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1 GENERAL INTRODUCTION
Sexuality, in sickness and in health

It is nowadays increasingly recognized that sexual health is important to overall health and well-being (1). For both men and women, satisfaction with the sexual life is strongly associated with quality of life in many aspects. It is associated with a positive outlook on life in general, family life, financial wellbeing and better physical health. Furthermore, it is a very important factor for a loving relationship (1;2).

But, as with all good things in life, it can also be harmed. The other, dark side of sexuality is that it can lead people (mostly men) to commit sexual offences such as rape, child pornography and incest. In contrast to the positive effects a healthy sexual life can have for peoples’ mental and physical health, sexual abuse highly impacts victim’s mental and physical condition, often affecting them for the rest of their lives (3;4). It is commonly known that sexual abuse, especially childhood sexual abuse, often results in sexual dysfunction in later life too (5).

Women have been documented to experience sexual abuse more frequently than men (6) and subsequently experience lower levels of sexual interest and frequent anorgasmia, especially after abuse that involved penetration and force or recurrent sexual victimization (7). Sexual abuse in men is recently more reported, especially since this topic got a lot of attention due to the reports concerning abuse in the Roman-Catholic church. However, due to the negative feelings associated with being overpowered by a woman or the fear of being labeled homosexual when the abuse is perpetrated by a male, sexual abuse remains underreported in men. Associated sexual difficulties in men that experienced sexual abuse are erectile dysfunction (ED, also known as impotence), premature ejaculation and low sexual desire (8).

Sexual dysfunctions in itself have been shown to negatively impact quality of life, psychological well-being and marital/partnership satisfaction (9;10).

Life time prevalence of adult sexual abuse, in the broadest sense of the term, in modern western societies is estimated up to 10% for males and up to 25% for females (11-13).

According to the British national survey of sexual attitudes and lifestyle among individuals in a sexual relationship for the past year, 18% of men and 17% of women reported that their partner had sexual difficulties. Of men and women in the oldest age group (65-74 years), 43% of women and 31% of men reported sexual dysfunction in the past year (14).

But, in spite of these high prevalence rates, we know from the literature that sexual abuse and sexual dysfunction are frequently underdiagnosed, and untreated (15-18). Multiple factors are accountable for the fact that these subjects are not routinely discussed in clinical practice. On the one hand, patients seldom dare to initiate discussion about
sexual abuse or ‘even’ sexual dysfunction spontaneously in clinical settings (14;19). On the other hand, physicians may feel several barriers raising either of these subjects. Due to the fact that physicians still seem to trust in the concept that disease has something to do with survival and self-preservation and that sexuality comes in the second instance, when the disease problem is resolved. However, both dimensions go together as integral parts of patients’ lives. In a patient-centered approach the global dimension of health and sexuality both have to be taken into account (20).

**Sexual health in disease**

Improvements in medical care have allowed individuals with chronic disease to survive and live longer. This greater life expectancy with disease has led healthcare providers to change their focus from ‘survival’ to improving ‘quality of life’. Sexuality is a phenomenon in which biological and psychological factors interact; therefore, both physical condition and psychological well-being are cornerstones of sexual health. Figure 1 presents a basic conceptual framework about the association of chronic disease and sexuality.

As shown in Figure 1, physical condition and psychological functioning are interrelated. For example, the prevalence of pain in patients with a depressive disorder and, vice versa, the prevalence of depression in patients with pain are much higher compared to the prevalence’s of patients without a depression and without pain respectively (21). As well, the relationship with a sexual partner should be taken into account because this relationship plays an important role in adaptation to the disease state, thereby impacting psychological well-being and sexuality.

Furthermore, to control the symptoms of the disease or to prevent further progress, patients should comply with the prescribed treatment regimen. Noncompliance to (drug) treatment is nonetheless a well-known problem in medical practice, which often contributes to the burden of disease. As shown in Figure 1, compliance may be affected by changes in the physical condition. On the one hand, the conviction of the patient that a condition is ‘asymptomatic’ may lead to non-compliance with therapy, whereas insight about the necessity of treatment or the feeling of control may promote compliance (22). On the other hand, experience of medication induced adverse effects (such as sexual dysfunction) often leads to non-compliance with therapy (21;23).

At last, disease activity may have a direct or indirect influence on sexual functioning. Apart from this, short term and long term complications may affect sexuality independent from the primary disease activity.
This framework displayed in Figure 1 is applicable in both physical and mental disease and provides insight into the process by which disease-related psychological and relational factors impact sexual functioning and well-being of patients, necessary to place this thesis in the right context.

**This thesis**

In this thesis two seemingly different subjects will be discussed, however, both can be placed in the categories quality of life, quality of care, sexual health and patient centeredness. In part I, care for sexual dysfunction in cardiovascular disease is evaluated and in part II, care for sexual abuse in the gastroenterology practice is assessed. Both parts can be read separately and are not interrelated. But as mentioned before, both comprise clinical problems that are commonly seen and both are written with the same goals in mind: improvements for quality of life and quality of care.

**Figure 1.** A conceptual framework about the impact of disease on sexual functioning and sexual well-being

Sexual health in cardiovascular disease

The age-adjusted mortality rates of cardiovascular disease (CVD) in Western Europe lay between 170 and 240 per 100,000 (24). Men and women in countries with higher development status (measured in terms of gross domestic product per capita) experience CVD events at an older age and die much later than in less developed countries. For example, in Australia, France, and Sweden, the median age at death from ischemic heart disease averages 85 years in women and 77 years in men. Men in these countries experience an acute myocardial infarction (MI) more than a decade before their median age at death (25).

CVD causes mass disability: within the coming decades the disability-adjusted life years (DALYs) estimate is expected to rise from a loss of 85 million DALYs in 1990 to a loss of ~150 million DALYs globally in 2020, thereby remaining the leading somatic cause of loss of productivity (26).

A less obvious problem which often comes hand in hand with CVD is sexual dysfunction. Sexual dysfunctions are very prevalent among both men (prevalence 50-75%) and women (prevalence 43-87%) with CVD compared to those without CVD (27-29). Reasons for this association include the vascular causes, the use of antihypertensive agents and the psychological problems such as depression, anxiety for cardiac events and changes in the relationship due to the disease (30).

Especially erectile dysfunction (ED), defined as the persistent inability to achieve and maintain an erection to permit satisfactory sexual intercourse, is commonly associated with cardiovascular disease, with prevalence rates ranging between 47 and 75% in studies (31-33). Due to the prolonged life expectancy of patients with CVD and the aging of the population, the projected prevalence of ED for the year 2025 is expected to rise to 322 million men worldwide (34).

ED and CVD share the same risk factors such as age, dyslipidemia, hypertension, diabetes, smoking etc. Endothelial dysfunction is believed to be the pathophysiologic link. Frequently, the clinical consequences of ED frequently manifest 2-3 years before the consequences of coronary atherosclerosis. The last years mounting research has been investigating this link and ED was shown to be an independent marker of increased CVD risk (32,35-37), commonly preceding clinical coronary artery disease (38), and peripheral arterial disease and stroke (39).

The artery-size hypothesis (40) is the proposed mechanism explaining why patients frequently report ED before coronary artery disease is detected. The lumen of the penile arteries (1–2 mm) is considerably smaller than that of the coronary (3–4 mm), carotid (5–7 mm), and femoral (6–8 mm) arteries, endothelial dysfunction or plaque burden that
significantly impairs circulation in the penile arteries may be associated with sub clinical plaque disease of the larger vessels. Thus, atherosclerosis sufficient to trigger ED may not be sufficient yet to cause ischaemic symptoms in other vascular beds (see Table 1).

A very important finding, which may be extrapolated to female sexual dysfunction such as vaginal dryness and dyspareunia as well (41). However, research in this context has focused predominantly on ED and has almost completely neglected female sexual dysfunction (FSD) and other male sexual dysfunctions. In fact, the patients’ side of the story did not receive much attention at all. For patients the fact that ED may predict cardiovascular disease is obviously not the only relevant aspect of it. Obviously, the ED in itself is important for most patients as well. This side of care for patients with CVD remains understudied and FSD in CVD from the female patients’ point of view has virtually not been highlighted at all.

Still, both care for ED, FSD, other sexual difficulties, such as counseling about safely restarting sexual activity after a cardiac event, and counseling about adverse effects of antihypertensive agents are all very important issues to address in the cardiac clinic.

Figure 2. The ‘artery size’ hypothesis

**Sexual abuse and gastrointestinal disease**

Many studies have documented that striking numbers of patients presenting with functional gastrointestinal complaints have endured sexual abuse. In 1990, Drossman et al. found that 38.5% of patients who presented to a university-based gastroenterology practice reported a history of sexual abuse (13). Only 17% of patients with an SA history had previously informed their physicians about the abuse, and almost one third had never discussed it with anyone. Patients that reported a history of SA were more likely to report chronic pelvic pain (odds ratio, 4.0) and multiple other somatic symptoms (odds ratio, 7.1). Furthermore, they had more lifetime surgeries (odds ratio, 2.8) compared to patients who did not report SA (42). The high prevalence of sexual abuse in patients with irritable bowel syndrome (IBS) and other gastrointestinal symptoms (GI) was shown repeatedly (43-50). Significantly higher levels of sexual abuse have been reported in patients with pelvic floor disorders (51-53). Patients with chronic pelvic pain were found to have experienced significantly higher levels of sexual abuse; this was often accompanied by significant levels of psychiatric dysfunction (46;54). Furthermore, it has clearly been shown that sexual abuse is a common concomitant of functional gastrointestinal disorders.

The exact relationship between functional gastrointestinal disorders and a positive abuse history remains to be defined completely; however, several studies have found evidence of physiologic disturbance outside the gastrointestinal tract. For example, in women with chronic pelvic pain, chronic dysfunction of the hypothalamic-pituitary-adrenal axis, a positive abuse history, and a diagnosis of posttraumatic stress disorder was correlated (55;56). Severity of abuse has been correlated positively with deteriorating health status, as measured by significantly more days in bed, greater pain severity, and psychological problems as well as poorer functioning in activities of daily life (48).

Research comparing the brains of abused children and control subjects, showed that abuse seems to induce a cascade of molecular and neurobiological effects that alter the development of specific areas in the brain. These areas include the limbic system, left hemisphere, corpus callosum and cerebellar vermis. The limbic system is the brain’s emotional processing center and includes the amygdala and hippocampus. MRI scans also revealed an association between early maltreatment and the reduction in the size of the adult left hippocampus or amygdala (57).
In Figure 3, a bio psychological model was laid out to conceptualize the pathogenesis and clinical expression of (functional) gastrointestinal symptoms. This model proposes that early-life factors (e.g. genetic factors, GI infection and family environment) may be factors associated with susceptibility towards functional gastrointestinal symptoms. Abuse history has an amplifying effect on the experience and clinical expression of these symptoms, which may be associated with greater ‘body awareness’ due to earlier trauma. Psychosocial factors as noted may further amplify the symptom experience and clinical state, leading to adverse health outcomes, including increased physician visits, referral to gastroenterologists, specialized centers and, when severe, disability (58).

Figure 3. Conceptual relationship of abuse history and other psychosocial co-morbidities on gastrointestinal symptoms and adverse health outcomes

CNS= central nervous system, ENS= enteric nervous system; MD= medical doctor
Sexual abuse is of course a highly sensitive topic and therefore patients may find it difficult to start talking about it. Thus, the importance of taking an abuse history cannot be overstated for patients presenting with chronic gastrointestinal or any other chronic unexplained medical complaint. To aid general practitioners and gastroenterologists in inquiring about sexual abuse, reviews of the literature and guidelines how to approach this topic have been published (4;59;60) as well as an instrument to measure abuse severity (49). However, these recommendations have never been tested in normal outpatient settings. Until now, we are even unaware whether attention is paid to SA in the day to day gastroenterology practice. But without attention for sexual abuse, no one will ever put the knowledge about its impact for patients with gastrointestinal symptoms or the valuable recommendations from the literature actually into practice.

Outline of the thesis
The aim of this thesis was to evaluate to what extend cardiologists and gastroenterologists succeed in the provision of patient-centered healthcare with regard to sexual health. To be more specific: this investigation was aimed to identify the lacunas in the cardiology practice regarding attention and care for sexual health and in the gastroenterology practice regarding attention and care for victims of sexual abuse. In order to obtain the required information to meet these aims, the problem was approached from two sides: the specialists’ point of view and the patients’ point of view.

In part I, the cardiologist and the cardiac patient are evaluated regarding the omissions in care for sexual health in cardiology.

In part II, the gastroenterologist and the colonoscopy patient are surveyed regarding the omissions in care for sexual abuse victims in gastrointestinal disease.
REFERENCE LIST


