirect consequence – a more efficient physiological and psychological stress regulation (i.e. reduced secretion of hormones, lowered blood pressure) or enhanced recovery processes. Besides preventive effects, physical activity may strengthen other protective personal resources (i.e. self-esteem) (Ekeland et al., 2005; Schmalz et al., 2007) and social resources (i.e. social support), which in turn have the potential to influence the stress-health relationship (Gerber & Pühse, 2009).

#### Sense of coherence

The medical sociologist Aron Antonovsky introduced the salutogenic perspective which focuses on what are the sources for people's resources and capacity to create health (Salutogenesis) rather than the classic focus on risk, ill health and disease (Pathogenesis). Antonovsky tried to find the solution to the salutogenic question why some people, regardless of major stressful situations stay healthy, while others do not. The answer was formulated in terms of Sense of Coherence (SOC) and General Resistance Resources (GRR) (Antonovsky, 1979; Eriksson, 2007). SOC is defined 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, 2) the resources are available to one to meet the demands posed by these stimuli; and 3) these demands are challenges, worthy of investment and engagement" (Antonovsky, 1987 p. 107). This combination of cognitive, behavioural and motivational aspects form the concept of SOC and the three components are named comprehensibility, manageability and meaningfulness. The other key factors are the general resistance resources (GRR) available to make such a movement towards health possible. The GRRs can be found within people as resources bound to their person and capacity but also to their immediate and distant environment as of both material and non-material qualities from the person to the whole society. The key factor is not what is available but to

be able to use and re-use them for the intended purpose. The GRRs provide a person with sets of meaningful and coherent life experiences thanks to the resources at the person's disposal (Eriksson, 2007).

Antonovsky (1987) claimed that a person's SOC develops throughout childhood into the latter stages of adolescence and becomes more or less stabilized in the period of early adulthood. During this time, people are repeatedly exposed to tension states requiring that they actively respond to stressors by mobilizing appropriate resources. However, findings have shown that development of a person's SOC is a lifelong process (Eriksson, 2007; Lindström & Eriksson, 2010), making it important to investigate SOC in adolescent populations more thoroughly.

A strong SOC is associated with good mental health and quality of life, among adult and adolescent samples (Lindström & Eriksson, 2010; Neuner et al., 2011; Öztekin & Tezer, 2009). SOC is strongly and inversely associated with anxiety and depression; the stronger the SOC, the lesser are symptoms of emotional problems (Blom, Serlachius, Larsson, Theorell, & Ingvar, 2010; Moksnes, Espnes, & Lillefjell, 2011; Öztekin & Tezer, 2009; Ristakari, Sourander, Rønning, Nikolakaros, & Helenius, 2008). Moreover, boys seem to report stronger SOC than girls (Natvig, Hanestad, & Samdal, 2006; Moksnes, Rannestad, Espnes, & Byrne, 2011). People with strong SOC seem to be more resilient under stress than people with weak SOC (Eriksson & Lindström, 2005; Lindström & Eriksson, 2010). Individuals with a strong SOC, it is postulated, will have a general confidence that resources are available to meet the demands posed by stressful situations, and will thus consider a stressor more as a challenge than as a threat. This confidence increases the likelihood of positive coping expectancies, which will prevent stress from turning into potentially harmful tension (Antonovsky, 1987). In adolescents, SOC is found to moderate the association between stress and self-reported health status (Richardson & Ratner, 2005) and the association between stress and recent illness (Nielsen & Hansson, 2007). Moksnes & Espnes (paper submitted) also found that SOC moderated the association between stress and state depression. However, inconsistent findings regarding the moderating role of SOC in relation to stress and subjective health complaints have been found (Moksnes, Rannestad et al., 2011; Torsheim, Aaroe, & Wold, 2001).

#### Self-esteem

Self-esteem is a large part of adolescents' self-understanding (Baldwin & Hoffman, 2002; Räty, Larsson, Söderfeldt, & Larsson, 2005). Rosenberg (1965) defined self-esteem as an individual's set of thoughts and feelings about his or her own worth and importance. This definition reflects the notion of "global" or "general" self-esteem or self-worth.

The importance of self-esteem for the well-being of adolescents is underscored by decades of theory and research supporting its link with psychological health and well-being during adolescence (Greene & Way, 2005; Muris, Meesters, & Fijen, 2003; Trzesniewski et al., 2006). Furthermore, the numerous biological, psychological and cognitive changes that occur during adolescence highlight the importance of examining self-esteem during this period (Boden, Fergusson, & Horwood, 2008; Cote, 2009).

Low self-esteem has been considered as an important factor in relation to symptoms of depression (Bos, Huijding, Muris, Vogel, & Biesheuvel, 2010; Hammen, 2005; Orth, Robins, & Roberts, 2008; Orth, Robins, Trzesniewski, Maes, & Schmitt, 2009), and anxiety (Boden et al., 2008; Bos, et al., 2010). Especially in the face of stressful events, adolescents with low self-esteem is considered to have fewer coping resources and are therefore more vulnerable for the development of psychological symptoms, whereas those with high selfesteem are buffered against this effect (Abela, Webb, Wagner, Ho, & Adams, 2006; Orth, Robins, & Meier, 2009). Orth, Robins, & Meier (2009) state that "following stressful events, protective factors such as high self-esteem, may prevent the outcome of depressive symptoms by decreasing the negative impact of depressogenic thoughts on the affective, cognitive, behavioural, and physiological symptoms of depression" (p. 308). The self-esteem buffering hypothesis has been tested in numerous studies; however, previous research testing the moderating role of self-esteem has yielded inconsistent results (see Abela et al., 2006; Orth, Robins, & Meier, 2009). The study by Moksnes et al. (2010b) found a weak moderating role of self-esteem on the association between stress of peer pressure and the outcome of state depression and anxiety, as well as between each of stress of school performance and romantic relationships in association with state anxiety. This finding supports the protective role of self-esteem in association with adolescent stress and emotional health outcomes and the importance of strengthening self-esteem during the adolescent years.

#### *Implications*

The identification of the link between stressful life events and negative health outcomes represents an important step toward developing interventions for children and adolescents. One target for preventive interventions could certainly be to reduce the burden on children and adolescents by decreasing their exposure to stress. These might include efforts to reduce stressors in the family environment as well as in the school environment. However, given the limited control that can be gained over young people's exposure to many forms of stressful situations, an even more important focus for intervention is to increase children's and adolescents' abilities to cope with stress (Grant, Behling, Gipson, & Ford, 2005).

An important target for the prevention of negative health outcomes, as well as for positive adolescent development, is to increase adolescents' awareness of their potential, their internal and external general resistance resources, and their ability to use the resources available. This may promote adolescents' ability to handle the challenges that one may experience during the adolescent period, and make their journey through adolescence a positive growth-oriented experience (Compas, Champion, & Reeslund, 2005). Previous studies suggest that effective health promotion is multifaceted, and is most successful when integrated into several arenas such as schools, families, school-health services as well as organisations where adolescents meet with peers to provide a supportive context which facilitate development of a number of protective factors in adolescents (Haugland, 2001; Natvig et al., 2006).

One way of promoting a good school environment is to focus on positive class environment and engagement in school – both social and academically. Furthermore, pedagogical methods might be used to improve notions of support among students (Joronen, Rankin, & Åstedt-Kuri, 2008; Natvig et al., 2006). An equally important aspect is to include parents, family and afterschool programs to integrate all environments that adolescents are part of. Parents need to be in close dialog with their child and to be seen as crucial actors in relation to their children's healthy development through adolescence (Compas et al., 2005; Laursen & Collins, 2009). After-school programs are also important as supportive and health promoting arenas where adolescents can form and develop a set of protective resources. It is important however, if successful, that the type of activity is in accordance with the adolescents' individual interests and preferences, and that the environment is adjusted for different activities. The discussion above shows that within health promotion among adolescents lay both personal, social and environmental conditions. A systematic approach

that aims to reduce high levels of negative stress and to develop adolescent resources may facilitate positive developmental outcomes in adolescence.

#### References

- Abela, J.R.Z., Webb, C.A., Wagner, C., Ho, M.R., & Adams, P. (2006). The role of self-criticism, dependency, and hassles in the course of depressive illness: A multiwave longitudinal study. *Personality and Social Psychology Bulletin*, 32, 328-338.
- Antonovsky, A. (1979). Health, stress and coping. San Francisco: Jossey-Bass.
- Antonovsky, A. (1987). *Unraveling the mystery of health. How people manage stress and stay well.* San Fransisco: Jossey-Bass.
- Baldwin, S.A., & Hoffmann, J.P. (2002). The dynamics of self-esteem: A growth-curve analysis. *Journal of Youth and Adolescence*, *31*, 101-103.
- Blom, E.C.H., Serlachius, E., Larsson, J.O., Theorell, T., & Ingvar, M. (2010). Low sense of coherence (SOC) is a mirror of general anxiety and persistent depressive symptoms in adolescents girls a cross-sectional study of a clinical and a non-clinical cohort. *Health and Quality of Life Outcomes*, 8, 1-13.
- Boden, J.M., Fergusson, D.M., & Horwood, L.J. (2008). Does adolescent self-esteem predict later life outcomes? A test of the causal role of self-esteem. *Development and Psychopathology*, 20, 319-339.
- Bos, A.E.R., Huijding, J., Muris, P., Vogel, L.R.R., & Biesheuvel, J. (2010). Global, contingent and implicit self-esteem and psychopathological symptoms in adolescents. *Personality and Individual Differences*, 48, 311-316.
- Bouma, E.M.C., Ormel, J., Verhulst, F.C., & Oldehinkel, A.J. (2008). Stressful life events and depressive problems in early adolescent boys and girls: The influence of parental depression, temperament and family environment. *Journal of Affective Disorders*, 105, 185-193.
- Byrne, D.G., Davenport, S.C., & Mazanov, J. (2007). Profiles of adolescent stress: The development of the adolescent stress questionnaire (ASQ). *Journal of Adolescence*, *30*, 393-416.
- Caltabiano, M.L., Sarafino, E.P., & Byrne, D. (2008). *Health Psychology* (2<sup>nd</sup> ed). Australia: John Wiley & Sons Ltd.
- Charbonneau, A.M., Mezulis, A.H., & Hyde, J.S. (2009). Stress and emotional reactivity as explanations for gender differences in adolescents' depressive symptoms. *Journal of Youth and Adolescence*, *38*, 1050-1058.

- Compas, B.E., Champion, J.E., & Reeslund, K. (2005). Coping with stress: Implications for preventive interventions with adolescents. *The Prevention Researcher*, *12*, 17-20.
- Compas, B.E., & Reeslund, K.L. (2009). Processes of risk and resilience during adolescence. In: R.M. Lerner & L. Steinberg (Eds.) *Handbook of adolescent psychology* (3<sup>rd</sup> ed) (pp. 561-588). New Jersey: John Wiley and Sons, Inc.
- Cote, J.E. (2009). Identity formation and self-development in adolescence. In: R.M. Lerner & L. Steinberg (Eds.) *Handbook of adolescent psychology* (3<sup>rd</sup> ed) (pp.266-304). New Jersey: John Wiley and Sons, Inc.
- Edwards, S. (2006). Physical exercise and psychological well-being. *South African Journal of Psychology*, *36*, 357-373.
- Ekeland, E., Heian, F., & Hagen, K.B. (2005). Can exercise improve self-esteem in children and young people? A systematic review of randomised controlled trials. *British Journal of Sports Medicine*, *39*, 792-798.
- Eriksson, M. (2007). *Unravelling the mystery of salutogenesis. The evidence base of the salutogenic research as measured by Antonovsky's Sense of Coherence Scale.*(Research Report No. 1). Turku: Folkhälsan Research Centre, Health promotion research programme.
- Eriksson, M., & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: A systematic review. *Journal of Epidemiology and Community Health*, 59, 460-466.
- Gerber, M., & Pühse, U. (2009). Do exercise and fitness protect against stress-induced health complaints? A review of the literature. *Scandinavian Journal of Public Health*, 37, 801-819.
- Graber, J.A., & Sontag, L.M. (2009). Internalizing problems during adolescence. In:

  R.M. Lerner & L. Steinberg, *Handbook of adolescent psychology* (3<sup>rd</sup> ed) (pp. 642-682). New Jersey: John Wiley and Sons, Inc.
- Grant, K.E., Behling, S., Gipson, P.Y., & Ford, R.E. (2005). Adolescent stress: The relationship between stress and mental health problems. *The Prevention Researcher* 12, 3-6.

- Grant, K.E., Compas, B.E., Stuhlmacher, A.F., Thurm, A.E., McMahon, S.D., & Halpert, J.A. (2003). Stressors and child and adolescent psychopathology:

  Moving from markers to mechanisms of risk. *Psychological Bulletin*, 129, 447-466.
- Grant, K.E., Compas, B.E., Thurm, A.E., McMahon, S.D., Gipson, P.Y., Campbell, A.J., Krochock, K., & Westerholm, R.I. (2006). Stressors and child and adolescent psychopathology: Evidence of moderating and mediating effects. *Clinical Psychology Review, 26,* 257-283.
- Greene, M.L., & Way, N. (2005). Self-esteem trajectories among ethnic minority adolescents: A growth curve analysis of the patterns and predictors of change. *Journal of Research on Adolescence*, 15, 151-178.
- Hallal, P.C., Victoria, C.G., Azevedo, M.R., & Wells, J.C.K. (2006). Adolescent physical activity and health. *Sports Medicine*, *36*, 1019-1030.
- Hammen, C. (2005). Stress and depression. *Annual Review of Clinical Psychology, 1*, 293-319.
- Hankin, B.L., Mermelstein, R., & Roesch, L. (2007). Sex differences in adolescent depression: Stress exposure and reactivity models. *Child Development*, 78, 279-295.
- Haugland, S. (2001). School related stress, physical activity, and health complaints in adolescence. (Doctoral dissertation, Research Centre for Health Promotion, University of Bergen, Norway).
- Jerstad, S.J., Boutelle, K.N., Ness, K.K., & Stice, E. (2010). Prospective reciprocal relations between physical activity and depression in female adolescents. *Journal of Consulting and Clinical Psychology*, 78, 268-272.
- Joronen, J., Rankin, S.H., & Åstedt-Kurki, P. (2008). School-based drama interventions in health promotion for children and adolescents: systematic review. *Journal of advanced nursing*, 63, 116-131.
- Laursen, B., & Collins, W. A. (2009). Parent–child relationships during adolescence. In R. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology: Vol. 2.*Contextual influences on adolescent development (3<sup>rd</sup> Ed) (pp. 3–42). New York, NY: Wiley.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publication.

- Lindström, B., & Eriksson, M. (2010). *The hitchhiker's guide to salutogenesis*.

  Salutogenic pathways to health promotion. Folkhälsan Research Center Health Promotion Research (Research Report No. 2), Helsinki.
- McLaughlin, K.A., & Hatzenbuehler, M.L. (2009). Stressful life events, anxiety sensitivity, and internalizing symptoms in adolescents. *Journal of Abnormal Psychology*, *118*, 659-669.
- McLaughlin, K.A., Hatzenbuehler, M.L, & Phil, M.S. (2009). Mechanisms linking stressful life events and mental health problems in a prospective, community-based sample of adolescents. *Journal of Adolescent Health*, *44*, 153-160.
- Moksnes, U.K., Byrne, D.G., Mazanov, J., & Espnes, G.A. (2010). Adolescent stress: Evaluation of the factor structure of the Adolescent Stress Questionnaire. *Scandinavian Journal of Psychology*, *51*, 203-209.
- Moksnes, U.K. & Espnes, G.A.(2011). Stress, Sense of Coherence and Emotional States in Adolescents. Paper submitted for publication.
- Moksnes, U.K. & Espnes, G.A. (2011). Evaluation of the Norwegian version of the Adolescent Stress Questionnaire (ASQ-N): Factorial validity across samples. *Scandinavian Journal of Psychology*, *52*, 601-608.
- Moksnes, U.K., Espnes, G.A., & Lillefjell, M. (2011). Sense of coherence and emotional health in adolescents. *Journal of Adolescence*, *35*, 433-441.
- Moksnes, U.K., Moljord, I.E.O., Espnes, G.A., & Byrne, D.G. (2010a). Leisure time physical activity does not moderate the relationship between stress and psychological functioning in Norwegian adolescents. *Mental Health and Physical Activity*, *3*, 17-22.
- Moksnes, U.K., Moljord, I.E.O., Espnes, G.A., & Byrne, D.G. (2010b). The association between stress and emotional states in adolescents: The role of gender and self-esteem. *Personality and Individual Differences*, 49, 430-435.
- Moksnes, U.K., Rannestad, T., Espnes, G.A., & Byrne, D.G. (2011). The association between stress, sense of coherence and subjective health complaints in adolescents: sense of coherence as a potential moderator, *Stress and Health*, *27*, e157-e165.
- Muris, P., Meesters, C., & Fijen, P. (2003). The self-perception profile for children: Further evidence for its factor structure, reliability, and validity. *Personality and Individual Differences*, *35*, 1791-1802.

- Natvig, G.K., Hanestad, B.R., & Samdal, O. (2006). The role of the student: Salutogenic or pathogenic. *International Journal of Nursing Practice*, 12, 280-287.
- Neuner, B., Busch, M.A., Singer, S., Moons, P., Wellmann, J., Bauer, U., Nowak-Göttl, U., & Hense, H.W. (2011). Sense of Coherence as a predictor of quality of life in adolescents with congenital heart defects: A register-based 1-year follow-up study. *Journal of Developmental & Behavioral Pediatrics*, 32, 316-327.
- Nielsen, A.M., & Hansson, K. (2007). Associations between adolescents' health, stress and sense of coherence. *Stress and Health*, *23*, 331-341.
- Orth, U., Robins, R.W., & Meier, L.L. (2009). Disentangling the effects of low self-esteem and stressful events on depression: Findings from three longitudinal studies. *Journal of Personality and Social Psychology*, 97, 307-321.
- Orth, U., Robins, R. W., & Roberts, B. W. (2008). Low self-esteem prospectively predicts depression in adolescence and young adulthood. *Journal of Personality and Social Psychology*, *95*, 695–708.
- Orth, U., Robins, R.W., Trzesniewski, K.H., Maes, J., & Schmitt, M. (2009). Low self-esteem is a risk factor for depressive symptoms from young adulthood to old age. *Journal of Abnormal Psychology*, 118, 472-478.
- Ozer, E.M., & Irwin, C.E. (2009). Adolescent and young adult health: From basic health status to clinical interventions. In: R.M. Lerner & L. Steinberg (Eds.) *Handbook of Adolescent Psychology* (3<sup>rd</sup> ed) (pp.618-641). USA: John Wiley and Sons, Inc.
- Öztekin, O., & Tezer, E. (2009). The role of sense of coherence and physical activity in positive and negative affect of Turkish adolescents. *Adolescence*, 44, 421 431. Piko, B.F., & Keresztes, N. (2006). Physical activity, psychosocial health, and life goals among youth. *Journal of Community Health*, 31, 136-145.
- Räty, L.K.A., Larsson, G., Söderfeldt, B.A., Wilde Larsson, B.M. (2005). Psychosocial aspects of health in adolescence: The influence of gender, and general self-concept. *Journal of Adolescent Health*, *36*, 530.e21-530.e28.
- Richardson, C.G., & Ratner, P. (2005). Sense of coherence as a moderator of the effects of stressful life events on health. *Journal of Epidemiology and Community Health*, *59*, 979–984.

- Ristakari, T., Sourander, S., Rønning, J.A., Nikolakaros, G., & Helenius, H. (2008).

  Life events, self-reported psychopathology and sense of coherence among young men A population-based study. *Nordic Journal of Psychiatry*, *62*, 464 471.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. New Jersey: Princeton University Press.
- Salmon, P. (2001). Effects of physical exercise on anxiety, depression, and sensitivity to stress: A unifying theory. *Clinical Psychology Review*, *21*, 33-61.
- Schmalz, D.L., Deane, G.D., Birch, L.L., & Davison, K.K. (2007). A longitudinal assessment of the links between physical activity and self-esteem in early adolescent non-hispanic females. *Journal of Adolescent Health*, *41*, 559-565.
- Shih, J.H., Eberhart, N.K., Hammen, C.L., & Brennan, P.A. (2006). Differential exposure and reactivity to interpersonal stress predict sex differences in adolescent depression. *Journal of Clinical Child and Adolescent Psychology*, 35, 103-115.
- Steinberg, L.D. (2008). Adolescence (8<sup>th</sup>ed.). Boston: McGraw-Hill Higher Education.
- Sundblad, G. B., Jansson, A., Saartok, T., Renström, P., & Engström, L. M. (2008). Self-rated pain and perceived health in relation to stress and physical activity among school-students: A 3-year follow-up. *Pain, 136,* 239-249.
- Torsheim, T., Aaroe, L.E., & Wold, B. (2001). Sense of coherence and school-related stress as predictors of subjective health complaints in early adolescence: Interactive, indirect or direct relationships? *Social Science and Medicine*, *53*, 603-614.
- Trzesniewski, K.H., Donnellan, M.B., Moffitt, T.E., Robins, R.W., Poulton, R., & Caspi, A. (2006). Low self-esteem during adolescence predicts poor health, criminal behavior, and limited economic prospects during adulthood. Developmental Psychology, 42, 381-390.

# 14. Knowledge based health promotion in Public Health, the HUNT Study, Norway

# Opportunities for health promotion research

#### STEINAR KROKSTAD

HUNT Research Centre, Deptartment of Public Health and General Practice, Faculty of Medicine,

Norwegian University of Science and Technology, Norway

#### Abstract

Health promotion needs to be based on several types of knowledge, not at least data on the public health development. The HUNT Study constitutes a large population database for medical and health related research in Norway. So far three large health surveys of the total adult population in the Nord-Trøndelag County, have been completed; HUNT1 (1984-86), HUNT2 (1995-97), HUNT3 (2006-08). Adolescents aged 13-19 years have also been invited to the Young-HUNT Study from 1995-97. Health promotion researchers have proposed a quality of life model relevant for health promotion research. Nine domains are described, for understanding how personal and community factors influence health and well-being. All of these domains are more or less covered by the HUNT Study. New initiatives in health promotion research should take advantage of established population based longitudinal health studies like HUNT, looking for factors contributing to positive health development and well-being.

# Need for knowledge

Health promotion needs to be based on several types of knowledge (1986; Marmot, 1998): The public health development for the population to be served, background contextual information about the political situation, historical, cultural and economic conditions, and knowledge relevant for implementation of health promotion measures.

This chapter is primarily about obtaining knowledge of public health development. We need to know what people are exposed to, their health related behaviour and the prevalence of good health, quality of life, health complaints and diseases. Humans have historically often been exposed to life threatening surroundings and diseases. This is still the case for large populations, suffering from famine, disaster and war. However, an increasing share of the world's population benefit from improved living conditions and modern medical

treatment. This contributes to reduced mortality and increasing life expectancy. The need to study the causes of premature death is increasingly being superseded by the need to study what contributes to quality of life and good health. This also reflects what has been the focus of the HUNT Study, from the 1980s until today.

# The HUNT Study, Norway

The HUNT Study (an abbreviation of the Norwegian name: "Helseundersøkelsen i Nord-Trøndelag) constitutes a large population database for medical and health related research (www.ntnu.edu/hunt). So far three large health surveys of the general adult population in the Nord-Trøndelag County, Norway (Figure 1) have been completed, HUNT1 in 1984-86, HUNT2 in 1995-97, and HUNT3 in 2006-08 (Krokstad et al, 2012). At the time of HUNT2 and HUNT3, adolescents aged 13-19 years also were invited to the Young-HUNT Study, with partly overlapping scientific program. All questionnaires are published on our webpage: http://www.ntnu.edu/hunt/data/que.

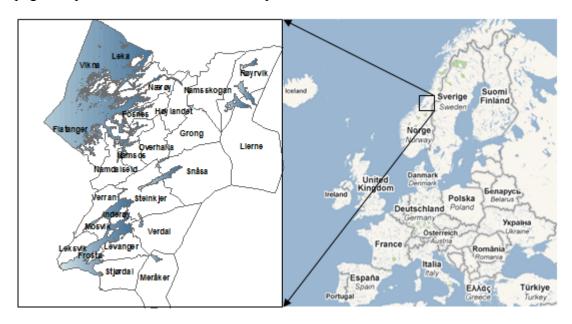


Figure 1. The HUNT Study research area, the Nord-Trøndelag County, the 24 municipalities, Norway.

#### Setting

Norway is a North-European country characterized as a social democratic welfare state, (Esping-Andersen, 1990) with generous universal public health insurance coverage, and predominately public health services. The average life expectancy (2009) is 83 years in women and 79 in men. Nord-Trøndelag constitutes one of 19 counties, geographically situated in the mid part of the country. The population size is relatively stable and increased slowly in size from HUNT1 (125 835 in 1981) to HUNT3 (128 694 in 2006), and except for

young adults moving out to get education and other reasons, the in and out migration has been low.

HUNT1 (1984-86), based in primary care, was designed to address arterial hypertension, diabetes and chest X-ray screening of tuberculosis. These were central health topics in the 1980ies, the mortality of cardiovascular diseases was still high, the treatment programmes for diabetes was under development and the health authorities were still occupied with tuberculosis control. However, data on health related behaviour and quality of live were also included, highly relevant for health promotion research. (Moum, Naess, Sorensen, Tambs, & Holmen, 1990)

The scope of HUNT has since then expanded over time and contributed to important knowledge regarding health promoting factors, health related life style, prevalence and incidence of good health, illness and disease, causal relationships and associations between disease phenotypes and genotypes.

The surveys have been set up by the HUNT Research Centre, organized under the Norwegian Institute of Public Health until 2001, and thereafter The Norwegian University of Science and Technology (NTNU).

HUNT has largely been publicly funded. HUNT3 was mainly funded by The Norwegian Ministry of Health, NTNU, The Norwegian Research Council (the FUGE programme), Central Norway Regional Health Authority, The Nord-Trøndelag County Council and The Norwegian Institute of Public Health. Funding also has been given by some commercial enterprises.

#### The HUNT1 Survey, adults aged 20+ (established 1984-86)

In 1984-86 every citizen of Nord-Trøndelag County being 20 years or older (or turning 20 years during the year of survey) were invited. Totally 77 212 persons participated (89% of those invited). Questionnaires and clinical measurements were applied. Participants with findings indicating pathology were advised to see their family doctor. The design applied in HUNT1 was largely repeated in HUNT2 and HUNT3. The material is in epidemiological terminology considered being a cohort, because the participants may be followed up in later surveys and other health registers described below.

### The HUNT2 Survey, adults aged 20 + (established 1995-97)

HUNT2 constituted both a new cross sectional survey and a follow-up of HUNT1.(Holmen et al., 2003) The scientific programme was extended to include several large public health issues in accordance with current national health priorities. These were in addition to cardiovascular diseases, and diabetes, obstructive lung disease, osteoporosis, headache, mental health, chronic musculoskeletal pain and urinary incontinence. In addition to questionnaires, interviews and clinical examinations, the participants contributed with blood samples for instant analysis and storage. A total of 65 237 participated in HUNT2 (70% of those invited).

#### The HUNT3 Survey, adults aged 20+ (established 2006-08)

The scientific programme of HUNT3 included several main public health issues as in HUNT2, but included also topics like culture participation and religious affiliation. Data on health related behaviour like alcohol use, tobacco use, diet and physical activity was collected as in all surveys. For traditional medical research, optimal handling and storage of blood and urine samples were given high priority, as part of the establishment of a new upto-date biobank (Krokstad et al, 2012).

#### The Young-HUNT1 Survey, adolescents aged 13-19 years (established 1995-97)

The Young-HUNT Study was decided to include adolescents aged 13 – 19 years in HUNT, starting from HUNT 2 in 1995-97, forming the Young-HUNT1 Survey. The Young-HUNT Study was designed to cover a broad scale of topics in relation to major public health issues in adolescents. The main focus of somatic health problems has been respiratory and allergic diseases, subjective health problems, different types of headaches and eating problems including overweight and obesity. Mental health focus includes anxiety and depression, self esteem, personality and well being. Health behaviours focus on alcohol use, tobacco use, diet, regularity of meals, dieting and physical activity. Puberty, school problems and leisure time activity were also included. The Young-HUNT questionnaires are published on our web-page: http://www.ntnu.edu/hunt/data/que.

#### The Young-HUNT2 Survey, adolescents aged 16-19 years (2000-2001)

This survey was a four years follow-up of the youngest participants aged 13-16 years in Young-HUNT1, thus following the lower secondary school cohort into upper secondary school.

The Young-HUNT3 Survey, adolescents aged 13-19 years (established 2006-08)

A new total cohort, the Young-HUNT 3 survey was included in HUNT3 (2006-08). The topics from Young-HUNT1 were largely continued, but questions about resilience were included. The participation rates have been high in Young-HUNT, not at least because data are collected at schools (all secondary schools and vocational schools in the county, a total of about 60 schools).

# HUNT-data are being linked to national complete high quality registers in several studies

Researchers always receive de-identified data for research purpose. However, all HUNT data are stored in HUNT databank linked to the unique personal identification number (PIN) enabled every Norwegian citizen at birth. This makes it possible to link data between surveys and study parts for each participant in HUNT, to link data from Young-HUNT to the adult part of HUNT for each participant, enabling family and longitudinal studies. It also makes it possible to link HUNT data to regional and National health registers with very few individual data missing. All registers are based on the Norwegian PIN. Data has in several studies been linked to the Norwegian Birth Register and the Norwegian Family Register, the National Cancer Register, the Causes of Death Register, the Prescription Register, the Social Security Registers (FD-trygd), the National Education Database, the Income- and tax Register, and local hospital disease registers.

#### Data relevant for health promotion research in the HUNT Study

Raphael et al have proposed a quality of life model relevant for health promotion research. Nine domains are described, and might serve as means of understanding how personal and community factors influence health and well-being (Table 1). (2010)

**Table 1.** Quality of life domains (2010)

Physical being	Physical health, mobility, nutrition, fitness, appearance
Psychological being	Independence, autonomy, self-acceptance, freedom from stress
Spiritual being	Values and standards, spiritual beliefs
Physical belonging	Physical aspects of the immediate environment
Social belonging	Relationships with family, friends and acquaintances
Community belonging	Availability of societal resources and services
Practical becoming	Home, school and work activities
Leisure becoming	Indoor and outdoor activities, recreational resources
Growth becoming	Learning, improving skills and relationships, adapting

All of these domains are more or less covered by the HUNT Study, not necessary all in one survey, but many domains have often been covered and might be studied together. All questionnaire data are presented at our web-site: http://www.ntnu.edu/hunt/data/que.

All the HUNT surveys cover demographic data, sex and marital status, and families may be clustered with the Family Register, now also being integrated in the HUNT Databank from 2012. Thus, for adolescents for example, a lot of information on health and socioeconomic conditions in their families is registered in the data from their parents.

Physical being (table 1) is covered by all surveys, physical health and mobility are carefully described, and nutrition is covered by clinical measurements of body mass index (BMI) and some diet questions. Fitness are partly covered, questionnaires for people aged 70+ cover activities of daily life (ADL).

Psychological being is covered to some extent in all surveys by questions about personality traits, loneliness, and symptoms of anxiety and depression, quality of life, psychosocial factors at home and at work. In Young-HUNT3 data on resilience was included.

*Spiritual being* was included in the latest survey for adults, HUNT3, with questions of life philosophy, religious attendance and seeking God's help.

*Physical belonging* and physical aspects of the immediate environment might be analysed. By linking individual data from HUNT to geographic information about the municipality of living, residential circuit, or GIS (geographic information systems)-data, multi-level and other designs might be utilized.

Social belonging is quite extensively covered in all surveys, not at least in Young-HUNT. In HUNT3, data on serious events and childhood experiences are covered, including questions that might indicate post traumatic stress. In HUNT2 and HUNT3 data on social capital in the neighbourhood is covered in questionnaire 2.

Community and practical belonging, regarding availability of societal resources and services, is partly covered by data on social capital in the neighbourhood in HUNT2 and HUNT3. More data is available by linkage to GIS-data in the county and in the municipalities. The importance of distances between home and the resources of society might be analyzed.

Leisure becoming is quite extensively covered by all the HUNT surveys. In the latest survey (HUNT3), several questions on active and passive culture and leisure activity participation are covered.

Growth becoming might be analysed in the HUNT Study, not at least by the opportunities in the longitudinal cohort design, and life course approaches. Data on physical health at birth might be linked from the National Birth Register, data on education achievement from HUNT data or from the National Education Database (Statistics Norway), data on occupational status from HUNT data and data on need for public social services might be linked from the National Social Security Database (FD-Trygd) form Statistics Norway.

### Quality of life research opportunities

Integration of quality of life data in HUNT1 (1984-86), made research in this area possible from the very beginning. (Moum et al., 1990) A recent study has compared in-patients quality of life with the HUNT-population, utilizing HUNT as a reference normal population sample. (Helvik, Engedal, Krokstad, & Selbaek, 2011) Derdikman-Eiron et al have looked at gender differences in subjective well-being, self-esteem and psychosocial functioning in adolescents with symptoms of anxiety and depression. (Derdikman-Eiron et al., 2011)

#### The culture and health initiative

Highly relevant for health promotion, the HUNT Research Centre has cooperated with the Nord-Trøndelag County Council, The Nord-Trøndelag University Collage and municipalities in the county on a public health culture and health initiative (http://www.folk2.no/). The main aim has been to exploit the possible effects of stimulating cultural participation in public health, not at least among vulnerable groups. (Knudtsen, Holmen, & Hapnes, 2005; Knudtsen, Holmen, & Hapnes, 2005) From a public health point of view, the motivation has been the constraints seen in traditional methods in health care and in public health efforts to influence health-related behaviour. (Illich, 1975; Rose, 2001) However, a recent published overview shows that the scientific basis for utilizing culture participation in public health is still scarce. (Cuypers et al., 2011)

Thus, this collaboration has resulted in the inclusion of questions on active and passive cultural participation in the questionnaires in the HUNT3 Survey (2006-08). Behaviour in the population based on these data has been mapped geographically, and has been used in the culture strategic work in the county. (2011) The first international scientific paper based on these data was published in 2011, (Cuypers et al., 2011) and attracted considerable international attention.

# Religion and health research opportunities

Population-based research on the relationship between religion and health is now possible using HUNT3-data. Several scientific papers have recently been published regarding the association between religious attendance and blood pressure. (Sørensen, Danbolt, Lien, Koenig, & Holmen, 2011).

# The opportunities for health promotion research by using data from HUNT are excellent

New initiatives in health promotion research should obviously take advantage of established population based longitudinal health studies like HUNT, looking for factors contributing to positive health development and well-being. The HUNT Study has several strengths: It covers a total population aged 20 to 100 years within a specific geographical area, including coastal and inland municipalities with different characteristics. HUNT has a wide age range, thereby covering groups of people with different cohort exposures. Data in each survey has been collected over a two years period, giving opportunity for studies of seasonal variations in health. HUNT databank includes data on an extensive range of topics. To follow an

unselected population in a well defined geographically area in North-Europe during decades, allows for a wealth of opportunities. So far, data from HUNT have been the basis for 80 PhDs (http://www.ntnu.no/hunt/doktorgradsavhandlinger).

The Norwegian Research Council has just stated that "Norway has succeeded in creating large, important and very impressive longitudinal population-based databases, which, together with national health registries and the personal identification number, constitute unique possibilities to do excellent research in an international perspective".(2011) The Research Council recommends strongly that the databases are used in new areas of research.

Data from the HUNT Study are available for researchers who satisfy some basic requirements (www.ntnu.edu/hunt), whether affiliated in Norway or abroad. To provide the researcher or research group exclusive rights, the HUNT Research Centre signs a contract with the research institution in charge. The exclusive rights are connected to a specific publication plan based on an application form, a scientific protocol, an ethical approval, other necessary approvals (if any), and a variable specification list.

More details about the contents of the questionnaire and clinical measurements can be found on our website (<a href="www.ntnu.edu/hunt">www.ntnu.edu/hunt</a>).

# The HUNT Study and health promotion in the Nord-Trøndelag County, Norway

The researchers behind the HUNT Study have always cooperated with the health authorities in the county, municipalities and the health services on public health issues, and located the research centre in the middle of the county. The cooperation has been formalized through the establishment of an advisory group for HUNT, through meetings and conferences. This has been important for the development of a relevant content in the health surveys, attendance among the invited population, assessment of the health study's impact on workload in the health service and cooperation on prevention and health promotion.

HUNT Research Centre has attached great importance to safeguard the legal, privacy and ethical aspects of the study, and compiled health statistics based on the collected data to be used in public health. (2011) This "locally present - reinvestment approach" has been termed a *sustainable population-based research strategy*.

#### References

- Ottawa charter for health promotion. (1986). Ottawa, WHO.
- Health promotion and quality of life in Canada (2010). Toronto: Canadian Sholars' Press Inc.
- Evaluation of Biology, Medicine and Health Research in Norway (2011). Report of the Principal Evaluation Committee. The Research Council of Norway: Oslo.
- Public Health Development. The HUNT Study Norway. HUNT1 (1984-86) HUNT2 (1995-97) HUNT3 (2006-08) (2011). Levanger: HUNT Research Centre, Department of Public Health and General Practice, Norwegian University of Science and Technology.
- Strategi for folkehelsearbeidet i Nord-Trøndelag 2011-2014. (Strategy for public health in Nord-Trøndelag County 2011-2014). (2011). Steinkjer: Nord-Trøndelag Fylkeskommune. (The Nord-Trøndelag County Council).
- Cuypers, K., Knudtsen, M. S., Sandgren, M., Krokstad, S., Wikström, B. M., & Theorell, T. (2011). Cultural activity and public health: research in Norway and Sweden. An overview. *Arts and health*, *3*, 6-26.
- Cuypers, K., Krokstad, S., Lingaas, H. T., Skjei, K. M., Olov, B. L., & Holmen, J. (2011). Patterns of receptive and creative cultural activities and their association with perceived health, anxiety, depression and satisfaction with life among adults: the HUNT study, Norway. *Journal of Epidemiology and Community Health*.
- Derdikman-Eiron, R., Indredavik, M. S., Bratberg, G. H., Taraldsen, G., Bakken, I. J., & Colton, M. (2011). Gender differences in subjective well-being, self-esteem and psychosocial functioning in adolescents with symptoms of anxiety and depression: findings from the Nord-Trondelag Health Study. *Scandinavian Journal of Psychology*, *52*, 261-267.
- Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Cambridge: Polity Press.
- Helvik, A. S., Engedal, K., Krokstad, S., & Selbaek, G. (2011). A comparison of life satisfaction in elderly medical inpatients and the elderly in a population-based study: Nord-Trondelag Health Study 3. *Scandinavian Journal of Public Health*, *39*, 337-344.

- Holmen, J., Midthjell, K., Krüger, Ø., Langhammer, A., Holmen, T. L., & Bratberg, G.
  H. et al. (2003). The Nord-Trøndelag Health Study 1995-97 (HUNT 2).
  Objectives, Cintants, Methods and Participation. *Norsk Epidemiologi, 13*, 19-32.
- Illich, I. D. (1975). *Medical nemesis: the expropriation of health*. London: Calder and Boyars.
- Knudtsen, M. S., Holmen, J., & Hapnes, O. (2005). Cultural approaches to treatment and public health work. *Tidsskrift for Den Norske Legeforening*, 125, 3434-3436.
- Knudtsen, M. S., Holmen, J., & Hapnes, O. (2005). What do we know about participation in cultural activities and health? *Tidsskrift for Den Norske Legeforening*, 125, 3418-3420.
- Krokstad, S., Langhammer, A., Hveem, K., Holkem, T.L., Midthjell, K., Stene, T., Bratberg, G., Heggland, J., Holken, J. Cohort profile: The HUNT Study, Norway. Int J Epidemiol, 2012; in press.
- Marmot, M. (1998). Improvement of social environment to improve health. *Lancet*, *351*, 57-60.
- Moum, T., Naess, S., Sorensen, T., Tambs, K., & Holmen, J. (1990). Hypertension labelling, life events and psychological well-being. *Psychological Medicine*, *20*, 635-646.
- Rose, G. (2001). Sick individuals and sick populations. *International Journal of Epidemiology*, 30, 427-432.
- Sørensen, T., Danbolt, L. J., Lien, L., Koenig, H. G., & Holmen, J. (2011). The relationship between religious attendance and blood pressure: The HUNT Study, Norway. *International Journal of Psychiatry in Medicine*, 42, 13-28

# 15. Self-transcendence, well-being, and nurse-patientinteraction in cognitively intact nursing home patients

#### **GØRILL HAUGAN**

Sør-Trøndelag University College, Faculty of Nursing, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Within the overall trends towards older populations worldwide, the most rapidly growing segment is that of people over 80. Because of the characteristic patterns of gains and losses seen in the "young old" and the "old old", the last part of the life-span have been divided into two separate phases. For many of the "old old" (80+) physical illness, disabilities and multiple losses necessitate the need for long-term care in nursing homes. Finding new and alternative approaches to enhance wellbeing among nursing home patients is highly warranted. Research indicates that self-transcendence can be such a positive approach, revealing significant influence of self-transcendence on physical, emotional, social, functional, and spiritual wellbeing in nursing home patients. Self-transcendence is described as a dynamic process involving adaption to past physical, emotional, and spiritual distress, and a powerful coping mechanism encountering difficulties and significant life experiences. Involvement and interpersonal and intrapersonal connectedness is the core of selftranscendence. While most nursing home patients have few relationships left to provide dialogue, self-reflection, and meaningful communication, the nurse-patient interaction appears to be a vital resource to promote self-transcendence, and thus multidimensional wellbeing.

#### Introduction

The document *An Aging World* (Kinsella & He, 2009) highlights a huge shift to an older population and its consequences. In the next 30 years, the number of people over 65 worldwide will almost double to 1.3 billion, and in 10 years' time, older people will outnumber children for the first time. Within the overall trends towards older populations, the most rapidly growing segment is that of people over 80 years old: by 2050, the percentage of those 80 and older will be 31%, up from 18% in 1980 (OECD 1988). These changes have given rise to the notions of the "third" and "fourth" ages in the life-span developmental literature (Baltes and Smith 2003). This differentiation of the final part of the

life-span into two separate phases is important because of the characteristic patterns of gains (growth) and losses (decline) seen in the "young old" and the "old old" (Kirkevold 2010).

For many of the "old old" (80+), issues such as illness, disabilities, and experiences of loss of bodily functions and social relationships necessitate the need for long-term care in nursing homes. The medical status of patients admitted there are often complex, with multiple diagnoses; they require different types of medical treatment, not to cure their illnesses, but for palliation. Because of the numbers of elderly requiring advanced care and treatment, knowledge about quality-of-life and wellbeing in nursing homes is becoming more important in research and practice. Disabilities, experiencing loss of functions and social relations, and approaching mortality lead to vulnerability and distres: in particular, loneliness and depression are identified as risks to emotional wellbeing of older people (Savikko 2008, Routasalo et al. 2006). Rates of depression in nursing homes are three to four times higher than in community-dwellings for older adults (Jongenelis et al. 2004). Older people lacking social and emotional support tend to be more depressed (Grav et al. 2012). Simultaneously, nursing home care increasingly targets those elderly with the greatest needs in terms of personal daily activities, while services supporting their psychosocial and spiritual needs tend to be ignored (Vaarama and Tiit 2007). Additionally, the in-house nursing home daily life typically brings about loss of independence and privacy, feelings of isolation and loneliness, lack of meaningful in-house activities, which are all identified as risk factors for depression and thereby affect wellbeing (Konnert et al. 2009, Meeks et al. 2009, Namkee et al. 2008).

Thus, to promote wellbeing is a fundamental and a major nursing concern in long-term care (Drageset et al. 2009, Nakrem et al. 2011). Finding new and alternative approaches to increase wellbeing is highly warranted. Self-transcendence is a vital resource for wellbeing that could offer a positive approach among vulnerable populations and at the end of life (Ellerman and Reed 2001, Reed 2009a, Baker 2008, Hoshi 2008). Hence, efforts to extend knowledge about the measurement of self-transcendence, and the relationships between self-transcendence and multidimensional wellbeing are needed to assist nurses in promoting wellbeing.

# Self-transcendence – a resource for wellbeing

The concept of self-transcendence has been studied in various disciplines, but is of particular interest to nursing. Themes of self-transcendence are evident in foundational nursing theories

(Reed 1996); internationally acknowledged nursing theories such as Watson (1988), Parse (1992), and Newman (1994) outline transcendence integral to understanding the essence of patients' health, wellbeing, and nursing. Holistic nursing care focuses on healing the whole person through the unity of body, mind, emotion, spirit, and environment. Within the framework of body-mind-spirit as a whole, self-transcendence has been considered a central aspect of humans' spirituality (Quinn 2005, Wang 2011), and has been related to spiritual as well as non-spiritual factors. Self-transcendence is a dynamic process involving adaption to past physical, emotional, and spiritual distress, and as such, is a powerful coping mechanism: it is a correlate to and an explanatory factor of patients' wellbeing.

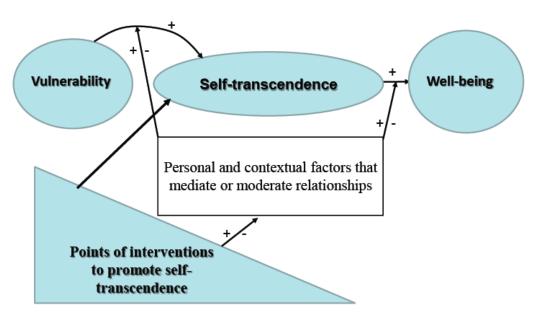
When experiencing difficulties and significant challenges, self-transcendence can lead to personal transformation and provide wellbeing and improved quality-of-life (Teixera 2008, Runquist and Reed 2007, Reed 1992). The concept of *vulnerability* is one of the self-transcendence theory's basic concepts and reflects awareness of personal mortality, which is an existential experience. Nursing home patients are considered a particular vulnerable population, while transcending many losses, illnesses, and facing death.

The self-transcendence theory addresses an enhanced understanding of wellbeing in vulnerable populations (Reed 2008). Wellbeing, vulnerability, and self-transcendence are the basic concepts, followed by three major propositions. The first is that, due of vulnerability, self-transcendence is greater in persons facing end-of-own-life issues than in persons not facing such issues. End-of-own-life issues are interpreted broadly, as they arise with life events, illness, aging, and other experiences that increase the awareness of personal mortality. The second proposition is that conceptual boundaries are related to wellbeing (Reed 1991b). And thirdly, personal and environmental factors function as correlates, moderators, or mediators of the relationships between vulnerability, self-transcendence, and wellbeing (Reed 2008).

Self-transcendence is defined as a "characteristic of developmental maturity wherein there is enhanced awareness of the environment and an orientation towards broader life perspectives" (Reed 2008, p.107). Hence, Reed (2008) presents self-transcendence as a major psychosocial resource of developmental maturity which allows one to overcome ego concerns and search for new perspectives and deeper understandings of life, death, oneself, meaning, and acceptance of the self, others and one's life situation, and thus wellbeing (Reed 2008). This idea is inspired by human developmental theory emphasizing maturity as the developmental task in later life (Erikson 1950). In accordance with this theory the

developmental crisis in old age entails integrity versus despair, and is resolved by the development of inner resources such as personal maturity and wisdom, which are qualities providing wellbeing. Consequently, the developmental process of self-transcendent maturity is stimulated by the challenges of aging and coming to terms with death (Dalby 2006).

The central core of self-transcendence is expansion of the self-boundaries through multi-level connectedness; *intrapersonal* connectedness (inwardly; within the person through self-acceptance and meaning in life), *interpersonal* connectedness (outwardly/between; by reaching out to others or connecting with nature), *transpersonal* connectedness (upwardly; beyond the person by reaching out to a higher entity), and *temporality* (by integrating one's past and future into the present) all of which positively influence healing and wellbeing (Reed 1997, Reed 2008, Coward and Reed 1996). Figure 1 portrays a model of the essential propositions of the Self-Transcendence theory:



**Figure 1**. Model of self-transcendence theory from Reed (2008) Theory of Self-transcendence. In Smith & Liehr (eds 2008) Middle Range Theory for Nursing. Springer, New York. Used by permission.

# Research on self-transcendence and wellbeing

Early studies by Reed (1986, 1991a, 1989) involving people aged 80-100 years indicate a significant inverse relationship between self-transcendence and depression, results supported in later and recent studies (Klaas 1998, Hsu 2009, Haugan and Innstrand 2012). Intrapersonal and interpersonal expressions of self-transcendence are positively related to emotional wellbeing, health, and functioning in adults confronting personal mortality because of advanced age and/or chronic illness (Coward and Reed 1996, Neill 2002, Baker 2008, Nygren et al. 2005, Mellors et al. 1997, Upchurch and Muller 2005). Self-transcendence is

linked to wellbeing in a variety of populations (Reed 1991a, Mellors et al. 1997, Ellerman and Reed 2001, Hunnibell et al. 2008, Bickerstaff et al. 2003), and has been previously examined among vulnerable groups, particularly those who have experienced a life-changing diagnosis, such as AIDS (Mellors et al. 1997, Kausch and Amer 2007), cancer (Coward 1990c, Coward and Kahn 2005, Carpenter et al. 1999, Coward 1990b, Coward 1990a, Coward 1991) stem cell transplantation (Williams 2008), and in the homeless (Runquist and Reed 2007). Self-transcendence has also been explored in healthy populations (Coward 1996, Baker 2008) and in older adults (Reed 1991a, Upchurch 1999, Hoshi 2008).

Still, research on self-transcendence and wellbeing among nursing home patients is in its infancy, as well as research exploring the plausible causal relationships between selftranscendence and multidimensional wellbeing. A recent study of the factor structure of the self-transcendence measurement among cognitively intact nursing home patients, revealed a two-factor construct comprising interpersonal and intrapersonal self-transcendence, as psychometrically superior to the one-factor-construct (Haugan et al. 2011). Interpersonal self-transcendence involves variables such as reaching outwardly toward awareness of others and the environment by involving, sharing wisdom, helping, learning, and engaging in hobbies/interests. The interpersonal self-transcendence factor explained the greatest amount of the variance in self-transcendence (ibid.). In accordance with empirical research in nursing homes, this is an interesting finding. Nursing home patients report that relations to other people, in particular the staff nurses, family, and friends, as well as being capable of helping others in the nursing home, are fundamental to their experience of meaning in the in-house daily life (Haugan Hovdenes 2002, Haugan Hovdenes 1998, Bergland and Kirkevold 2006, Nakrem et al. 2011). The intrapersonal self-transcendence factor covers the intrawork of selfacceptance, adjusting to one's life situation, physical disabilities and one's slower pace of life, letting others help and finding meaning in past experiences. This two-factor construct of self-transcendence provides a more complex investigation of the associations between selftranscendence and other essential human aspects.

Self-transcendence and multidimensional wellbeing - interrelationships By utilizing advanced statistical analysis such as Structural Equation Modelling (SEM), the plausible causal relationships between self-transcendence and wellbeing have been examined (Haugan et al. 2012a, Haugan et al. 2012b). The two-factor construct of self-transcendence demonstrates direct influence of interpersonal self-transcendence on social and emotional wellbeing, while intrapersonal self-transcendence relates directionally to functional

wellbeing. Moreover, intrapersonal self-transcendence demonstrates total effects on physical, emotional, and functional wellbeing in cognitively intact nursing home patients (Haugan et al. 2012a). This finding is noteworthy, implying that self-transcendence not only affects nursing home patients' emotional and social wellbeing, but their physical wellbeing as well, mediated by functional and emotional wellbeing.

A separate investigation (Haugan et al. 2012b) was undertaken focusing on the interrelationships between self-transcendence and a three-factor construct of spiritual wellbeing comprising meaning, peace, and faith (Canada et al. 2008). Directional relations were found between interpersonal self-transcendence and meaning, peace, and faith, while intrapersonal self-transcendence related directly to peace, and significantly influenced on meaning, mediated by peace (Haugan et al. 2012b). Additionally, significant direct effect of self-transcendence on depression is recently demonstrated in cognitively intact nursing home patients (Haugan & Innstrand 2012).

Thus, self-transcendence affects all dimensions of wellbeing, demonstrating significant implications for promoting multidimensional wellbeing among nursing home patients. Consequently, the potential for self-transcendence - and thus wellbeing - are important considerations in nursing home care. Nurses may promote self-transcendence by facilitating patients' connections with others, family, and friends, and by stimulating reflections and connections to patients' inner thoughts and emotions. Facilitating hobbies, helping others, learning, and sharing wisdom could increase meaning in life, self-acceptance, supporting the individual to adjust and accept his or her situation, pace of life, and the forthcoming death. Self-acceptance and adjustment seem necessary for wellbeing and thriving (Haugan et al. 2012a). Because length of stay in nursing homes is long, much time is available to enter into meaningful relationships and communication with patients, pursuing appropriate interventions to promote self-transcendence and thus wellbeing. Hence, the nurse-patient-interaction is a potential resource for connectedness, supporting nursing home patients' self-acceptance, adjustment, and facilitating meaning, peace, and wellbeing.

#### Self-transcendence and the nurse-patient interaction

The nursing discipline's understanding of how a nursing process is manifested has shifted. Throughout the previous decades, the importance of establishing the nurse-patient-relationship as an integral component of nursing practice has been well documented (Rchaidia et al. 2009, Nåden and Eriksson 2004, Nåden and Sæteren 2006, Appleton 1993).

Internationally recognized nursing theorists describe nursing as a participatory process that transcends the boundaries between patient and nurse and can be learned and knowingly deployed to facilitate wellbeing (Watson 1995, Watson 1988, Travelbee 1979, Eriksson 1995b, Eriksson 1995a, Martinsen 1993, Neuman 1995, Reed 2009b, Eriksson 2001). The mid-20<sup>th</sup> century's rather mechanistic conception of nursing as a process external to patients and conducted by the nurse has been replaced by the view of nursing as a relational process and practice (Reed 2009b). Reed (2009b) argues that good nursing involves a process that is developmental, progressive, and sustaining, and a process through which wellbeing occurs.

Insight into the quality-of-life in institutionalized older adults is provided, following a symbolic-interactionistic approach. The perceptions of people living in care homes clustered around four main interrelated themes: sense of self, the care environments, relationships, and activities (Tester et al. 2004). The sense of self, meaning in life, and emotional and spiritual wellbeing is influenced by relationships, connectedness, and the caring environment. Wellbeing is influenced by communication with others, self-reflection of responsibilities, inner dialogue, and by completing unfinished business (Mok et al. 2010, Haugan Hovdenes 2002, Dwyer et al. 2008, Buck et al. 2009). Most nursing home patients have few relationships left which provide dialogue, self-reflection, and connectedness. The social climate in a nursing home environment is largely determined by the staff-patient-interactions that take place within it (Zarit et al. 1998). The nursing home daily life is institutionalized, representing loss of social relationships, privacy, self-determination, and connectedness. Additionally, rates of depression in nursing home patients are three to four times higher than in community-dwelling older adults (Jongenelis et al. 2004), and the elderly who lack social and emotional support report more depression (Grav et al. 2012). Hence, the nurse-patientrelationship might serve as a vital resource of human involvement, interaction, connectedness, and facilitator of meaningful in-house activities for nursing home patients (Haugan Hovdenes 2002).

#### Excellence in nursing care

Nursing home patients are in general extremely vulnerable, characterized by frailty, mortality, disability, powerlessness, and dependency. Accordingly, the interaction with staff nurses is critical to their self-respect, feelings of self-worth, dignity, and thus wellbeing (Clarke et al. 2003, Pipe et al. 2010, Heliker 2009). Nursing practice comprises interwoven relational, moral, and practical aspects (Martinsen 1989, Watson 2007a,b) where nursing care encompasses the patient's fundamental needs, as well as the patient's values and

experiences. Excellent nursing care is characterized by a holistic view with inherent human and moral values. Thus, excluding the patient as a unique human being is regarded as noncaring and amoral practice (Austgard 2008, Watson 1988, Nåden and Eriksson 2004, Haugan Hovdenes 2002).

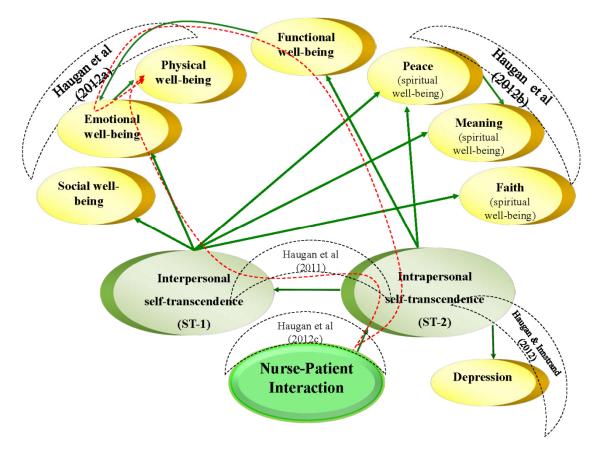
Caring nurses engage in person-to-person relationships with patients as unique individuals. Professional nursing care is defined by the nurses' way of "being-in-caring-healing-relation" (Watson, 2007), all the while performing nursing activities, in which attitudes and competences are inseparably connected. The caring nurse is present and respectful, sincere, friendly, sensitive, and responsive to the patient's feelings of vulnerability; she/he understands the patient's needs, is compassionate to patients' different sufferings, and provides emotional-social support and confirmation (Rchaidia et al. 2009, Appleton 1993, Nåden and Eriksson 2004, Haugan Hovdenes 2002, Asmuth 2004, Watson 1979, Watson 2007a,b, Watson 2005). Thus, nursing care as a moral relational practice increases patients' wellbeing (Rchaidia et al. 2009, Gastmans et al. 1998, Hollinger-Samson and Pearson 2000, Nakrem et al.). Nurse-patient-interaction can help patients to gain a sense of trust, comfort, safety, and enhanced wellbeing. Patients who are listened to feel good, satisfied and cared about (Finch 2006, Finch 2005). If nursing home patients experience not being attended to or treated with indifference then these patients describe suffering (Finch 2005, Finch 2006, Haugan Hovdenes 2002).

Recent researches provide evidence that the nurse-patient-interaction positively and significantly affects intrapersonal and interpersonal self-transcendence (Haugan et al. 2012c), hope (Haugan et al 2012d), and anxiety and depression (Haugan et al 2012e). Consequently, the nurse-patient-interaction vitalizes and encourages both interpersonal and intrapersonal self-transcendence and hope among nursing home patients. The excellence in the staff nurses' interaction with the patients has a great impact on patients' self-transcendence, hope, anxiety, and depression and thus on their wellbeing.

# Summing up and Implications

In summary, research indicates that self-transcendence is significantly related to all dimensions of wellbeing among cognitively intact nursing home patients, and also to their physical wellbeing. In the present sample about 55% reported fatigue, whilst about 50% had pain. Thus, to promote wellbeing, knowledge about how to deal with physical conditions such as fatigue and pain are essential in nursing home care (Haugan et al 2012d). Moreover,

the nurse-patient-interaction exerts significant influence on both interpersonal and intrapersonal self-transcendence, hope, anxiety and depression meaning that the nurse-patient-relationship is a fundamental resource to enhance wellbeing among nursing home patients. Facilitating nursing interventions to enhance self-transcendence possibly will promote integrity and wellbeing, and prevent despair, frustration, and suffering. Figure 2 portrays a summary of the above described significant interrelationships that are documented in recent research on self-transcendence among cognititely intact nursing home patients (Haugan et al. 2011, Haugan 2012, Haugan et al. 2012a, Haugan et al. 2012b, Haugan et al. 2012c, Haugan et al. 2012d, Haugan & Innstrand 2012):



**Figure 2** puts together the significant relationships found by means of three different SEM-models illustrated as direct and mediated influences: = mediated influence.

Nurses and professional caregivers are increasingly aware that good nursing care consists of more than the competent performance of a number of nursing activities. However, for many professional caregivers it is much less clear what this "more" means and what importance it has in nursing, wellbeing, and health. Research points out that staff contribute to nursing home patients' self-transcendence when listening interestingly to the patient, communicating, and treating the patients with respect, by empathic understanding, and acknowledging the patient as an individual who should be taken seriously, and whose needs are attended to. Since self-transcendence significantly relates to all dimensions of wellbeing, and the nursepatient-interaction relates to self-transcendence – it is reasonable to assume that nursepatient-interaction affects multidimensional sense of wellbeing, mediated by selftranscendence. Consequently, educational nursing curricula should underline and facilitate caregivers' excellence in nurse-patient-interaction and caring nursing behaviour. In order to develop a more comprehensive and practice-based view on good nursing care, that really inspires nursing home staff nurses as they perform their daily care practice, more attention should be paid to nursing home patient's' perceptions of wellbeing and good nursing care. Further research to explore these relationships among nursing home patients and other vulnerable populations as well as chronically ill persons is warranted, as is an exploration of possible self-transcendence based nursing interventions aimed at increasing wellbeing. As the number of older people increases globally and increases most rapidly among those over 80, the importance of finding new and alternative approaches to enhance wellbeing in vulnerable populations is highly warranted. Self-transcendence appears as just such a positive approach.

#### References

- Appleton, C. (1993). The art of nursing: the experience of patients and nurses. *Journal of Advanced Nursing*, 18, 892-899.
- Asmuth, M.V. (2004). Developing and sustaining interpersonal relationships between certified nursing assistants and residents in long-term care facilities (Doctoral dissertation, University of South Florida, 2004).
- Austgard, K.I. (2008). What characterises nursing care? A hermeneutical philosophical inquiry. *Scandinavian Journal of Caring Science*, *22*, 314-319.
- Baker, C.D. (2008). Self-Transcendence, death anxiety, and older adult's participation in health promotion behaviours. (Doctoral dissertation, University of Wisconsin, 2008).
- Baltes, P.B., & Smith, J. (2003). New frontiers in the future of aging: from successful aging of the young old to dilemmas of the Fourth Age. *Gerontology*, 49, 123-135.
- Bergland, A., & Kirkevold, M. (2006). Thriving in nursing homes in Norway: contributing aspects described by residents. *International Journal of Nursing Studies*, 43, 681-691.
- Bickerstaff, K., Grasser, C., & McCabe, B. (2003). How elderly nursing home residents transcend losses of later life. *Holistic Nursing Practice*, 17, 159-65.
- Buck, H.G., Overcash, J., & McMillan, S.C. (2009). The geriatric cancer experience at the end of life: testing an adapted model. *Oncology Nursing Forum*, *36*, 664-673.
- Canada, A.L., Murphy, P.E., Fitchett, G., Peterman, A.H., & Schover, L.R. (2008). A 3-factor model for the FACIT-Sp. *Psycho-Oncology*, *17*, 908-916.
- Carpenter, J.S., Brockopp, D.Y., & Andrykowski, M.A. (1999). Self-transformation as a factor in the self-esteem and well-being of breast cancer survivors. *Journal of Advanced Nursing*, 29, 1402-1411.
- Clarke, A., Jane Hanson, E., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing*, *12*, 697-706.
- Coward, D.D. (1990a). *Correlates of self-transcendence in women with advanced breast cancer*. (Doctoral dissertation, University of Arizona, 1990).

- Coward, D.D. (1990b). The lived experiences of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly*, *3*, 162-169.
- Coward, D.D. (1990c). The lived experiences of self-transcendence in women with advanced breast cancer. *Nursing Science Quarterly*, *3*, 162-169.
- Coward, D.D. (1991). Self-Transcendence and Emotional Well-Being in Women with Advanced Breast Cancer. *Oncology Nursing Forum*, *18*, 857-863.
- Coward, D.D. (1996). Self-transcendence and correlates in a healthy population. *Nursing Research*, 45, 116-121.
- Coward, D.D., & Kahn, D. (2005). Transcending Breast Cancer: Making Meaning from Diagnosis and Treatment. *Journal of Holistic Nursing*, *23*, 264-283.
- Coward, D.D. & Reed, P.G. (1996). Self-transcendence: a resource for healing at the end of life. *Issues in Mental Health Nursing*, *17*, 275-288.
- Dalby, P. (2006). Is there a process of spiritual change or development associated with ageing? A critical review of research. *Aging & Mental Health 10*, 4-12.
- Drageset, J., Natvig, G.K., Eide, G.E., Bondevik, M., Nortvedt, M.W., & Nygaard, H.A. (2009). Health-related quality of life among old residents of nursing homes in Norway *International Journal of Nursing Practice*, *15*, 455-466.
- Dwyer, L., Nordenfelt, L., & Ternestedt, B.M. (2008). Three Nursing Home Residents Speak About Meaning at The End of life. *Nursing Ethics*, *15*, 97-100.
- Ellerman, C., & Reed, P. (2001). Self-transcendence and depression in middle-aged adults. *Western Journal of Nursing Research*, *23*, 698-713.
- Erikson, E.H. (1950). *Childhood and Society*, W.W. Norton & Company, Inc: New York.
- Eriksson, K. (1995a). *Det Lidende Menneske* (The Suffering Human Being). TANO AS: Otta.
- Eriksson, K. (1995b). *Mot en Caritativ Vårdetik (Towards a Caritative Caring Ethics)*, Åbo Akademi: Åbo.
- Eriksson, K. (2001). Vårdvetenskap som akademisk disiplin (Caring science as academic discipline), Department of Caring Science, Åbo Akademi University, Vasa, Finland.
- Finch, L.P. (2005). Nurses' communication with patients: examining relational communication dimensions and relationship satisfaction. *International Journal for Human Caring*, *9*, 14-23.

- Finch, L.P. (2006). Patients' communication with nurses: relational communication and preferred nurse behaviors. *International Journal for Human Caring*, 10, 14-22.
- Gastmans, C., Dierickx de Casterlé, B., & Schotsmans, P. (1998). Nursing considered as moral practice: a philosophical-ethical interpretation of nursing. *Kennedy Institute Ethics Journal*, *8*, 43-69.
- Grav, S., Hellzèn, O., Romild, U., & Stordal, E. (2012). Association between social support and depression in the general population: the HUNT study, a cross-sectional survey. *Journal of Clinical Nursing*, *21*, 111-120.
- Haugan, G. (2012) Nurse-patient-interaction affects meaning-in-life in cognitively intact nursing-home patients. *Journal of Advanced Nursing*, **In press**.
- Haugan, G., Espnes, G.A., Rannestad, T., Hammervold, R., & Garåsen, H. (2012a).Self-Transcendence in Nursing Home Patients a Resource for Well-Being.Journal of Advanced Nursing, In press.
- Haugan, G. & Innstrand, S.T. (2012). The Effect of Self-Transcendence on Depression among Cognitively Intact Nursing Home Patients. *ISRN Psychiatry*, Article ID 301325.
- Haugan, G., Rannestad, T., Hammervold, R., Garåsen, H., & Espenes, G.A. (2012b). The Relationships between Self-Transcendence and Spiritual Well-Being in Cognitively Intact Nursing Home Patients. *International Journal of Older People Nursing*, **In press**.
- Haugan, G., Rannestad, T., Hammervold, R., Garåsen, H., & Espnes, G.A. (2011). The
   Self-Transcendence Scale An investigation of the Factor Structure among
   Nursing Home Patients. *Journal of Holist Nursing, doi:* 10.1177/0898010111429849
- Haugan, G., Rannestad, T., Hansen, B., & Espens, G.A. (2012c). Self-Transcendence and Nurse-Patient Interaction in Cognitively Intact Nursing Home Patients. *Journal of Clinical Nursing*, **In press**.
- Haugan, G., Moksnes, U. K., & Espnes, G. A. (2012d). Nurse-patient-interaction affects hope among cognitively intact nursing home patients. *Singapore Nursing Journal*, **In press**.
- Haugan, G., Innstrand, S. T., & Moksnes, U. K. (2012e). The Effect of Nurse-Patient-Interaction on Anxiety and Depression in Cognitively Intact Nursing Home Patients. *Journal of Clinical Nursing*, **In press**.

- Haugan Hovdenes, G. (1998). Et meningsfullt liv i sykehjemmet tross alt. [A meaningful life in the nursing home after all.]. *OMSORG Nordisk Tidsskrift for Palliativ Medisin [CARING Nordic Journal of Palliative Medicine]*, 2/3, 70-74.
- Haugan Hovdenes, G. (2002). Pleier-pasient-relasjonen i sykehjem: virkeliggjørelse eller tilintetgjørelse. [The Nurse-patient-relationship in nursing homes: fulfillment or destruction]. *Vård i Norden, 22*, 21-26.
- Heliker, D. (2009). Enhancing Relationships in Long-term Care Through Story Sharing. *Journal of Gerontological Nursing*, 35, 43-49.
- Hollinger-Samson, N., & Pearson, J.L. (2000). The relationships between staff empathy and depressive symptoms in nursing home residents. *Aging and Mental Health*, 4, 56-65.
- Hoshi, M. (2008). *Self-transcendence, vulnerability, and well-being in hospitalized Japanese elders.* (Doctoral dissertation, University of Arizona, 2008).
- Hsu, Y. (2009). A cultural psychosocial model for depression in elder care institutions: the roles of Socially Supportive Activity and Self-Transcendence. Doctoral dissertation, University of Arizona, 2009).
- Hunnibell, L., Reed, P., Quinn-Griffin, M., & Fitzpatrick, J. (2008). Self-Transcendence and Burnout in Hospice and Oncology Nurses. *Journal of Hospice and Palliative Nursing*, 10, 172-179.
- Jongenelis, K., Pot, A.M., Eisses, A.M.H., Beekman, A.T.F., Kluiter, H., & Ribbe, M.W. (2004). Prevalence and risk indicators of depression in elderly nursing home patients: the AGED study. *Journal of Affective Disorders*, 83, 135-142.
- Kausch, K.D. & Amer, K. (2007). Self-transcendence and depression among AIDS Memorial Quilt panel makers. *Journal of Psychosocial Nursing & Mental Health Services*, 45, 44-53.
- Kinsella, K., & He, W. (2009). *An Aging World: 2008*. Washington, DC: U.S. Department of Health and Human ServicesNational Institutes of HealthNATIONAL INSTITUTE ON AGING, U.S. Department of CommerceEconomics and Statistics
- Kirkevold, M. (2010). *Translating Chronic Illness Researc Across the Lifespan*. Blackwell Publishing Ltd: Oxford.
- Klaas, D. (1998). Testing two elements of spirituality in depressed and non-depressed elders. *International Journal of Psychiatric Nursing Research*, *4*, 452-462.

- Konnert, C., Dobson, K., & Stelmach, L. (2009). The prevention of depression in nursing home residents: a randomized clinical trial of cognitive-behavioral therapy. *Aging & Mental Health*, *13*, 288-299.
- Martinsen, K. (1989). Omsorg, sykepleie og medisin [Care, nursing and medicine], TANO: Oslo.
- Martinsen, K. (1993) Fra Marx til Løgstrup. Om etikk og sanselighet i sykepleien (From Marx to Løgstrup. About ethics and awareness in nursing), TANO AS: Otta.
- Meeks, S., Shah, S.N., & Ramsey, S.K. (2009). The Pleasant Events Schedule nursing home version: a useful tool for behavioral interventions in long-term care. *Aging & Mental Health*, *13*, 445-455.
- Mellors, M., Riley, T., & Erlen, J. (1997). HIV, Self-transcendence, and Quality of Life. *Journal of the Association of Nurses in AIDS Care*, 82, 59-69.
- Mok, E., Wong, F., & Wong, D. (2010). The meaning of spirituality and spiritual care among the Hong Kong Chinese terminally ill. *Journal of Advanced Nursing*, 66, 360-370.
- Nakrem, S., Vinsnes, A.G., & Seim, A. (2011). Residents' experiences of interpersonal factors in nursing home care: A qualitative study. *International Journal of Nursing Studies*, 48, 1357-1366
- Namkee, G., Choi, S.R., & Richard, J.W. (2008). Depression in older nursing home residents: The influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy. *Aging and Mental Health*, *12*, 536-547.
- Neill, J. (2002). Transcendence and transformation in the life patterns of women living with reumathoid arthritis. *Advances in Nursing Science*, *24*, 27-47.
- Neuman, B. (1995). *The Neuman Systems Model*, Appleton & Lange, Norwalk: Connecticut.
- Newman, M. (1994). *Health as expanding consciousness*, National League for Nursing: New York.
- Nygren, B., Alex, L., Jonsen, E., Gustafson, Y., Norberg, A., & Lundman, B. (2005).

  Resilience, sense of coherence, purpose in life and self-transcendence in relation to perceived physical and mental health among the oldest old. *Aging and Mental Health*, *9*, 354-362.

- Nåden, D., & Eriksson, K. (2004). Understanding the Importance of Values and Moral Attitudes in Nursing Care in Preserving Human Dignity. *Nursing Science Quarterly*, 17, 86-91.
- Nåden, D., & Sæteren, B. (2006). Cancer Patients' Perception of Being or Not Being Confirmed. *Nursing Ethics*, 13, 222-235.
- OECD (1988). Aging Populations: Social Policy Implications. Paris.
- Parse, R. Human becoming: Parse's theory of nursing. *Nursing Science Quarterly*, *5*, 35-42.
- Pipe, T., Hansen, R., Hentz, J., & Hartsell, Z. (2010). Rediscovering the art of healing connection by creating the tree of life poster. *Journal of Gerontological Nursing*, 36, 47-55.
- Quinn, J. (2005). Transpersonal Human Caring and Healing. In: B. Dossey, L. Keegan,
   & C. Guzzetta (Eds). *Holistic Nursing. A Handbook for Practice*, (4<sup>th</sup> Ed). Jones and Bartlett Publishers: Boston-Toronto-London-Singapore.
- Rchaidia, L., Dierckx de Casterlé, B., De Blaeser, L., & Gastmans, C. (2009). Cancer Patients' Perceptions of the Good Nurse: a Literature Review. *Nursing Ethics*, *16*, 528-542.
- Reed, P.G. (1986). Developmental resources and depression in the elderly. *Nursing Research*, *35*, 368-374.
- Reed, P.G. (1989). Mental Health of Older Adults. *Western Journal of Nursing Research*, 11, 143-163.
- Reed, P.G. (1991a). Self-transcendence and mental health in oldest-old adults. *Nursing Research*, 40, 5-11.
- Reed, P.G. (1991b). Toward a nursing theory of self-transcendence: Deductive reformulation using developmental theories. *Advances in Nursing Science*, *13*, 64-77.
- Reed, P.G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing and Health, 15*, 349-357.
- Reed, P.G. (1996). Transcendence: Formulating nursing perspectives. *Nursing Science Quarterly*, *9*, 2-4.
- Reed, P.G. (1997). The place of transcendence in nursing's science of unitary human beings: Theory and research, National Leaguge for Nursing Press: New York.
- Reed, P.G. (2008). Theory of Self-Transcendence. In: M.J. Smith, & P.R. Liehr (Eds.)

  Middle Range Theory for Nursing. (2<sup>nd</sup> Ed). Springer Publishing Company LLC:

- New York.
- Reed, P.G. (2009a). Demystifying Self-Transcendence for Mental Health Nursing Practice and Research. *Archives of Psychiatric Nursing*, *23*, 397-400.
- Reed, P.G. (2009b). Nursing: The Ontology of the Discipline. In: P.G. Reed, & N.B.C. Shearer (Eds.) *Perspectives on Nursing Theory*. Wolters Kluwer Lippincott Williams & Wilikns: Philadelphia Baltimore New York London Buenos Aires Hong Kong Sydney Tokyo.
- Routasalo, P., Savikko, N., Tilvis, R., Strandberg, T., & Pitkälä, K. (2006). Social contacts and their relationship to loneliness among aged people a population-base study. *Gerontology*, *52*, 181-187.
- Runquist, J.J., & Reed, P.G. (2007). Self-transcendence and well-being in homeless adults. *Journal of Holistic Nursing*, 25, 5-13.
- Savikko, N. (2008). Loneliness of older people and elements of an intervention for its alleviation. (Doctoral dissertation, Annales Universitatis Turkuensis University of Turku, Finland, 2008).
- Teixera, M.E. (2008). Self-Transcendence. A Concept Analysis for Nursing Praxis. *Holistic Nursing Practice*, 22, 25-31.
- Tester, S., Hubbard, G., & Downs, M. (2004). What does quality of life mean for frail residents? *Nursing & Residential Care*, *6*, 89-92.
- Travelbee, J. (1979). *Interpersonal Aspects of Nursing*, F.A. Davis Company: Philadelphia.
- Upchurch, S. (1999). Self-transcendence and Activities of daily Living: The woman with the Pink Slippers. *Journal of Holistic Nursing*, *17*, 251-266.
- Upchurch, S., & Muller, W.H. (2005). Spiritual influences on ability to engage in selfcare activities among older African Americans. *International Journal of Aging* & *Human Development*, 60, 77-94.
- US Census Bureau (2009) *An Aging World* 2008. (www.census.gov/prod/2009pubs/p95-09-1.pdf, U. G. P. O. A. a. ed.
- Vaarama, M., & Tiit, E.M. (2007). *Quality of life of older homecare clients* Springer: New York.
- Wang, J.J. (2011). A structural model of the bio-psycho-socio-spiritual factors influencing the development towards gerotranscendence in a sample of institutionalized elders. *Journal of Advanced Nursing*, 67, 2628-2636.

- Watson, J. (1979). *Nursing: the philosophy and science of caring*, Little Brown; Boston (USA).
- Watson, J. (1988). *Nursing: human science and human care. A theory of nursing.*National League for Nursing: New York.
- Watson, J. (1995). Postmodernism and knowledge development in nursing. *Nursing Science Quarterly*, 8, 60-64.
- Watson, J. (2005). Caring science as a sacred science, F.A Davis: Philadelphia, USA.
- Watson, J. (2007a). Theoretical Questions and Concerns: Response From a Caring Science Framework. *Nursing Science Quarterly*, 20, 13-15.
- Watson, J. (2007b). Watson's theory of human caring and subjective living experiences: Carative factors/Caritas processes as a disciplinary guide to the professional nursing practice. *Texto Contexto Enferm, Florianópolis, 16*, 129-135.
- Williams, B. (2008). Rebirth: The Experience of Self-Transcendence in Patients who have undergone Stem Cell Transplantation. *The College of Nursing at The College of Dentistry*, (Doctoral dissertation, New York University, New York).
- Zarit, S.H., Dolan, M.M., & Leitsch, S.A. (1998). Interventions in Nursing Homes and other Alternative Living Settings. In: I.H. Nordhus, G.R. VandenBos, S. Berg, P. Fromholt (Eds). *Clinical Geropsychology*. American Psychological Association: Washington, DC.

# 16. Religion and mental health in the elderly: An exploration of possible associations

MARIANNE NILSEN KVANDE 1,2 & TORGEIR SØRENSEN 3,4

 Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway
 Norwegian University of Science and Technology, Faculty of Social Sciences and Technology Management, Department of Social Work and Health Science, Trondheim, Norway
 <sup>3</sup>MF Norwegian School of Theology, Oslo, Norway
 <sup>4</sup>Center for Psychology of Religion, Innlandet Hospital Trust, Ottestad, Norway

#### Abstract

Even though cohorts and contexts might have some influence on an individual's religiosity, there are also strong reasons to believe that individuals tend to gain an interest in religion and spirituality as they grow older. The spiritual and religious aspects of life have been of interest to several theoreticians of developmental psychology and have also shown to be important for a healthy development in old age. Church- based social support and religious coping are important domains in the link between religion and mental health. In gerontological research, church-based social support and religious coping are found to be a unique facilitator for development of good mental health. In Norway and Scandinavia in general, research on the relationship between religion and health is particularly sparse, and even more so for the older age groups. In the final part of this chapter we look at some of the "ongoing" projects on religion/spirituality and health: we argue that new knowledge on the subject will influence how we care for those in the process of aging.

#### Introduction

Empirical studies on the association between religion and mental health is a large field within the psychology of religion. Since 1980, research on religion and health has grown extensively (Koenig, King, & Carson, 2012). The large body of evidence supporting a valid association between religion and mental health, both positive and negative, should however be further studied for two reasons. First, knowing that religiosity might serve as an important coping mechanism for some people experiencing great challenges in life (hospitalizations, injuries, loss of loved ones) could help advancing the health care system from a mere focus on a person's physical aspects to include also existential concerns that might be of importance to the individual. Second, the research performed to explore a possible link

between religion and health is, for the most part, conducted in USA in the Christian tradition (Koenig, et al., 2012). To implement research on the connection between religiosity and mental health in other parts of the world such as Europe and Asia, and in other religious traditions, e.g. Islam and Buddhism, would consequently develop the knowledge base within this field to be relevant for more than one culture.

The objective with this paper is to explore why religion is perceived to be an important part of life in older age groups, and to discuss possible mechanisms between religiosity and mental health.

A task of great difficulty but nevertheless of great importance is, of course, to define religion and spirituality. The two concepts traditionally associate differently in terms of qualitative meaning. Religion is more often understood as organized and collective and where formal doctrines are emphasized (Koenig, et al., 2012). Spirituality, on the other hand, represents the private sphere and less characterized by the obvious, formal and systematic aspects. It is more emotional and emphasizes relationships with family, friends, work, religion, God, and oneself. Spirituality is addressed inward with little or no emphasize on authorities (Edwards, Pang, Shiu, & Chan, 2010).

In the definition of religion proposed by Harold Koenig and colleagues (2012), both the subjective and private versus the objective and social are considered. It is stated that "religion involves beliefs, practices and rituals related to the transcendent, where the transcendent is God, Allah, HaShem, or a Higher Power in Western religious traditions, or to Brahman, manifestations of Brahman, Buddha, Dao, or ultimate truth/reality in eastern traditions" (Koenig, et al., 2012, p. 45). The mystical and supernatural are often involved as are beliefs about life after death and rules on how to behave in social groups. The beliefs, behaviors, rituals and ceremonies may be performed or held both within private and public framing, but is derived from traditions that has been established over time. "Religion is also an organized system of beliefs, practices, and symbols designed (a) to facilitate closeness to the transcendent, and (b) to foster an understanding of one's relationship and responsibility to others in living together in a community" (Koenig, et al., 2012, p. 45). The concept of spirituality is defined in close association with religion, whereas the key point for both religion and spirituality is the relationship to the transcendent where the difference between the two is that spirituality extends beyond but also begins before organized religion (Koenig, et al., 2012).

It is argued that the concept of spirituality sometimes - and maybe too often - overlaps with secular concepts and positive mental health concepts (Koenig, et al., 2012). If the concepts overlap, research is difficult to carry out since the effect on the dependent variable might be due to some aspects of the dependent variable itself. The relationship is predetermined by how spirituality is defined since it overlaps with positive mental health (e.g. meaning, purpose, peace, existential well-being). If measurements overlap, a risk of producing circular and tautological research increases. Consequently, it is important to be aware of this problem when defining spirituality. Spirituality and religiosity is thus defined close to each other and with the common feature of the transcendent whereas spirituality is termed by a search for the transcendent as well as having discovered the transcendent. Koenig and colleagues (2012) distinguish between those who are spiritual but not religious, religious but not spiritual, religious and spiritual, and those who are secular. The mechanisms associating religiosity and health may be different depending on which group one identifies with. The existence of a specific association also depends on which groups are being referred to.

Even though an interest in religious matters is not limited to those of a specific age group, it is often shown that there is a positive correlation between age and religiosity (Argue, Johnson, & White, 1999; Wink & Dillon, 2001). The reasons for this are, however, not clear. Where some argue that developmental changes through the lifespan are associated with increased religiosity (Wink & Dillon, 2001), others hold that differences in cohorts and periode effects have the greatest impact on the correlation between age and religiosity (Schwadel, 2011). To distinguish between period and cohort effect, one can think of period effect as being changes related to specific cultural and social events that affects everyone regardless of someone's year of birth. Cohorts are influenced by a particular process of socialization, being unique for their time of birth.

A three wave panel study was conducted to compare the effects of age, periods and cohorts (Argue, et al., 1999). The results from the study showed stronger evidence to support a simple age effect rather than both cohort and period effects. A prospective study followed a group of respondents over a 40-year period. Religiosity was found to be important early in life, declined in the 30-40s, and inclined in the 50-60s (Wink & Dillon, 2001).

Some psychologists have been especially interested in the development of religion/spirituality in late life, and the role that it plays. Erik Eriksson and his theory of psychosocial development suggest eight stages, each representing a conflict that must be

resolved for the individual to develop a particular strength (Erikson & Erikson, 1998). Joan and Erik Erikson developed a ninth stage of development with an onset in the last period of an individual's life, the 80s and 90s (Erikson & Erikson, 1998). The ninth stage is indissolubly linked to the changes in the physical body in which the physical body's strength is starting to diminish. Through loss of autonomy, the eight stages from infancy to old age once again becomes a challenge for the oldest old. For example, Erikson (1998) explains how basic trust is important for developing hope in the first stage of life. Everyone develops *some* degree of hope. For our own protection we also depend on mistrust which is a counterbalance to hope. On the other hand, mistrust may obstruct one's ability to engage in loving relationships with others (Erikson & Erikson, 1998). The physical challenges of the oldest old are the source of frequent mistrust of own capabilities, and hope is challenged by despair. A healthy development throughout the final ninth stage is, according to Erikson (1998), believed to result in gerotranscendence.

Tornstam (1989) shows gerotranscendence to be a characteristic in satisfied elders. It is a developmental state recognized by a shift in attention from materialistic and physical aspects of life towards a mere internal focus. This may include the following as stated by Tornstam (1989, p. 60) "An increasing feeling of a cosmic communion with the spirit of the universe; a redefinition of the perception of life and death and a decrease in fear of death; an increased feeling of affinity with past and future generations; a decrease in interest in superfluous social interaction; a decrease in interest in material things; a decrease in self-centeredness; more time spent in "meditation". The theory of gerotranscendence is also supported by empirical findings. A review study was conducted in order to investigate empirical findings on spiritual development associated with aging. The researchers concluded that despite the limited number of the studies reviewed there seems to be some evidence of a development towards gerotranscendence in old age (Dalby, 2006).

Parts of the holistic approach to development towards gerotranscendence in old age are the aspects of religion and spirituality. Even though Erikson (Erikson & Erikson, 1998) does not explicitly mention aspects of religiosity, she speaks of "faith" as a way to cope. Concerning the ninth stage, she explains that faith and humility are important when coping with the hope and trust that can no longer be taken for granted in old age (Erikson & Erikson, 1998).

According to both empirical findings and developmental theories it seems plausible that religiosity/spirituality becomes increasingly important with age. The bodily change that

follows ageing challenge a development towards positive health for the ageing individual. Since religion/spirituality and health has shown to be associated (Koenig, et al., 2012; Koenig & Larson, 2001; Miller & Kelley, 2005), it may be that, for some individual's, religion/spirituality may facilitate positive mental health in old age and further increase his or her quality of life and well-being.

# Relationships between religion and mental health

This area of research is subject to great controversy for several reasons. As we have seen the phenomenon is challenged as being too individualistic, with great differences in how religion and spirituality is defined for each individual. Also, there are those who believe that the connections between religion and health can never be studied scientifically, and the major reason for this is the great number of confounding variables and methodological shortcomings within the field of research (Sloan, Bagiella, & Powell, 1999). On the other hand, it is extensively argued that the accumulating evidence of an association between religion and health does indeed exist; both associated with negative and positive health outcomes (Koenig, et al., 2012; Koenig, McCullough, & Larson, 2001; Miller & Kelley, 2005).

Religiosity is a highly complex and multidimensional phenomenon. This is shown in several important books within the field (Hill & Hood, 1999; Hood, Spilka, & Hill, 2009; Koenig, 1998; Koenig, et al., 2012). Even in their definition of religion, Harold Koenig and colleagues list 23 major dimensions (Koenig, et al., 2012), and in the book "Measures of Religiosity"(Hill & Hood, 1999) over 120 instruments grouped in 17 Chapters are listed and reviewed.

There are also several paths where religiosity is believed to influence both positive and negative mental health outcomes. The dimensions of church-based social support and religious coping responses will be elaborated here within a life course perspective. These dimensions are probably closest to a mainstream understanding on how religion can facilitate positive health and prevent negative health outcomes.

Since the terms spiritual and religious are used interchangeably in empirical studies, we choose to use the term religious when explaining associations to account for both terms. Although the distinction between the two sometimes becomes obvious (when, for instance, empirical research on church-based social support is explained), at other times the paths

would be common for all categories of people (spiritual, but not religious etc.) as long as they share a relationship with the transcendent.

## Mental health and church-based social support

Social relationships are important to both mental and physical health (Cohen, 2004). Religion can be a provider of social relationships that are somewhat heterogeneous in terms of religious beliefs and values, and are also able of providing a feeling of social cohesion. It may also create a sense of affiliation with a caring group (Moreira-Almeida, Lotufo Neto, & Koenig, 2006).

Although we know little about how and if church-based social support changes in the course of aging, we have some knowledge on how social support in congregations might be unique or similar, compared to secular social support. Some scientists claim that the support in church-based communities is especially close and supportive (Ellison & Levin, 1998). In a study on the stress-buffering effects of social support on health, two types of social support networks were compared; religious and secular (N = 786) (Krause, 2006a). The main object of the study was to investigate if church-based social support (versus secular) would reduce the effects of financial strain on self-rated health. The results from the study showed that people receiving social support from people in church reduced the impact of financial strain on self-rated health, whereas no such effects were found for secular emotional support. The results were moderated by ethnicity, whereas no buffering effect of church-based social support was found for Whites compared to African Americans (Krause, 2006a). Another study found that mental health benefits (lower scores on depression) from religious institutional participation was mediated by church-based social support (Nooney & Woodrum, 2002). Both negative and positive mental health outcomes have been empirically associated with church attendance (Mitchell & Weatherly, 2000). It can be speculated that previous studies showing positive associations between church attendance and mental health outcomes is largely due to the intervening variable of church-based social support. At the very least, empirical findings as well as theoretical explanations together support the significance of church-based social support. Neal Krause (Krause, 2006b) explains how a theoretical perspective presented by Trice & Wallace (2003) on the reflected self might contribute to the field by showing how church-based social support might affect health. He explains that in the process of forming a sense of self, significant others are important. As a component of the self, the ideal self is formed through internalizing appraisals from others. This is effective when these appraisals are congruent with the ideal self. Also, we strive to

behave in ways that reflects the appraised ideal self (Krause, 2006b). Furthermore, Krause (2006b) argues that religion can provide a set of values and define goals to life that people perceive as ideal. Religion thus becomes functional in the search for, and in the attainment of, the ideal self (Krause, 2006b).

Even though an increasing amount of research has been accumulated which supports the significance of church-based social support to be unique and qualitatively different when compared to secular social support, there are studies that have found no difference between religious and secular social support. In a study on older adults aged 60-93 years (n=93), the researchers aimed to investigate differences in social support and emotional comfort. Both congregational and secular friendships were compared for the same individuals, and no difference on social or emotional support and comfort were found between groups of friends (McFadden, Knepple, & Armstrong, 2003). Since the sample contained largely White females, McFadden and colleagues argued that this could have influenced the results, knowing that research has shown that older Whites experience less spiritual and emotional support from a congregation than older African Americans (Krause, 2002). However, the great advantage of this study is that the same individuals were compared. This reduces the risk of possible confounding variables when comparing two different groups.

As individuals develop into old age, the need for deeper and less superficial friendship with fewer individuals increase (Tornstam, 1997). Since some studies have shown that the congregation might be an important source to attain support characterized by close ties, the elders who are part of social groups that genuinely cares about others might undoubtedly receive great benefit from those groups. According to Krause (2006b) there is little empirical research on age-related changes in church-based social support, and more studies are needed.

#### Mental health and religious coping responses

Together with social support, religious coping responses are probably the most widespread conceptual understanding of how religion and mental health is associated. The two concepts are closely related, whereas church-based social support might be viewed as a resource to individual coping responses. Kenneth Pargament is probably the best known researcher within the field of religious coping, and founder of that concept (Pargament, 1997). Religious coping involves drawing on one's religious beliefs and practices to understand and deal with stressors in life (chronic disease, impairment, loss of loved ones, divorce etc.).

Kenneth Pargament and colleagues (Pargament, Koenig, & Perez, 2000) defined five functions of religion that serve a purpose in everyday life, as well as in crisis. They are meaning, control, comfort, intimacy and life transformation. This indicates that religion may be a key role in the search for meaning, providing the individual with a framework to interpret and understand experiences in life. Religion may offer a sense of control in times where individual resources are challenged. Religion offers a way to connect with something greater than oneself to experience comfort. It also serves as a possibility to experience social cohesiveness, and finally it may guide people that seek change and new significance in life (Pargament, et al., 2000). The coping responses may be facilitating and effective as well as ineffective and potentially dysfunctional (Pargament, et al., 2000). Positive religious coping reflects a relationship with God that is secure; it reflects feelings of connectedness with others and a belief that life has great meaning. Negative religious coping reflects on the other hand an unsecure attachment to God where significance in life is less established, and a view of the world as unstable. The coping strategies may be expressed in various forms. It is shown that discontent and pleading is more associated with distress than are religious support- seeking and spiritual connection (Pargament, et al., 2000). In a study conducted on 577 elderly hospital patients, positive religious coping was associated with posttraumatic growth (Koenig, Pargament, & Nielsen, 1998). Being an active agent in solving conflicting issues made it easier for the patients to accept their situation (Koenig, et al., 1998). Several other studies have also tied positive and secure religious coping to various health outcomes. A study on nursing home residents (N = 140) showed that those who viewed religion as very important to them and applied positive religious coping strategies, had better psychological well-being than those who viewed religion as less important or applied negative religious coping (Scandrett & Mitchell, 2009). Also, a study on the relationship between religious coping and well-being among three groups of Presbyterians where one of the groups consisted of 823 elders, showed that positive religious coping was associated with higher levels of well-being (Pargament, Tarakeshwar, Ellison, & Wulff, 2001).

The body of research on the relationship between religious coping and positive mental health outcomes seems persuasive, both in terms of empirical findings and theoretical perspectives. However, in comparing religious coping across age groups there seems to be little research on the subject matter. One study conducted by Derks and colleagues (2005) found that older patients ( $\geq 70$  years) with head and neck cancer relied more heavily on religious coping strategies than their younger (45-60 years) counterparts. This study used

"The Utrecht Coping List" (Radloff, 1977) which separates between five different coping styles; active problem-solving, avoidance coping, palliative coping, religious coping and seeking support. The study showed that the younger patients relied more heavily on active coping strategies and experienced more internal control over their disease than did older patients (Derks, et al., 2005).

## Conclusions

Both theoretical perspectives and empirical research show that religion and spirituality may facilitate healthy development. Church-based social support and religious coping responses may be a unique resource in both dealing with difficulties and enhancing positive health outcomes. We have shown that social support in a religious/spiritual context may be unique compared to other secular sources to social support (Ellison & Levin, 1998; Krause, 2006a; Moreira-Almeida, et al., 2006), and that positive religious coping may be important for psychological well-being (Pargament, et al., 2001; Scandrett & Mitchell, 2009). We have also shown that little is known about church-based social support and religious coping for the elderly compared to younger counterparts and the extent of age specific mechanisms. However, there are reasons to believe that, with age, comes an increased interest in religion and spirituality (Argue, et al., 1999; Wink & Dillon, 2001) which illustrates that the spiritual/religious life of older individuals is an important area upon which to focus. Older individuals are faced with stressors that may be experienced as great in both magnitude and intensity. The challenges they face are closely linked to physical decline as well as other stressors that is more common with age (e.g. loss of loved ones). This is why it is important to become aware of any subjective potential the individual might possess that can help him or her to cope and to facilitate positive mental health in terms of greater quality of life and well-being.

Unfortunately, there has been little or no research on the relationship between religion and health in Norway, and consequently the knowledge on this association is also lacking for some specific age groups. The psychology of religion in Norway has been carried out mainly by qualitative research methods, but for the last five years or so several research projects have been initiated using quantitative methods as well. When the Nord-Trøndelag Health Study (HUNT) was performed for the third time in 2006-2008 (HUNT, 2012), it included items on religion together with a large number of variables linked to physical and mental health, blood samples and clinical measures as height, weight, blood pressure etc. The variables of religion in HUNT 3 has been described and assessed for research in relation to

health (Sørensen, Lien, Holmen, & Danbolt, 2011). The first study from HUNT 3 which investigated religion and physical health showed a significant inverse relationship between attendance at church and blood pressure (Sørensen, Danbolt, Lien, Koenig, & Holmen, 2011). Corresponding findings between attendance and depressive symptoms moderated by death of a close relative is also reported (Sørensen, Danbolt, Holmen, Koenig, & Lien, 2012). Likewise, at the Centre for Health Promotion and Resources HiST/NTNU there are two ongoing projects on religion/spirituality and health. One study investigates self-transcendence and well-being among nursing home patients. The other study also has great potential in exploring diverse hypotheses on religion and self-reported health/mental health. This study may also explore age-specific groups like the younger olds from retirement at 64 years to those turning 75 years. Results from these studies are already available, and will accumulate in the future. They will also give more in-depth knowledge on how this research should be focused in a Norwegian context, both concerning the oldest population and from a broader age-perspective.

Even though hypotheses are stated and research questions are framed in reference to a large body of research, it is important to acknowledge that this large body of research is mainly based on USA samples from Christian congregations. There are great differences between Norway (and other Scandinavian countries) and the USA with regard to cultural and religious contexts as well as to medical treatment contexts (Sørensen, Lien, Holmen, & Danbolt, 2011). For example, 40% of the USA population attends church weekly or more often, while the corresponding figure in Norway is 3-4%.

However, it can be argued that despite great cultural differences in the scope of religion, the psychology of religion might be similar for those who *do* hold religious beliefs even though the magnitude of the phenomenon in Norway cannot be compared to USA. It is not about enforcing anyone to relate to a deity, but rather being able to recognize possible individual resources, and to take those into account in our care for others.

#### References

- Argue, A., Johnson, D. R., & White, L. K. (1999). Age and Religiosity: Evidence from a Three-Wave Panel Analysis. *Journal for the Scientific Study of Religion, 38*, 423-435.
- Cohen, S. (2004). Social Relationships and Health. *American Psychologist*, *59*, 676-684. doi:
- Dalby, P. (2006). Is there a process of spiritual change or development associated with ageing? A critical review of research. *Aging & Mental Health*, *10*, 4-12. Derks, W., de Leeuw, J. R. J., Hordijk, G. J., & Winnubst, J. A. M. (2005). Differences in coping style and locus of control between older and younger patients with head and neck cancer. *Clinical Otolaryngology*, *30*, 186-192.
- Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a metastudy of qualitative research. *Palliative Medicine*, *24*, 753-770.
- Ellison, C. G., & Levin, J. S. (1998). The Religion-Health Connection: Evidence, Theory, and Future Directions. *Health Educ Behav*, *25*, 700-720.
- Erikson, E. H., & Erikson, J. M. (1998). The life cycle completed. New York: Norton.
- Hill, P. C., & Hood, R. W. (1999). *Measures of religiosity*. Birmingham: Ala. Religious Education Press.
- Hood, R. W., Spilka, B., & Hill, P. C. (2009). *The psychology of religion: an empirical approach*. New York: Guilford Press.
- HUNT. (2012). *The Nord-Trøndelag Health Study* Retrieved 02.02., 2012, from <a href="http://www.ntnu.no/hunt">http://www.ntnu.no/hunt</a>
- Koenig, H. G. (1998). *Handbook of religion and mental health*. San Diego, Calif.: Academic Press.
- Koenig, H. G., King, D. E., & Carson, V. B. (2012). *Handbook of religion and health*. New York: Oxford University Press.
- Koenig, H. G., & Larson, D. B. (2001). Religion and mental health: Evidence for an association. *International Review of Psychiatry*, 13, 67-78.
- Koenig, H. G., McCullough, M. E., & Larson, D. B. (2001). *Handbook of religion and health*. Oxford; New York: Oxford University Press.

- Koenig, H. G., Pargament, K. I., & Nielsen, J. (1998). Religious coping and health status in medically ill hospitalized older adults. *The Journal of nervous and mental disease*, 186, 513-521.
- Krause, N. (2002). Church-Based Social Support and Health in Old Age: Exploring Variations by Race. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *57*, S332-S347.
- Krause, N. (2006a). Exploring the Stress-Buffering Effects of Church-Based and Secular Social Support on Self-Rated Health in Late Life. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61, S35-S43.
- Krause, N. (2006b). Religion and health in late life. In J. Birren & K. W. Schaie (Eds.), *Handbook of the Psychology of Aging* (6 ed., pp. 499-518): Academic Press.
- McFadden, S. H., Knepple, A. M., & Armstrong, J. A. (2003). Length and Locus of Friendship Influence Church Members' Sense of Social Support and Comfort with Sharing Emotions. *Journal of Religious Gerontology*, 15, 39-55.
- Miller, L., & Kelley, B. S. (2005). Relationships of Religiosity and Spirituality with Mental Health and Psychopathology. In R. F. Paloutzian & C. L. Park (Eds.), *Handbook of the psychology of religion and spirituality* (pp. 460-479). New York: The Guilford Press.
- Mitchell, J., & Weatherly, D. (2000). Beyond church attendance: Religiosity and mental health among rural older adults. *Journal of Cross-Cultural Gerontology*, *15*, 37-54.
- Moreira-Almeida, A., Lotufo Neto, F., & Koenig, H. G. (2006). Religiousness and mental health: a review. *Revista Brasileira de Psiquiatria*, 28, 242-250.
- Nooney, J., & Woodrum, E. (2002). Religious Coping and Church-Based Social Support as Predictors of Mental Health Outcomes: Testing a Conceptual Model. *Journal for the Scientific Study of Religion*, 41, 359-368.
- Pargament, K. I., Koenig, H. G., & Perez, L. M. (2000). The many methods of religious coping: Development and initial validation of the RCOPE. *Journal of Clinical Psychology*, *56*, 519-543.

- Pargament, K. I., Tarakeshwar, N., Ellison, C. G., & Wulff, K. M. (2001). Religious Coping Among the Religious: The Relationships Between Religious Coping and Well-Being in a National Sample of Presbyterian Clergy, Elders, and Members. *Journal for the Scientific Study of Religion, 40*, 497-513.
- Radloff, L. S. (1977). The CES-D Scale. *Applied Psychological Measurement, 1*, 385-401.
- Scandrett, K. G., & Mitchell, S. L. (2009). Religiousness, religious coping, and psychological well-being in nursing home residents. *Journal of the American Medical Directors Association*, *10*, 581-586.
- Schwadel, P. (2011). Age, period, and cohort effects on religious activities and beliefs. *Social Science Research*, *40*, 181-192.
- Sloan, R. P., Bagiella, E., & Powell, T. (1999). Religion, spirituality, and medicine. *The Lancet*, *353*, 664-667.
- Sørensen, T., Danbolt, L., Lien, L., Koenig, H., & Holmen, J. (2011). The Relationship between Religious Attendance and Blood Pressure: The Hunt Study, Norway. *The International Journal of Psychiatry in Medicine*, 42, 13-28.
- Sørensen, T., Danbolt, L. J., Holmen, J., & Koenig, H. G. (2012). Does Death of a Family Member Moderate the Relationship Between Religious Attendance and Depressive Symptoms? The HUNT Study, Norway. *Depression Research and Treatment, special issue: Religious and Spiritual Factors in Depression*.
- Sørensen, T., Lien, L., Holmen, J., & Danbolt, L. J. (2011). Distribution and understanding of items of religiousness in the Nord-Trøndelag Health Study, Norway. *Mental Health, Religion & Culture*, 15, 571-585.
- Tornstam, L. (1989). Gero-transcendence: A reformulation of the disengagement theory. *Aging*, *1*, 9.
- Tornstam, L. (1997). Gerotranscendence: The contemplative dimension of aging. *Journal of Aging Studies, 11*, 143-154.
- Trice, D. M., & Wallace, H. M. (2003). The reflected self: Creating yourself as (you think) others see you. In: M. R. Leary & J. P. Tangney (Eds.), *Handbook of self and identity* (pp. 91-105). New York: Guilford.
- Wink, P., & Dillon, M. (2001). Religious involvement and health outcomes in late adulthood: Findings from a longitudinal study of women and men. In: T. G. Plante & A. C. Sherman (Eds.), *Faith and health: Psychological perspectives* (pp. 75-106). New York: Guilford.

# 17. School wellbeing among children: The dialogue and possibilities

#### AUDHILD LØHRE

Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Social Work and Health Science, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

Children's wellbeing is of great public concern and schools may provide an essential impact on children's welfare. Generally, risk factors have received a lot of attention, whereas the promotion of children's wellbeing has been less emphasized. In this chapter, I illuminate factors that may promote children's wellbeing in schools, and I put forward a question on the significance of agreement in perception of a child's life at school. To exemplify, I picture some children, use data provided by teachers, parents, and 419 children in grades 1-10, and lean on existing literature. Previous research indicates that the teacher may be the most important key in promoting the child's school wellbeing. In Norway, we have scarce empirical data on interventions that aim to support the teacher in promoting school wellbeing, and therefore such interventions and related research are highly appreciated.

#### Introduction

What creates children's wellbeing in school? That was the main question that I kept coming back to during my many years as a school psychologist. We observed many factors that adversely influenced the children, and the literature confirmed our observations. But knowledge related to protective processes, i.e. mechanisms that protect against adverse outcomes (Rutter, 1987) was sparse, as was the case for promoting processes as illustrated by Bengt Lindström's *Health in the River of Life* (Eriksson & Lindström, 2008). Therefore, I kept asking myself: Are we doing the right thing? Do we promote a practice in school that stimulates the children in the right direction? And how can we best facilitate children's wellbeing in school?

To search for answers, I gathered data on primary and secondary (grades 1-10) school children (Løhre, 2011). In the following, I briefly outline the concept of school wellbeing, measurements, and relations to subjective health. Next, I present a study to illustrate the

match and mismatch in reports of school wellbeing provided by the children, their teachers, and their parents. Finally, I look at the addressed problems through health promotion glasses (Lindström & Eriksson, 2010; Raphael, 2010) and point to some possible roads to promote school wellbeing and health among children.

## School wellbeing

In the 1970s, there was an incipient wave of interest in children's wellbeing at school. Epstein and colleagues initiated research on the quality of life among school children (Epstein & Mcpartland, 1976), and in Norway, the term "skoletrivsel" was discussed and studied (Hauge, 1974). The Norwegian word "trivsel" has no exact synonym in English, but it connotes "thriving" (Løhre, 2011) or "flourishing" (Lindström & Eriksson, 2009). Befring argued that the term included qualities linked to experiences like satisfaction ("tilfredshet") and wellbeing ("velvære"), and in addition, an active aspect (Befring, 1972). Here, I will use the term "school wellbeing" to describe "skoletrivsel".

There is no general consensus as to how to identify the concept of school wellbeing (or "skoletrivsel"), and consequently, the wellbeing among school children has been measured by different instruments (St Leger, 2000). A Finish team constructed an instrument to evaluate improvements on different domains in schools (Konu & Lintonen, 2006; Konu & Rimpela, 2002), but their model does not provide a global school wellbeing score for each child. Further, Opdenakker and colleagues used a questionnaire with eight indicators of students' wellbeing (Opdenakker & Van Damme, 2000). Five of the indicators were related to academic issues (including learning tasks, attentiveness, and academic self-concept), two were devoted to relational issues (social integration and relationships), and one indicator included general wellbeing at school. On the other hand, children's school wellbeing has also been measured by one single question (Løhre, Lydersen, & Vatten, 2010b).

In addition, scales have been developed to explore the closely related concept of "school satisfaction" (Aarø, Wold, Kannas, & Rimpela, 1986; Epstein & Mcpartland, 1976; Huebner, 1994; Randolph, Kangas, & Ruokamo, 2009). These scales have a minimum of three items, and like the measurements on wellbeing in school, the satisfaction scales also differ in their thematic profiles. The constructs of school wellbeing and school satisfaction have received general interest, and it has been suggested that students' satisfaction with their

school experiences should regularly be included in assessment protocols of students' general wellbeing, academic achievement, and behavior (Zullig, Koopman, & Huebner, 2009).

## School wellbeing and health

Self-reported health is strongly related to life experiences and this may be an important indicator in measuring the effects of strategies aimed to promote wellbeing among the children. It is well documented that ill health in childhood and adolescence may lead to restrictions in daily life, including absence from school as well as sleep and eating disorders (Roth-Isigkeit, Thyen, Stoven, Schwarzenberger, & Schmucker, 2005; Zhang, Li, & Liu, 2010). Moreover, children's perceptions of ill health may be linked to problems later in life. It has, for example, been reported that somatic symptoms in adolescence may be associated with medically unexplained symptoms in adulthood (Hotopf, Mayou, Wadsworth, & Wessely, 1999) and also with depression and panic attacks (Campo et al., 2004; Zwaigenbaum, Szatmari, Boyle, & Offord, 1999). Health symptoms are often categorized as emotional (internalized) or somatic symptoms, and these symptoms have shown a high comorbidity (Anttila et al., 2004; Brady & Kendall, 1992; Dufton, Dunn, & Compas, 2009; Kristjansdottir, 1997; Snyder et al., 2009; Strine, Okoro, McGuire, & Balluz, 2006).

# One illustrating study

The first aim was to assess the association of children's self-reported school wellbeing with their reports on health symptoms (sadness, anxiety, stomach ache, and headache). Secondly, this study explored the concordance among children, teachers, and parents in reports of school wellbeing.

#### Methods

In this cross-sectional population study, I used the self-reported data of 230 boys and 189 girls in grades 1-10 from five schools. Also the children's teachers and parents participated by providing information related to each child. The survey, from which the data were extracted, is described in more detail elsewhere (Løhre, 2011; Løhre, Lydersen, & Vatten, 2010a).

School wellbeing was addressed by one global question: "How do you like it at school?" with four response options; very bad (1), not so good (2), good (3), and excellent (4). The significant adults, teachers and parents, reported their perceptions of the child's school wellbeing on a corresponding four-level ordinal scale.

Children's health symptoms were measured by four questions: "Lately, how often have you felt: 1) sadness, 2) anxiety, 3) stomach ache, or 4) headache?" Each question had five response options; never (1), seldom (2), sometimes (3), often (4), and always (5). Sadness and anxiety were denoted as emotional symptoms; stomach ache and headache were denoted as somatic symptoms.

The associations were analyzed with proportional odds logistic regression (Ananth & Kleinbaum, 1997) using sadness, anxiety, stomach ache and headache as dependent variables. Precision of the associations (odds ratios) were assessed using 95% confidence intervals. Correlations were analyzed by Spearman's rho. Tests for statistical significance were two-sided, and p-values < 0.05 were considered significant.

#### Results

For boys as well as for girls, self-reported school wellbeing was related to a lower degree of health symptoms (Table 1). Among girls, school wellbeing was negatively associated with all the four health symptoms; odds ratios ranged from 0.48 to 0.37. For boys, school wellbeing demonstrated statistically significant associations with emotional problems and headaches, with odds ratios from 0.67 to 0.59 (all p-values < 0.05).

**Table 1.** School wellbeing reported by boys or girls associated with health symptoms reported by the same informant in logistic regression\*

	Sadness		Anxiety		
	Odds ratio	p-value	Odds ratio	p-value	
	Estimate (95% CI)	p-value	Estimate (95% CI)	p-varue	
Boys	0.67 (0.48 to 0.95)	0.023	0.56 (0.39 to 0.79)	0.001	
Girls	0.42 (0.26 to 0.68)	< 0.001	0.48 (0.30 to 0.78)	0.003	
	Stomach-ache		Headache		
Boys	0.75 (0.53 to 1.05)	0.097	0.59 (0.42 to 0.83)	0.002	
Girls	0.37 (0.23 to 0.58)	< 0.001	0.38 (0.24 to 0.61)	< 0.001	

<sup>\*</sup>Proportional odds logistic regression with sadness, anxiety, stomach ache, and headache as the dependent variables and school wellbeing, adjusted by grade, as the independent variable

Generally, all three groups of informants reported school wellbeing to be good or excellent; this was reported by 92% of the children, 93% of the teachers, and 95% of the parents. But the concordance between informants was low to moderate. The estimated

correlations, Spearman's rho (p-value), among responses were 0.15 (0.003) for children and teachers, 0.34 (<0.001) for children and parents, and 0.23 (<0.001) for teachers and parents.

Table 2. Concordance of school wellbeing (numbers) reported by different informants

School wellbeing	Teachers			Parents					
reported by:	1	2	3	4	_	1	2	3	4
Children									
1: Very bad	0	2	6	1		2	2	6	0
2: Not so good	0	6	14	2		0	4	13	3
3: Good	0	16	145	46		0	8	125	60
4: Excellent	0	5	110	41		1	1	61	82
Teachers									
1: Very bad						0	0	0	0
2: Not so good						0	4	17	3
3: Good						2	9	145	95
4: Excellent						0	1	37	47

Cross tables of reports from 394 children-teacher pairs, 368 children-parent pairs, and 360 teacher-parent pairs are presented in Table 2. Further, in dichotomizing the school wellbeing scale into bad (very bad/not so good) and good (good/excellent) school wellbeing, it became obvious that the agreement between children and significant adults was quite different for those with bad and those with good school wellbeing. Children who reported their school wellbeing to be bad showed high disagreement with significant adults and correspondingly low agreement; only 26% had an agreement with their teachers and 27% had an agreement with their parents. For children who reported their school wellbeing to be good, the match and mismatch with significant adults was reversed, and among those children, 94% had an agreement with teachers and 97% had an agreement with parents.

Separate gender analyses of the dichotomized school wellbeing scale demonstrated a lower concordance for boys than for girls with bad school wellbeing (Table 3). Only 20% of the boys with bad school wellbeing showed an agreement with teachers, and 23% indicated an agreement with parents. Among girls with bad school wellbeing, 36% had an agreement with teachers and 37% had an agreement with parents. For both genders reporting positive

school wellbeing, the agreement with teachers and parents was high, ranging from 93 to 98%.

Table 3. Cross-tables of school wellbeing reported by boys, girls, teachers, or parents

Reports from informants		Teachers			Parents			
		Neg Pos		Total	Neg	Pos	Total	
		N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	
Boys	Neg <sup>1</sup>	4 (20)	16 (80)	20 (100)	5 (23)	17 (77)	22 (100)	
	Pos <sup>2</sup>	13 (7)	179 (93)	192 (100)	6 (3)	172 (97)	178 (100)	
Girls	Neg <sup>1</sup>	4 (36)	7(64)	11 (100)	3 (37)	5 (63)	8 (100)	
	Pos <sup>2</sup>	8 (5)	163 (95)	171 (100)	4 (2)	156 (98)	160 (100)	

<sup>&</sup>lt;sup>1</sup>Neg: Very bad/Not so good

#### Discussion

School wellbeing reported by the children was strongly related to their reports of health symptoms. Girls reporting good school wellbeing had a lower prevalence of sadness, anxiety, stomach aches and headaches. Boys demonstrated similar strong and negative associations, except for stomach aches. Further, for more than 90% of the children, school wellbeing was perceived to be good or excellent either by teachers, parents, and the children. However, the concordance in reports on school wellbeing was generally low to modest and examined more thoroughly; children who reported good school wellbeing had an exceptionally high agreement with significant adults whereas children who reported bad school wellbeing showed low agreement.

Strengths of the study include the population-based information and reports from three sources. However, it is not reasonable to conclude on causality because of the cross-sectional nature of the data. It is uncertain as to whether children's perceived school wellbeing, agreement with significant adults, or both have an impact on health symptoms or whether children's health symptoms influence the informant's perceptions on school wellbeing.

The findings of strong relations between school wellbeing and perceived health correspond to well established associations of school satisfaction or belongingness to school with health (Bond et al., 2007; Samdal, Nutbeam, Wold, & Kannas, 1998; Shochet, Dadds, Ham, & Montague, 2006). However, a lack of knowledge exists regarding concordance in

<sup>&</sup>lt;sup>2</sup>Pos: Good/Excellent

reports of school wellbeing. Hauge (1974) suggested that parents generally estimated better school wellbeing than their children, and moreover, children with bad school wellbeing might show lower agreement with their parents than other children. But to my awareness, no previous study has aimed to assess the agreement in teacher-, parent-, and self-reports of children's school wellbeing. The low to moderate concordance is, however, in line with findings from other domains, e.g. children's quality of life (Jozefiak, Larsson, Wichstrom, Mattejat, & Ravens-Sieberer, 2008) and peer victimization (Bradshaw, Sawyer, & O'Brennan, 2007; Ladd & Kochenderfer-Ladd, 2002; Løhre, Lydersen, Paulsen, Maehle, & Vatten, 2011).

It has been argued that a combination of reports from multi-informants may enrich the perspective on children's adjustments (Achenbach, McConaughy, & Howell, 1987; Jozefiak et al., 2008; Ladd & Kochenderfer-Ladd, 2002). Additionally, proposals have been presented on modifying the measurement instruments to achieve better agreement (De Los Reyes & Kazdin, 2005). Others have proposed informant-specific reports to make the large variations in the different reports visible (Munkvold, Lundervold, Lie, & Manger, 2009; Offord et al., 1996). Our results may support this latter view.

Further in this chapter, the problems addressed by this study will be discussed from the perspective of health promotion (Lindström & Eriksson, 2010; Raphael, 2010).

# Promoting school wellbeing and health

One research path has been to study children's wellbeing in relation to their perception of belongingness to school, or their connection/bonding to school (Blum & Libbey, 2004). School connectedness may be defined as "...the belief by students that adults in the school care about their learning as well as about them as individuals" ("Wingspread Declaration on School Connections," 2004). Others have defined "school bonding" as the presence of attachment (an emotional link to school) and commitment (an investment in a group) (Libbey, 2004).

Connection to school may have long term consequences (Bond et al., 2007). In an intervention program aimed at increasing the students' school bonding, Catalono and colleagues found that intervention was associated with higher levels of academic success and with reductions in school and social problems, including violence, alcohol abuse, and risky sexual behavior measured six and nine years after the intervention (Catalano, Haggerty, Oesterle, Fleming, & Hawkins, 2004). Also, the influence of belongingness on health status

has been studied; school belongingness predicted health status one year later, but health status at baseline was not associated with school belongingness the following year (Shochet et al., 2006).

Support from teachers may be of great importance in children's bonding to school (Catalano et al., 2004). Perceived support from teachers has also shown strong associations with children's school wellbeing (Løhre et al., 2010b), with their school satisfaction (Danielsen, Samdal, Hetland, & Wold, 2009; Danielsen, Wiium, Wilhelmsen, & Wold, 2010; DeSantis King, Huebner, Suldo, & Valois, 2006; Randolph, Kangas, & Ruokamo, 2010; Samdal et al., 1998; Takakura, Wake, & Kobayashi, 2005; Verkuyten & Thijs, 2002), and with later health behavior (McNeely & Falci, 2004). What happens in the classroom seems, therefore, to be more important to perceived school wellbeing than relationships among students in recess (Løhre et al., 2010b; Samdal et al., 1998).

Typically, teacher support may comprise an academic component related to the children's school work and an emotional component related to caring. In one study, the teacher's academic support appeared to be more strongly associated with emotional problems and somatic pain than was the teacher's emotional support (Bru, Boyesen, Munthe, & Roland, 1998). However, in most studies the two dimensions of teacher support are included in the same explaining variable, for example in studies of school satisfaction (Samdal et al., 1998; Takakura et al., 2005).

## The need for dialogue

The unsatisfying concordance in reports of school wellbeing makes us focus on channels of information. Through observation, teachers learn a lot about their students, and parents believe that they are well oriented about essential aspects in the child's life. Our results, however, tell other stories. Both in questions on school wellbeing and in the perception of adverse experiences like being victimized by bullying (Løhre et al., 2011) the concordance among informants is surprisingly low.

How then, might the child's message reach the teacher or the parent? One answer may be through dialogue. Sitting face to face or side by side in confident surroundings, the child will have the possibility to tell about pleasures and provocations, about feelings and thoughts. At times, small interventions may be helpful in lessening heavy burdens from a child's mind

#### The school health services

Employees in the school health services have unique opportunities to work with health promotion, and according to laws and regulations in Norway (Helsedirektoratet, 2010a, 2010b) they are supposed to do so. In some districts, the school nurses were trained to interview children by using a school wellbeing questionnaire (Løhre, 2011), and the nurses met individually with all students at school or all students in selected classes. Here we experienced that minor interventions were significant to some children. Sitting together with the school nurse in a dedicated room, a child told about his feelings of loneliness at school, and the nurse was in position to search for solutions. After a few sessions, the situation changed and the child reported that the feelings of loneliness had disappeared. This example is meant to illustrate the importance of promoting programs that reach out to everyone. The pain of loneliness was not seen in class, but in the dialogue with a trustworthy adult, the child felt able to express his hurtful feelings.

#### The anxious boy

Working as a school psychologist I had the opportunity to help teachers promote wellbeing in their classes, which typically ranged from 15-30 children. In one of those classes, I met him – the anxious boy. At first, I did not really *see* him because he was hidden behind a haze of noise and trouble brought about by other students. After several observations in class, I decided to do a half structured interview (Løhre, 2003) with each of the students. There, in a quiet room, he told me: He used to cry in the evenings. It was difficult to fall asleep and he often woke up during the night because he feared the next day at school. He was afraid. What would happen in the classroom? Would someone hit him? He did not feel victimized by bullying; rather it was the uncertainty related to impulsive movements. It was December, and almost every day since August he had experienced the pain of a headache.

One of the changes brought about by the intervention was to restructure the classroom. The anxious boy was now pleased to sit with his back against the wall so that nobody could hit him from behind. Visiting the class a couple of weeks later I saw a smile on his face, and during the springtime, he sat confidently in his place. By the end of May, most of the other students also reported better wellbeing in lessons together with reduced loneliness and bullying (Løhre, 2003).

# Summary and implications

We have seen that good school wellbeing is related to lower odds of ill health, and furthermore, our data indicates that the concordance in reports of school wellbeing may be related to the child's self-reported level of school wellbeing. For more than nine out of ten children reporting good or excellent school wellbeing, teachers or parents had the same opinion, and among those children, the prevalence of health problems was low. On the contrary, for those children reporting very bad or not so good school wellbeing, more than seven in ten teachers or parents disagreed and judged their school wellbeing as good or excellent, and among those children, a high prevalence of health problems was shown.

To face the inequalities it seems necessary to promote strategies that include every child at school, and by adding personal stories, my intention was to demonstrate the power of trustful dialogues in interventions.

Based on existing knowledge (Bond et al., 2007; Løhre et al., 2010b; McNeely & Falci, 2004; Samdal et al., 1998), it appears that the role of teachers should be central in the promoting strategies. One challenge will be to model interventions to support teachers in their core activities so that every child is *seen*, and the teachers can execute fair treatment, caring, and academic backing. The other challenge will be to plan and link research to the suggested interventions. In Norway, as in other European countries, empirical knowledge is scarce on interventions that aim to promote children's school wellbeing. In addition, it seems reasonable to further explore the significance of concordance in reports of school wellbeing in relation to children's current and future health.

## References

- Aarø, L. E., Wold, B., Kannas, L., & Rimpela, M. (1986). Health behaviour in schoolchildren. A WHO cross-national survey. A presentation of philosophy, methods and selected results of the first survey. *Health Promot. Int.*, 1, 17-33.
- Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychol Bull*, *101*, 213-232.
- Ananth, C., & Kleinbaum, D. (1997). Regression models for ordinal responses: A review of methods and applications. *International Journal of Epidemiology*, 26, 1323-1333.
- Anttila, P., Sourander, A., Metsähonkala, L., Aromaa, M., Helenius, H., & Sillanpää, M. (2004). Psychiatric symptoms in children with primary headache. *J Am Acad Child Adolesc Psychiatry*, 43, 412-419.
- Befring, E. (1972). Ungdom i et bysamfunn. Oslo: Universitetsforlaget.
- Blum, R. W., & Libbey, H. P. (2004). Executive Summary. *Journal of School Health*, 74, 231-232.
- Bond, L., Butler, H., Thomas, L., Carlin, J., Glover, S., Bowes, G., & Patton, G. (2007). Social and school connectedness in early secondary school as predictors of late teenage substance use, mental health, and academic outcomes. *J Adolesc Health*, 40, e9-18.
- Bradshaw, C. P., Sawyer, A. L., & O'Brennan, L. M. (2007). Bullying and peer victimization at school: Perceptual differences between students and school staff. *School Psychology Review*, *36*, 361-382.
- Brady, E. U., & Kendall, P. C. (1992). Comorbidity of anxiety and depression in children and adolescents. *Psychological Bulletin*, *111*, 244-255.
- Bru, E., Boyesen, M., Munthe, E., & Roland, E. (1998). Perceived social support at school and emotional and musculoskeletal complaints among Norwegian 8th grade students. *Scandinavian Journal of Educational Research*, 42, 339-356.
- Campo, J. V., Bridge, J., Ehmann, M., Altman, S., Lucas, A., Birmaher, B., & Brent, D.A. (2004). Recurrent abdominal pain, anxiety, and depression in primary care.*Pediatrics*, 113, 817-824.

- Catalano, R. F., Haggerty, K. P., Oesterle, S., Fleming, C. B., & Hawkins, J. D. (2004). The importance of bonding to school for healthy development: Findings from the social cevelopment research group. *Journal of School Health*, 74, 252-261.
- Danielsen, A., Samdal, O., Hetland, J., & Wold, B. (2009). School-related social support and students' perceived life satisfaction. *The Journal of Educational Research*, 102, 303-320.
- Danielsen, A., Wiium, N., Wilhelmsen, B., & Wold, B. (2010). Perceived support provided by teachers and classmates and students' self-reported academic initiative. *Journal of School Psychology*, 48, 247-267.
- De Los Reyes, A., & Kazdin, A. E. (2005). Informant discrepancies in the assessment of childhood psychopathology: A critical review, theoretical framework, and recommendations for further study. *Psychological Bulletin*, *131*, 483-509.
- DeSantis King, A., Huebner, S., Suldo, S., & Valois, R. (2006). An ecological view of school satisfaction in adolescence: Linkages between social support and behavior problems. *Applied Research in Quality of Life*, 1, 279-295.
- Dufton, L. M., Dunn, M. J., & Compas, B. E. (2009). Anxiety and somatic complaints in children with recurrent abdominal pain and anxiety disorders. *Journal of Pediatric Psychology*, *34*, 176-186.
- Epstein, J. L., & Mcpartland, J. M. (1976). The concept and measurement of the quality of school life. *American Educational Research Journal*, 13, 15-30.
- Eriksson, M., & Lindström, B. (2008). A salutogenic interpretation of the Ottawa Charter. *Health Promot. Int.*, *23*, 190-199.
- Hauge, T. E. (1974). Skolemiljø og elevholdninger. Trondheim: Tapir.
- Helsedirektoratet. (2010a). *Folkehelsearbeidet veien til god helse for alle*. Oslo: Helsedirektoratet.
- Helsedirektoratet. (2010b). *Utviklingsstrategi for helsestasjons- og skolehelsetjenesten*. Oslo: Helsedirektoratet.
- Hotopf, M., Mayou, R., Wadsworth, M., & Wessely, S. (1999). Childhood risk factors for adults with medically unexplained symptoms: Results from a national birth cohort study. *American Journal of Psychiatry*, *156*, 1796-1800.
- Huebner, E. S. (1994). Preliminary development and validation of a multidimensional life satisfaction scale for children. *Psychological Assessment*, *6*, 149-158.

- Jozefiak, T., Larsson, B., Wichstrom, L., Mattejat, F., & Ravens-Sieberer, U. (2008).

  Quality of Life as reported by school children and their parents: a cross-sectional survey. *Health and Quality of Life Outcomes*, *6*, 34.
- Konu, A., & Lintonen, T. (2006). School well-being in Grades 4-12. *Health Education Research*, *21*, 633-642.
- Konu, A., & Rimpela, M. (2002). Well-being in schools: a conceptual model. *Health Promotion International*, 17, 79-87.
- Kristjansdottir, G. (1997). Prevalence of pain combinations and overall pain: A study of headache, stomach pain and back pain among school-children. *Scandinavian Journal of Public Health*, *25*, 58-63.
- Ladd, G. W., & Kochenderfer-Ladd, B. (2002). Identifying victims of peer aggression from early to middle childhood: analysis of cross-informant data for concordance, estimation of relational adjustment, prevalence of victimization, and characteristics of identified victims. *Psychological Assessment 14*, 74-96.
- Libbey, H. P. (2004). Measuring student relationships to school: attachment, bonding, connectedness, and engagement. *Journal of School Health*, 74, 274-283.
- Lindström, B., & Eriksson, M. (2010). The hitchhiker's guide to salutogenesis. Helsinki.
- Lindström, B., & Eriksson, M. (2009). The salutogenic approach to the making of HiAP/healthy public policy: illustrated by a case study. *Global Health Promotion*, *16*, 17-28.
- Løhre, A. (2003). Foreldredeltagelse i klassesnu et eksempel fra småtrinnet. In: G. S. Vaaland (Ed.), *Høyt spill om samspill Å snu vanskelige klasser* (pp. 56-83). Stavanger: Senter for atferdsforskning.
- Løhre, A. (2011). Wellbeing among school children in grades 1-10: Promoting and adverse factors. (Doctoral dissertation, Norwegian University of Science and Technology, Trondheim, 2011).
- Løhre, A., Lydersen, S., Paulsen, B., Maehle, M., & Vatten, L. J. (2011). Peer victimization as reported by children, teachers, and parents in relation to children's health symptoms. *BMC Public Health*, *11*, 278.
- Løhre, A., Lydersen, S., & Vatten, L. J. (2010a). Factors associated with internalizing or somatic symptoms in a cross-sectional study of school children in grades 1-10. *Child and Adolescent Psychiatry and Mental Health, 4*, 33.
- Løhre, A., Lydersen, S., & Vatten, L. J. (2010b). School wellbeing among children in grades 1-10. *BMC Public Health*, *10*, 526.

- McNeely, C., & Falci, C. (2004). School connectedness and the transition into and out of health-risk behavior among adolescents: a comparison of social belonging and teacher support. *Journal of School Health*, 74, 284-292.
- Munkvold, L., Lundervold, A., Lie, S. A., & Manger, T. (2009). Should there be separate parent and teacher-based categories of ODD? Evidence from a general population. *Journal of Child Psychology and Psychiatry*, *50*, 1264-1272.
- Offord, D. R., Boyle, M. H., Racine, Y., Szatmari, P., Fleming, J. E., Sanford, M., & Lipman, E. L. (1996). Integrating assessment data from multiple informants.

  \*Journal of the American Academy of Child and Adolescent Psychiatry, 35, 1078-1085.
- Opdenakker, M. C., & Van Damme, J. (2000). Effects of Schools, Teaching Staff and Classes on Achievement and Well-Being in Secondary Education: Similarities and Differences Between School Outcomes. *School Effectiveness and School Improvement*, 11, 165-196.
- Randolph, J., Kangas, M., & Ruokamo, H. (2009). The Preliminary Development of the Children's Overall Satisfaction with Schooling Scale (COSSS). *Child Indicators Research*, *2*, 79-93.
- Randolph, J., Kangas, M., & Ruokamo, H. I. (2010). Predictors of Dutch and Finnish children's satisfaction with schooling. *Journal of Happiness Studies*, 11, 193-204.
- Raphael, D. (2010). *Health promotion and quality of life in Canada*. Toronto: Canadian Scholars' Press Inc.
- Roth-Isigkeit, A., Thyen, U., Stoven, H., Schwarzenberger, J., & Schmucker, P. (2005). Pain among children and adolescents: Restrictions in daily living and triggering factors. *Pediatrics*, *115*, 152-162.
- Rutter, M. (1987). Psychosocial resilience and protective mecanisms. *American Journal of Orthopsychiatry*, *57*, 316-331.
- Samdal, O., Nutbeam, D., Wold, B., & Kannas, L. (1998). Achieving health and educational goals through schools a study of the importance of the school climate and the students' satisfaction with school. *Health Education. Research.*, 13, 383-397.

- Shochet, I. M., Dadds, M. R., Ham, D., & Montague, R. (2006). School connectedness is an underemphasized parameter in adolescent mental health: Results of a community prediction study. *Journal of Clinical Child & Adolescent Psychology*, 35, 170-179.
- Snyder, J., Bullard, L., Wagener, A., Leong, P. K., Snyder, J., & Jenkins, M. (2009). Childhood anxiety and depressive symptoms: Trajectories, relationship, and association with subsequent depression. *Journal of Clinical Child & Adolescent Psychology*, *38*, 837 849.
- St Leger, L. (2000). Developing indicators to enhance school health. *Health Education*. *Research.*, *15*, 719-728.
- Strine, T. W., Okoro, C. A., McGuire, L. C., & Balluz, L. S. (2006). The associations among childhood headaches, emotional and behavioral difficulties, and health care use. *Pediatrics*, *117*, 1728-1735.
- Takakura, M., Wake, N., & Kobayashi, M. (2005). Psychosocial school environment, satisfaction with school, and health complaints among Japanese high school students. *School Health 1*, 1-8.
- Verkuyten, M., & Thijs, J. (2002). School Satisfaction of Elementary School Children: The Role of Performance, Peer Relations, Ethnicity and Gender. *Social Indicators Research*, *59*, 203-228.
- Wingspread Declaration on School Connections. (2004). *Journal of School Health*, 74, 233-234.
- Zhang, J.-J., Li, N.-X., & Liu, C.-J. (2010). Associations Between Poor Health and School-Related Behavior Problems at the Child and Family Levels: A Cross-Sectional Study of Migrant Children and Adolescents in Southwest Urban China. *Journal of School Health*, 80, 296-303.
- Zullig, K., Koopman, T., & Huebner, E. (2009). Beyond GPA: Toward More Comprehensive Assessments of Students' School Experiences. *Child Indicators Research*, 2, 95-108.
- Zwaigenbaum, L., Szatmari, P., Boyle, M. H., & Offord, D. R. (1999). Highly somatizing young adolescents and the risk of depression. *Pediatrics*, *103*, 1203-1209.

#### V. Best Practice in Health Promotion

The ability to gather and use relevant evidence of 'what works', commonly known as best practices, is a key component to promote health and healthy living conditions. There is increasing demand in all sectors across the research, policy, practice continuum for evidencebased decision-making and accountability. Evidence in health promotion is important because society pays a high cost when interventions that yield the highest health returns are not implemented. Evidence is also important because practitioners need justifications for the decisions they make. Ideally, practitioners should always incorporate evidence in selecting and implementing programs, developing policy, and evaluating progress. This section provides both theoretical and practical examples within best practice in health promotion. In chapter 18, Lillefjell, Knudtsen, and Wist presents a pilot study that describes existing knowledge, research, and development needs, as well as the skills required for counties and municipalities to put evidence-based health promotion strategies into practice. In chapter 19, Lindström presents views and reflections on concepts for health promotion practice – plotting a roadmap towards New Health and the Salutogenic Society. In chapter 20, Jaastad presents two research studies concerning leisure activities, focusing on cultural participation and health among seniors in Trondheim municipality.

We hope that this section of best practice in health promotion is a useful contribution to the debate on the concepts and principles for health promotion practice.

## 18. Evidence-based health promotiongetting evidence into practice

#### Experiences from a Norwegian study

MONICA LILLEFJELL<sup>1, 2</sup>, MARGUNN SKEI KNUDTSEN<sup>3</sup> & GURI WIST <sup>3</sup>

<sup>1</sup> Sør-Trøndelag University College, Faculty of Health Education and Social Work, Department of Occupational Therapy, Trondheim, Norway

<sup>2</sup> Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim Norway

<sup>3</sup> Nord-Trøndelag County Counsil, Steinkjer, Norway

#### Abstract

County and local governments are required to implement evidence-based public health programs. The need for municipalities to become skilled in implementing policies and translating plans into effective actions has been highlighted in political visions, international directives and agreements, as well as in national policies. Based on qualitative and quantitative data, this pilot study describes existing knowledge, research, and development needs, as well as the skills required for counties and municipalities to put evidence-based health promotion strategies into practice.

#### Introduction

Public health research and practice are credited with several notable achievements, including gains in life expectancy (The Norwegian Directorate of Health, 2010). A large part of this increase is the result of safer water and food supplies, sewage treatment and disposal, discouragement of tobacco use, injury prevention, control of infectious disease, and other population based interventions (The Norwegian Directorate of Health, 2010). Despite these successes, many additional opportunities to improve public health remain. With better living conditions and economic growth, we see a changed clinical picture with more complex problems that require a different approach in practice as well as in research.

Political visions and principles of health promotion as outlined in WHO directives, international agreements, and national policies, suggest that increased efforts in health promotion move from a 'repair' to 'prevention' model (WHO, 1986; Tones & Green, 2004; Barry, Allegrante, Lamarre et al., 2009). The adoption of evidence-based strategies has been recommended in order to achieve international and national objectives for improvements in

population health, (WHO 1986, Tones & Green, 2004: Barry, Allegrante, Lamarre et al., 2009; White paper nr 20, 2006-2007).

Due to the new public health act (Prop 90L, 2010-2011), county and local governments are now required to implement evidence-based public health programs. County governments are given the task of ensuring the overall the health and living conditions of the population as well as the related factors and trends in the environment and local communities, while municipalities are given greater responsibility for solving local health problems. There is a particular focus on the role that community structures such as local services, public transportation, healthy food, affordable housing, and community activities promoting health play in the promotion of health (Mittelmark & Hauge, 2003; White paper nr 20, 2006-2007; White paper nr 47, 2008-2009).

Based on these political visions and principles of health promotion (WHO 1986; Barry et al., 2009; Prop 90L, 2010-2011), there is a need for municipalities to become skilled in implementing policies and translating plans into effective actions tailored to the social, cultural, economic, and political context and realities of local population groups and settings (Mittelmark & Hauge, 2003; White paper nr 47, 2008-2009). Ideally, public health practitioners should always incorporate evidence in selecting and implementing programs, developing policy, and evaluating progress (Brownson, Gurney & Land, 1999; Brownson, Fielding & Maylahn, 2009).

#### The question of evidence in public health and health promotion

The concept of health promotion is based on the assumption that human nature is heterostatic rather than homeostatic, a statement that is in accordance with the salutogenic orientation (Antonovsky, 1979; 1987; 1996). Its practice involves not only the question of which individual factors lead to poor health, but also a strong focus on the interactions between people and the societal structures in which they function (Mackenbach, Van Den Bos, Van De Mheen et al., 1994; Marmot 2000; 2011; Wilkinson & Marmot, 2005). Besides focusing on human resources, the contextual conditions of living situations are also addressed (Davis, Nutley & Smith, 2000; Speller, Wimbush & Morgan, 2005; Brownson et al., 2009; Raphael, 2010).

The ability to gather and use relevant evidence of 'what works', commonly known as best practices, is a key component of a municipality's capacity to promote healthy living conditions (Davies et al., 2000). There is increasing demand in all sectors across the

research, policy, practice continuum for evidence-based decision-making and accountability. However, the question of what constitutes appropriate evidence in health promotion and public health is an ongoing debate. Evidence in its broadest sense includes everything that is used to determine or demonstrate the truth of an assertion (www.wikipedia.no).

Some might argue that the origins of evidence based health promotion and public health lie in the evidence-based movement in health care. Unlike evidence-based public health, evidence-based medicine has been well defined and its processes developed in the last decades (Egger, Davey, Smith, & Altman, 2001). Primary research based on randomized controlled trails (RCT) is based on the assumption that the stronger the evidence, the more powerful its influence on practice should be (Speller et al., 2005). This has created a hierarchy of research designs. However the pre-eminence of RCT method is controversial when applied to health promotion and wider public health intervention. Although RCT is recognized for providing the best possible information about effectiveness when the research design is appropriate to the intervention type (MacIntyre, Chalmers, Horton et al., 2001), RCT has been found to be an inappropriate research design for evaluating complex community-based public health interventions (Nutbeam, 1998). There have been several attempts to define evidence-based public health. At the moment, there appears to be a consensus among investigators and public health leaders that a combination of scientific evidence and values, resources, and contextual factors should be taken into account in decision-making processes (Speller et al., 2005; Browning, 2009; Raphael, 2010).

Evidence in health promotion is important because society pays a high cost when interventions that yield the highest health returns are not implemented (Brownson et al., 2009). Evidence is also important because practitioners need justifications for the decisions they make (Raphael, 2000). According to the third element in The Population Health Template Working Tool (Strategic Policy Directorate of the Population and Public Health Branch, Canada, 2001; Raphael 2010), evidence-based decisions should:

- 1. Use the best evidence available at all stages of policy and program development
- 2. Explain criteria for including or excluding specific evidence
- 3. Draw on a variety of data
- 4. Generate data through mixed research methods
- 5. Identify and assess interventions for effectiveness
- 6. Disseminate research findings and facilitate policy uptake

Therefore, evidence on health status, the determinants of health, and the effectiveness of intervention should be used to assess health, identify priorities, and develop strategies to improve health (Strategic Policy Directorate of the Population and Public Health Branch, Canada, 2001; Raphael, 2010).

#### Aim

The study described here aimed to identify existing knowledge as well as the research, development needs, and skills needed for counties and municipalities to put evidence-based health promotion into practice.

#### Methods

The study was carried out in collaboration between research institutions and county and local governments.

#### Databases and regional/local initiatives

In order to identify existing knowledge, research, and development needs, as well as the skills needed in county and municipal agencies, available data from databases on public health, regional and local initiatives in Nord-Trøndelag County, and opportunities related to the Nord-Trøndelag health survey (HUNT) were identified and systemized (Holmen, Midthjell, Krüger, et al., 2003).

#### Focus group discussions

In addition, focus group discussions (Kreuger & Casey, 2009) with public health leaders and/or leaders with organizational and policy responsibilities were performed in order to clarify and illuminate the subject area. The participants in the focus group discussions were asked about their knowledge, opinions, beliefs, and attitudes towards the concept of evidence-based public health. Questions were asked in an interactive group setting in which participants were free to talk with other group members. A semi-structured interview guide was used to promote discussions related to the following themes:

- Perspectives on the concept of public health and public health practice
- Perspectives on the concept of evidence-based public health
- Required competencies in evidence-based public health development

Four focus group discussions with 5 to 6 participants per discussion were performed, for a total of 22 participants. The durations of the focus group discussions ranged from one to two hours. The participants represented the following departments/agencies: culture,

health, community planning/structures, research, and policy. The participants were invited in order to provide a cross-section of interdisciplinary expertise. Participation was voluntary, and data was anonymized. All interviews were transcribed and coded. Analysis was empirically driven (Charmaz, 2006). Keywords were used to identify concurrent themes that emerged in the focus group discussions (Babour, 2007). Data were then organized in order to clarify similarities and differences in the data between the informants and across focus groups.

#### Results

#### Available public health data – regional and local initiatives

In the county or municipal context, access to health data is not characterized as a barrier to health promotion. Rather, lack of competency in selecting what data is most relevant to the public health context represents the largest barrier. There is, however, a need for data that illuminate the relationship between various health indicators and other influencing factors. In addition, the study shows that emphasis is placed on disease indicators rather than on indicators that promote health.

Data from the Nord-Trøndelag Health Survey (HUNT) provides an overview of the health of the population and health trends over time. HUNT data make it possible to develop municipal profiles and examine trends in the development of each municipality in Nord-Trøndelag County. HUNT data also point out specific health-promoting factors as well as health challenges within municipalities. Such data indicate potential areas that may be better targeted by policy. Moreover, this study shows that regional and local initiatives, as well as both structural and general priorities, have knowledge-based profiles with the clear goals of competence building and inter-agency and cross-sectoral collaboration.

#### Focus group discussions

The following themes emerged from the analyses of the focus group discussions as particularly relevant when translating evidence into public health: *Stakeholders and settings; Competencies: From knowledge to action – how to make it work; Interaction between stakeholders and decision makers.* 

The focus group discussions highlighted the need for, as well as the potential challenges related to, interdisciplinary and cross-sectoral expertise in public health practices. A forum across sectors was proposed as a potentially effective means to promote

collaboration in developing and implementing evidence-based health promotion and public health strategies.

In the focus group discussions there was a consensus among the participants that evidence-based practice combines the use of the best available scientific evidence, the experience and expertise of the practitioners, as well as users' competence. The importance of taking into account values, resources, and situational contexts in decision-making was also discussed. The participants in the focus groups pointed out that there is considerable knowledge about risk factors, but less knowledge about health-promoting factors and how to convert such knowledge into targeted measures.

Some of the participants argued that we lack knowledge about the causes of health and disease as well as knowledge of effective intervention and implementation strategies. Lack of knowledge about political processes and how to get politicians to use evidence in policy decisions was raised as another potential barrier to progress. The focus group discussions additionally concentrated on the challenges related to progressing from obtaining knowledge to intervention design, implementation, and adaption. Political challenges, funding challenges, and challenges related to competencies, as well as the need for workforce training, were all themes discussed as critical in the implementation of evidence-based practices in public health.

The following strengths and barriers supporting or hindering the implementation of evidence-based practices in health promotion and public health emerged from the focus group discussions:

#### Strengths:

- Strong regional and local political foundation
- Availability of health data (national, regional, and local)
- Availability of necessary skills in counties and research sectors to support municipalities
- Considerable expertise of practitioners

#### Barriers:

- Lack of knowledge about effective interventions and how to implement these interventions – How to best interpret the results
- Scientific skills
- Using data and information systems systematically

- Systematic planning
- Conducting sound evaluations
- Cross-sectoral communication
- Workforce training needs competencies required
- Demonstrating to decision makers that health promotion works and is an effective strategy in public health
- Making policy makers aware of research results

In other words, clearly defined access to data gives a good overview of the health of the population. However, knowledge about the effects of interventions and the measurement processes used, as well as knowledge of the political processes guiding decision-making were described as inadequate. Progressing from knowledge to the use of evidence-based approaches was described as particularly challenging.

#### Discussion

This study aimed to identify existing knowledge, research, and development needs, as well as the skills needed by counties and municipalities to implement evidence-based health promotion.

Within the health promotion field there is an understanding of the complex relationship between context and behaviour, and the necessity of influencing systems and structures as well as individuals to promote change (Davis et al., 2000; Speller et al., 2005; Brownson et al., 2009; Raphael, 2010). This study shows, in line with political visions and principles of health promotion as outlined in directives, international agreements, and national policies (WHO, 1986; Prop 90L, 2010-2011), that increased efforts in evidence-based health promotion is necessary for regional and local initiatives. The political vision and principles of health promotion require skilled employees on the municipal level capable of implementing policies and translating plans into effective actions (Brownson et al., 2009). The present study highlighted several points of facilitation as well as barriers to making use of the best available evidence in a public health context.

Among the strengths recognized in the present study were first and foremost the accesses to national, regional, and local data on public health, as well as a strong political foundation. Moreover, the expertise of public health practitioners was mentioned as a regional and local strength. According to Brownson et al., 2009, public health practitioners should always incorporate evidence in selecting and implementing programs, developing

policies, and evaluating progress. This requires scientific skills, which are not necessary competences that practitioners possess (Speller et al., 2005). Collaboration with the research sector is therefore necessary to meet the requirements of evidence-based public health practice, indicating that the relationship between research and practice needs to be mediated.

Several barriers to the implementation of evidence-based public health were identified in the present study. These are the political environment, the competencies required, cross-sectoral collaboration, systematic planning, implementation strategies, and decision-making. These barriers indicate the need for a national initiative to facilitate knowledge exchanges among practitioners, policy-makers, and researchers about evidence-based health promotion and public health. There appears, however, to be a consensus among researchers and public health leaders that a combination of scientific evidence and values, resources, and contexts should be taken into account in decision making (Speller et al., 2005; Browning, 2009; Raphael, 2010), as well as in evaluating complex community-based public health interventions (Nutbeam, 1998; Pawson, 2006; Gray & Ison, 2009).

It is therefore of great importance to develop and publish national consensus guidelines (including evidence-based criteria, values, beliefs, and practical experience) for the implementation of evidence-based practices so that the existing evidence base can be transferred into practice. Such a consensus would also contribute by giving practitioners the justifications they need for the decisions they make (Raphael, 2000). It is, however, important to remember that best practice approaches, models, and available evidence are dynamic and ever-changing.

Evidence on health status, the determinants of health, and the effectiveness of intervention should be used to assess health, identify priorities, and develop strategies to improve health (Strategic Policy Directorate of the Population and Public Health Branch, Canada, 2001; Raphael, 2010). This requires, according to the participants in the focus discussions, enhanced communication and collaboration among key stakeholders involved in evidence-based practices like research, policy, and practice, in order to provide a standardized approach for identifying and classifying best practices. In order to move from intervention decisions based on short-term opportunities and lack of systematic planning, greater review of the best evidence regarding effective interventions in the implementation of best practices must occur, and increased cooperation between the research and public health management sectors is required (Tones & Green, 2004; Davis et al., 2000; The Norwegian Directorate of Health, 2010).

#### Limitations of this study

The selection of participants for the focus group discussions may have affected the type of information that emerged. The participants represented a strategic sample selected on the basis that the informants possessed broad cross-sectoral expertise in the field of public health. The question of whether those who were selected were those who were best suited to participate in the discussions can of course be problematized. A different group composition could have given different results. The number of participants in each group might also have influenced the results. Some of the participants might have taken too much of the time available for discussions, meaning that other participants had less time available to express their opinions. Furthermore, the design of the interview guide probably influenced the type of information that emerged.

#### Conclusion

Regional and local initiatives have sufficient data to make evidence-based decisions.

Decisions about program and policy interventions/approaches should include evidence-based criteria, but must also be based upon values, beliefs, and practical experiences.

Communication and collaboration among key stakeholders involved in evidence-based practices like research, policy, and practice should be enhanced. Moreover, enhanced knowledge of political processes is recommended in order to promote evidence-based decision-making.

#### References

- Antonovsky, A. (1979). *Health, Stress and Coping*. New Perspectives on Mental and physical well-being. San Francisco: Jossey-Bass.
- Antonovsky, A. (1987). *Unraveling the mystery of health: how people manage stress and stay well.* San Francisco: Jossey-Bass.
- Antonovsky A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International*, 11, 11-18.
- Barbour, R. (2007). Doing focus groups. Sage. XV: London.
- Barry, M., Allegrante, J. P., Lamarre, M-C., Auld, E. M., & Taub, A. (2009). The Galway Consensus Conference: International collobaration on the development of core competencies for health promotion and health education. *Global Health Promotion*, 16, 5-11.
- Brownson, R. C., Fielding, J. E., & Maylahn, C. M. (2009). Evidence-Based Public Health: A Fundamental Concept for Public Health Practice. *Annual Review of Public Health*, 30, 175-201.
- Brownson, R. C., Gurney, J. G., & Land, G. (1999). Evidence-based decision making in public health. *Journal of Public Health Management and Practice*, *5*, 86-97.
- Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. Introducing qualitative methods (p. 208). Sage: London,.
- Davies, H. C., Nutley, S. M., & Smith, P. C. (2000). What works? Evidence-based policy and practice in public services. Bristol: The Policy Press.
- Egger, M., Davey Smith, G., & Altman, B. G. (2001). *Systematic Reviews in Healthcare: Meta- analysis in Context*. London: BMJ Books.
- Gray, J.A.M., & Ison, E. (2009). Evidence-based healthcare and public health: how to make decisions about health services and public health. Edinburgh: Churchill Livingstone Elsevier.
- Holmen, J., Midthjell, K., Krüger, Ø., Langhammer, A., Holmen, T.L., Bratberg, G. H., Vatten, L., & Lund-Larsen, P. G. (2003). The Nord-Trøndelag Health Study 1995-97 (HUNT 2): Objectives, contents, methods and participation. *Norsk Epidemiologi*, *13*, 19-32.
- Krueger, R. A., & Casey, M.A. (2009). Focus groups: A practical guide for applied research (4th Ed) (p. 219). XVIII, Los Angeles: Sage.

- MacIntyre, S., Chalmers, I., Horton, R., & Smith, R. (2001). Using evidence to inform health policy: Case study, *BMJ*, *322*, 222-225.
- Mackenbach J.P, Van Den Bos J., Van De Mheen H., & Stronks K. (1994). The determinants of excellent health: Different from the determinants of ill-health? International. *Journal of Epidemiology*, *23*, 1273-1281.
- Marmot, M. (2000). Multilevel Approaches to Understanding Social Determinants. In:

  L. Berkman, I. Kawachi (Eds.). *Social Epidemiology*. New York: Oxford

  University Press.
- Marmot, M. (2011). *The Marmot Review. Fair Society, Health Lives*. Strategic Review of Health Inequalities in England post -2010.
- Mittelmark, M. B., & Hauge, H. A. (2003). Helsefremmende politikk for vurdering av helsekonsekvener. Hvorfor lokalsamfunn og nærmiljø er de sentrale arenaene. I: H.A. Hauge, & M.B. Mittelmark (Eds.). *Helsefremmende arbeid i en brytningstid: Fra monolog til dialog?* (p. 39-51). Bergen: Fagbokforlaget.
- Nutbeam, D. (1998). Evaluating health promotion- progress, problems, solutions. *HPI*, 13, 27-44.
- Pawson, R. (2006). *Evidence-based Policy, A Realistic Perspective*. London: Sage Publications.
- Prop. 90 L. (2010-2011): Flere leveår med god helse i befolkning og reduserte sosial forskjeller Likhet og rettferdighet, "Helse i alt vi gjør" (In Norwegian).
- Raphael, D. (2000). The question of evidence in health promotion. *Health Promotion International*, 15, 355-367.
- Raphael, D. (2010). *Health promotion and quality of life in Canada. Essential Readings*. Toronto, Ontario, Canada: Canadian Scholar's Press Inc.
- Speller, V., Wimbush, E., & Morgan, A. (2005). Evidence based health promotion practice: how to make it work. *IUHPE Promotion & Education Supplement* 12, 15.
- Strategic Policy Directorate of the Population and Public Health Branch (2001). Canada. http://www.phac-aspc.gc.ca/ph-sp/pdf/discussion-eng.pdf'
- The Norwegian Directorate of Health (2010). *Health Promotion—achieving good health for all*. Oslo: IS-1846.
- Tones, K., & Green, J. (2004). *Health promotion: Planning and Strategies*. London: Sage Publications.

- White paper nr. 20 (2006-2007). *Nasjonal strategi for å utjevne sosiale helseforskjeller*Tilråding fra Helse- og omsorgsdepartementet av 9. februar 2007 (In

  Norwegian).
- White paper nr. 47 (2008-2009) *Samhandlingsreformen*. *Rett behandling på rett sted til rett tid*. (In Norwegian).
- Wilkinson, R., & Marmot, M. (2005). *Social determinants of Health*. Regional Office for Europe of the World Health Organization.
- World Health Organization (WHO) (1986). *The Ottawa Charter for Health Promotion*. http://www.who.int/healthpromotion/conferences/previous/ottawa/en/index1.htm l.

www.wikipedia.no. 04.03.2012.

# 19. A journey to the Center of Health some views and reflections on concepts for health promotion practice – plotting a roadmap towards New Health and the Salutogenic Society

#### BENGT LINDSTRÖM

Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Social Work and Health Science, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

IUHPE Global Working Group on Salutogenesis

#### Abstract

The Ottawa Charter gave health promotion both a value and principle base, further five main action areas were described. However, the charter was not theory driven which has created many problems as of effectiveness and comrehensability. In this presentation health promotion is contextualized in a salutogenic framework. Its central principles and concepts are commented on in a salutogenic perspective. Further the Health for All Policy and the expected outcomes of the Ottawa Charter Action areas are presented in terms of the global evidence base on salutogenesis. The intention is to present a salutogenic roadmap to health promotion as a guidance for future debate and more effective health promotion interventions.

#### Introduction

Health promotion faces many challenges both externally and internally. Being the "new kid on the block" both public health and medicine initially reacted rather bluntly to this new movement, adopted some of the ideas but continued to operate as before but their view of health did not change. Internally health promotion is a rather disperse phenomenon trying to cover all and everything, making it difficult to find a definite core for health promotion especially since it was not initially theory driven. No doubt are the principles in its key policy document, The Ottawa Charter, appropriate but demanding: starting off with the activation and involvement of the population in health issues through empowerment. From there moving on to changing the environment and reorient the focus of health services to primary health, further, shifting from the individual to a contextual population approach, finally, setting up policies for overall health, healthy public policies, reaching far beyond the

health sector in inter-sectorial action. However, it seems health promotion never really got this act together into a full comprehensive approach. One reason is that initially health promotion was only based on values and principles and lacked a strong theoretical basis. This has continued to be the Achilles heel of health promotion making it utterly vulnerable and making it difficult to model, evaluate and find a focus for action. Indeed, one of the most highly celebrated persons in contemporary International Health, Sir Michael Marmot, was firm in his critique of health promotion in the last WHO Global Health Promotion Conference (Nairobi 2009). He said: "Having read the background documentation on the values, objectives and intentions of health promotion, there is no doubt it carries a good argument for how contemporary health activities should be developed - but looking at the practice of health promotion, I say, "Why on Earth are you not doing what you are supposed to do!!??"

So let me take the challenge and respond to all of this and put the scene together in line with the original intentions of health promotion and touch upon some difficulties while trying to demonstrate how this could be carried out in practice to create a health promoting or Salutogenic Society.

#### First the issue of health.

"Health is not bought with the doctor's pills or the cut of the surgeon's knife. Health is not only the absence of ills but the fight for the fullness of life."

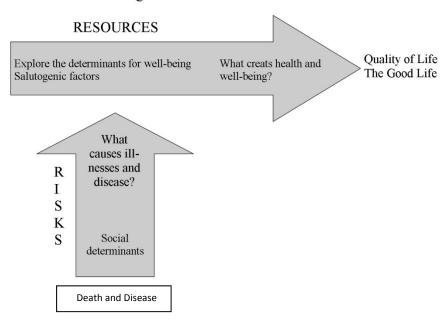
(P.Hein, WHO 40<sup>th</sup> Anniversary 1988)

Officially "health" has three dimensions: the physical, psychological and social (WHO 1948). This means there is a dimension for medicine (physical) one for public health (social) and one for psychology and behavioral science. However, there are good arguments to include a fourth dimension, the spiritual/existential, as suggested in 1987 by the former WHO Director General Halfdan Mahler. Some claim spirituality should be incorporated in the psychological dimension. My argument is that psychology mainly deals with psychoemotional issues. The spiritual/existential dimension in my opinion is different than the psychological, and a wider and more substantial concept than "religion", touching on meaningfulness and existentiality and the driving force behind a state like psychoemotionality. This argument is supported by the contemporary evidence base on the salutogenic approach to health. In health promotion it is important to find what motivates people, what issues are important to understand what people mean with quality of life. Here

meaningfulness is central as is known from salutogenic research. All health dimensions are of course interlinked therefore discussions and interventions on health should consider them all – "the whole". Relating back to the Ottawa charter health is no longer the outcome or objective, it is the process that supports people's ability to lead a good life or enjoy a high quality of life. In a sense it is a change of direction health is here linked to life and conditions that led to a good life again supportive to a different direction than if we focus only on disease and risks.

It still seems the dominant understanding of health is strongly related to disease and risks for ill health having the consequence that most interventions and actions are directed toward disease and risks. Health as a resource for wellbeing is largely a neglected issue. We could talk of two directions for research and practice: a risk-disease approach and on the one hand a resource approach (see figure below). Michael Marmots research that forms the basis for the WHO global efforts to reduce inequity in health focusing on social determinants of health is in its implementations in practice misinterpreted and by large only based on the reduction of risks for disease. As such, there is nothing wrong with this, but the "whole" becomes skewed forming a classic risk-reduction and disease-prevention approach rather far from the objectives of health promotion. We need a synergy of both to create the framework for "Next Health" but the present strategies are still rather truncated not using health as a resource concept. What would be the consequences of putting more emphasis on the resource/asset approach? It is noteworthy that Antonovsky in his original salutogenic approach does not describe the nature of health he describes what makes us move in a healthy or health promoting direction on the health continuum and provides his answer, the Sense of Coherence, the ability to use one's health resources the GRRs.

#### Well-being in the context of health research



**Figure 1.** The main activities and directions of health interventions vew health to the opposite of causes of death and disease (pathology) and prevention of risks for ill health. The other direction where health is directly related to resources and assets and directed towards life (salutogenesis), developing wellbeing, quality of life is much less explored.

#### **Participation**

Citing the Ottawa Charter "the process to gain control over one's health determinants". This is the question of empowerment, getting the population involved in health initiating processes that lead to a healthy development. The origin of the empowerment concept stems from Paolo Freire who successfully mobilized what he called "the ignorant and oppressed" i.e the illiterate with new pedagogic methods in Brazil. He was successful to the extent he became a threat to the Government and was expelled from the country. Since then the concept has travelled a long way through different disciplines landed in sociology and also found a central platform in health promotion. Many strategies are needed to address populations because there are so many different ways of understanding and learning ranging from an individual perspective to cultural, education, group and organization/community perspective or a mix of it all when addressing a society. Therefore the practice of empowerment needs many approaches where professionals humbly have to learn and consider how people, cultures, groups and organizations think, feel and act. There is sometimes a need to mix participatory and directed learning methods - it is not a question of one or the other. Learning is a lifelong process starting in infancy that should be based on people being regarded as active participating subjects (according to the UN Declaration on

Human Rights). It is a dialogue between the environment and the target group - be it an individual or a system (such as an organization) or the big challenge, society. The role of the facilitator/teacher is to be the "enabler" who abides to the above principles and makes it possible for the subject to build competence in a coherent learning process based on life experiences. The learning process itself needs to be conducive to constructive interpretations of experiences - one could say it should induce wellbeing and serve as a "healthy learning process (For further details see for instance The Hitchhiker's Guide to Salutogenesis)

#### The heart of the Ottawa Charter – its values and principles.

The Ottawa Charter (OC) contains both the values and basic principles of health promotion. Basically it is built on what is said in the above text about participation - seeing the human being in context as an active participating subject involved in a process of understanding what factors and processes are conducive to health and learn how to use these to improve not only the individual but the contextual quality of life and life competence. The role of the professional is to motivate and enable and point to constructs that can lead to improvement of health where the "learners"/systems ultimately can lead an active and productive life i.e a good life or enjoy a good quality of life. Thus "learning health" is of key importance here and should be conducive to *life*.

Further the OC includes five central action areas: improving individual skills/building competence, the community approach, the environment/ecology approach, reorientation of health services and building healthy public policy. Most of the time these action areas are dealt with as separate entities, however, in a population health promotion/ salutogenic and coherent approach it would be important to consider all at the same time in other words to work on a healthy public policy level in coordinated action shifting from the individual to a population approach, focusing on creating health promoting contexts/environments, shifting from health care only to a community approach involving all sectors and disciplines and finally directing the actions towards capacity building - developing health assets ultimately improving the QoL of the population. Can this be done? ".

In terms of Antonovsky's Sense of Coherence theory (SOC) and the Ottawa Charter (OC) we have many similarities to the degree it is rather surprising nobody thought of salutogenesis when the Ottawa Charter was written and constituted.

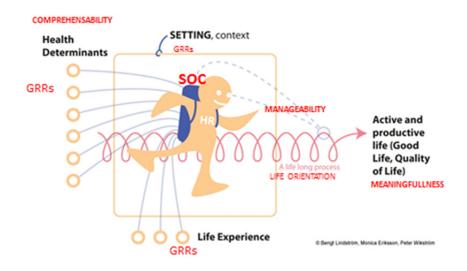


Figure 2. Comparison of the core concepts of the Ottawa Charter and the SOC theory

As a summary the following points are made explicit:

- 1. The OC talks about **health determinants** while the SOC theory talks about **General Resistance Resources** (GRRs) are available.
- 2. The OC talks about **gaining control over one's health determinants** while the SOC theory talks about **manageability** how to deal with a situation utilizing ones GRRs
- 3. The OC aims at creating conditions for an active and productive life i.e a good life or high QoL while the SOC theory talks about what makes life meaningful and what motivates people.
- 4. The OC is focused on 5 action areas as stated earlier where **Healthy Public Policy** binds it all together the SOC theory again talks about Coherence. The **synergy** between individual group and society/organization level is essential.
- 5. Both underline a contextual structural understanding of "grasping the whole" a holistic contextual view of the OC action areas that create health promoting environments while the SOC theory aims at constructing a Salutogenic Society

An important **difference** is the fact that because the OC was developed by a UN agency (i.e. WHO) it also automatically includes an ethical code, based on the UN Declaration on Human Rights, while "good health" or a" strong SOC" can develop without any moral or ethical basis. Therefore the SOC theory needs to be combined with an ethical code ensuring nobody has the moral right to develop good health or a strong SOC at the cost of other human beings or by destroying the ecology of our World. If health promotion based

on the OC is built on a salutogenic basis one always have to remember this aspect and can be expressed in a simple logic formula.

$$HP oc = (SAL + QoL) HR$$

HR= Human Rights

The added value of the SOC theory and the salutogenic approach to health in terms of the four health dimensions, in term of the Ottawa Charter and in terms of the Health for All Polcy

Most research articles describing salutogenesis and Antonovsky's theory on SOC include the now classical descriptions of the characteristics of Antonovsky's two core concepts SOC and GRR. Because Antonovsky died in 1994 he never had the opportunity to know what we know today almost 20 years later when salutogenic research has been carried out all over the globe for more than 30 years. It is now time to synthetize and look forward and describe the concepts in terms of what they can achieve in respect to health promotion and the production of health. The first results of a large scale systematic analysis of this research area was published in 2005 (Eriksson and Lindström) and later was defended as and academic dissertation (Eriksson 2007). The same year the IUHPE Global Working Group on Salutogenesis was established and the web database was started (www.salutogenesis.fi converted to www.salutogenesis.hv.se in 2011). This means we now have rich data source on salutogenesis easily accessible. Therefore it is much easier today to make conclusions on overall and specific details of studies with a salutogenic research perspective. I will here try to describe the SOC theory in terms of its outcomes as a response to Marmots statement mentioned earlier: "What happens when we do what we are supposed to do in health promotion!!"

#### SOC as described through its outcomes

This will be a first description. We do not have all needed data available, many areas have not been penetrated thoroughly enough while others have yet to be explored. However, this is an attempt to show the potential the salutogenic approach to health by looking at overall outcomes. To make this comprehensible I will use the objectives of the WHO Health for All Policy (HFA, historically probably the most important global public health policy). The Ottawa Charter on Health Promotion with its five Action Areas can in this context be seen as instrumental becoming the tool for how WHO wanted to implement its HFA Policy. In the HFA policy document the objectives of health action was described in terms of: addling

years to life (AYL making it possible to improve life expectancy) adding life to years (ALY to improve quality of life). Further goals were sustainability, equity achieved through intersectorial and interdisciplinary action.

#### SOC and age (Adding years to life and Sustainability (HFA; OC).

Still lacking the evidence of a longitudinal study following SOC from birth to death we have as an alternative compiled research made on various age groups over the globe and put them together. Understanding the limitations of this operation we still can say the mean SOC in general increases over age and we see the highest mean SOC values in old age. At present there are longitudinal studies of about 15 years that also demonstrate mean SOC increases. This gives us two indications of the characteristics of SOC: 1) On a population level the SOC grows stronger over the life span it is sustainable and 2) Attaining a strong SOC is something we learn over time. According to the theory SOC develops through the way we deal with our life experiences and integrate them in our overall knowledge. The better we get at this the stronger the SOC.

### SOC related to the physical dimension of health (responding to Medicine, Public Health and the Health Concept: H).

There is some research that indicates there is a weak correlation between SOC and physical/somatic health. We cannot discern these results. However, I find overwhelming results speaking in favor of the opposite. This is the abundant research on various specific diseases and SOC. We can see that a strong SOC is positively related to people's ability to deal with disease i.e doing better even when ill. In other words people manage most conditions of disease better if they have a strong SOC. My interpretation is that SOC is strongly and positively correlated to health as related to somatic disease. We can take almost any disease, even the major NCDs (diabetes, cancer, heart disease, chronic lung disease and mental disorders), and find that a strong SOC makes it possible for people to manage disease better than if the SOC is weak. This evidence base is convincingly strong wherever it has been undertaken.

## SOC related to the Psychological Dimension of Health (mental health, wellbeing and Quality of Life); (Adding life to years; OC, HFA, H).

A strong SOC is strongly and positively correlated to wellbeing, quality of life and mental health. The same results are found all over the world, be the studies based on longitudinal, cross sectional or qualitative research. The strongest and most convincing evidence comes

out of this psycho emotional dimension of health. A strong SOC is thus related to mental health, perceived health, quality of life and wellbeing.

#### SOC and the Social Dimension of Health (Equity; HFA, H).

Trying to get hold of Marmots health gap and studies of social position and health the evidence base regarding SOC is not strong enough. At present the structural political approach has a strong position in public health where one has always been trying to relate ill health to social position. Vital and national statistics are collected and analyzed on this basis. What we completely lack are the statistics of wellbeing. We know that people with a lower social position are exposed to more risks and in many ways have fewer resources available (also such GRRs) that are related to socio economic conditions. However these groups are seldom described in terms of their resources. These could be decisive for their health outcome. This other questions what to do with this knowledge, how to promote change should be much more a question of health promotion action. The SOC theory could in a sense be the software that for the socioeconomic weak mobilizes health resources. It is evident we need to look at this mobilization-empowerment much more carefully in the future. In terms of Paolo Freire we do have an answer and other recent frameworks, such as Bruun Jensen's concept "action competence" speak in favor of this. In respect to gender and equity there is a general trend of males having a slightly stronger SOC than women. Further, SOC seems to be more related to psycho-emotionality than to socio-economic conditions but this means also you do not have to be rich to feel well and have a strong SOC. As a conclusion, this his means SOC operates beyond gender and socioeconomic position as an independent process if it is activated properly. Further exploration is much needed in the future. Overall these issues have to be addressed both from a social political public health perspective, we need the political will to allocate resources just as the Marmot recommendations suggest and in addition a salutogenic/health promotion perspective. Let public health and social policy build the structures and let the mobilization of the less advantageous groups in society with less resources and GRRs happen through health promotion and salutogenesis.

#### SOC related to existential/spiritual health (OC,H).

According to Antonovsky the SOC construct as such had a strong foundation in meaningfulness which he regarded as the most important dimension of SOC. I touched upon this issue in the introduction on the health dimensions. The existential dimension is as

discussed earlier linked to quality of life and mental health research. At present there is an explosion of research focusing on how to achieve happiness, positive health, mental health promotion, mindfulness healthy learning wellbeing QoL through existential questions and meaningfulness.

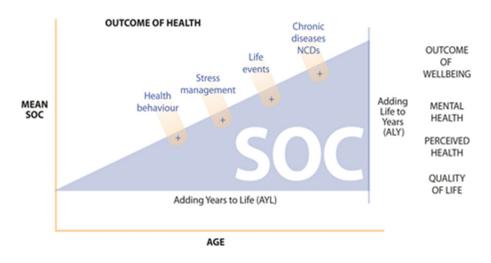
#### SOC related to Health Behaviors and improvement of "personal skills" (OC Action).

It was rather surprising when the analysis of the international SOC review data indicated that people who had developed a strong SOC also were more inclined to develop constructive health behaviors. There also seems to be a trans-generational function since children having parents with a strong SOC were more likely to develop positive health behaviors too. The same can be seen in many compliance studies on medical treatment and interventions. This means the appearance of classic negative behaviors such as of bad food habits, low physical activity, high use of alcohol, tobacco and drugs is more common when the SOC is weak and on the other hand a strong SOC is conducive to constructive behaviors. SOC and health promotion is mainly focusing on behaviors on group, population and contextual levels.

## SOC related to social networks, the environment, like workplace, organizations (OC Action).

Semantically sense of coherence means interaction and communication between at least two agents be it individuals, systems or organizations. Research into systems and organizations, communities and societies where social capital and cultural capital are seen as GRRs is still largely lacking. However the system approach is a merging research area also when focus is put on the salutogenic approach such as positive aspects of workplaces. People who develop a strong SOC are more likely to adjust to transitions such as returning to working life after sick leaves aso.

#### THE HFA 2000 POLICY AND OUTCOMES RELATED TO SALUTOGENESIS



© Bengt Lindström, Monica Eriksson, Peter Wikström

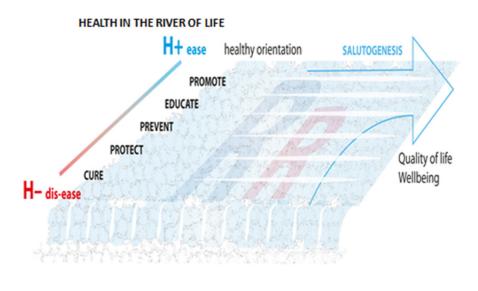
Figure 3. Outcomes of SOC related to Health For All Policy

#### Next Health - Building the Salutogenic Society.

I have in this text tried to discuss several matters relevant to the future of health practice and research. I have given it a name: the NEXT HEALTH meaning we have to take the full step into the paradigm shift of health promotion through the salutogenic framework. We have had too many halfhearted "new public health" and "health-renewal" discussions ending up in much the same old perspectives. I am waiting for the "new health promotion"?!! Therefore, I have tried to show a direction, point out and penetrated some of the existing problems and touched upon some of the untapped potential to create the Next Health. The direction is to connect health to life rather than to death, disease and risks. Starting exploring the health concept itself, explaining the core of principles, values and objectives of public health policy and health promotion thereafter moved on to the salutogenic framework and analyze the scenery in a salutogenic perspective. I feel by no means I have been able to cover the whole area. We should be much more focused on seeing the similarities, call on the strengths of the various perspectives rather than only point at the differences. This is a much more salutogenic way of thinking, what makes things work together in synergy to be more productive and effective and last and not least bring more quality to life.

To be able to carry on this work we need good research for practice and vise versa. We need to shift focus to constructive frameworks aiming at solutions. We need to use the science and art of interdisciplinarity to find synergies and strengths in and between disciplines and systems. We still lack a proper vocabulary and scientific framework for

wellbeing and health. We need to build vital statistics based on population assets and resources and build contexts structures and institutions based on this knowledge. We shall never forget the fundament of human capital and human rights, the notion that the UN Declaration of 1948 is mainly focusing on the individual while the 1989 UN Convention on the Rights of the Child also focusing on strengthening the context of the child, in that sense much more in line with health promotion and salutogenesis. Vital to the success will be a constructive communication with Public Health and Medicine, to draw on each other strengths, the deep knowledge of pathogenesis in medicine combined with the system and structured risk approaches of Public Health and integrate these in the health promotion and salutogenesis frameworks. We need to travel beyond these sectors and create synergy and strengths regarding human assets to make a Roadmap for the New Health.



**Figure 4**. The New Health Scenery: Medicine, Public Health and Health Promotion and Salutogenesis swim in the River of Life

© Bengt Lindström, Monica Erikson, Peter Wikström

#### The Global Working Group on Salutogenesis

We are pleased IUHPE has set up a Global Working Group on Salutogenesis that now has a core group of 10 research centers developing different aspects of the salutogenic framework in theory and practice. Some of the achievements today are: the systematic analysis of salutogenic research and the open access database on our website now run by the Trollhättan Center; the initiative of the HEMIL Senter to prepare a framework for an IC-Wellbeing to complement the existing WHO IC-Disease and IC-Function. We need practice based institutions like the RCHPR and Wagningen Health and Society Chair developing practice based research. We need the pioneering job on Mental Health and Flourishing at Newcastle

and Emery and the shift towards organization development based on salutogenesis as developed in Zurich. We need life course studies and research on specific age groups like adolescents by Ben Gurion Univ and the Asset Approach group at NICE in London. We need good learning models and tools like the ones developed at the STENO Center.

#### References

- Antonovsky, A. (1979). Health, Stress and Coping. San Francisco: Jossey-Bass.
- Antonovsky, A. (1985). The life cycle, mental health and the sense of coherence. *The Israel Journal of Psychiatry and Related Sciences*, *22*, 273-280.
- Antonovsky, A. (1987). *Unraveling the Mystery of Health. How people manage stress and stay well.* San Francisco: Jossey-Bass.
- Antonovsky, A. (1987a). Health promoting factors at work: The sense of coherence. In:
  M. Kalimo, M. Eltatawi, & C. Cooper (Eds.) *Psychosocial factors at work and their effects on health*. (pp. 153-167). World Health Organisation, Geneva.
- Diener, E. (2009). The Science of Well-Being. The collected works of Ed Diener. General Reviews and Theories of Subjective Well-being. New York: Springer.
- Eriksson, M. (2007). Unravelling the Mystery of Salutogenesis. The evidence base of the salutogenic research as measured by Antonovsky's Sense of Coherence Scale.

  (Doctoral dissertation, Åbo Akademi University Vasa). Folkhälsan Research Centre, (Research Report No.1), Turku.
- Eriksson, M., & Lindström, B. (2008). A salutogenic interpretation of the Ottawa Charter. *Health Promotion International*, *23*, 190-199.
- Eriksson, M., Sagy, S., & Lindström, B. (In press). A salutogenic perspective on mental health across the life time. Cultural aspects on the Sense of coherence. In: C-H. Mayer, & C. Krause. (Eds.). *Mental health: theoretical and empirical discourses on salutogenesis*. A text collection.
- Fayers, P. M., & Machin, D. (2000). *Quality of life. Assessment, analysis and interpretation*. New York: John Wiley & Sons, Ltd.
- Freire, P. (1970). *Pedagogy of the oppressed*. New York: Herder & Herder.
- Garmetzy, N. & Rutter, M. (Eds.) (1988). *Stress, coping, and development in children*. Baltimore: The Johns Hopkins University Press.
- Honkinen, P.-L., Aromaa, M., Suominen, S., Rautava, P., Sourander, A., Helenius, H. & Sillanpää, M. (2009). Early childhood psychological problems predict a poor sense of coherence in adolescents. A 15-year follow-up study. *Journal of Health Psychology*, 14, 587-600.
- Keleher, H., MacDougall, C., & Murphy, B. (Eds.) (2007). *Understanding health promotion*. New York: Oxford University Press.

- Keyes, C. L. (2002). The mental health continuum: From languishing to flourishing in life. *Journal of Health and Social Research*, *43*, 207-222.
- Kickbusch, I. (Ed.) (2009). Policy innovation for health. New York: Springer.
- Koelen, M. A., & Lindström, B. (2005). Making healthy choices easy choices: the role of empowerment. *European Journal of Clinical Nutrition*, *59*, 10-16.
- Lezwijn, J., Vaandrager, L., Naaldenberg, J., Wagemakers, A., Koelen, M., & van Woerkum, C. (2011). Healthy ageing in a salutogenic way: building the HP 2.0 framework. *Health and Social Care in the Community*, 19, 43-51.
- Lillefjell, M., & Jakobsen, K. (2007). Sense of coherence as a predictor of work reentry following multidisciplinary rehabilitation for individuals with chronic musculoskeletal pain. *Journal of Occupational Health Psychology*, 12, 222-31.
- Lindström, B. (1994). *The Essence of Existence. On the quality of life of children in the Nordic countries Theory and practice in public health.* (Doctoral dissertation, Nordic School of Public Health, 1994).
- Lindström, B., & Eriksson, M. 2009. The salutogenic approach to the making of HiAP/Healthy Public Policy: illustrated by a case study. *Global Health Promotion*, 16, 17-28.
- Lindström, B., & Eriksson, M. (2010). *The Hitchhiker's Guide to Salutogenesis*.

  Salutogenic pathways to health promotion, Helsinki, Folkhälsan IUHPE Global Working Group on Salutogenesis.
- Moksnes, U. K. (2011). *Stress and health in adolescents: The role of potential* protective factors. (Doctoral dissertation, Trondheim, Norwegian University of Science and Technology, 2011).
- Pahkin, K., Väänänen, A., Koskinen, A., Bergbom, B., & Kouvonen, A. (2011).

  Organizational change and employees' mental health: The protective role of sense of coherence. *Journal of Occupational and Environmental Medicine 53*, 118-123.
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology, *American Journal of Community Psychology*, *15*, 121-148.
- Reid, A., Bruun Jensen, B., Nikel, J., & Simovska, V. (eds.) 2008. *Participation and learning. Perspectives on education and the environment, health and sustainability.* New York: Springer.

- Rutter, M. (1985). Resilience in the face of adversity, *British Journal of Psychiatry*, 147, 598-611.
- Sagy, S., & Antonovsky, H. (1999). Factors related to the development of the sense of coherence (SOC) in adolescents. A retrospective study. *Polish Psychological Bulletin*, *30*, 255-262.
- Sagy, S., & Antonovsky, H. (2000). The development of the sense of coherence: A retrospective study of early life experiences in the family. *Journal of Aging and Human Development*, *51*, 155-166.
- UN. 1948. *Universal Declaration of Human Rights* [Online]. http://www.un.org/Overview/rights.htlm (accessed February 29, 2012).
- UN 2011. Happiness: towards a holistic approach to development.

  http://www.un.org/en/mdg/summit2010/pdf/mdg%20outcome%20document.pdf
  . 20
- Werner, E., & Smith, R. (1982). Vulnerable but invincible. A longitudinal study of resilient children and youth. New York: McGraw Hill.
- Werner, E., & Smith, R. (2001). *Journeys from childhood to midlife. Risk, resilience, and recovery.* Ithaca: Cornell University Press.
- Westerhof, G. J., & Keyes, C. L. (2010). Mental illness and mental health: The two continua model across the lifespan. *Journal of Adult Development*, 17, 110-119.
- WHO 1948. WHO Constitution and Declartion of Health.
- WHO 1981. Global Strategy for Health for All by the Year 2000, Geneva, World Health Organization.WHO (2001) Mental health: strengthening our response. Available from: http://www.who.int/mediacentre/factsheets/fs220/en/ (Accessed 9 December 2011).
- WHO 1986. The Ottawa Charter for Health Promotion.

#### 20. Cultural activities as health promotional strategy

#### LISE JAASTAD

Norwegian University of Science and Technology, Faculty of Social Sciences and Technology

Management, Department of Social Work and Health Science, Trondheim, Norway

Research Centre for Health Promotion and Resources HiST/NTNU, Trondheim, Norway

#### Abstract

This article gives a short presentation of two research studies concerning leisure activities, especially focusing on cultural participation and health among seniors in Trondheim municipality. Both studies that will be presented in this paper are part of an investigation which aims to reveal information that may be used to invigorate the number of pensioners participating in cultural activities on a regular basis. The objectives were to map knowledge about cultural- and spare time- interests and activities among seniors in the Trondheim Municipality. Access to inspiring cultural- and other leisure activities is considered a tool for individual and social health promotion, contributing to better life quality and sense of coherence. Results: These surveys should be interpreted with caution. Nonetheless, they fall in line with larger national and international studies, pointing at enriched environments, participation and association in meaningful cultural- and social activities as significant life quality and health promotional factors.

A growing number of observations and research studies point to the correlation between participation in cultural activities and a sense of wellbeing (Cohen, Perlstein, Chapline, Kelly, Firth, Simmens, 2006). A number of Swedish studies have strongly contributed to putting culture and health on the public health agenda (Bygren, Konlaan, Johansson, 1996, Bygren, Johanssen, Konlaan, Gribovski, Wilkinson, Sjöström, 2009, Bygren, et al., 2009) as well as creating a demand in research and health settings for clarification of the possibilities of using culture activities as part of effective health promotion programs (Knudtsen, Holmen, Håpnes, 2005). Major multidisciplinary research programs on health benefits from cultural activities are currently being carried out at Gothenburg University/Sahlgrenska Institute (Bjursell, 2009). Although randomized population studies concerning the impact on health from cultural activities have not been carried out in Norway, results from a broad long-term public health research program (HUNT) strongly indicate that the role of cultural participation may be of great importance,

and deserves serious attention in the development for future socio-political health strategies. In May 2009, an amendment was passed by the Norwegian parliament aiming to implement the development of research methods on how to measure quality of life on a national scale as a supplement to GNP. Internationally, the political interest for developing methods to measure national QOL is growing. Embedded is the acknowledgment that good quality of life prerequisite a healthy nation.

Seniors are the fastest growing population in the world. We live longer and women live longer than men. Differences in lifespan, self-reported health, age difference in marriages, (as elderly men tend to live with significantly younger wives), are among perspectives actualizing the need for more gender specific research. Globally, in 2000, approximately 605 million people were 60 years or above. For the first time in history it is expected that the number of seniors outnumber children (up to 14), by 2050. By 2020 the number of "single ladies 90+", living in Oslo is expected to be 6 times higher than the same group of men (Vangen, Jenum, Graff-Iversen, Idland, 2009). Men represent a minority in the senior population, in cultural participation, and in research surveys. As a total, many elders do not participate in research surveys. We are far from having sufficient knowledge about the senior population in our society, and most information includes both genders. In surveys based on voluntary participation, there is reason to believe that more women than men participate and the majority of all participants will be recruited among the most resourceful, active, and most healthy elders. This is also the case in these two surveys, with a total of 308 informants. 91 (35%) are men, the majority aged 70+.

The cultural activity program for seniors offered by Trondheim Municipality Section for Culture, includes around 250 arrangements per year including: concerts, theater plays, film, literature, fine art exhibitions, as well as opportunities to actively participate in: these include choir, drama- group, dancing, physical work out, trips, travels and nature walks. Activities are organized in cooperation with volunteer groups, a variety of organizations/NGOs, public health care, and several public and private cultural arenas.

#### The Studies

#### Study 1

In 2010, RCHPR carried out a survey concerning cultural participation and self-reported health status among elders (most of them pensioners) living within Trondheim (Jaastad, 2011). Informants were recruited among participants in Trondheim County's Senior Culture

program: recruitment took place from different practical performing activity, (drama, choir, dance and physical work out), and audiences (at concerts, art exhibitions, museums etc.). Our aim was to prepare the ground for a larger study examining possible links concerning cultural participation and health.

#### Methods

#### **Participants**

Out of 600 approached with questionnaries 188 women and 48 men responded (265 respondents, response rate 42%). 20 failed to report gender. The mean age was 73 years. The highest education level showed an equal division within four main categories: primary school, secondary school, university/college: 3 years and 5 years. Civil status was reported as 42% married/living with a partner and 56% living alone. A vast majority reported social support as "to have friends who would support if needed." Most respondents commonly used public health services, composed of regular, single appointments with a medical doctor/specialist and dentist.

#### Administration

With reference to demographical information, frequency level and meaningfulness in cultural participation, and basic information on self-reported health status, QOL/SOC was in focus. The methodological approach was both quantitative and qualitative. A questionnaire was supplemented by six semi-structured interviews and observations from choir- and drama-activities. *Statistical analysis* was performed with SPSS 18, including Frequency- and crosstabs, Spearman correlation test and Kruskal-Wallis H test for significance (at 0.01 and 0.05). All information was collected between August and November 2010.

#### Results

Within the group of informants the level of participation was generally high for all activities included in the survey. The highest attendance score was found for those attending concerts, cinema and theater plays (88%). The second highest attendance score was for nature walks/mountain hiking (86%), followed by physical work out/sports (75%). These findings are in accordance with other national surveys with wider age- and time spans. Next in popularity was organization work (68%), followed by visiting museums and art exhibitions (65%). 59% participated in dancing, playing music, singing and/or acting (drama group). Attending church services involved 51%, sport arrangements 35% and last, church member's

congregational activities 19%. The most commonly reported frequency level (by 47%) was for going to concerts, cinema and theatre; this was 1-6 times during the last 6 months. Those engaged in physical work out/sports (37%) train more than once a week. For nature walks/mountain hiking, 33% reported to participate more than once a week. 32% of those involved with dancing participated more than once a week. 25% of all informants reported not active in any sport activity. Educational background seemed of little significance for most activities with a few exceptions. In accordance with other national surveys (Vaage, 2010) visiting museums and art exhibitions may seem more popular among those with higher education, and dance, seemingly more popular among those with lower education.

**Table 1.** Frequency rate for participation in cultural activities included in the survey

Activity	%
Consert, cinema, theater	88%
Nature walks/mountain hiking	86%
Physical activitiy/Sports	75%
Organization work	68%
Museum/art exhibitions	65%
Dance	59%
Music, singing or theatre	59%
Going to church	51%
Sports arrangements	35%
Congregational work	19%

#### Meaningfullness and self-reported health status; QOL/SOC.

Of the respondents, 94% rated cultural activities as being *currently important*. On a 5 level Likert scale, 77% rated cultural activities as being "*very important*" or "*important*" in their lives for the time being. "*Since when/for how long*" has cultural activities been of importance to you, gave the following results: "*Yes, since childhood*: " 36%, "*Yes, since I was a teenager*", 10%, "*since I became an adult*", 31%, "*since I became pensioner*," 16%. The aspect of meaningfulness was a popular topic at coffee-break conversations during rehearsals and in interviews. On the question of what is most important, the cultural activity itself or the social activity, both dimensions received a high score, suggesting reciprocal links. Although a clear significance between level of cultural participation and health status was not found, results indicate that cultural activities stand out as possible health resource promotional factors strongly connected to good life quality (QOL) (Raphael, 2010) and sense of coherence (SOC) (Antonovsky, 1987).

#### Study 2

The cultural programs for seniors offered by the Trondheim municipality seem to engage far more women than men, the difference in participation being 3:1 in our first survey. As a result an additional survey was initiated exclusively focusing on men. Our aim was to learn more about men's cultural and leisure activities, interests and preferences, whether or not the communal culture program is well known, and what could be done to increase an interest in cultural participation among senior men (Jaastad, 2012).

#### Methods

#### **Participants**

Informants were recruited by the municipality Cultural Host, and through an advertisement in a magazine which is sent to every citizen above 70 years within the Trondheim municipality. The total number of male informants aged 70+ is 43, out of which 15 participated in focus-group interviews. *The age span* is 70-86 years. All 43 are, or have been married; of these, 7 are widowers, living alone. Professional background: *The majority came from* different kinds of practical labor and 6 hold a higher academ*ic degree*.

#### Administration

A questionnaire was designed for telephone- and focus group interviews. The only *statistical* analysis performed (with SPSS18) was Frequency tabs. Three focus group interviews, with 4, 5, and 6 participants, were taken. In one group all are members of a volunteer organization. For the other two groups, the participants represent two different local suburban areas. *Due to challenges trying to find* men willing to participate in interviews, the cultural hosts urged them to share their experiences. Additional interviews were made with the 6 Culture Hosts (focus-group interview), the Coordinator for Trondheim municipality Culture Hosts, and with one representative from Trondheim Senior's Information Office. All interviews were conducted in October and November 2011.

#### Results

The information gathered includes leisure time activities and interests, frequency level, and meaningfulness. The most popular leisure activities are caretaking of residential- and domestic properties, personal hobbies, tasks and duties concerning other needs within the circle of near family and friends. Participation in a variety of societies and organizations, sport- and physical activities, a variety of musical activities as well as going to concerts, also

show a high attendance score. Out of 43 respondents: 33 answered "yes" to whether or not they know some cultural activities offered in their local area. 22 answered "never" or "less then ones a week" participate in such activities. The Trondheim Municipality's cultural program for seniors is known to 34 respondents in this survey. Although these cultural programs are given a high quality ranking by many, they are also considered "more attractive to women". When asked: "What is needed for you to want to join a cultural activity" the core message in most answers was: Cultural programs (like other leisure activities), must be interesting, engaging and challenging and of high quality. "Watching the TV-sports", "hanging around supermarkets" "sitting idle" as well as being more or less forced to take part in "empty coffee-table conversations" was considered the worse scenario among most informants. Lectures and seminars within history, politics, economy, new technology, (communication technology in particular) nature, and culture, along with courses in wood carving, cooking, and nearby lawns for "Bocca", were considered particularly attractive to men. To some, "having an appointment" seems pivotal for social- or cultural participation. Access to near parking is another important factor, along with individual priorities. Many claim to be "too busy doing other things." Stimulating locations and environment was mentioned by many as a crucial factor for participation. Geriatric institutions and other locations known as "meeting arenas for the elderly" were considered "not attractive" arenas for social- and cultural activities among healthy elderly men. Although some had attended cultural events at geriatric institutions, others claimed they avoid such places because it makes them feel depressed.

#### Discussion

Is aging a taboo of our time and culture? These surveys and Study 2 in particular, raised several questions concerning how our society deals with aging. In spite of being well known, the interest to participate in senior's cultural programs appears low, even among those who often participate in a wide range of other activities. Their current label: "The Cultural Walking Stick", is a name easily connected to "old age". Irrespective of age, many did not consider themselves representative of the target group for these programs. According to the Coordinator of Cultural Hosts, to be a pensioner, "free from work" is considered positive, whereas to be counted among "elders" is not. In general people seem to dislike age related identity marks beyond "adult". Labels like old, elderly and senior seem loaded with associations such as being out dated, weak, useless and of no interest to anybody. Could it be

that many, and men in particular, out of fear of losing personal identity, value and purpose, avoid taking part in any activity that bare mark of old age?

- How to advertise cultural and other leisure activities for seniors?
- To which degree does society recognize seniors individually and collectively as resources?
- To what degree is variety and quality made a priority when designing cultural programs and other leisure activities for elderly men and women?

#### "Good-life factors"

The majority of informants from both surveys coincide with the theoretical model for measuring Quality of Life factors from the University in Toronto (Raphael, 2010). Both surveys describe a group of 70-80 years old "super elders". Thus group is active, well fit, with comfortable economy, and a joyous urge to keep exploring all good things life has to offer. These are resourceful people, eager to learn, to share, and actively make use of their experience and knowledge in everyday challenges. Creative- and social stimulation is sought with engagement through membership and participation in various organizations/ fellowships, cultural- sport and other leisure activities. All activities contribute (individually and collectively) to a physically and mentally enriched environment.

#### Family, freedom and fellowship

During the focus-group interviews in Study 2, every group, and in fact every participant, ranked family activities as most important, meaningful and giving. This was more important than several wealth indicators such as spouse, offspring, private properties (house, garden, cottages, boat and car), as well as personal and economic freedom. Not to be a burden, to be independent and able to manage every day challenges are emphasized by many as crucial life quality factors, along with access and ability to drive one's own car. Driving seems strongly connected to male identity, to freedom, independency, and to still being in control of daily duties. In Norway 87% of men aged 65-69 and 72% of men aged 80+ have access to a car at any time (Hjorthol, Nordbakke, 2008). The importance of friendship is strongly emphasized. Within this circle, of family members and friend-associated fellowships, is the comfort zone for giving and receiving help and support when needed.

#### Social integration, cultural participation and health

Growing divorce rates increases the number of elders living in single households. This may lead to lack of social participation, loneliness, weaker economy and negative stress, all factors that affect social, psychological and physiological environmental determinants (Næss, Rognerud, Strand 2007, Sund, Krogstad, 2005). More research is needed concerning the interplay of socio-economic conditions and health risk factors in a life span perspective. Still there are indications pointing to social support as a considerable buffer against diseases and psychological stress (Cohen, S. & Wills, 1985, George, 1996) Loneliness and lack of social participation have recently been given more academic attention (Bauman, 2000, Barstad, 2000, Barstad, 2004). Although results are not clear, there are strong indications that the risk for experiencing unwanted loneliness increases with age (Halvorsen, 2005, Holmen, & Furukawa, 2002, Thorsen, 2005). An interesting gender difference is found, as elderly men tend to live with significantly younger women (Nolen-Hoeksema, & Rusting, 2000). Being single, feeling lonely may be a barrier difficult to break, according to our informants. In focus-group-interviews, most participants more or less "confessed" that they are not good at welcoming or even speaking to newcomers. Some had experienced how difficult it may be to "join in" among strangers by going to a dance activity. Old friends had fun. Newcomers remained outsiders. According to our informants, men put restrictions on themselves by demanding some basic skills or knowledge prior to participation, and as result, many prefer to stay at home. Other given reasons for not attending cultural- and other leisure activities, is a lack of interest in earlier years, and a notion that most activities are run "on women's terms." Activities must be considered interesting and challenging, and preferably involve some kind of pre-established friend- or family-based fellowship.

Today's pensioners represent a political époque where socio-democratic egalitarianism and development of a strong national welfare state has had first priority. Norwegian citizens have enjoyed solid predictability and security at the job marked. Access to work, a decent income, material goods, education, individual and colloquial security are also considered important national health factors (Strand, Kunst, 2006). Over the past few decades we have seen a tendency of higher cultural participation among working class groups, especially among women (Loga, 2010, Vaage, 2010). In our studies, the majority of informants are culturally and socially active, with small demands for health care services. Current interests and activities seem to have followed even since childhood. Over the past 30 years, social inequality has been on the rise, and with it, a growing tendency towards socio-

economic exclusion. The most resourceful groups tend to keep themselves busy with friendsand family-based activities as well as participation in various activities according to
individual interests (Wilhelmsen, 2009). Among repercussions of the "globalized" market
economy are pressures on democracy and national sovereignty (Smedshaug, 2011, Brox,
1994). A continuous growth in socio-economic differences is a future threat to public health
standards. In this perspective, common access to stimulating and inclusive cultural arenas
may be of crucial importance for future public health strategies.

#### Closing comments

Although results from these surveys should be interpreted with caution, they fall in line with results from larger national and international studies, highlighting the importance of enriched environments, participation and association in meaningful cultural and social activities as major life quality and health promotional factors. The cultural programs offered by Trondheim Municipality seem to be of great significance for its participants. The vast majority of informants live an active life with little hindrance from practical, economical as well as physical and psychological health related matters. The opportunity to pick up on old interests after retirement seems to have contributed to more joy, growth, social participation, meaning and purpose in life. During the survey period for Study 1, several concerts and the like were arranged at nursing homes, health centers, and other geriatric institutions. These arrangements have become quite popular, both among staff and seniors. In accordance with the "Culture Law Regulation" passed by the Parliament in 2007 (Stortingsmelding Nr. 48), giving every citizen the legal right to a culturally enriched environment and access to cultural participation irrespective of social- or health-conditions, a great effort is being made to maintain these types of activities. More knowledge concerning the use of cultural activities in health promotion may turn out to be of great value for future public health, environmental and socio-economic development strategies. More research is needed, including longitudinal population studies, focusing on quality of life as well as on biomedical effects.

#### References

- Antonovsky, A. (1987). *Unraveling the mystery of health*. San Francisco: Jossey-Bass Publishers.
- Barstad, A. (2000). Hvem er de ensomme og isolerte? *Tidsskrift for Velferdsforskning*, 2, 67–84.
- Barstad, A. (2004). Få er isolerte, men mange er plaget av ensomhet. *Samfunnsspeilet*, 5, 19–26.
- Bauman, Z. (2000). Savnet felleskap. Oslo: Cappelen.
- Bjursell, G. (2009). Culture and health. Research Plan. University of Gothenburg.
- Brox O. (1994). Dit vi ikke vil. Oslo: Exit.
- Bygren, L.O., Konlaan, B.B., & Johansson, S.E., (1996). Unequal in death: Attendance at cultural events, reading books or periodicals, and making music or singing in choir as determinants for survival. *BMJ*, *313*, 1577-80.
- Bygren, L. O., Johanssen, S. E., Konlaan, B. B., Gribovski, A. M., Wilkinson, A. V., & Sjöström, M. (2009). Attending cultural events and cancer mortality: A Swedish cohort study. *Arts & Health 1*, 64 73.
- Bygren, L. O., Weissglass, G., Wikström, B.M., Benson, B., Grjibovski, A., Karlsson, A.B., Andersson, S. O., & Sjöström, M. (2009). Cultural participation and health: A randomized controlled trial among medical care staff. *Psychosomatic Medicine*, *71*, 469-473.
- Cohen, G.D., Perlstein, S., Chapline, J., Kelly. J., Firth, K.M., & Simmens, S. (2006). The Impact of Professionally Conducted Cultural Programs on the Physical Health, Mental Health, and Social Functioning of Older Adults. *The Gerontologist*, 46, 726–734.
- Cohen, S., & Wills, T. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin*, *98*, 310–357.
- George, L. K. (1996). Social factors and illness; In: R. H. Binstoc & I. K. George (Ed.), *Handbook of aging and the social sciences* (4th ed) (pp. 229–251). San Diego CA: Academic Press.
- Halvorsen, K. (2005). *Ensomhet og sosial isolasjon i vår tid*. Oslo: Gyldendal Akademisk.
- Hjorthol, R., Nordbakke, S. (2008). *Bilens betydning for eldres velferd og livskvalitet*. Rapport 1000/2008. Oslo: Transportøkonomisk institutt (TØI).

- Holmen, K., & Furukawa, H. (2002). Loneliness, health and social network among elderly people; A follow-up study. *Archives of Gerontology and Geriatrics*, *35*, 261–274.
- Jaastad, L. (2011). Kulturdeltakelse og helse. Den kulturelle spaserstokken, arena for kulturell deltakelse for seniorer i Trondheim kommune. (Rapport 2011/1). Senter for helsefremmende forskning HIST/NTNU.
- Jaastad, L. (2012). Den kulturelle dørstokkmila. Et bidrag til kartlegging av kultur og fritidsinteresser blant hjemmeboende men i alderen 70+ i Trondheim kommune. (Rapport 2012). Senter for helsefremmende forsning HiST/NTNU.
- Knudtsen, M. S., Holmen, J., Håpnes, O. (2005). Kva vet vi om kultur og helse? *Tidsskrift for Den Norske Lægeforening, 125*, 3418-20.
- Loga, L. (2010). Livskvalitet Betydningen av kultur og frivillighet for helse, trivsel og lykke. En kunnskapsoversikt. Senter for forskning på sivilsamfunn og frivillig sektor.
- Nolen-Hoeksema, S., & Rusting, C. L. (2000). Gender differences in well-being. In: D. Kahneman, E. Diener & N. Schwarz (Eds.). Well-being: The foundations of hedonic psychology. New York: Russel Sage Foundation.
- Næss, Ø., Rognerud, M., & Strand, B.H. (2007). Sosiale ulikheter i helse. En faktarapport. Folkehelseinstituttet.
- Raphael, D. (2010). *Health Promotion and Quality of Life*. Toronto/Ontario: Canadian Scolars Press Inc.
- Smedshaug, C. A. (2011): GJELD. Hvordan Vesten lurte seg selv. Res Publica.
- Stortingsmelding nr. 48 (2002-2003). Kulturpolitikk fram mot 2014.
- Strand, B.H., & Kunst, A. (2006). Childhood socioeconomic status and suicide mortality in early adulthood among Norwegian men and women. A prospective study of Norwegians born between 1955 and 1965 followed for suicide from 1990 to 2001. *Social Science & Medicine*, 63, 2825-34.
- Sund, E.R., & Krogstad, S. (2005). *Sosiale ulikheter i Norge. En kunnskapsoversikt*. Oslo: Sosial-og helsedirektoratet.
- Thorsen, K. (2005). Flere ensomme? Om ensomhet i den senmoderne tid. *Aldring og livsløp*, 22, 2-6.

- Vangen, S., Jenum, A.K., Graff-Iversen, S., & Idland, G. (2009). Trengs det et kjønnsperspektiv på eldres helse? *Tidsskrift for Den Norske Legeforening, 129*, 538-9.
- Vaage, O. F.(2010). Oslo-befolkningens bruk av kulturtilbud. Resultater fra kultur- og mediebruksundersøkelsene fra 1991 til 2008 og Levekårsundersøkelsen 2007. (Report No. 17). Oslo: Statistisk sentralbyrå.
- Wilhelmsen, M. (2009). *Dokumentasjonsrapport (2009/40): Levekårsundersøkelsen 2008: helse, omsorg og sosial kontakt.* Oslo: Statistisk sentralbyrå.





