



Is ignorance bliss?

Young men's lack of knowledge and concern for their health

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One Love,

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Abstract

Testicular cancer is an increasing health concern in Norway. It afflicts young men who often think they are impervious to serious illness, causing them to delay help-seeking. This is a major concern for the health care system, as the prognosis takes a steep fall if the cancer has had time to metastasise. The present study assessed the knowledge and awareness level of testicular cancer and testicular self-examination in 110 subjects currently in the at-risk group for the disease. A factor analyses was undertaken on the obtained data, and the obtained factors together with general psychological measures of depression, anxiety, optimism and health locus of control, were used to find possible explanations for lack of testicular self-examinations or delay of help-seeking. Results are discussed in light of earlier literature. Suggestions on how to improve the problems that causes delayed help-seeking are made.

Keywords: *Testicular cancer, self-examination, masculinity, young men and health, help-seeking, delay.*



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Abstrakt – norsk versjon

Testikkel kreft er et økende helseproblem i Norge. Den rammer unge menn som ofte føler at alvorlige sykdommer ikke kan ramme dem, noe som fører til at de utsetter å oppsøke medisinsk hjelp. Dette er et stort problem for helsevesenet, ettersom prognosen raskt blir dårligere hvis kreften har rukket å spre seg. Denne studien målte kunnskaps- og bevissthetsnivået om testikkelkreft og testikkelselvundersøkelse hos 110 subjekter som befinner seg i risikogruppen for testikkelkreft. En faktoranalyse ble utført på datamaterialet. Disse faktorene sammen med generelle psykologiske målinger av depresjon, angst, optimisme og helse locus of control ble brukt til å finne mulige forklaringer for manglende selvsjekking av testiklene og/eller utsetting av å søke hjelp. Resultatene er diskutert i lys av tidligere litteratur, og forslag på hvordan man kan forbedre situasjonen som forårsaker den problematiske utsettingen av medisinsk hjelp blir drøftet.

Nøkkelord: *Testikkelkreft, selvsjekking, maskulinitet, unge menn og helse, søker helsehjelp, utsetting.*



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Preface

Through battling his own disease and reading as much as he could about testicular cancer, the author found a common thread in both the literature that was written and personal stories that were told. Namely that procrastination was nearly the sole reason why testicular cancer still takes lives. The author was fortunate enough that he caught it early and persisted in getting medical help even after the first misdiagnosis. Hence he was able to take great comfort in the statistics that showed that testicular cancer has a recovery rate of approximately 99% when caught early. Still the literature was filled with stories and statistics about young men who faced a worse faith, and almost exclusively this was because the cancer was not caught early enough.

Also when the author told people about his illness, he was shocked by how many around him had gone through something similar without him knowing anything about it. So the author became very interested in how such a potentially dangerous disease could attract so little attention that the young men in the at-risk group he talked to knew little to nothing about the illness, and that it was still taboo to discuss the topic.

Together with the supervisor, who had previously published articles on quality of life with cancer survivors, the author sketched out a blueprint of the questionnaire. To include the general psychological instruments and run a factor analysis was the supervisor's idea, while the design of the questionnaire, collection and analysing of the data was done by the author.

Introduction

What is testicular cancer?

Our bodies are made up of billions of cells that grow, divide, and then die in a more or less predictable manner. Cancer occurs when something goes wrong with this system causing uncontrolled cell division and growth resulting in tumours. A malignant tumour is capable of spreading from its original site unless it is treated promptly. Most testicular cancer starts in the sperm cells, and usually only one of the testicles is affected, however the lymphatic system can spread the disease to other organs including abdomen and lungs, which worsens the prognosis significantly.

Little is known about the causes of testicular cancer; however there are some factors that are assumed to increase the risk of developing malignant tumours of such kind. Having had a problem with an undescended testicle(s), which has not dropped into the scrotum at birth, or within the first year, is the strongest predictor of being at-risk. Men born with such a condition run a 5-10 times higher risk of developing testicle cancer than the average man (McCullagh & Lewis, 2005). Statistics also show that men with a familial history i.e. having a father or brother with testicle retention have an increased risk of getting it. Such a genetic link can be seen in one third of the total patient population. Having a brother with testicle cancer makes you 6-10 times more likely to develop the disease. In addition Caucasian males are four to five times more likely than black males to be afflicted (Moore & Topping, 1999; McCullagh & Lewis, 2005).

There will not always be clear symptoms, at least in the early stages, and the symptoms are not exclusive to testicular cancer, which makes self-diagnosing difficult. However the most common symptoms of testicular cancer are listed below. It is highly recommended to seek medical help if one experiences some of these symptoms

<http://www.tcaw.org/issues/testicles.html#testicular>

- *a lump in one testis or a hardening of one of the testicles
- *An increase or in some cases a significant decrease in the size of one testis.
- *Abnormal sensitivity
- *Loss of sexual activity
- *Blood in, or watery semen
- *Generally feeling tired.
- *A build up of fluid within the scrotum

The road from seeking help to a potential surgery goes through the general practitioner who will refer the patient to a specialist who will in turn undertake an examination usually in the form of an ultrasound scan and blood tests. If suspicion of malignancy is sustained the surgeon will look at the testicle through an incision in the groin (Health encyclopaedia, 2008) and if cancer cannot be ruled out the testicle will be removed. To examine if the cancer has spread a computerised tomography scan and an X-ray of the chest is taken to look at the lymph glands in the abdomen and chest. These tests will be taken with certain regularity the following years after surgery to make sure no new malignant tumours are being formed. If it has spread, the lymph glands can be removed through additional surgery. There might also be a need of either chemotherapy or radiotherapy.

Testicular cancer differs from other types of cancer in two important aspects, namely the at-risk age group and the high survival rate when it is treated timely and appropriately (Mason & Strauss, 2004b). Thirty percent of the population in the western world will develop some type of cancer during their lifetime and no less than two thirds of these people will die from it. Seventy-five percent of all cancer victims are over the age of 60. These numbers stand in sharp contrast to testicular cancer victims who are most vulnerable between the age of 15-40 (<http://www.tcaw.org/issues/testicles.html#testicular>) and a prognosis of over 95 % chance of full recovery.

Prevalence

As previously mentioned, Caucasians run a much higher risk of getting testicular cancer, and so it is in North America, Australia and north-west Europe the prevalence is highest. In the United States about 8000-9000 (11.6 per 100,000) new diagnoses of testicular cancer are made each year, and you have about 0.4% chance of getting it during your lifetime (testicular cancer; Moore & Topping, 1999). Approximately the same facts are found in Europe as a whole, although it differs greatly from country to country; Spain has a prevalence of only 3 out of 100,000 compared to more than 15 per 100 000 in Denmark and Switzerland (Ondrusove & Ondrus, 2007). In 2006, Norway became the leading nation in afflicted men per capita (Miljøverndepartementet, 2006).

Why focus on testicle cancer?

Although these are low prevalence figures compared to other forms of cancer, there are a number of reasons why they definitely deserve attention. The incidence of testicular cancer is increasing rapidly in several European countries, with as much as 3-4 times during the last couple of decades (Ondrusove & Ondrus, 2007; Moore & Topping, 1999). In Norway it has more than doubled the last quarter of a century from 123 new reported cases in 1983 to 255 in 2006. The prognosis is a continual increase of approximately 3% annually (Rudberg, Nilsson, Wikblad & Carlsson, 2005a).

Even though it has a good prognosis it is still a leading cause of death in young men aged 15-44 in westernized countries (Barling & Lehmann, 1999). So if one looks beyond the plain prevalence rate and sees who the at-risk group is and use "the years of potential life loss" as the measurement, testicular cancer rise to the top of male cancers concerning mortality.

The prognosis also depends greatly on when the cancer is diagnosed and treated. If it is discovered during stage I, where it has not had a chance to metastasised from the affected

testicle, surgery to remove that testicle is often sufficient and the recovery rate is close to 100%. This cure rate has seen a drastic improvement over the last couple of decades, from 10% in the 70s to the current >95% (Wynd, 2002), and is considered one of modern oncology's real success stories (Moore & Topping, 1999).

However, if the cancer has had time to spread the prognosis takes a steep fall, especially if it reaches stage III where it not only affects the lymph nodes, but also lungs, neck, liver etc (Testicular Cancer Info: Staging). Such an advanced stage of the disease results in cure rates as low as 44% (Barling & Lehmann, 1999). Not only is the prognosis drastically lower if the cancer has metastasised, it also leads to a more invasive and severe treatment, as additional surgery, chemotherapy and/or radiotherapy become necessary with all their side effects. Top of that list is fertility, as chemotherapy can lead to sterilization (<http://www.cancercouncil.com.au/editorial.asp?pageid=894#pdf>). Other dreadful side effects include loss of hair, nausea and general tiredness. Research shows that only half the patient population present their symptoms before they have advanced (McCullagh & Lewis, 2005).

Breast cancer has received a lot of the media attention. Between 1952 and 1996 the percentage of women who experienced total delays of more than six months sank from 55% to 21%, indicating a general increase in the public awareness of breast cancer (Bish, Ramirez, Burgess & Hunter, 2005). Since then much of the taboo has vanished and studies show that the public education campaigns have had great success in terms of increasing women's awareness of the symptoms, most notably a painless breast lump (Meechan, Collins & Petrie, 2003). Unfortunately typical male cancer has not received anything near the same publicity. Prostate cancer and colorectal cancer have for instance only received one third of the media coverage breast cancer has attracted (Ruth, Brotherstone, Miles & Wardle, 2005). While some of the reasons for this are related to the higher prevalence of breast cancer, it also "highlights

the fact that male health concerns have a lower profile across society as a whole.” (Ruth et al., 2005, p. 214).

What is patient delay?

Patient delay was defined in 1973 by Hackett, Cassem & Raker as “the time from the patient’s first awareness of symptom or sign to the first consultation with the physician” (Zervas, Augustine & Fricchione, 1993, p. 9). Worden and Weisman (Mason & Strauss, 2004b) criticized the term patient delay, saying it isolates the patient as guilty of negligence, and thus loses sight of important psychosocial factors. Still it will be used in this article along with the overwhelming majority of published articles on the subject. A time boundary also needs to be set for what constitutes delay. Studies have used cut-off points of one week to six months, and some have opted to use delay as a continuous variable without any set cut-off point. The most commonly used cut-off point is three months though, which has been used for decades with basis in the findings that approximately one third of cancer patients delay at least 3 months (Mason & Strauss, 2004b).

In addition to patient delay one has provider delay, which is any “unnecessary” delay in any of the steps aforementioned from the first consultation to the potential operation. There is an ongoing discussion whether the time period between the first help-seeking act, consisting of making an appointment and the actual consultation should be considered provider or patient delay (Mason & Strauss, 2004b). Both sides have good points, as the waiting lists are often long even in Norway: However there is also the opportunity to get an emergency appointment which should be used if there are symptoms that might indicate testicular cancer. Also misdiagnoses constitutes a type of provider delay, however it can lead to prolonged patient delay, as many patients would be hesitant to seek another consultation even if the symptoms persisted or worsened signalling that the original diagnoses was wrong.

The average provider delay has decreased though (Ondrusove & Ondrus, 2007) as testicular cancer has received more attention within the medical community.

Surprisingly no clear connection between delay and worsened prognoses has been established. Most studies, including a large-scale study undertaken by Huyghe et al. (2007), show a negative correlation between delay and survival rate. In their sample of patients only one of the 65 patients who waited less than a month died equalling 1.5%, while this leapt up to 17 % for those who had surgery more than three months after the initial onset of symptoms (Huyghe et al., 2007). There are studies who actually have found an inverse relationship between patient delay and relapse-free survival (Mason & Strauss, 2004b). However, even in the studies that showed no negative effects of delay on staging or five-year prognosis, alternative explanations for these contradictory results were suggested and these articles also strongly recommended that men who suspect they have testicular cancer should seek help as quickly as possible.

Testicular Self-Examination

Since little is known about the causes of testicular cancer or about preventive measures, the focus of health promotion has been on testicular self-examination (Moore & Topping, 1999). Studies show however that knowledge level and practice of TSE is very low, and that the information about TSE is not reaching the target population (Moore & Topping, 1999). Much of the blame for this is put on young men's tendency to not feel vulnerable or on their lack of concern for their health, and hence their lack of interest in health education. Even from those who knew how to perform TSE in Moore & Topping's study (1999) less than half reported that they would actually seek help if they noticed changes.

McCullagh, Lewis & Warlow (2005) summarized nineteen studies addressing the knowledge of testicular cancer and the performance of testicular self-examination. Out of those nineteen, only one sample showed a rate over 22% practicing TSE at the recommended

interval of once a month, while the mean was nine per cent. In 1994 the practice of TSE was evaluated by questionnaire in nineteen European countries. Out of the combined sample of 16,486 students recruited 87% reported never having practised TSE and only 3% reported monthly practice. A smaller survey in Ireland showed that only 40 out of the 500 men sampled had learned how to perform TSE (Huyghe et al., 2007).

Million-Underwood and Sanders (1991) found a significant positive correlation between knowledge of TSE procedures and the percentage of self-reported TSE practice. The more correct information about both incidence and warning signs the subjects had the more likely they performed TSE (Wynd, 2002). The contrasting view is that knowledge about unhealthy behaviour such as smoking and unsafe sex have not prevented smoking initiation or resulted in increased condom use, and that knowledge about the effectiveness of TSE may not be sufficient.

Numerous studies have lent support to the conclusion that awareness is an important prerequisite to undertake successful self-examination (McCullagh et al., 2005), which indicates that proper knowledge about testicular cancer may be sufficient to ensure that young men perform self-examination (McCullagh et al., 2005; Barling & Lehmann; Moore & Topping, 1999).

There is still an ongoing debate whether TSE should be encouraged to the broad public, as the critics proclaim that the costs outweigh the benefits, both because of the relatively low incidence compared to other health concerns and because of the anxiety they feel such a focus would provoke (Moore & Topping, 1999). Proponents (Firman & Finney, 1990) argue that a focus on TSE will make young men more alert and responsible for their own personal health and a focus on health issues like testicular cancer might actually reduce anxiety. In 1996 a study by Wynd provided information about TSE to 1,286 high school male students, and compared them to a control group after 6 and 18 months. While the knowledge

level increased significantly, the anxiety level did not (Wynd, 2002). A popular compromise is taken from the breast awareness campaign for women, and involves that men should be aware of the normal shape and feel of their testicles, thus being more capable to seek help when appropriate, even in the absence of an obvious lump or pain (Chapple, Ziebland & McPherson, 2004).

Factors involved in decision making

It is a fact that people tend to avoid, at least postpone having to take hard decisions that forces them to leave their status quo. We are creatures of habit and most of us appreciate being in a comfort zone where everything is familiar and “normal”. To make a deliberate choice of seeking information that can force you out of that zone is frightening to the extent that even in the instances when unconsciously we know that the alternative might bring with it consequences which are ten times more unpleasant, we prefer the omission bias of staying inactive (Anderson, 2003).

The theory of loss aversion refers to the tendency for people strongly to prefer avoiding losses than acquiring gains. Losses are sometimes rated psychologically as twice as powerful as gains (Wikipedia; Slovic, Peters, Finucane & MacGregor, 2005). Previous research has also shown the potential anticipated regret is far greater if a deliberate act from oneself has caused it, then if it were merely a consequence of staying in status quo (Anderson, 2003).

With these three psychological facts in mind, it is easier to understand why the decision of actively seeking help for symptoms of cancer is not an easy one. A confirmation of cancer brings with it several losses, and even though objectively they are tiny compared to what you gain by seeking help, psychologically it might not feel so clear-cut. It definitely brings you out of that comfort zone and it was a deliberated act that was the cause of it.

The decision to react to the symptoms and seek help is a purposeful and important action (Facione & Facione, 2006). It can be the result of two different types of reasoning which are part of decision-making. While the first one is more automatic, rule of thumb and intuitive; the other one demands more attention, deliberation and reflection. The first one is more prone to errors e.g. misuse of availability and representativeness, which is why we tend to make use of the more deliberate reasoning when we are making difficult decisions.

Few clear guidelines exist today as far as when to seek medical help for potential testicular cancer, resulting in every potential testicular cancer patient having to make a deliberate reasoning why he should seek help. However, this is not all good as each one is "being allowed" to consider all the possibly negative aspects of seeking help. Cancer societies are working to make some of these decisions much easier for the population, by saying if you experience this or that symptom you should urgently seek help.

Integrated Change Model

The integrated change model could serve purpose to explain why delay occurs, even though the more deliberate reasoning is used. It is a newer version of the attitude-social influence-self-efficacy model, which is a summarization and combination of multiple models well known in the field of social psychology; including Ajzen's Theory of Planned Behaviour, Bandura's Social Cognitive Theory, the Health Belief Model, Implementation and Goal setting theories and Prochaska's Transtheoretical Model (De Vries, Mesters, De Steeg & Honing, 2005).

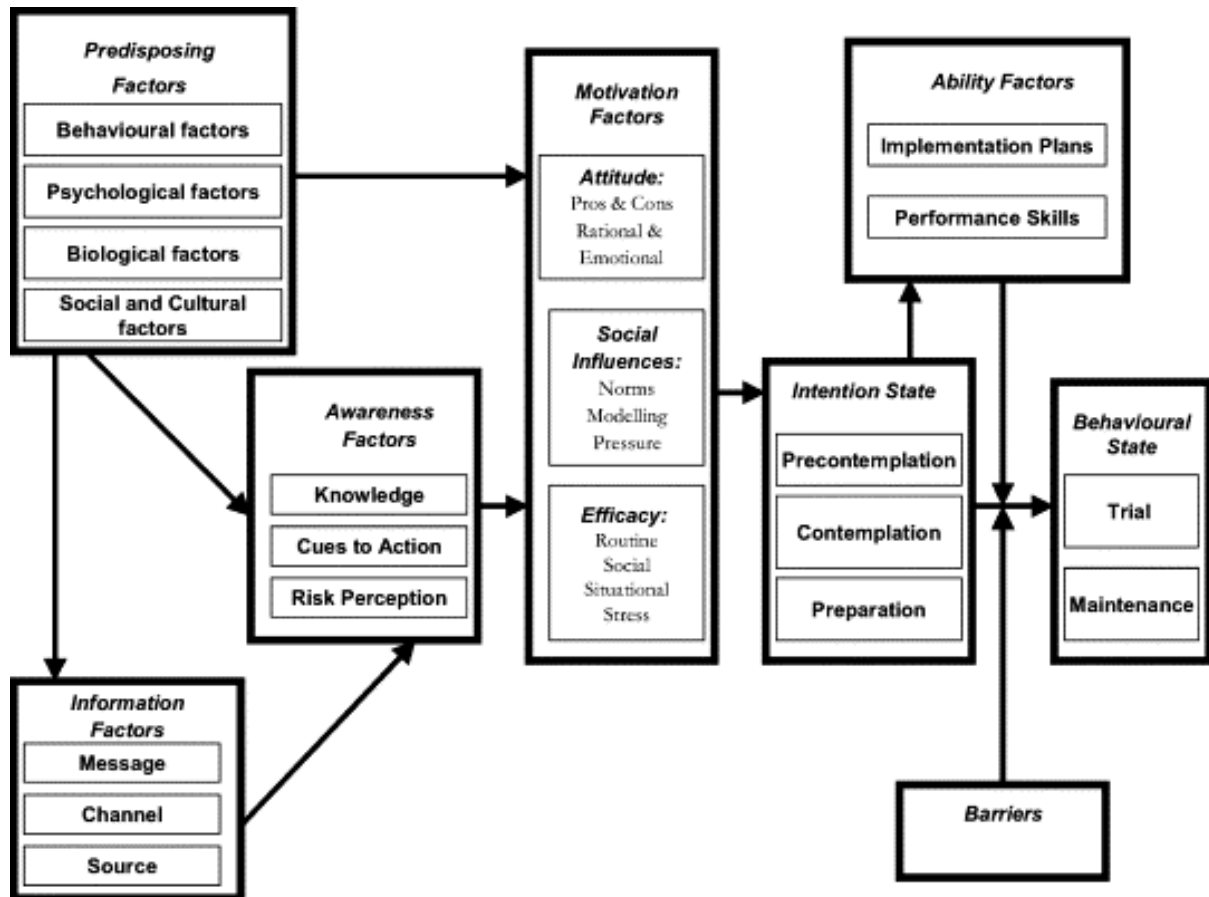


Figure copied from De Vries et al. 2005, p 155.

A brief explanation of the general model is that your intentions control your behaviour strongly, although external barriers and/or your (perceived) ability influence this link. These intentions are based on motivational factors; including your own attitude towards both the behaviour and possible outcomes of it, how capable you think you are to perform the behaviour, and the social influence you encounter in the form of support from others, social modelling of others exerting the behaviour and the existing social norms. These motivational factors again are determined by both predisposing factors, which include individual differences, and social and cultural factors, e.g. price of healthcare, and awareness factors, which include your knowledge level of the behaviour and its objective pros and cons.

Why does delay occur?

The literature on the subject shows that there are two main reasons why TSE is not sufficiently practised, and why delay to seek proper medical treatment for men with testicular

cancer symptoms occurs; lack of knowledge and less than optimal subjective cognitive and emotional reactions to the appraisal of the symptoms. Using the I-Change Model, we will start of by looking at the level of awareness/knowledge.

Both qualitative studies with testicular cancer survivors (Chapple et al., 2004) and quantitative studies with samples from the general population (Wynd, 2002; Rudberg et al., 2005a) show a remarkably low level of general knowledge both when it comes to symptoms, fact awareness of the disease and testicular self-exams. "If a person is expected to interpret certain symptoms as cancer signals, this person has to know what these warning signals are." (Nooijer, Lechner & De Vries, 2001, p.472). In Nooijer et al. (2001) study five of the participants said that they had delayed because they had not perceived themselves being at risk, since cancer only affects old people.

Scott, Grunfeld, Main & McGurk (2006) conducted a study on oral cancer and found similar results. Patients failed to recognize the symptoms as cancerous because the symptoms differed from the cognitive schemas the patients had. Hence a lack of factual based knowledge of the clinical picture of cancer may lead to a false if not absent schema, which in turn leads to incorrect help-seeking. In oral cancer, much like testicular cancer, the early symptoms are painless and therefore often escape the necessary attention (Scott et al., 2006). While most recognize a lump as a warning sign (Rudberg et al. 2005a), probably caused by lumps being the most common symptom for cancer in general, the other symptoms raise little concern. One of the testicular cancer survivors in Chapple et al. study (2004, p. 28) explained his reason for not seeking help straight away stating: "My testicle was larger than it should be, very, very firm, it was like a rock, but no pain, no sensation, nothing. And I thought; well maybe it's just something that will go away on its own, so I just carried on with life".

In Mason & Strauss' study (2004a, p. 99) most men "assessed their initial symptoms using their existing knowledge about potential testicular illness". Although the possibility of

the symptoms being malignant was considered, most decided that they were benign and did not warrant consulting with a doctor, often because they were not completely sure if changes actually had taken place.

Knowledge can also lead to help-seeking behaviour, as the patient understands that the symptoms will most likely not disappear by themselves and that consultation with general practitioners is the best option, regardless of the outcome. If it turns out to be benign then the fear and anxiety can be put to rest or if it is malignant then appropriate action can be taken, thus reducing the danger (Nooijer et al., 2001). In McCaffery, Wardle & Walley's study (2003) knowledge significantly predicted attitudes toward cancer and more importantly screening behaviour, independent of socio-demographic factors.

Lack of confidence in the health care system is also a by-product of not being aware of the facts and statistics. In their qualitative study on how people decided to seek health care, Shaw, Brittain, Tansey & Williams (in press) stated that the decision came down to an appraisal of the costs and benefits of treatment and the perceived impact the symptoms had. Both appraisals requiring proper knowledge and if the subjects interviewed did not think there was a suitable treatment available they often did not consider it worth consulting a doctor (Shaw et al., in press). As one of the subjects who suffered from arthritis put it when asked why she had never made an appointment with a doctor; "Because I don't think there is any point, I don't think it's a curable disease." (Shaw et al., in press, p. 5).

Men hear the word testicular cancer and feel it is a sort of death sentence at least for their sexual life, because they are not aware of the strides that have been made resulting in very promising prognosis. Some might have previous personal experience that has weakened their faith. This hopelessness caused by misleading availability heuristics or simply a lack of factual knowledge is seen as the strongest contributor to delay behaviour (Zervas et al., 1993).

Motivational factors

In other words knowledge or at least awareness about symptoms is a prerequisite to appropriate help-seeking behaviour. However studies (Sheikh & Ogden, 1998; Mason & Strauss, 2004a) have shown that proper knowledge is not sufficient to ensure lack of delay, and that it is far more complicated than a one to one relationship, as people with approximately the same symptoms and knowledge differ greatly in how long they delay.

When confronted with a health threat, we are usually exposed to a lot of information from diverse sources ranging from our own bodily sensations to information from physicians and medical tests, advice and reactions of other people, and even reports in the media. The processing of this information is embedded in the personal and social context within which we live. The results of this information processing are cognitive representations of the health threat and related emotional representations (Benyamini, Gozlan & Kokia, 2004, p. 578).

Attitudes play an important role and are made up of the perceived cognitive and emotional advantages and disadvantages of the behaviour. They allow factors including embarrassment, fear, fatalistic beliefs, overly altruistic attitude and lack of faith in the health care system to influence ones decision to seek help.

Fear

Cancer is by many thought of as the most life threatening illness, so the aspect of fear definitely is relevant. "I think when you hear the word cancer it seems to hit you between the eyes, ...you hear about other diseases, that can be just as bad, but there is something about cancer." (Sheikh & Ogden, 1998, p. 38). Misconceptions about the consequences of the disease, such as cancer being a death sentence will often lead to delay (Nooijer et al., 2001). One of the men interviewed by Gascoigne, Mason & Roberts (1999, p. 147) expressing his fear towards cancer; "I hesitated to use the word cancer because of the life threatening

connotations it had. I just wanted it to go away. I could not entertain the prospect of chemotherapy, radiotherapy, surgery; it was beyond my ability to take that on board.”

If the perceived threat is sufficiently frightening, most people will adapt less than optimal coping strategies. Denial is the most common one, and easily causes delay as the affected men simply overlooks the symptoms and hope they will disappear by themselves, even though they suspect it might be something serious. “Yeah, I had a funny feeling but then I was just sort of in denial ... I suppose I don't like to know the truth ... I just want it to go away” (Mason & Strauss, 2004a, p. 98).

The parallel response model stipulates that people cope with a threat either by minimizing the danger or reducing their fear. Danger control takes place if one suspects a symptom to be cancer but also believes there is a cure. Normally people will evaluate the recommended responses to the threat and attempt to act accordingly, which in this case is a consultation with a GP who can take the appropriate measures. However if one is unaware of, or sceptical towards the recommended response, or simply overwhelmed by fear; one is left with fear reducing mechanisms, i.e. denial, which could be hazardous to one's health.

It is really a catch 22 situation, either the man thinks it is benign and does not bother to get it checked out, or he thinks it is malignant resulting in destructive defense mechanisms, e.g. denial. Arguably denial can be healthy too, as a mean of giving oneself time to adjust and cope with the idea of the potentially scary reality (Zervas et al., 1993). The suspecting thought of having cancer represents a life-altering shock, which needs time to assimilate. In an attempt to make it less overwhelming, one blocks out some of the implication and emotional impact of the potential disease. The all-important difference here is that one does it without denying the reality that something is wrong and that action needs to be taken to fix it.

It is not just the potential of bad news that frightens people into a delay of seeking help, as many men fear the examination itself. The testicles are a highly sensitive area as far

as pain threshold is concerned, and some men fear both the pain and embarrassment an examination brings about (Chapple et al., 2004).

Embarrassment

Embarrassment has acted as a barrier to help seeking of medical treatments and examinations for a long time but it is just in the last decade that this trend has been examined thoroughly in studies. Qualitative studies have shown that medical procedures that are intimate in nature produce feelings of anxiety and embarrassment in patients.

“According to the literature on emotions, embarrassment arises in response to a host of elicitors which, although varied, are linked in that the individual feels that they are being negatively or undesirably evaluated by others, that they have violated a social norm, and/or in the presence of an awkward social interaction.” (Consedine, Krivoshekova & Harris, 2007, p. 441).

The most relevant here is the last, as most men would definitely rate having to strip down in front of a stranger as an awkward social interaction and most embarrassing experience. One of the subjects in Chapple et al. study (2004, p. 29) commented “I don't really want to go into a doctor's surgery and drop my trousers and get the crown jewels out for him to look at.” Similar feelings were expressed by one of the interviewed by Gascoigne et al. (1999, p. 148) “To have somebody explore, examine and hold that part of the body, was potentially threatening. I think it's almost an invasion of privacy, an invasion of the self.”

The first two reasons for embarrassment can however also apply if one has delayed seeking help and then suspect that one has caused more harm to oneself, and will be subject to criticism for their lack of timely response. This can in turn very well lead to an even longer delay as the easiest remedy is the simple avoidance of the embarrassment-eliciting setting.

The role of others also seems to be important when it comes to help-seeking for men, as men seek information, advice and comfort from people close to them. In qualitative studies

(Chapple et al., 2004; Mason & Strauss, 2004a), a common theme has been that loved ones have persuaded the men to take the symptoms seriously and act accordingly. Hence, men who share their experience are more likely to promptly seek help. Similar results have also been shown in breast cancer patients (Bish et al., 2005). Unfortunately most men feel uncomfortable even talking about their genitals, in the context of something being wrong with them. "I suppose because it's the private area ... us men don't like talking about that sort of area or going to the doctor, anything like that. ...it's a macho thing I suppose." (Chapple et al., 2004, p. 29).

Also, because it is normal for the majority of men to not feel comfortable raising these concerns, other men feel a need to reduce the tension or anxiety by just dismissing the problem (Gascoigne & Whitear, 1999). In some of the interviews the cancer patients had told other men about their symptoms and were reassured that there was nothing to worry about (Gascoigne et al., 1999; Mason & Strauss, 2004a), that the difference in shape was perfectly normal, and even a change in the size was a part of normal aging process.

The Institute of Cancer Research in England found that only eight per cent of males 15-34 year olds listed personal health issues as a frequent subject of conversation and only 28 % would choose to talk to a close male friend about his health worries. Clare Moynihan concluded on the basis of numerous interviews with healthy men, that men thought cancer and health issues in general to be a private matter and not a topic that should be raised in public conversations, but that almost everyone wished for more and easier access to information (http://www.icr.ac.uk/press/press_releases_1999/3363.shtml).

All the different factors and characteristics about having to seek medical help for symptoms in the genital area, that might evoke embarrassment, including a lack of privacy, the presence of other people, genital touching, awkward interaction and fear of being labelled

a hypochondriac can all be summarized in two main factors: bodily embarrassment and judgement concerns (Consedine et al., 2007).

Masculinity

For some men even the act of seeking help is a sign of weakness, and they feel there is a risk of being labelled a wimp or hypochondriac (Chapple et al., 2004). As one of the men in Mason and Strauss' study (2004a, p. 101) put it "Well, as far as I can understand, a man feels as if he's the provider, he's the strong one... He's the one that looks after the female, so it's all right for a female to feel weak and vulnerable... but for a man to do that, then... he's admitting defeat."

This quote underlines the dilemma many men are facing when they suspect that there might be a physical problem that they should get checked out, while at the same time trying to live up to the traditional masculine role which emphasizes toughness, self-reliance and emotion control. Just take professional sports as an example where the athletes are heroic and get idealized when they are able to ignore pain and keep playing despite severe risk of aggravating their injury. People might think that our society has progressed from such damaging gender stereotyping, but both the interviews and the facts tell a different story.

This finding is certainly not limited to testicular cancer. There is ample evidence that men's use of health services are far less than women's across the board, from therapeutic help, to help fighting substance abuse, to seeking medical help (Galdas, Cheater & Marshall, 2005). In the developed world women live on average a stunning seven years longer (Addis & Mahalik, 2003) and before the age of 50, men have a 1.6 to 1 ratio of premature death compared to women (Smith, Braunack-Mayer & Wittert, 2006). In the United States men have higher rates of the fifteen leading causes of death.

In a meta-analysis by Addis and Mahalik (2003) of a large number of studies comparing men's and women's utilization of the health care system, across situations, age,

nationalities, and ethnicity, a consistent finding was that men do not seek help for their problems soon enough. One of the problems that have assisted this process is that men have been looked at as the standard, and the focus have been on the women's overuse of the health care system, instead of the problematic underutilization by the men.

Mason & Strauss (2004a) found that most of the men in their study showed a reluctance to seek help if they were not absolutely sure the symptoms warranted it. Many of them waited for some sort of crisis point where the symptoms incapacitated them in any way, be it sexually, problems sleeping or everyday activities. Others needed someone close to them to persuade them that it was necessary. "I don't think they (men) like to make a fuss, perhaps to be seen to be weak, caring for their bodies" (Chapple et al., 2004).

Many men dread the consequences of a potential operation as far as having a testicle removed. Losing a testicle to cancer has been rated as the second most humiliating experience by college-age men, second only to being unable to maintain an erection during sex and followed by being teased about penis size (Gurevich, Bishop, Bower, Malka & Nyhof-Young, 2004). Even though losing a testicle usually doesn't affect your ability to have sex, it may cause a changing of ones' body image. "Having cancer is difficult but losing a testicle is something else. You feel like you are not a man anymore; that you can't function properly" (understanding testicular cancer, p. 30).

This is seen in females facing breast cancer as well (Facione & Facione, 2006), where loss aversion, both the loss of one's breast and/or one's normal healthy image, is a major contributor to delay. Especially with young people who face tremendous pressure to conform to norms of body shape, fear of looking abnormal can lead to delays (Gascoigne et al., 1999).

There is a certain irony that the concept of masculinity, leads many men to avoid help seeking, and thus threatening "the very embodiment of maleness" (Mason & Strauss, 2004a). "I was almost prepared to put myself in serious danger and let cancer grow inside me rather

than let my sexual drive and maybe a bit of my personality be taken away from me" (Chapple et al., 2004, p. 30).

Social Influence, Stigmatization and Marginalization

Uncertainty and taboo still loom like a black cloud over the whole subject of testicular cancer. Especially compared to breast cancer, which has become a household illness, one does not get a lot of "free" information about testicular cancer. All the participants in Mason and Strauss' study (2004a) complained about this type of marginalisation and expressed difficulties both accessing information and being examined in a discrete way. They requested that the medical establishment and society as a whole made sure that testicular cancer go through the same process as breast cancer has done.

Since the general population's knowledge level is so low, stigmatization often occurs. Not knowing what to say or how to respond, people sometimes tend to shy away from the awkward situation, instead of being there for the affected person when he needs it the most. One of the subjects in Gascoigne and Whitear's study (1999, p. 67) expressed how he felt people treated him after being diagnosed with testicular cancer; "People avoided us when I had it. You would walk down the street and people would cross over like it was contagious. All my best mates, as they were supposed to be, disappeared." Fear of being subjected to this type of stigmatization also contributes to few men wanting to go public with their illness.

Harwood and Sparks (2003) made an additional point of the importance of getting the success stories more available, as they said that patients who were diagnosed with cancer often develop an identification as a cancer *patient* or *victim*. If one looks beyond the obvious positive consequence of the possibility of seeking social support, the stereotyping of the disease is crucial in determining how beneficial this identification really is. If the stereotype is in the form of an empowered man who actively is fighting cancer, this identification will have a positive effect, because people tend to live up to the stereotype and also this will produce a

social model. However if the cognitive representation is at the other end of the spectrum, featuring a terminal ill person who has resigned to the fact that he is a powerless victim, then identification will be of negative consequence (Harwood & Sparks, 2003). Unfortunately the stigmatization and taboo is leading many men who could potentially serve as social models/success stories, to not share with others their experiences.

There is one well known exemption to this: Lance Armstrong, the professional American road racing cyclist. His fight against testicular cancer, and what he has been able to accomplish after he won this battle is well documented. It is a truly feel-good story about one of the greatest athletes in modern history putting all his determination and strength to rid him of testicular cancer. However this story has a catch to it, because when people hear about testicular cancer they often think about Lance's heroic battle, and many believe that all testicular cancer victims need to inherit these qualities to beat the disease, which is not true. Lance's disease had metastasised to both his lungs and brain, which of course made the healing process much more complicated and amazing.

Self-Efficacy

Naturally not many men feel that they could match Armstrong's strength and determination, and this success story might actually contribute to people's fear of testicular cancer, simply because many don't know the full story. Self-efficacy also greatly impacts the practice of testicular self-exam. As mentioned people with knowledge on how to correctly perform TSE is much more likely to perform it than people who lack this knowledge. Barling and Lehmann's study (1999) supported earlier findings as self-efficacy was a significant predictor of TSE, along with knowledge, intention and outcome expectancy.

Intention = behaviour?

The sum of all these aforementioned factors leads you to a state of intention. Studies on TSE and help-seeking behaviour within different types of cancer show consistently that

intention is a significant predictor of behaviour. Facione, Miaskowski, Dodd & Paul (2002, p. 405) state in their study on self-reported likelihood of patient delay in breast cancer that research on intention formation “argues that reporting a likelihood to delay is a relatively stable characteristic and signals a greater risk for actual delay in the event of a breast symptom's occurrence”.

As the I-Change Model illustration shows the ability factors and barriers have some impact on this relationship. Barriers can be in the form of provider delays, lack of funds or feeling that you can not afford the luxury of being sick, etc. Implementation intention takes all factors into consideration, including the potential barriers, and creates a specific plan of action. The more concretized plan on which types of action one has to do if one experiences a symptom, the more automatic the behaviour will feel/be. Hence the effect of barriers will diminish, and the intention state will be a better predictor of behaviour. That is why it is important that either men form their own implementation intentions or that the society as a whole finds a way to make them for us.

Aim

The aim of this study was twofold. The main objective was to assess the general knowledge about and attitudes towards both testicular cancer and testicular self-examination among the at risk population in Norway. A second aim was to study the relationship between obtained factors from the first part with psychological measures of depression, anxiety, optimism and health locus of control.

Materials and Methods

Participants

A convenience sample of 110 participants completed a set of questionnaires. Since the main objective was to establish the general knowledge level of the at risk group about testicular cancer, the entire sample consisted of young men in the age group of 18-35. The sample also comprised exclusively young men without prior history with testicular cancer treatment. Effort was made as to include subjects with various educational backgrounds.

The mean age of the sample was 23.8 years old with a range of 18 to 35 years. Of the total sample (N=110) 41.8 per cent of the sample had finished at least a lower university degree and 92.7 per cent had graduated from high school. More than one third were working full time (N=42), one third were students (N=32) and the rest were part working part time (N=35), the majority of them combining this with studying (N=26). Only one participant who was not studying was currently unemployed. Sixty-seven per cent of the young men were single (N=74), while only four of the subjects listed themselves as family men.

Procedure

A self-report questionnaire was chosen as the most effective and practical method as to elicit the required information. It bears another valuable advantage, as it allows the subjects to remain anonymous, while responding to questions about a sensitive topic. Pilot testing of the questionnaire was performed to ensure clarity and comprehensibility, which resulted in three of the questions being reworded. Other than that none of the items needed to be changed or eliminated before being distributed to the final target population.

All subjects were approached either by the author or an assistant and informed about the reason for the study and its main topic. If they agreed to participate they were given the questionnaire which took about 15 minutes to complete. The majority completed it as a paper and pencil version while some (N=12) had the form sent by e-mail and completed it online.

The first page of the handout was a short description of the author, the purpose of the study, the content of the questionnaire and an assurance that their responses would be kept confidential and anonymous. The collection of data took place in May, June and July 2008.

The Questionnaire

The test battery consisted of 146 items representing validated instruments such as Hospital Anxiety Scale (HADS) 14, State Trait Anxiety Inventory (STAI) 40, Life Orientation Test Revised (LOT-R) 10, Health Locus of Control scale (HLOC) 18, questions either found in or based on existing literature and some new relevant questions for this study.

They could be divided into the following five main areas demographics (4 questions), testicular self exam practice, intentions and help seeking behaviour (22 questions), knowledge of testicular cancer and treatment (22 questions), attitudes towards the illness (7 questions) and the above mentioned instruments (82 questions). Instructions were included at the beginning of questions where more than one response was required.

Following are examples of questions from each part.

Area 1	The subjects were asked about their age, highest obtained education level, working situation and cohabiting/marital status.
Area 2	Do you intend to check your testicles in the future and seek medical help if you suspect any abnormalities to be symptoms of testicular cancer? <i>Response format:</i> Yes, No, and don’t know.
Area 3	Consisted of a list of twelve abnormalities that the participants had to evaluate if they were common symptoms of testicular cancer, e.g. “swollen testicle”. <i>Response format:</i> yes, no, and do not know. Five of these are recognized as actual symptoms by the vast majority of cancer information sites, while some of them list blood in semen and sexual problems as added symptoms. Eleven questions were also included to measure factual knowledge about treatment, where seven of them

	were derived from "Testicular cancer and testicular self-examination" (Rudberg et al., 2005a), e.g. "Patients with testicular cancer can get additional treatment with chemotherapy". <i>Response format:</i> yes always, yes sometimes, no not at all, and do not know.
Area 4	Attitudes towards the illness were measured by questioning the subjects fear and beliefs e.g. "Which of these factors would you dread the most if you had to have treatment for testicular cancer?" Three of these questions were also derived from "Testicular cancer and testicular self-examination (Rudberg et al., 2005a), e.g. "Doctors have great knowledge of testicular cancer.
Area 5	The participants were asked 82 questions to measure their level of anxiety, depression, and optimism and their feelings of whether or not they controlled their own health. E.g. "Whenever I don't feel well, I should consult a medically trained professional." <i>Response format:</i> Strongly agree, moderately agree, slightly agree, slightly disagree, moderately disagree and strongly disagree.

Psychological assessment

HADS

A Norwegian version of the Hospital Anxiety and Depression Scale was included to measure levels of depression and anxiety. It is a 14 item instrument, seven of them measuring anxiety and the other seven measuring depression, and they are scored using a four-point scale ranging from zero (not present) to three (considerable). Subjects are asked to rate how they have felt the past week. The sums are added on each subscale and give a maximum score of 21.

A score of eleven or more is seen as indicative of anxiety or depression that will need further investigation and possible treatment. If someone scores between 8 and 10 it is

regarded borderline case suggesting that there might be something that needs to be examined, while a lower score is usually not alarming. The subscales can also be added to give a combined anxiety and depression score, as some patients suffers from both. In this case the threshold is 19 to be classified as needing further testing/treatment and 15 to be a borderline case.

It was initially designed to be used as a simple tool in medical practice, as a screening instrument in a clinical setting. However, numerous studies throughout the world have confirmed its validity in more community like settings (Snaith, 2003). HADS has also been validated as a well suited instrument for adolescents as well as elderly and it is time-economic (takes 2-5 minutes to complete).

The concurrent validity of HADS compared to other questionnaires yields a validity score between .60 and .80 on both subscales. The internal consistency of the HADS-A and the HADS-D showed coefficient alpha of .89 and .86, respectively, similar to earlier studies (Snaith, 2003). In the current study the Cronbach alpha coefficient was .72 and .62 respectively, and the scale as a whole showed a .81 coefficient alpha. Bjelland, Dahl, Haug & Neckelmann (2002) did a review on 747 identified papers that had used HADS, and found HADS-A to have a Cronbach's alpha varying from .68 to .93 (mean .83) and for HADS-D from .67 to .90 (mean .82). They drew the conclusion that "HADS was found to perform well in assessing the symptom severity and caseness of anxiety disorders and depression in both somatic, psychiatric and primary care patients and in the general population." (Bjelland et al., 2002, p. 69).

STAI

A Norwegian version of State Trait Anxiety Inventory was also included to test anxiety levels of the subjects. The instrument was first developed by Charles D. Spielberger in the 1960s, and was later revised in 1983. It is comprised of two separate 20 item self report

assessments, measuring both state and trait anxiety, evaluating feelings of nervousness, worry tension and apprehension.

The state-scale is scored on a four point intensity scale and reflects a “transitory emotional state or condition of the human organism that is characterized by subjective, consciously perceived feelings of tension and apprehension, and heightened autonomic nervous system activity” (State-Trait Anxiety Inventory). It would be relevant in this context if a fear was evoked by the questionnaire itself or by for instance recently hearing about a friend who had to deal with cancer (Nooijer et al., 2001).

The trait-scale is scored on a four point frequency scale and is meant to pick up more of a general tendency/psychological pattern to how much anxiety is *normally* evoked in the subjects to perceived threats in the environment. In this context it would be fear of cancer or fear of the medical inability to cure it, which is more stable over time than those cues to action mentioned above. Scores on both subscales can vary from 20 to 80, with higher scores indicating a higher level of anxiety.

Various tests have shown that STAI has an adequate level of reliability, with the trait section ranging from .65 to .86 (State-Trait Anxiety Inventory). Naturally the reliability numbers decrease dramatically, as low as .16 when testing the state section, but that is expected as this section is meant to reflect the *here and now*. Alpha coefficients for the state-anxiety scale are .90 and higher, as was the case in this study, with STAI trait had a alpha of .90 and STAI state had a alpha of .91.

STAI correlates well with other instruments measuring anxiety, depression and personality and has been validated as an appropriate instrument to test anxiety in research and clinical settings. It has been translated into more than 40 languages and is written at the 6th grade reading level.

LOTR

Life Orientation Test was originally developed to measure individual differences in generalized optimistic expectancies about outcomes in life. In 1994 a revised version was published trying to increase the accordance between the test and the theory behind it by emphasizing more the expectations for the future (Scheier, Carver & Bridges, 1994).

It consists of 10 questions, where 4 of them are filler items to disguise the purpose of the instrument. The optimism score is the sum of the six questions that measure optimism which are rated on a 5-point Likert-type scale ranging from strongly disagree (0) to strongly agree (4). Half of the core questions are negatively worded items. Sum scores vary from 0 to 24 with higher scores indicating greater optimism. There is no set cut off point, and the majority of articles use it as a continuous dimension of variability.

The LOT-R has adequate reliability and validity. Scheier et al. (1994) found the test-retest reliability to be .79 over a 28 month interval. Its Cronbach alpha was .74 in the current study. It only takes a minute or two to complete which makes it well suited in questionnaires, especially if combined with other instruments. Another reason for this is that LOT-R has modest correlations with other tests measuring neuroticism, trait anxiety and self-esteem (.35 to .54) which is an indication that it has convergent and discriminant validity.

MHLC

Multidimensional Health Locus of Control is an adapted version of Rotter's original locus of control which was designed in the 60's and meant to test generalized beliefs concerning who or what influences things along a bipolar dimension from internal to external control. At one end you have the belief that oneself controls the future outcomes, while the external side argues that the future outcomes are in the hands of powerful other people or that chance/fate decides them. Later (in 1972-73) Hannah Levenson proclaimed that locus of control was better seen as a three dimension model; internality, chance and powerful others.

Wallston, Wallston & Devellis (1978) developed a new scale, MHLC, which kept this latest view but focused their questions to a more narrow specific health domain (Sørli & Sexton, 2003).

Each dimension contains 6 items, with six answer categories resulting in scores from 6 to 36. The alpha reliabilities of the six-item subscale hover around .70 (.65-.75), and the test-retest reliabilities are in the range of .70-.80 (Wallston, 2004). In the current study the subscales of self control and powerful others fell within this range, while the chance/faith scale had a .47 alpha value. One of the items "If it's meant to be, I will stay healthy" decreased both this alpha value and that of the overall MHLC scale (.70), however it was decided to retain it on the basis of MHLC being an established scale. The instrument has been widely used providing ample evidence that it has validity as far as measuring individuals' health locus of control beliefs (Wallston, 2005).

One of the main purposes of using the instrument during the last decades was to predict health behaviour. The reasoning behind this is that people who score high on internal control will make more of a conscious effort to take the recommended health behaviour steps than those who regard their own health as out of their control.

Data analysis

Data analysis included basic descriptive statistics and a principal component analysis with Varimax rotation. All analysis was conducted using the statistical software package SPSS 15.0 for Windows.

Results and discussion

Knowledge and Awareness of Testicular Cancer

A list of twelve symptoms was presented and the subjects were asked to indicate whether or not they were regular symptoms of testicular cancer. Two of the symptoms (blood in semen and sexual problems) were excluded because of inconclusiveness within medical sources whether or not they should be considered primary symptoms of testicular cancer. A total score was summed up from the remaining ten symptoms, half of them being actual warning signs of testicular cancer, where the correct answer was rewarded 1 point, the incorrect answer meant subtracting one point, while an answer of “do not know” meant 0 points. The total score varied from -3 to 8 with an average of 2.29.

By far the most recognizable symptom was “a lump on the testicle”, with 72.2% of the subjects correctly identifying it. A warning signal is that less than half of the sample identified “swollen testicle”, “pain in the testicle” and “pain or heavy sensation in the groin area” (49.1, 56.5 and 31.5% respectively) as symptoms of testicular cancer. However, compared to a similar questionnaire handed out to 727 adolescent Swedish men by Rudberg et al. (2005a) these numbers are encouraging. In their study only 52.8 % identified a lump in the testicle to be a common symptom. This was followed by 47.3 % recognizing “pain in the testicle”, “a swollen testicle” (44.2%), and “ache or a heavy feeling in groin” (27.1%).

In McCullagh et al. (2005) study 81.5% (N=422/518) of the men actually identified a lump as a potential symptom of the disease. The other symptoms brought much more sombre results though with under half of those recognizing “testicular discomfort” and “heaviness and enlargement of testicle” (40.5% and 39.8% respectively). The fact that “a lump on the testicle” is so recognizable compared to the others in all the studies, could be attributed to an educated guess based on lumps being associated with all forms of cancer.

When asked where they had got their information about testicular cancer from, well over half the subjects (N=62) in this current study responded that they did not feel they had any knowledge of the illness. The results of the factual knowledge questions gave support to this claim as for instance only 26.4% thought it was usually men of their age that got testicular cancer. This finding is in accordance with McCullagh et al. (2005) study where 27.4% knew the correct age group. It is significantly lower than in Rudberg et al.'s (2005a) study and Moore & Topping's (1999) study though as 48.0 and 45.8% respectively of their sample agreed to the statement. Thirty-five of the 48 who checked off at least one source of information said the Media as an origin of knowledge. Very few checked off their doctor or their past teachers, 8 and 4 respectively.

More than seventy per cent of the subjects expressed a wish of more information on testicular cancer (N=79/110). These findings partly replicate and complement findings from Moore & Topping's study (1999) as 78% of their sample answered positively to being interested in more information/education about TSE.

In De Vries et al. (2005) study it was found that higher education correlated positively with a higher level of interest in receiving information about testicular cancer and self-examination and Wynd (2002) found the same correlation with education and performance of TSE. This was not replicated in the current study though, as education (dichotomised into people having more than high school) showed no significant differences on the other variables, and actually showed a trend (P=.09) where education was negatively correlated with wanting more information.

Awareness, practise of and intention to perform testicular self-examination

Over half of the sample reported never performing testicular self-examination (N=58), and only nine subjects said they performed it at the recommended interval of once a month. Sombre results compared to McCullah et al. (2005) where 57.5% of the sample said they

performed TSE regularly. The result of the current study is however more in line with other earlier studies (Wynd, 2002; Barling & Lehmann, 1999; Moore & Topping, 1999).

When asked if they knew how to perform a testicular self-examination, under one fifth of the sample (N=21) answered confirmatively. This supports the findings of Moore & Topping (1999), where 32.2 % of their sample (N=63) had been told about TSE, but only 13 of them indicated that they were confident in their abilities to perform it correctly, and only one of them actually reported the right procedure. Running a T-test, the knowledge of how to perform testicular self-examination correlated significantly with both the performance of TSE ($p < .001$) and the intention to perform it ($P < .001$).

In contradiction with other studies which have reported a significant increase from people who currently perform TSE to those who state an intention of performing TSE, i.e. Lechner, Oenema & Nooijer's study (2002) where only 3 % had heard of TSE prior to the questionnaire and 42% had positive intentions on performing it regularly now that they knew of its existence, this increase was not significant in the current study. While 58 subjects said they would check their testicles in the future and report suspicious symptoms to the doctor, this only totalled to six more than the 52 who were currently performing it. The remaining subjects said they had no intention of doing it (N=18) or they did not know (N=34). This in spite of the vast majority of the sample being aware that they could learn to discover testicular cancer themselves (87.3%), in line with Rudberg et al. study (2005a).

Fears and beliefs

73.4 % reported losing their reproduction ability as the one thing they would fear the most if they were to be treated for testicle cancer. Out of the 97 that checked of three things they would fear, only seven did not have sterilization as one of them and out of the 101 that filled at least two factors they would be scared from, only 10 did not rank sterilization among the top two.

The questions concerning both personal fear and beliefs about other men's fear for testicle cancer showed a much lower score than previous studies, i.e. Rudberg et al. (2005a). In the current study 63.6% reported being scared of getting testicle cancer compared to 71.6%, and only 59.1% believed the majority of men were scared of testicular cancer compared to 84.6%.

Even though 16.4 % did not think the majority of men would be healthy again if they got testicular cancer, this is still a much lower percentage than in Rudberg et al. study (2005a), which showed 33 % of the subjects believing that the majority of men with testicular cancer would not fully recover. Overall though, the subjects in these two studies responded fairly similar on the general questions on testicular cancer and about its treatment and consequences.

Doctor – patient relationship and help seeking behaviour

Earlier studies have shown the majority of men wanting testicular self-examination to be included in the overall examinations at the general practitioner, i.e. 68% in Moore and Topping (1999). The current study was more inconclusive though as 37% wanted it, while 19% answered no and 44% did not have a distinct opinion on the matter.

Following the question; "If in your current life situation you got some ailments that you feared were symptoms of a serious disease, would you have told it to anyone? If so, who?", the subjects were presented with the following list of choices; "girlfriend/wife, friends, parents, female friend, doctor, other family members, no one", and told to check off as many options as they wanted. Only 60% (N=66) said they would share their symptoms with a doctor.

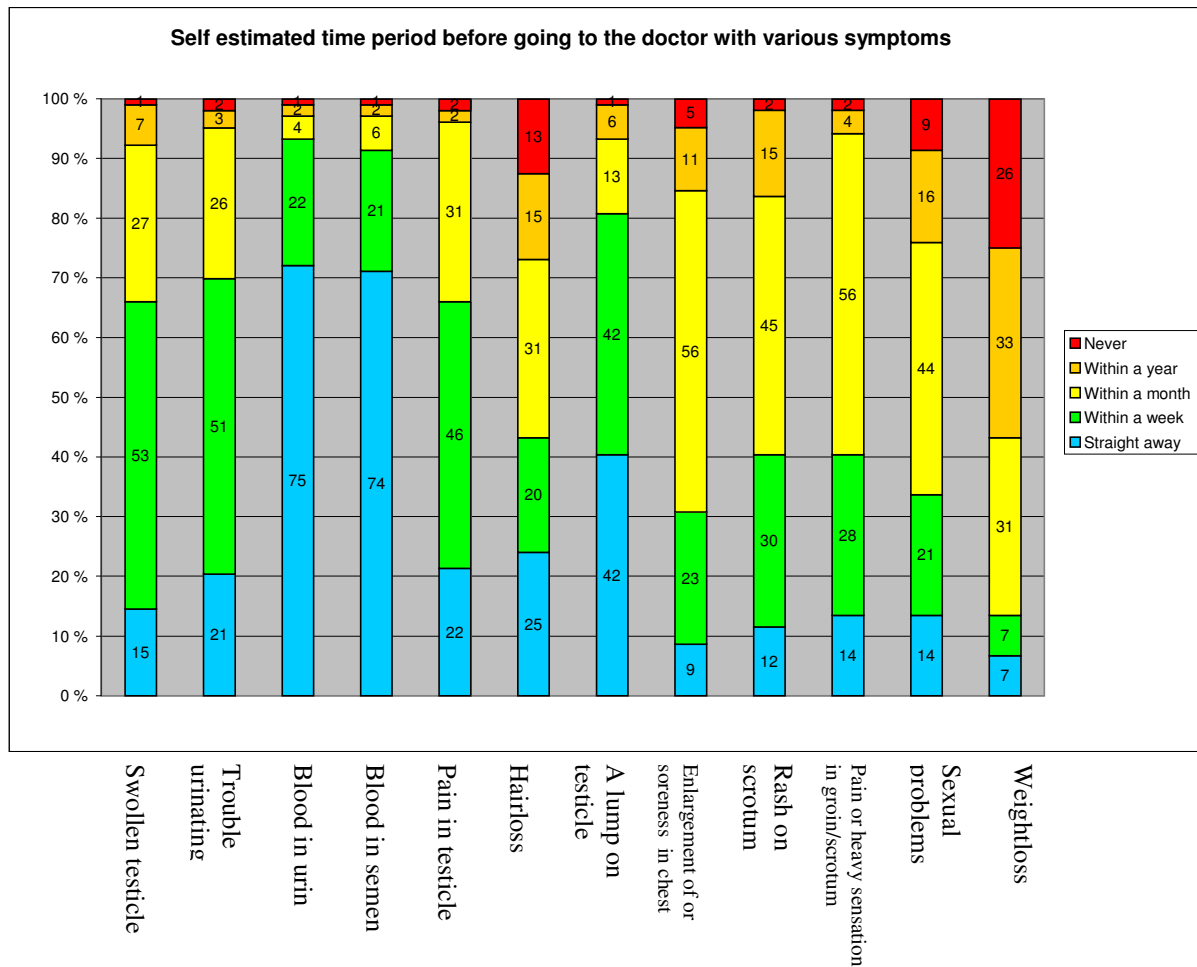
A comparison between those who would share their concerns with a doctor and those who would not showed no differential on their relationship with their doctor, as both groups had approximately 85% saying they would not have any problems discussing symptoms of

testicular cancer with their doctor and both groups had over 95% saying they felt confident that their doctor would take them serious. Both groups had over 80% agreeing with the statement that doctors have good knowledge about testicular cancer.

The only differences between the groups worth mentioning was that 10% more of those who would not seek a doctors help believed testicular cancer could hurt men's potency (55.8% vs. 46.2 %). Same findings with "treatment makes you lose your hair" (51.2% vs. 38.5%). These findings, although not significant, implies that people who perceive the consequences to be more "intrusive and damaging" are often the ones who show the most reluctance to possibly having their concerns confirmed, hence they do not seek professional help.

Interestingly, only three participants said they would not talk to anyone about their symptoms. Eight out of ten said they would be encouraged to seek help immediately and all but one of the subjects felt confident that the people he informed would not just try to trivialize their problem.

Another positive aspect that can be seen from this study is the self reported prompt help seeking behaviour from the subjects when faced with diverse symptoms.



The vast majority of the men in this study seem to have a reasonable help-seeking intention. Although some of these results are most likely influenced by social desirability/response bias as seen by the immediate help seeking for fairly innocuous symptoms like weight loss and balding, it still is uplifting findings. For instance 8 out of 10 would seek help within the first week after noticing a lump on their testicle. In Moore & Topping's (1999) study 86% of their sample indicated that they would seek medical advice if they discovered a lump, but no time frame was set in that study.

Factors/determinants associated with testicular self-examination

When splitting the data into those who reported not having any knowledge about testicular cancer and those who did, independent T-tests were performed and found significant differences between the two groups on both performance of TSE, intentions to perform it, and

overall a significant lower mean of delay time to seek help. This was expected as studies have shown knowledge as a highly, in not most important predictor of performing self-examination (Barling & Lehmann, 1999; McCullagh et al., 2005). Also a study done by Moore and Topping (1999) revealed that those who were aware of the correct causes were significantly more likely to practice TSE at the recommended interval.

Out of the 62 subjects who reported being uneducated about testicular cancer only 40% had an intention of performing self examination, and only 32% of them performed it at the present time. This was increased to 69% and 67% respectively in the knowledgeable group ($p < 0.01$). Looking at the wider range of help seeking behaviour by adding the time for all twelve symptoms in the current questionnaire the latter group also reported a much smaller delay time ($p < 0.05$). Another interesting finding was that the latter group had lower scores on the scales measuring anxiety and depression, although the difference was not statistical significant it implies to a certain extent that the belief that knowledge about testicular cancer leads to anxiety is false.

After collapsing relationship status into two categories; singles and not singles, a correlation test between this and TSE performance (also collapsed into "never" and "at least a couple of times a year") a significant negative correlation was found ($p < 0.05$), in other words men currently in a relationship performed self examination more often than the single men. This was also found in Tromp, Brouha & de Leeuw's (2004) study on patients with head and neck cancer. However, when controlling for age in the current study this relationship became non significant. No other significant correlation was found between the demographical variables and performance of testicular self examination or intention to perform TSE.

There have not been many studies examining a potential relationship between psychological factors and delay in seeking help for cancer symptoms. The majority of these have been on populations at risk for breast cancer, and a significant relationship has only been

determined in a few of them. For instance Keinan, Camil & Reick (1991) could not find a significant correlation between health locus of control or trait anxiety and delay time for women discovering a lump in their breast.

Optimism is however one of the psychological traits that has consistently been associated with less delay time (Lauver & Tak, 1995; Tromp et al., 2004). Tromp et al. (2004) found that those who delayed seeking help for more than 3 months scored significantly lower on the life optimism test than those who had gone to a doctor within the first three months. In the current study there was a negative correlation between optimism and delay time, albeit not significant.

The seven questions included in HADS that measures depression correlated negatively with intention to practise testicular self-examination ($p < 0.01$). It also correlated with delay to seek medical help for the twelve symptoms listed ($p < 0.1$). Neither the anxiety part of HADS nor the state trait anxiety test correlated significantly with delay to seek help, the performance of testicular self-examination or the intent to perform TSE. Although these associations might not be as strong as initially hoped for, it is interesting and meaningful that such general psychological self report measures can help explain specific behavioural measures such as delaying help-seeking or testicular self-examination performance (Tromp et al., 2004).

Factor analyses

In the initial factor analyses made up from the 51 items from area two, three and four in the questionnaire, 15 factors had a eigenvalue of >1 , while the screeplot suggested a three factor model and parallel analysis program set the cut off at 6 factors. Going with the Parallel analyse programs suggestion, the 6 factor explained 45 %. Factor 5 and 6 only had two variables each. So a four factor model was tried, explaining 36.60 %. A closer look at the variables showed low extraction communalities for items; fear side-effects 1, TC statement 3,

4, 5, 6, 9, 12, 13 and 14, so they were excluded. This yielded a total variance explained by four factors of 42.30 % with KMO at .67.

Two more items were excluded after not correlating with any of the factors at .4 level; "TC statement 8 and 15", reducing the total number of items down to 40. Another important reason for the 4 factor model is a priori, with 4 distinctive groupings in the questionnaire; symptom knowledge, help-behaviour for symptoms, knowledge about treatment, and fear appraisal towards testicular cancer.

Presented below is the final rotated component matrix, using Principal Component Analysis for extraction and Varimax rotation method with Kaiser Normalization.

	Factor			
	1	2	3	4
Symptom help 09	.762			
Symptom help 10	.747			
Symptom help 08	.740			
Symptom help 07	.733			
Symptom help 03	.661			
Symptom help 02	.645			
Symptom help 05	.644			
Symptom help 04	.607			
Symptom help 01	.606			
Symptom help 11	.589			
Symptom help 12	.576			
Symptom help 06	.457			
Treatment 10		.732		
Treatment 06		.706		
Treatment 11		.695		-.447
Treatment 02		.686		
Treatment 08		.671		
Treatment 01		.659		
Treatment 07		.654		
Treatment 09		.646		
Treatment 04		.564		
Treatment 05		.543		
Treatment 03		.496		
TC symptom 05			.696	
TC symptom 01			.681	
TC symptom 04			.655	
TC symptom 03			.644	

TC symptom 06			.595	
TC symptom 10			.581	
TC symptom 09			.578	
TC symptom 12			.568	
TC symptom 08			.563	
TC symptom 11			.553	
TC symptom 02			.533	
TC symptom 07			.505	
TC statement 01				.573
TC statement 07				.556
TC statement 11				.516
TC statement 10				.508
TC statement 02				.444

This model explains 43.45% of the total variance; it has a KMO of .68, Bartlett's Test of Sphericity of .00. Each factor contains at least 5 items, which after rotation using Varimax with Kaiser Normalization shows correlation scores of at least 0.4. The component transformation matrix presented below indicates that the four factors are independent of each other, with the exception of a correlation between factors 2 and 3.

Factor	1	2	3	4
1	.955	-.087	.130	.253
2	.044	.807	.561	.178
3	-.130	-.575	.799	.121
4	-.264	.102	.173	.943

Factor 1 has a Cronbach alpha of .87 with 12 items.

Factor 2 has a Cronbach alpha of .86 with 11 items. Item "Treatment 11" is the only one with a cross loading of more than .4, but is none the less kept in because of the logical connection to the other items in factor 2.

Factor 3 has a Cronbach alpha of .84 with 12 items.

Factor 4 has a Cronbach alpha of .64, which is fairly low, but considering there are only 5 items in this factor this is to be expected. Item "TC statement 11" is a problematic item as it is the only item which theoretically do not fit with its factor despite a high loading. While the four other items are negatively worded and deals with how severe testicular cancer is and

how much fear it elicit, item "TC statement 11" asks if there is many things one can do to avoid getting testicular cancer, so it really should have been a negative correlation.

Correlating these four factors up against the different psychological measures of depression, anxiety, optimism and health locus of control that were included in the test battery showed a number of significant correlations. Factor 1 which consists of the 12 items for help seeking correlated negatively with two of the subscales of multi health locus of control, the ones who points to powerful others and faith as controlling for ones health ($p < .01$). Factor 4 shows a correlation ($p < 0.05$) with testicular self examination, while factor 1 and factor 2 shows trends of negative correlation ($p < 0.01$)

A stepwise linear regression analyses was performed using the four factors extracted and the psychological test batteries as independent variables and having the intention to perform testicular self-examination as the dependent variable. The final model consisted of the same two subscales of multi health locus of control; faith ($p < 0.01$) and powerful others ($p < 0.05$), and had an explained variance of 15.8% (adjusted R square = .14).

When the independent variable was changed to the performance of testicular self-examination the final model consisted of factor 4 with an explained variance of 5.4 % (adjusted R square = .04).

General Discussion

The aim of this project was twofold. The main objective was to assess the level of knowledge and awareness of and attitude towards both testicular cancer and testicular self-exam among the highest at-risk population in Norway. A second objective was to investigate potential relationships between the factors deduced from the factor analyses with psychological measures of depression, anxiety, optimism and health locus of control.

The primary finding of this study is that the general knowledge level is alarmingly low, both concerning symptom recognition, treatment procedures and the probable consequences of the disease. A study recently done by the cancer association in Norway shows that these deficits are far from limited to young men and testicular cancer, as 59% of the sample knew very little about cancer symptoms, only half the sample ever checked their bodies for symptoms of cancer and just 3 out of 10 felt they knew how to do this (Paaske, 2008). Focusing on testicular cancer this deficit in knowledge among at-risk males is even larger and creates a significant obstacle, as the men fail to acknowledge their susceptibility to the disease and therefore see no point in practising testicular self-examination.

How to educate young men?

Some male cancer campaigns have appealed to women using slogans such as “women take care of your man”. Although these campaigns can have some positive outcomes, making women more alert and ready to persuade men to seek help, as has been shown to be the case in the qualitative studies (Chapple et al., 2004; Sanden, Larsson & Sätterlund, 2000; Mason & Strauss, 2004a), they can also have a negative impact by furthering the view that guys should not worry about their own health. This not only leaves women with a double burden, making them responsible for their own as well as their man's health, it can also trigger a form of reactance from the men. The reactance theory suggests that many men are reluctant to seek help, because they feel like they will lose control over the situation. In that sense the

encouragement and/or pressure from loved ones to seek help will work against its purpose, because now by merely complying to seek help they feel like they lose control over the decision-making process as well (Addis & Mahalik, 2003).

The question that presents itself is clear; what can be done to make young men more aware of testicle cancer and what they should do to minimize the risk of morbidity/mortality?

The illusion of invincibility that young men have has to be broken. "Perceived susceptibility/vulnerability to a health problem is known to influence uptake of health-related behaviours and responses to health threats and is a key construct in many social cognition models" (Scott, McGurk & Grunfeld, 2007, p.628). Among them is the extended parallel process model by Witte (1992), which states that individuals will appraise the perceived threat, and if the threat is appraised as legit and the individual feels personal vulnerable to it, then fear will be elicited. Only if this takes place will the individual bother to go on to the next step of evaluating the efficacy of the recommended response.

In other words, as long as young men have a feeling of invincibility, their motivation for self-examination or learning about symptoms and recommended plans of action will be nonexistent. De Hoog, Stroebe & Wit (2007) found vulnerability to have significant effect on intention and behaviour, even though it did not change attitudes which are more an objective evaluation of the facts. In Lechner et al.'s study (2002) those who said they were the most fearful of detecting testicular cancer were also the ones who scored the highest on positive intentions of practicing testicular self-examination. Although the current study did not replicated this finding and excessive fear, as will be discussed later, can lead to procrastination, a majority of studies lend support the notion that a certain amount of fear and feeling of susceptibility leads to improved health behaviour (Lagerlund, Hedin, Sparén, Thurfjell & Lambe, 2000; Diefenbach, Miller & Daly, 1999).

This point also backs up the argument that teaching self-examination can contribute to poking a hole in this illusion, so that young men will be more aware and responsible for their own health beyond just testicular self-examination (Firman & Finney, 1990). While the argument against such widespread education has been that it stirs up unnecessary amount of anxiety and possible depression, this argument is controversial at best (Firman & Firman, 1990; Weist & Finney, 1996). In the current study an opposite trend was shown, as the ones who scored the highest on knowledge questions about testicular cancer had lower scores on both the HADS and STAI inventory.

When one has penetrated this invincibility bubble it is imperative that the efficacy of the recommended response is highlighted. If the threat elicits fear and the recommended response is not seen as efficient, or the consequences of the threat seem harmful and inevitable, the individual will turn to fear controlling processes, in the form of maladaptive responses (Witte, 1992). As in this study 1/6 of the subjects did not think that the majority of men would be healthy again if they got cancer in their testis. This study also showed the same concern as was seen in previous studies (Gascoigne & Whitear, 1999; Gascoigne et al., 1999) about being unable to father children. Luckily the excellent prognosis of testicular cancer should render this fear control option as unnecessary. This however hinges on that the importance of self-examination to catch it early and the subsequent high prognosis and little morbidity reaches the targeted population.

Designing a theoretical framework

Next step is designing a theoretical framework that is specially constructed to make men adaptive help-seekers (Addis & Mahalik, 2003), and teach them about testicular self-examination. One of the hurdles to overcome is to make young men do something without an immediate reward. People in this stage of their lives often have problems with the concept delay of gratification, and although few will dispute that testicular self-examination might

bring with it very positive outcome (quick reaction to a symptom leading to better prognosis) this outcome is if at all often far ahead in time, while the short term benefits are usually non-existent as self-examination can even cause tension, fear or anxiety for what one might find (Lechner et al., 2002).

In order to increase the performance rate of testicular self-examination many believe a social norm must be established, so that young men are encouraged by knowing that their peers are also performing it, a type of social modelling. This has not been proven to work however as there are prior studies that contradict that a perception of support and approval from significant others will enhance the intention of performing TSE (Wynd, 2002).

This current study follows a long line of studies that implies that knowledge about cancer symptoms plays an important role when it comes to help-seeking behaviour, but in the same token that it is not an absolute relationship. How the cancer is conceptualised, how its aetiology is understood, and how symptoms and treatments are interpreted differently by each individual helps explain this gap (Sheikh & Ogden, 1998). Therefore the framework has to consider all the different barriers to, and negative aspects of help seeking which men subjectively experience. Many of these are simply erroneous beliefs or unnecessary exaggerated fears about the illness, its prognosis, or the consequence of treatment.

Identifying these factors influencing delayed presentation of testicular cancer is an integral part of developing a framework. "The fight against cancer should increasingly include a fight against a cognitive appraisal of doom that often comes automatically with the diagnostic suspicion of malignancy" (Zervas et al., 1993, p.13).

The questionnaire in the current study shows that the majority of the subjects fear for their libido and for the risk of impotency when asked what frightens them about testicular cancer. In Chapple & Ziebland's study (2002) elderly men treated for prostate cancer were interviewed about them facing sexual problems as a consequence of the treatment and while

most of them felt it wasn't that disconcerting since they were in the latter stage of their lives, they did feel that if it had happened to them earlier in life it definitely would be a cause for concern. "Well they [hormone injections] make you totally impotent, which would not matter to me at my age, but would certainly matter to a younger man at 30, 35 or 40" (Chapple & Ziebland, 2002, p.832).

Testicular cancer mostly affects young men who are at the peak of their sexual lives and often are in the process of starting a family of their own, so the mere thought about anything negative happening to either their ability to father children or to their libido, is such a scary thought that many would prefer to stick their heads in the sand. That is why it is imperative to get the facts about these things right. Men who do not have to go through chemotherapy will almost certainly be able to father a child the natural way. If chemotherapy is a necessity, it may lower the number of sperm produced, sometimes resulting in infertility. This is often only temporary, and the sperm production usually returns within a couple of years. However sperm banking will be offered to all patients before such treatment is initiated, so even those few, whose production does not normalise, will be able to father children.

When it comes to loss of libido, it is strictly a temporary affair during treatment. When one testicle is removed, the remaining one will compensate and produce more testosterone and sperm. Even in the worst case scenario where both testicles are removed, your doctor can prescribe medication to uphold your natural testosterone level and sexual functioning.

In this study the men rated "looking disfigured" as number three when they were asked what scared them the most if they had to be treated for testicular cancer. In Richardson & Rabiee's qualitative study (2001) where they interviewed young men in a focus group setting, the interviewed subjects expressed clearly that health was not important until they got older, with one exemption and that was if it affected their image. As stated in the introduction,

having one testicle removed was rated as the second most humiliating experience by college-aged males (Gurevich et al., 2004). Therefore it is important that young men are informed that the health community has found ways to improve most side effects of medical procedures, including this one with the possibility of implanting a prosthesis being offered.

There is little doubt left that traditional masculine role serves as another barrier to help seeking as several studies have found this to be a significant factor influencing the help-seeking behaviour of men (Galdas et al., 2005; Richardson & Rabiee, 2001). The men in Gascoigne and Whitear's study (1999) felt that only when symptoms interfered with their daily life did they warrant attention.

So how can this conflict between the masculine role and adaptive help-seeking be resolved? Some of this conflict will automatically tone down if men become more enlightened about the health risk they face and reassured that the concerns they might have are justified. Ultimately though it seems that the conclusion drawn by Addis & Mahalik (2003) that either men as a whole has to change their perspectives of what is 'allowed' to do without losing some of their masculinity, or the health care has to change to better overcome this hurdle, is the correct one.

How to disseminate the message

Once the theoretical framework is designed, the focus has to be how to get the message out to the targeted audience. "Alonzo and Reynolds suggest that it is very difficult to educate the public because of several social and psychological complexities. Firstly, it is difficult to arouse a state of preparedness for an event that could be disabling if real, or potentially embarrassing if the event is a false alarm. Secondly, it is difficult to sustain awareness over extended periods of time because people tend to 'normalize' unpleasant information" (Caldwell & Miaskowski, 2001, p.5).

Previous attempts of education interventions of testicular cancer have almost unanimous come back with the same conclusion; young men are not concerned enough about their own health that they will go out of their way to seek information, meaning the information has to come to them. There is a clear trend developing that suggest men will respond to such interventions if they are available in places they already meet, hence reducing the discomfort most men feel when they engage with health services (Dolan, Staples, Summer & Hundt, 2005). This was echoed by the subjects in Mason and Strauss' study (2004a) who all commented that making information simple, accessible and accurate should be the top priority in the fight against delay.

Lechner et al. (2002) regards the school environment as the ideal place for education on testicular self-examination, since most boys are still in school when they are 15-17, which should be the age where they start practicing it. Rudberg et al. (2005a) support this idea by saying that a widespread media campaign is not called for as the prevalence is still fairly low, however it should be included in the regular development and sex education given in high schools.

Furthermore, nurses play an instrumental role in this process as they are responsible to give health education to all junior and senior high school students in Sweden (Rudberg et al., 2005a) and should resume a larger role in Norway. The young men in Moore and Topping's study (1999) indicated that they would feel less embarrassment if a woman showed them how to perform TSE than if a man did it. Unfortunately only 6% of the 129 nurses interviewed by Rudberg, Nilsson, Wikblad & Carlsson (2005b) provided information on testicular cancer and 9% informed the students on testicular self-examination. For the most part they were open to giving information, but the most formidable obstacle was their own insufficient knowledge about the topic.

The results of the current study, where only four and eight of the subjects indicated they had learned about testicular cancer from their teachers and their general practitioners respectively, show that both these potential sources of education need to become more aware themselves of the disease and more active in communicating relevant information. This will make them better suited, not only to educate young men about facts on testicular cancer and the importance of self-examination, but they will also be able to discuss fears and attitudes that naturally result from such a frightening word as cancer is.

Dolan et al. (2005) also stresses the idea about taking health promotion messages to "where men are". Using a small scale qualitative approach they found that generally men welcomed health campaigns specifically aimed at them. Even though such health promotion initiatives are becoming increasingly common, they usually have a narrow area of focus, instead of including all aspects of men's health. For instance the men in Dolan et al. study (2005) all agreed that the Employee Health Services were not there to improve the workers overall health, their only mission was to improve the attendance rate for work.

Information on internet

The last decade and a half a new media source has stormed into society and made its presence felt, namely the internet. It brings with it an incredible opportunity to seek information on just about any topic one can think of, including facts and stories about testicle cancer and other health related questions which comprise 4.5% of all searches on the internet and are among the top resources on the web when it comes to popularity (Ziebland, Chapple, Dumelow, Evans, Prinjha & Rozmovits, 2004; Amiel, 2005). Already in 2002 there were 9.5 million people in the United States alone who requested cancer information online, and an estimated 39% of cancer patients were users of the internet (Amiel, 2005).

Two of the main reasons for this popularity are the availability and privacy features. Today most homes in the westernized world have a personal computer with internet access,

and even those who lack one can usually go to a library or an internet café and surf the web. An 24-hour instant access makes it possible to seek and digest information at a preferred pace, contrary to a consultation with a doctor where one easily is overwhelmed by facts and often is either left with more questions than one came with, or forced to take use of detrimental defensive mechanisms.

The Internet also allows people to stay anonymous when searching for information on private matters, instead of having to discuss them face to face with another person. This anonymity leads to many positive things. First it allows the person seeking information to ask any question without being afraid of ridiculing himself. This protection of anonymity also allows him to discuss symptoms, problems and/or feelings that he wouldn't necessarily feel comfortable doing with his GP or loved one. A testicular cancer survivor put it like this;

“It's so personal because ... it's your body, but you have to go somewhere. What better place to go than – well certainly in my circumstances, where I have a computer at home that I can switch on, in total privacy. I don't need to feel that I'm asking a dumb question. I don't need to feel that I have to ask all the right questions first time round.” (Ziebland et al., 2004, p. 2).

Secondly, as mentioned in the introduction part, very few men feel comfortable discussing their experience with testicular cancer in public. However if one searches for testicular cancer on the Internet, hundreds of personal experiences and stories can be found. There are forums enabling direct contact with others in similar situations. In 2001 “The Database of Personal Experience of Health and Illness” (DIPEX) launched its website, where one can find a wide array of individual experiences from the patients point of view (Herxheimer & Ziebland, 2003).

This awareness of not feeling like you are the only one who has to go through this process is very comforting and supportive. As one of the men with prostate cancer in Ziebland et al. (2004) study put it:

“I think that the worst thing about getting a diagnosis like this is a feeling of isolation, because you feel that your world has suddenly shrunk and all you can think about is yourself and you feel very frustrated because nobody has maybe experienced this. And when you're able to talk to other patients it's just very good to know that other people have been through this and to kind of share the experience with other people, and you feel much less isolated” (Ziebland et al., 2004, p.5).

It is important to note that the internet has its pitfalls as well, first and foremost in the form of misleading or false information. It is extremely difficult, if not impossible to control what is put out for others to read, and when it comes to health related questions this can have devastating consequences if people are not sufficiently discriminative and double check the information given. There is also a real concern of an “inverse information law”, where those who need the benefit of information on the internet the most are the ones who are unable to obtain it. A major obstacle is illiteracy, which in this setting goes beyond the scope of simply reading and writing, as finding, evaluating and interpreting the information are all processes which demand much more.

These negative aspects of health information have received most of the research attention (Amiel, 2005). While this might be justified, it is important to not “throw the baby out with the bath water”. The arrival of the internet is bound to change the doctor-patient relationship, and hopefully also how people feel responsible for being enlightened about their own health. But instead of substituting the traditional meeting with general practitioner, the Internet should be used as an addition. Patients should be encouraged to seek information and then talk openly about what they found with their doctor as a way to quality check their

findings (Diaz, Griffith, Ng, Reinert, Friedmann, Moulton, 2002). Unfortunately in Diaz et al.'s study (2002) only 41% of the subjects who used the internet said that they shared what they found with their general practitioner.

Some encouraging findings emerged from Rozmovits & Ziebland's study (2003) where the participants seemed to be aware of the pitfalls, and that they had to exercise critical judgement and be discriminative towards the information from the internet. Most of them said they usually double checked the information from different web sites, to ensure its credibility. They also clearly preferred non-commercial sites and sites connected with well renowned titles. In de Vries et al. study (2005) the subjects mentioned internet along with leaflets and the GP, as the preferred channels for receiving information, especially the men in the study.

Considering that it is young men that are at the highest risk of getting testicular cancer and that this is the population who uses the internet most frequently and proficiently, it is clear that this should be one of the top priority outlets for education on testicular cancer and self-examination. "The information technology breakthrough of having the internet available is just unreal. ...so there is really no excuse for not becoming totally aware of testicular cancer." (Ziebland et al., 2004, p.3).

The opportunity to customize information according to individual needs is highly valuable. It is up to the medical community to make sure that the new way of information is used in a reputable manner. One way to help overcome the possibility of misleading information is to create an official web page on the topic and have links listed there to sites which are "supervised" by experts. In Norway the cancer association has already started this process by not only designing such a web page, but also adhering to the common advice from the studies and giving information about it on the males own premises. For instance using commercial spots during soccer matches and trying to undo the taboo that surrounds the

subject by using humour. So far the results have been overwhelmingly positive, as the website had over 35 000 people checking it out during its first week (Andreassen, 2008)

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Forespørsmål om å delta i en studie om oppfatninger, kunnskap og holdninger til testikkelkreft.

Mitt navn er Marius Lind og jeg er masterstudent ved Institutt for Psykologi ved Universitetet i Tromsø. Det siste året av studiet skal man skrive en masteroppgave og i den anledning søker jeg frivillige til å fylle ut det vedlagte spørreskjemaet.

Den eneste forutsetning er at du er mann og mellom 18 og 35 år. Alle besvarelser behandles konfidensielt og jeg **garanterer fullstendig anonymitet**.

I tillegg til spørsmål om dine kunnskaper om og holdninger til testikkelkreft består skjemaet av noen spørsmål som omhandler din allmenne mentale tilstand. Dersom svaralternativene ikke passer helt for deg, krysser du av for det som passer best.

Utfylte spørreskjemaer leveres enten direkte til meg eller tilbake til medhjelperen min som ga de ut og blir deretter sendt samlet til meg. Ved spørsmål vedrørende dette prosjektet kan du henvende deg til meg via e-mail: Marius.lind@gmail.com

Besvarelsen tar ca 15 minutter og er selvfølgelig helt frivillig. Når det er sagt håper jeg virkelig du tar deg tid til å gjennomføre undersøkelsen.

På forhånd takk for hjelpen! ☺

Mvh,
Marius Lind

Spørreskjema

Alder _____

Høyeste bestått utdanning:

- Ikke fullført grunnskole Grunnskole Videregående skole
 Høgskole/univ. lavere grad Høgskole/univ. høyere grad

Arbeidssituasjon (kryss av flere hvis det passer)

- Fulltid Deltid Arbeidssøkende
 Student/elev Hjemmeværende Uførepensjonist/sykemeldt

Sivilstatus

- Enslig Samboer Forlovet/gift Familiefar

Hvor har du fått kunnskapen din om testikkel kreft ifra?

- Media Venner Slektninger
 Lærere Kreftforeningen Lege
 Andre kilder Føler ikke jeg har noen kunnskap

Ønsker du mer tilgjengelig informasjon om testikkelkreft?

- Ja Nei

Hvis du i din nåværende situasjon fikk noen plager som du fryktet var symptomer på en alvorlig sykdom ville du fortalt det til noen? I så fall hvem?

- Kjæreste/kone Venner Foreldre
 Venninne Lege Andre familiemedlemmer
 Ingen

Hvis du fortalte om plagene til noen, hvor sannsynlig er det for at de hadde oppmuntret deg til å oppsøke lege?

- Veldig sannsynlig
 De ville sett situasjonen an
 De hadde sannsynligvis bagatellisert situasjonen for ikke å oppskake deg

Appendix

Hadde deres oppmuntring, eventuelt mangel på bekymring, påvirket ditt valg om å oppsøke lege?

- Veldig mye En god del Nei slike beslutninger må man ta selv

Hvilke av disse faktorene hadde du fryktet mest hvis du måtte behandles for testikkelkreft? Ranger de tre mest skremmende ved å sette 1, 2 og 3.

- Sjansen for å bli steril Miste håret Se misdannet ut
 Kle av seg foran mange folk Miste seksuallyst Testosteronnivået synker
 Ikke kunne være der 100 % for andre Stigmatisering fra andre

Vet du hvordan man utfører en selvundersøkelse av testiklene?

- Ja Nei

Sjekker du testiklene grundig for å undersøke etter noen forandringer/abnormaliteter?

- Aldri
 Et par ganger i løpet av siste året
 Et par ganger i løpet av de siste 6 månedene
 En gang i måneden

Synes du testiklene burde bli sjekket av legen under de vanlige helseundersøkelsene?

- Ja Nei Vet ikke

Har du intensjon om å sjekke testiklene dine framover og oppsøke lege ved mistanke om symptomer på testikkelkreft?

- Ja Nei Vet ikke

Appendix

Her kommer noen spørsmål om hvorledes du føler deg. For hvert spørsmål setter du kryss for ett av de fire svarene som best beskriver dine følelser den siste uken. Ikke tenk for lenge på svaret -- de spontane svarene er best.

Jeg føler meg nervøs og urolig

- Mesteparten av tiden Mye av tiden Fra tid til annen Ikke i det hele tatt

Jeg gleder meg fortsatt over tingene slik jeg pleide før

- Avgjort like mye Ikke fullt så mye Bare lite grann Ikke i det hele tatt

Jeg har en urofølelse som om noe forferdelig vil skje

- Ja, og noe svært ille Ja, ikke så veldig ille Litt, bekymrer meg lite Ikke i det hele tatt

Jeg kan se det morsomme i situasjoner

- Like mye nå som før Ikke like mye nå som før Avgjort ikke som før Ikke i det hele tatt

Jeg har hodet fullt av bekymringer

- Veldig ofte Ganske ofte Av og til En gang i blant

Jeg er i godt humør

- Aldri Noen ganger Ganske ofte For det meste

Jeg kan sitte i fred og ro og kjenne meg avslappet

- Ja, helt klart Vanligvis Ikke så ofte Ikke i det hele tatt

Jeg føler meg som om alt går langsommere

- Nesten hele tiden Svært ofte Fra tid til annen Ikke i det hele tatt

Jeg føler meg urolig som om jeg har sommerfugler i magen

- Ikke i det hele tatt Fra tid til annen Ganske ofte Svært ofte

Jeg bryr meg ikke lenger om hvordan jeg ser ut

- Ja, jeg har sluttet å bry meg Ikke som jeg burde Kan hende ikke nok Bryr meg som før

Jeg er rastløs som om jeg stadig må være aktiv

- Uten tvil svært mye Ganske mye Ikke så veldig mye Ikke i det hele tatt

Jeg ser med glede fram til hendelser og ting

- Like mye som før Heller mindre enn før Avgjort mindre enn før Nesten ikke i det hele tatt

Jeg kan plutselig få en følelse av panikk

- Uten tvil svært ofte Ganske ofte Ikke så veldig ofte Ikke i det hele tatt

Jeg kan glede meg over gode bøker, radio og TV

- Ofte Fra tid til annen Ikke så ofte Svært sjelden

Appendix

Vennligst besvar spørsmålene nedenfor så ærlig som mulig, ut ifra dine egne følelser. Det er ingen rette eller feile svar. Prøv å ikke la svaret på et spørsmål påvirke de andre svarene.

		Jeg er veldig enig	Jeg er litt enig	Jeg er verken enig eller uenig	Jeg er litt uenig	Jeg er veldig uenig
1.	I usikre tider, forventer jeg som oftest det beste	1	2	3	4	5
2.	Det er lett for meg å slappe av	1	2	3	4	5
3.	Hvis noe kan gå galt for meg, så blir det å skje	1	2	3	4	5
4.	Jeg er alltid optimistisk angående min framtid	1	2	3	4	5
5.	Jeg setter stor pris på mine venner	1	2	3	4	5
6.	Det er viktig for meg å hele tiden ha noe å gjøre	1	2	3	4	5
7.	Jeg forventer nesten aldri at ting skal gå min vei	1	2	3	4	5
8.	Jeg blir ikke lett oppskaket	1	2	3	4	5
9.	Jeg regner sjeldent med at noe bra vil skje meg	1	2	3	4	5
10.	Alt i alt forventer jeg at flere positive enn negative ting skal skje meg	1	2	3	4	5

Appendix

Nedenfor finner du en rekke setninger som ofte brukes for å beskrive hvordan en føler seg i øyeblikket. Les hver setning og sett ring rundt det tallet til høyre som passer best med hvordan du har det nå. Det finnes ikke gale eller riktige svar. Ikke tenk for lenge på hver setning, men svar slik du umiddelbart synes passer best for deg akkurat nå.

		Aldes ikke	Litt	Nokså mye	Svært mye
1.	Jeg føler meg rolig	1	2	3	4
2.	Jeg føler meg trygg	1	2	3	4
3.	Jeg er anspent	1	2	3	4
4.	Jeg føler meg presset	1	2	3	4
5.	Jeg føler meg vel	1	2	3	4
6.	Jeg føler meg oppskaket	1	2	3	4
7.	Akkurat nå tar jeg sorgene på forskudd	1	2	3	4
8.	Jeg føler meg tilfreds	1	2	3	4
9.	Jeg føler meg skremt	1	2	3	4
10.	Jeg har det behagelig	1	2	3	4
11.	Jeg er sikker på meg selv	1	2	3	4
12.	Jeg føler meg nervøs	1	2	3	4
13.	Jeg er skjelven	1	2	3	4
14.	Jeg er ubestemt	1	2	3	4
15.	Jeg er avslappet	1	2	3	4
16.	Jeg er fornøyd	1	2	3	4
17.	Jeg er bekymret	1	2	3	4
18.	Jeg føler meg forvirret	1	2	3	4
19.	Jeg føler meg stabil	1	2	3	4
20.	Jeg har det bra	1	2	3	4

Appendix

Nedenfor finner du en rekke setninger som ofte brukes for å beskrive hvordan en føler seg i alminnelighet. Les hver setning og sett ring rundt det tallet til høyre som passer best med hvordan du vanligvis har det. Det finnes ikke gale eller riktige svar. Ikke tenk for lenge på hver setning, men svar slik du umiddelbart synes passer best med hvordan du har det til vanlig.

		Aldes ikke	Litt	Nokså mye	Svært mye
21.	Jeg føler meg vel	1	2	3	4
22.	Jeg føler meg nervøs og rastløs	1	2	3	4
23.	Jeg er tilfreds med meg selv	1	2	3	4
24.	Jeg skulle ønske jeg var like lykkelig som andre synes å være	1	2	3	4
25.	Jeg føler meg mislykket	1	2	3	4
26.	Jeg føler meg uthvilt	1	2	3	4
27.	Jeg er rolig og avbalansert	1	2	3	4
28.	Jeg føler at vanskelighetene hopper seg opp slik at jeg ikke kan løse dem	1	2	3	4
29.	Jeg engster meg for mye over småting	1	2	3	4
30.	Jeg er lykkelig	1	2	3	4
31.	Jeg har urovekkende tanker	1	2	3	4
32.	Jeg mangler selvtillit	1	2	3	4
33.	Jeg føler meg trygg	1	2	3	4
34.	Jeg tar avgjørelser lett	1	2	3	4
35.	Jeg føler meg utilstrekkelig	1	2	3	4
36.	Jeg er fornøyd og tilfreds	1	2	3	4
37.	Jeg er plaget av uviktige tanker	1	2	3	4
38.	Jeg tar skuffelser så hardt at jeg ikke kan kvitte meg med dem	1	2	3	4
39.	Jeg er en stø og stabil person	1	2	3	4
40.	Jeg blir nervøs og ute av meg når jeg tenker på mine aktuelle problemer	1	2	3	4

Appendix

Nå følger det spørsmål som er mer konsentrert på dine kunnskaper om og holdninger til symptomer og behandling av testikkelkreft og om hva som skal til for at du oppsøker hjelp.

Er følgende plager vanlige symptomer på testikkel kreft?

		Ja	Nei	Vet ikke
1.	Hoven Testikkel	1	2	3
2.	Vanskelighet med urinering	1	2	3
3.	Blod i urinen	1	2	3
4.	Blod i sæden	1	2	3
5.	Smerte i testikkelen	1	2	3
6.	Hårtap	1	2	3
7.	En kul på testikkelen	1	2	3
8.	Forstørring eller ømhet av/i bryst	1	2	3
9.	Utslett på sekken	1	2	3
10.	Smerte eller tyngende følelse i lysken/sekken	1	2	3
11.	Seksuelle problemer	1	2	3
12.	Vekttap	1	2	3

Appendix

Når ville du oppsøkt lege for følgende symptomer?

		Straks	Innen en uke	Innen en måned	Innen et år	Aldri
1.	Hoven Testikkel	1	2	3	4	5
2.	Vanskelighet med urinering	1	2	3	4	5
3.	Blod i urinen	1	2	3	4	5
4.	Blod i sæden	1	2	3	4	5
5.	Smerte i testikkelen	1	2	3	4	5
6.	Hårtap	1	2	3	4	5
7.	En kul på testikkelen	1	2	3	4	5
8.	Forstørring eller ømhet av/i bryst	1	2	3	4	5
9.	Utslett på sekken	1	2	3	4	5
10.	Smerte eller tyngende følelse i lysken/sekken	1	2	3	4	5
11.	Seksuelle problemer	1	2	3	4	5
12.	Vekttap	1	2	3	4	5

Appendix

Er du enig i følgende påstander?

		Fullstendig enig	Enig	Det tror jeg ikke	Fullstendig uenig
1.	Majoriteten av menn er redd for testikkelkreft	1	2	3	4
2.	Flesteparten av menn blir aldri frisk fra testikkelkreft	1	2	3	4
3.	Risikoen for å få testikkelkreft er større hvis noen andre i familien har hatt testikkelkreft	1	2	3	4
4.	Det er vanligvis menn i min alder som får testikkelkreft	1	2	3	4
5.	I min alder løper jeg mindre risiko for å få testikkelkreft i forhold til andre menn	1	2	3	4
6.	Leger har god kunnskap om testikkelkreft	1	2	3	4
7.	Prognosen til testikkelkreft er dårlig i forhold til andre kreftformer	1	2	3	4
8.	Jeg kan lære å oppdage testikkelkreft selv	1	2	3	4
9.	Testikkelkreft rammer mange menn	1	2	3	4
10.	Jeg er redd for å få testikkelkreft	1	2	3	4
11.	Det er en del ting jeg kan gjøre for å unngå å bli rammet av testikkelkreft	1	2	3	4
12.	Prognosen til behandling av testikkelkreft avhenger mye av når det blir oppdaget.	1	2	3	4
13.	Jeg ville ikke hatt noen problemer med å snakke om symptomer på testikkelkreft med en lege.	1	2	3	4
14.	Jeg føler meg sikker på at legen min ville tatt meg på alvor.	1	2	3	4
15.	Behandlingen og bivirkningene skremmer meg mer enn selve sykdommen.	1	2	3	4

Appendix

Er følgende påstander om behandlingsforløp og følger av behandling av testikkelkreft korrekt?

		Ja, alltid	Ja, noen ganger	Nei, det stemmer ikke	Vet ikke
1.	Pasienter med testikkelkreft får tilleggsbehandling i form av cellegift	1	2	3	4
2.	Når man behandler testikkelkreft, så fjerner man bare den affekteerte testikkelen.	1	2	3	4
3.	Når man behandler testikkelkreft, så fjerner man hele sekken	1	2	3	4
4.	Pasienter med testikkelkreft kan få tilleggsbehandling i form av stråleterapi.	1	2	3	4
5.	Det kan være nødvendig å fjerne lymfeknutene i buken hvis kreften har spredd seg.	1	2	3	4
6.	Fruktbarhetsevnen etter behandling er svært begrenset	1	2	3	4
7.	Med vellykket behandling kan folk som har hatt testikkelkreft leve helt normale liv.	1	2	3	4
8.	Testosteronnivået synker	1	2	3	4
9.	Behandlingen gjør at man mister håret	1	2	3	4
10.	Seksuallyst og potens synker	1	2	3	4
11.	Behandling vil medføre midlertidig tap av hår	1	2	3	4

Appendix

Nedenfor finner du en rekke påstander som du skal ta stilling til. For hver påstand skal du sette et merke alt etter hvor enig eller uenig du er i påstanden.

		Helt uenig	Nokså uenig	Litt uenig	Litt enig	Nokså enig	Helt enig
1.	Hvis jeg blir syk, er det min egen atferd som avgjør hvor raskt jeg blir frisk igjen	1	2	3	4	5	6
2.	Hvis det er slik at jeg skal bli syk, blir jeg det uansett hva jeg foretar meg	1	2	3	4	5	6
3.	Regelmessig kontakt med legen er den beste måten for meg å unngå sykdom på	1	2	3	4	5	6
4.	De fleste ting som virker inn på min helse, skjer tilfeldig	1	2	3	4	5	6
5.	Når jeg ikke føler meg bra, bør jeg snakke med lege eller andre fagfolk på helsespørsmål	1	2	3	4	5	6
6.	Jeg har selv kontrollen over min helse	1	2	3	4	5	6
7.	Min familie har stor betydning for om jeg blir syk eller holder meg frisk	1	2	3	4	5	6
8.	Når jeg blir syk, er det jeg selv som må lastes	1	2	3	4	5	6
9.	Det er i stor grad flaks som avgjør hvor raskt jeg vil komme meg etter sykdom	1	2	3	4	5	6
10.	Leger og andre fagfolk på helsespørsmål har kontrollen med min helse	1	2	3	4	5	6
11.	Min gode helse er stort sett et spørsmål om at jeg har lykken med meg	1	2	3	4	5	6
12.	Det som først og fremst virker inn på min helse, er det jeg selv gjør	1	2	3	4	5	6
13.	Hvis jeg tar vare på meg selv, kan jeg unngå sykdom	1	2	3	4	5	6
14.	Når jeg blir frisk etter en sykdom, er det vanligvis fordi andre har tatt seg godt av meg	1	2	3	4	5	6
15.	Uansett hva jeg gjør, er det sannsynlig at jeg blir syk	1	2	3	4	5	6
16.	Hvis det nå engang er meningen at jeg skal være frisk, så vil jeg holde meg frisk	1	2	3	4	5	6
17.	Hvis jeg tar de riktige forholdsreglene, kan jeg holde meg frisk	1	2	3	4	5	6
18.	Når det gjelder min helse, kan jeg bare følge de råd legen gir	1	2	3	4	5	6