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**THE ROLE OF ONLINE SUPPORT GROUPS IN EMPOWERING  
INDIVIDUALS AFFECTED BY PROSTATE CANCER**

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**Thesis submitted to the University of Nottingham**

**for the degree of Doctor of Philosophy**

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## Abstract

The psychosocial challenges prostate cancer imposes on the lives of patients and their family members, relating to treatment decisions, recovery and side-effects have been well documented. Whilst informational and emotional support can help ameliorate these challenges, research points towards several barriers to obtaining support face-to-face. Recent research suggests that health-related online support groups can help empower members to become active health care participants through the provision of information and support. Few studies, however, have examined the role of these groups in the context of prostate cancer. This research programme seeks to examine how, if at all, participation within prostate cancer online support groups empowers members. In Study 1, an analysis of 631 messages posted to prostate cancer online support groups was undertaken to explore the beneficial processes observed in members' communication. In Study 2, open-ended surveys were employed to collect qualitative data from 147 group members to explore their perception of empowering processes and outcomes within the groups. In Study 3, quantitative surveys (n=195) were employed to examine the extent to which members experience these processes and outcomes and the relationship between the two. The combined results of the studies point towards the existence of several empowering processes, such as informational and emotional support exchange, encountering similar others and the ability to discuss sensitive issues. Empowering outcomes commonly experienced by the members included increased knowledge, the ability to participate in treatment-related decisions, an increased sense of community and enhanced communication with their medical practitioner. The processes significantly predicted the outcomes, with 'information exchange' consistently being the most significant predictor. This indicates that the processes, and particularly informational support in these groups,

play an important role in empowering members. Although some negative processes have been identified, the positive aspects outweigh the negatives. These findings suggests that prostate cancer online support groups can be an effective and cost-efficient source of support and information for prostate cancer patients and their caregivers, and have a significant impact on their sense of empowerment.

## **List of published papers and conference presentations**

### **Published papers:**

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Campbell, K.A., Coulson, N.S. & Buchanan, H. (2012). Empowering prostate cancer patients and their female partners within prostate cancer online support groups. Paper presented at British Psychological Society Division of Health Psychology Annual Conference, Liverpool, United Kingdom.

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## Chapter One: Introduction

This thesis presents a programme of research into the online support group experiences of individuals affected by prostate cancer; the main focus of the research was the potentially empowering effects participation in prostate cancer online support groups may have on members. In recent years, the popularisation of the Internet has revolutionised the way in which people can communicate, exchange knowledge and support. One of the important areas of Internet use pertains to health-related information seeking; with growing numbers of individuals who live with various conditions and diseases turning to online sources for advice and information (Eysenbach & Diepgen, 2001). In particular, one increasingly popular source of experiential knowledge and social support is health-related online support groups, within which members can communicate with other individuals affected by a similar condition about all issues related to symptoms, diagnosis, treatment and recovery (Eysenbach, Powell, Englesakis, Rizo & Stern, 2004). Recent research suggests that these groups play an important role in empowering patients (e.g. van Uden-Kraan et al., 2008c, 2009); however, few studies to date have explored their potential in relation to prostate cancer.

Research into the experiences of individuals affected by prostate cancer suggests that both patients and their family members experience several psychosocial challenges as a result of the diagnosis and treatment and that their need for informational and emotional support is greatly increased as a result (e.g. Bottoroff et al., 2008; Echlin & Rees, 2002). The extant literature further suggests that although social and emotional support can help reduce the negative impact of cancer-related stress and anxiety (e.g. Baider et al., 2003), prostate cancer patients and their family members experience many barriers to seeking support

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from family, friends and face-to-face support groups (e.g. Walsh & Hegarty, 2010). Recent policy guidelines (NICE, 2008) advocate the need to include prostate cancer patients and their family members in the process of treatment decision-making and recognise the necessity to empower them to become active and autonomous health care users through the provision of information and support. Whilst the guidelines point towards health care professionals as the main providers of these resources, informational and emotional support from medical professionals appears to be lacking in several areas (Capirci et al., 2005; Feldman-Stewart et al., 1998). For example, patients often report that important facts relating to treatment decisions are provided before they are ready to absorb them (Echlin & Rees, 2002); family members frequently feel neglected and disempowered in the communication with the medical team (Feltwell & Rees, 2004). Recent research suggests that individuals affected by prostate cancer may turn to online support groups for factual and experiential information as well as peer support (e.g. Gooden & Winefield, 2007), however, relatively little is known about the experiences of prostate cancer online support group members and about the effects participation may have on both patients and family members.

Therefore, the main aim of this thesis was to gain an in-depth understanding of the way in which individuals affected by prostate cancer use online support groups, examine their experiences and consider how participation affects their lives, with a particular focus on empowerment and the various processes which may benefit members.

The main body of this thesis comprises seven chapters. Chapter 2 presents a comprehensive review of the literature on the subject of prostate cancer, the psychosocial challenges that affect patients and their family members and the role of social support in overcoming these challenges. Chapter 3 reviews the literature pertaining to online support

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groups, with a particular focus on the processes and outcomes observed within various health-related online support groups, as well as the advantages and disadvantages of engaging in these groups.

Chapter 4 outlines the rationale for the empirical research presented within the thesis, including a rationale for considering this research within an empowerment framework (van Uden-Kraan et al., 2008c, 2009) as well as the reasons behind employing mixed-methodology to investigate online support. Philosophical issues underpinning triangulated research conducted across paradigms are also considered. Finally, this chapter concludes by articulating the research aims of the thesis.

Chapters 5, 6 and 7 present the findings of the empirical studies, including a rationale; research aims and specific research questions; results; discussion of the results as well as strengths and limitations of each study. To summarise, Chapter 5 presents a content analysis of messages posted to prostate cancer online support groups with a view to assess the range and the extent of the potentially empowering processes that can be observed within the naturally occurring communication between members. This research methodology provides a unique insight into the potentially empowering processes that occur within the groups, and thus was considered to be appropriate for the first step of the investigation. Chapter 6 builds on the findings of the study presented in Chapter 5, and explores members' perspectives regarding the empowering processes and empowering outcomes within prostate cancer online support groups. This study also investigates participants' motives for accessing online support groups and whether they experience any negative effects through participation. Chapter 7 aims to quantify the extent to which individuals experience empowering processes and outcomes. It also explores the potential differences in the extent to which patients and their family members experience these

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processes and outcomes. Next, the relationship between processes and outcomes is considered.

Chapter 8 brings together the findings of the three empirical studies and discusses them in light of the current literature pertaining to online support and prostate cancer. Methodological issues relating to the current studies are discussed; directions for future research and implications for practice are also explored.

## **Chapter Two: Prostate cancer**

### **Chapter overview**

This chapter is concerned with the impact that prostate cancer diagnosis and treatment can have on the patient and his partner. The chapter is comprised of three main parts. The first part presents a detailed review of literature pertaining to the biomedical aspects of prostate cancer diagnosis, together with its treatment and side-effects. The aim of this part is to help the reader understand the impact prostate cancer has on the patients, and to provide an insight into the biomedical factors that can affect the psychological well-being of the patient and the treatment decision-making processes. The second part describes and discusses the main psychosocial challenges associated with prostate cancer diagnosis and treatment, for both patients and their partners. The final part of this chapter discusses the importance of social support in overcoming these challenges and describes the barriers to accessing sources of face-to-face social support commonly experienced by the patients and their partners. The Internet and online support groups, which could potentially offer patients and their partners' new avenues to receiving social support are also introduced.

**PART ONE: Biomedical background: prostate cancer diagnosis and treatment**

**2.1 Prostate gland**

The prostate is a walnut sized gland which is a part of the male reproductive system. It is situated in the lower abdomen, directly below the bladder and in front of the rectum, encircling the upper part of the urethra. Nerve bundles responsible for erections are located on both sides of the prostate. Seminal vesicles, small glands producing fluid which forms a large proportion of the semen, open into the prostate gland. The gland consists of two lobes (left and right) and three main zones: peripheral (70-75% of the volume); central (20-25%) and transitional zone (5-10%) (Kirby & Patel, 2012). The peripheral zone, in which the majority of cancerous tumours form, is located closest to the rectum, in the posterior part of the gland. The prostate gland produces slightly alkaline, milky white fluid which contributes around 20-30% of ejaculate. Its presence helps neutralise the acidic environment of the vaginal tract and provides protection for the spermatozoa during ejaculation (Marengo, 2001; Torrey, 2006).

Diseases of the prostate are amongst the most common male conditions. Benign prostatic hyperplasia (BPH) and prostatitis are two of the most frequently reported benign prostate diseases. Prostatitis is a non-malignant, inflammatory condition of the prostate, common in men of all ages. It is usually a painful bacterial disease, treatable with antibiotics (Bartoletti et al., 2007; Naber, 2003).

Benign prostatic hyperplasia (BPH) or non-cancerous enlargement of the prostate gland is caused by the growth of the prostate gland as the man ages. Due to its localization, the enlarged prostate starts to press on the urethra resulting in lower urinary tract

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dysfunctions, including difficulties and pain during urination, diminished urinary flow, urgency to urinate and sometimes blood in urine and semen (Thompson, Thrasher, Moyard & Sylvester, 2003). It is estimated that around 50% of men develop some symptoms consistent with BPH by the age of 50 and this percentage rises to around 80% in men in their 80s.

### **2.2 Prostate cancer**

#### **2.2.1 Incidence and mortality**

Prostate cancer is currently the most common male cancer in Western countries and accounts for approximately 25% of all newly diagnosed cases of male cancers (ONS, 2011a, US Cancer Statistics Working Group, 2010). The reported incidence is 1.6 times higher than lung cancer in the UK (ONS, 2011a) and is 1.9 times higher in the US (US Cancer Statistics Working Group, 2010). In recent decades the incidence of prostate cancer, particularly in its early stages, has increased significantly, a phenomenon partially attributed to the advances in non-invasive screening methodology, such as testing serum levels of prostate specific antigen (PSA) (Kirby & Patel, 2012; Torrey, 2006). Although prostate cancer is the second most common cause of cancer-related deaths in males (ONS, 2011a), relative survival rates are high; due to the late onset and slow development of the disease, significantly more men die *with* prostate cancer rather than *of* prostate cancer (Selly, Donovan, Faulkner, Coas & Gillatt, 1997). For example, for UK men diagnosed between 2004 and 2008, 1- and 5-year age standardised relative survival rates were 93.1% and 80.6% respectively (ONS, 2011b).

### **2.2.2 Risk factors**

The occurrence of prostate cancer is strongly related to age – only 0.8% of all cases are diagnosed in men under 50 years of age, 10.3% in men aged 50-59, 32% in men aged 60-69 and 57% in men over 70 years of age (ONS, 2011b). Ethnicity has also been shown to be associated with prostate cancer incidence rates. The US Cancer Statistics Working Group reported that in 2007 prostate cancer was diagnosed 1.5 times more frequently in Black African/Caribbean Americans than in White Caucasian Americans. Although the exact pathogenesis of prostate cancer remains unclear, certain factors, such as genetic predisposition, dietary habits, smoking and obesity are believed to contribute to its development (Nelson, DeWeese & DeMarzo, 2002; Nupponen & Carpenter, 2002; Griffiths, Prezioso, Turkes & Denis, 2007).

### **2.2.3 Histology**

The most common type of prostate cancer is adenocarcinoma (accounting for approximately 95% of all cases), which is caused by a tumour growing in the epithelial cells of the glandular tissue (Torrey, 2006). In most cases this type of cancer causes an increase of PSA, and thus can be detected early through standard PSA testing. A digital rectal exam (DRE) is also a useful method in early detection, as the majority of prostate cancers develop in the posterior zone of the gland. Generally, adenocarcinoma of the prostate is a slow-growing tumour, with good prognosis and high long-term survival rates (Kirkby & Patel, 2012).

The Gleason grading of prostate cancer is a system used to assess the level of aggressiveness of the cancer cells, ranging from 1 to 5. Grade 1 tumours (least aggressive) consist of well differentiated cells, most resembling the normal prostate cells, while grade 5



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tumours (most advanced) consist mostly of undifferentiated cells with high levels of infiltration of neighbouring tissues. Since prostate cancers are commonly heterogeneous, the total Gleason score is calculated on the basis of the two most common types of cells and ranges from 2 to 10 (for example if the majority of cells are graded as 3, followed by 4 then a Gleason score is  $3+4=7$ ) (Gleason & Mellinger, 1974, cited in King, 2000; Kirkby & Patel, 2012).

Prostate cancer can also be classified according to the tumour volume and spread (Tumour-Node-Metastasis prostate cancer staging system) (Fleming, Cooper & Henson, 1997). The tumour stages are defined as T1a-c (unapparent and non-palpable tumour, discovered 'incidentally' e.g. through routine PSA test), T2a-b (locally confined tumour), T3a-b (tumour extending outside the gland), T4 (tumour invades other adjacent organs), N0-N1 (regional lymph nodes metastases) and M0-M1a-c (distant metastases). N0 and M0 refer to lack of metastasis, while N1 and M1 indicate the existence of metastases.

Early prostate cancer is usually asymptomatic. As the tumour grows, it can cause urinary and bowel symptoms similar to BPH (Kirkby & Patel, 2012). In advanced stages prostate cancer can spread, forming metastases in other organs, most commonly in surrounding lymph nodes and bones (Keller et al., 2002). Affected lymph nodes can become enlarged and palpable on examination of the abdomen. Bone metastases frequently results in bone pain around the pelvic and lumbar areas as well as pathological fractures, while widespread metastases causes systemic symptoms such as anaemia, weight loss and cachexia (loss of lean body mass) (Kirby & Patel, 2012).

#### **2.2.4 Screening and diagnosis**

The presence and the stage of prostate cancer can be assessed through various diagnostic tests. The 'gold standard' of prostate cancer detection is a biopsy, which allows detailed analysis and histological grading of the suspect tissue; it is however a painful, invasive method, associated with increased risk of rectal bleeding and infection (Chou et al., 2011). Several less invasive methods are therefore used to guide the decision as to whether biopsy is advisable in asymptomatic men (Kirkby & Patel, 2012). The most commonly used methods are serum prostate specific antigen (PSA) testing and digital rectal exams (DRE).

##### **2.2.4.1 Digital rectal examination**

As the majority of prostate cancers start in the posterior part of the gland, close to the rectum, DRE is a method which can be helpful in detecting larger, palpable physical changes to the prostate gland, and can increase chances of early diagnosis in patients with normal PSA levels (Mistry & Cable, 2003; Torrey, 2006). The DRE can help assess the clinical stage of the tumour – the size of the cancer and the proportion of prostate gland it occupies. However, this is a crude method and should be followed up more accurately through imaging, such as transrectal ultrasound (Downs, Kane, Grossfeld, Meng & Carroll, 2002).

##### **2.2.4.2 Prostate specific antigen (PSA) testing**

Prostate specific antigen (PSA) is a protein produced in small amounts by prostate gland cells. Since Kuriyama, Wang and Papsidero (1980) developed a sensitive assay for measuring blood serum PSA levels, this antigen has become the primary biomarker for prostate cancer (Mistry & Cable, 2003). Normal levels of total serum PSA (tPSA) have been

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established at 0-4ng/ml. Levels higher than 4ng/ml are a cause for concern, however, as the majority of men with prostate cancer have tPSA above 4ng/ml (Gann, 1996; Torrey, 2006). It is important to note that approximately 60-75% of all cases of tPSA 4-10ng/ml relate to benign prostate disorders such as BHP or prostatitis (de Kok et al., 2002). Although the sensitivity of PSA tests is consistently high for detecting prostate cancer, its specificity is low, resulting in high level of false positive results (Lin, Lipsitz, Miller & Janakiraman, 2008; Chou et al., 2011).

Randomised controlled trials of population-based PSA testing of asymptomatic men in some European countries point towards a significant reduction in prostate cancer related mortality and diagnosis of advanced disease in men undergoing routine screening (Aus, Bergdhal, Lodding, Lilja & Hugosson, 2007; Hugosson et al., 2010). Much controversy, however, surrounds the question of whether population-based screening leads to more benefits or harm (Chou et al., 2011), as the low specificity of PSA tests produces a high proportion of false positive results, leading to a number of unnecessary biopsies (Lin, Lipsitz, Miller & Janakiraman, 2008; Chou et al., 2011). Screening has also been associated with an increase in early stage diagnoses of prostate cancer that may not manifest itself during the man's natural life, resulting in administration of potentially unnecessary radical treatments (Selly et al., 1997). On the basis of evidence from early randomised trials, which suggest that benefits as well as harm can result from population-based PSA testing programmes, health authorities in some countries such as the UK or Australia currently advise against routine screening of asymptomatic men, leaving the decision whether to be screened to the man and his physician (Cancer Council Australia, 2010; NHS, 2012). In the US, where routine screening is currently carried out, American Cancer Association (Wolf et al., 2010) advised that men should be sufficiently informed about the risks and benefits, when offered prostate cancer screening.

### **2.2.4.3 Biopsy**

Currently the most commonly performed prostate biopsy is ultrasound guided transrectal biopsy (Davis, Sofer, Kim & Soloway, 2002). This type of biopsy is most often conducted under local anaesthetic, in an outpatient setting. The ultrasound and a biopsy gun or needle is inserted through the rectum and several samples of the gland are collected. The procedure is relatively simple and considered safe, although despite the common practice of administering antibiotics to minimise the risk of infection from the needle passing through the rectal wall (Davis et al., 2002), some risk of infection as well as rectal and urethral bleeding remains (Chou et al., 2011). Transperineal biopsy requires a small incision of the perineum and therefore tends to be performed under general or spinal anaesthetic. The needle does not pass through the rectal wall, therefore the risk of infection is decreased. Both techniques are considered to have good detection rates (Davis et al., 2002 Galfano et al., 2007). The samples are then analysed under the microscope and tumour volume and Gleason score is established.

Once the size of the primary tumour in the prostate gland is assessed and both PSA and Gleason scores are obtained, the existence of secondary tumours in lymph nodes and possible distant metastases are investigated to gain the full picture of the disease stage. This is done via techniques such as computed tomography (CT), magnetic resonance imaging (MRI) and bone scans (Kirkby & Patel, 2012). Small, organ-contained tumours, and lower PSA and Gleason scores indicate 'lower risk' cancer, while metastases, and higher PSA and Gleason scores point towards 'high risk' cancer, which may not be 'treatable' or has a higher chance of recurrence (Downs et al., 2002; Torrey, 2006).

### **2.2.5 Treatment options in prostate cancer**

Currently, the treatment/management options most frequently offered to prostate cancer patients are radical prostatectomy, radiation therapy and watchful waiting. Hormonal therapy can be suggested as an adjuvant treatment for patients undergoing other forms of treatment, rather than primary treatment (Torrey, 2006).

#### **2.2.5.1 Radical prostatectomy**

Radical prostatectomy is a surgical procedure aimed at removing the cancer-affected prostate gland and, if necessary, the neighbouring areas where the cancer has spread (Bivalacqua, Pierorazio & Su, 2009). According to the European Association of Urology (EAU) recommendations, radical prostatectomy can be offered to all patients with locally confined disease (T1a-T2b), with low to intermediate Gleason scores (2-7), PSA  $\leq$ 20 and a life expectancy of 10 years or more. It can also be offered to selected patients with high-risk/low-volume tumours and in the context of multimodality treatment to selected patients with very high-risk localised tumour (Heidenreich et al., 2011). The three main types of surgery for prostate cancer currently offered to patients are: open radical retropubic prostatectomy (RRP), laparoscopic radical prostatectomy (LRP) and robot-assisted laparoscopic radical prostatectomy (RALRP) (Bivalacqua et al., 2009).

RRP is considered to be the 'gold standard' surgical procedure with optimal chances of oncological cure as well as maximum preservation of potency and urinary control. It is performed through an 8-10cm incision in the lower abdomen which allows access to the prostate and surrounding organs such as seminal vesicles, nerves and urinary system. An optimal decision about the size of dissection (e.g. nerves sparing surgery) is possible as a result of the open access to the operative area. RRP also allows maximum freedom of

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manoeuvre and tactile feedback. The potential drawbacks include complications typical for open surgery and longer recovery time (Bivalacqua et al., 2009).

The LRP, a 'key-hole' procedure is conducted through several small incisions, but the limitations of this procedure are considerable, as the length of the procedure is significantly longer than that of RRP, and the surgeon has much less freedom to manoeuvre (Bivalacqua et al., 2009). The introduction of a fully jointed robotic arm with which the surgeon conducts the robot-assisted LRP has revolutionised the minimally invasive surgery for prostate cancer (Bivalacqua et al., 2009). This has greatly reduced the operating procedure time, made it easier to master, and the data on postoperative outcomes are encouraging (Masterton, Cheng, Boris & Koch, 2012), making RALRP an attractive treatment option for surgeons and patients.

### **2.2.5.2 Radiation therapy**

Radiation is used to destroy the DNA of cancer cells in the treated area, shrink the tumour or prevent spread outside the prostate. Similar to prostatectomy, radiation treatment is recommended predominantly for men with an early stage, confined tumour (T1a – T2c, N0 M0, (Heidenreich et al., 2011). Adjuvant hormonal treatment is often used in high-risk patients. Radiation therapy can also be used post-operatively, when positive margins have been detected and at the time of biochemical failure, to prolong survival (Heidenreich et al., 2011). Radiation therapy can be administered either externally (external beam radiation treatment; EBRT) or internally, through radioactive seed implantation (brachytherapy).

EBRT is a minimally invasive technique which involves the patient lying down while a machine administering the rays rotates around him. The radiation is administered in short sessions, five days a week for 6-8 weeks, and as such requires considerable time

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commitment from the patient. The treatment is not painful and the patient is able to continue to work throughout the treatment (Torrey, 2006).

Brachytherapy is usually a 'one off' procedure that does not require the time commitment associated with EBRT; it is however more invasive and requires local or general anaesthetic, but the patient is normally expected to resume his normal life activities within days. Minute tubular seeds containing radioactive material are inserted into the prostate with a needle, through the perineum. Once in place, they release radiation for several days, weeks or months. The seeds are placed using imaging technology which allows even distribution, ensuring that no parts of the tumour are missed, while minimising effects on healthy cells (Torrey, 2006).

### **2.2.5.3 Active surveillance and watchful waiting**

Active surveillance is most commonly described as deferring active treatment in patients with low-risk tumours (T1-T2, N0 M0, PSA $\leq$ 10, Gleason $\leq$ 6), with the intention to administer curative treatment as the cancer progresses. Watchful waiting refers to delaying symptomatic, non-curative treatment in patients who are not candidates for active treatment. Watchful waiting can also be an option for men who are candidates for aggressive treatment but choose not to have it – hormonal treatment is then applied when symptoms occur (Heidenreich et al., 2011).

### **2.2.5.4 Hormonal treatment**

Testosterone promotes the division of prostate cancer cells (Marengo, 2001), therefore testosterone deprivation can be used as an adjuvant therapy in prostate cancer or as a palliative treatment for advanced cancer not suitable for curative treatment. Testosterone

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deprivation can be achieved through surgical removal of testicles (castration or orchiectomy) as well as with medication that interrupts testosterone production (e.g.: estrogen) or action (antiandrogens) (Higano, Thompson & Sylvester, 2003). Testosterone deprivation has several side-effects, such as hot flushes, loss of libido, fatigue, weight gain and gynecomastia (Jani & Hellman, 2003)

### **2.2.5.5 Chemotherapy**

Chemotherapy is widely used in oncology, usually as an adjuvant treatment. In prostate cancer, chemotherapy is predominantly used as palliative treatment to relieve symptoms of advanced disease. Chemotherapy can cause side-effects such as nausea, fatigue and hair loss, which can be controlled with medication and will gradually disappear once the treatment is over.

### **2.2.5.6 Oncological and functional outcomes**

The success of treatment is often measured in terms of oncological outcomes, for example in terms of cancer specific survival (CSS) rates or lack of disease progression post-treatment, as well as in terms of functional outcomes, mainly urinary control and sexual function preservation.

There is some evidence to suggest that in early localized prostate cancer radical prostatectomy and radiation therapy offer a good chance for a long-term cancer specific survival (CSS) and even cure. For example, Eggener et al. (2011) reported CSS after 15 years post RRP at 93%. Similarly, Beyer, Thomas, Hilbe and Swenson (2003) found that patients with early localized prostate cancer had CSS rates at 5 and 10 years post brachytherapy of 98% and 87% respectively. In addition, the use of a multimodal approach, i.e.



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administration of an adjuvant therapy in conjunction with primary treatments, for example hormonal treatment with RRP or radiation, has been shown to be successful in improving survival in patients with higher risk prostate cancer (e.g. Briganti et al., 2011; Glode, 2006).

The short term side-effects of treatment typically associated with surgery such as discomfort, pain, inflammation and other postoperative complications vary between surgical treatments with better outcomes in robot assisted laparoscopic procedures (e.g. Kim et al., 2011). Patients undergoing radiation therapy are free from those issues however some degree of burns can occur to the skin in the irradiated area.

The majority of active treatments for prostate cancer are associated with increased risks of long-term side-effects such as erectile dysfunction and incontinence. Studies have indicated that sexual function is preserved post-surgery in 31-86% of pre-operatively sexually active men with organ-confined disease (Dubbleman, Dohle & Schröder, 2006). Age of patients, unilateral or bilateral nerve sparing surgery and level of pre-operative sexual function were found to be the most significant predictors of regaining potency post-surgery (Meuleman & Mulders, 2002; Dubbleman et al., 2006; Litwin et al., 2007). Radiation treatment is associated with similar side-effects to RRP, however they tend to occur with some delay (Litwin et al., 2007). Furthermore radiation was associated with higher levels of obstructive and irritative urinary symptoms, higher urinary bother and bowel dysfunctions, while surgery resulted in lower urinary control (leakage) (Litwin et al., 2007).

Although some studies suggest that sexual function should return to preoperative level within 24 months, this is not necessarily the case for many men (Meuleman & Mulders, 2003). In the case of radiation therapy the side-effects tend to worsen with time (Siglin,

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Kubicek, Leiby & Valicenti, 2010). Those men who do not achieve sufficient recovery of sexual function can try symptomatic treatment for erectile dysfunction. Oral medication (e.g. Viagra ®, Levitra®) or injections have been found to offer significant improvement in function, especially in those men who were sexually active prior to treatment and had nerve sparing surgery. In the case of a lack of progress within 2 years, penile implants are also possible (Meuleman & Mulders, 2003).

In watchful waiting or active surveillance patients do not have to endure any side-effects, however this option does not offer the chance of cure. Potency and urinary control remain unaltered and are only affected by the potential progression of the disease and natural factors such as aging. Studies indicate that in patients with T0-T2, NX M0 cancer, who have a life expectancy of 10-15 years or below, deferring treatment may offer approximately a 75% chance of being progression-free and a 50% chance of treatment-free survival (e.g. Adolfson, Tribukait & Levitt, 2007; Johansson et al., 2004). After this period the likelihood of progression increases significantly and therefore active surveillance is not recommended for young patients, without comorbidities, especially if the tumour is moderately or poorly differentiated (Adolfson et al., 2007).

### **2.2.6 Summary**

This section has highlighted the high prevalence of prostate cancer in the male population and the impact this disease and treatment has on the individual. Available treatment options are numerous and vary according to their oncological and functional outcomes, and treatment choice can be further complicated by patient and disease characteristics, such as age, general health or stage of cancer. Furthermore, prostate cancer treatments can result in a varying degree of long-lasting side-effects such as erectile and urinary

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dysfunctions which can affect the patient's quality of life. This section emphasised the complexity of treatment decision-making process from the biomedical point of view and the complications associated with prostate cancer survivorship.

### **PART TWO: PSYCHOSOCIAL CHALLENGES OF LIVING WITH PROSTATE CANCER**

Prostate cancer patients and their partners face a number of psychosocial challenges throughout the duration of the cancer journey, including the psychological effects of cancer screening, diagnosis, treatment and monitoring; the complexity of the treatment decision-making and increased need for information; the post-treatment side-effects that impact upon the lives of the patient as well as the couple. The following sections of this chapter will describe those challenges and discuss the effect they may have on the lives of the patient and his partner.

### **2.3 Psychological effects of prostate cancer**

#### **2.3.1 Psychological impact of prostate cancer on patients**

As highlighted earlier (see 2.2.4.1) population-based screening for prostate cancer can result in fewer men being diagnosed with advanced disease and reduced prostate cancer specific mortality (Aus et al., 2007, Hugosson et al., 2010). Several disadvantages of screening of asymptomatic men have also been identified, including increased number of unnecessary biopsies and radical treatments. As well as physical harm, participation in cancer screening can also cause adverse psychological effects, such as increased stress and anxiety (Dale, Bilir, Han & Meltzer, 2005). Although many studies reported low to moderate levels of anxiety in men undergoing population-based screening (e.g. Essink-Bot et al.,

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1998; Carlsson, Aus, Wessman & Hugosson, 2007), some men, for example those with an anxious personality (or high levels of trait anxiety) (Essink-Bot et al., 1998), maladaptive coping strategies (Perczek, Burke, Carver, Krongard & Terris, 2002) and those with relatives with prostate cancer (Cormier et al., 2002), were found to experience higher adverse psychological effects during the screening process. Men receiving a positive PSA test result were also found to have higher levels of anxiety, particularly after the biopsy and before the receipt of the biopsy results (Jadhav, Sukumar, Kumar & Bhat, 2010; Zisman, Leibovici, Kleinmann, Siegel & Lindner, 2001). The levels of anxiety and distress tend to drop to around baseline immediately after the receipt of negative biopsy results (Perczek et al., 2002), however, men who had increased PSA at testing but received negative biopsy results were found to worry more about prostate cancer than men who had PSA within normal range (Katz et al., 2007). Some studies also indicate that positive biopsy results can reduce anxiety (Gustafsson et al., 1995). This could suggest that the uncertainty about having the disease (Mishel & Braden, 1988) is one of the major stressors in the process of undergoing prostate cancer tests (see Dale et al., 2005). Conversely, other studies have found that a positive result further increases anxiety in some men, particularly those who were more distressed before screening and who used more maladaptive coping (Perczek et al., 2002).

Many studies found that once prostate cancer diagnosis is established, it can further evoke negative emotions in patients, typical for all cancer diagnoses, such as anxiety, sadness, anger, fear of disease progression, concerns about family and consideration of mortality (Lintz et al., 2003; Roos, 2003; Steginga et al., 2001; Walsh & Hagerty, 2010). Some degree of anxiety and sadness is expected in patients diagnosed with cancer; it is however important to differentiate between the normal and clinically significant levels of decreased mood and psychological distress (Kunkel, Bakker, Myers, Oyesanmi & Gomella, 2000).

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Although the majority of men manage to successfully adapt to the diagnosis of prostate cancer, studies report prevalence of psychological morbidity in around 30-40% of prostate cancer patients, typically with higher levels of anxiety rather than depression being commonly reported (e.g. Bennett & Badger, 2005; Balderson & Towell, 2003; Cliff & MacDonagh, 2000; Zabora, BrintzenhofeSzoc, Curbow, Hooker & Piantadosi, 2001). Men with high trait anxiety levels were found to have higher anxiety even a long time after treatment (Korfage, Essink-Bot, Janssen, Schröder & de Koning, 2006). Men undergoing PSA monitoring post-treatment or during watchful waiting were also found to have increased anxiety prior to the test and before tests results were known, which have been linked to fear and uncertainty of the illness recurrence and progression (Lofters, Juffs, Pond & Tannock, 2002).

General health-related quality of life (HRQOL) has also been found to be diminished in prostate cancer patients shortly after treatment (Visser et al., 2003), however a significant improvement with time has been observed (Mols et al., 2006). Mols and colleagues (2006) found that 5-10 years post-treatment the majority of HRQOL measures were comparable for the survivors and age-matched normative population. This could suggest that the majority of aspects of general HRQOL return to normal over time, however, the on-going anxiety and fear of recurrence resulting from increased PSA levels and PSA monitoring can have a negative impact on long-term HRQOL (Dale et al., 2005). In addition, prostate cancer survivorship is complicated by treatment side-effects such as incontinence and erectile dysfunction, which negatively impact on the man's quality of life (Harden et al., 2002; Helgason, Dickman, Adolfsson & Steineck, 2001; Litwin et al., 2007; Weber & Sherwill-Navaro, 2005).

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Several patient characteristics have been associated with increased susceptibility to mental health issues and lower quality of life post-diagnosis and treatment. Young age, progressive disease, poor physical functioning, pain, high levels of urinary and erectile dysfunction were associated with higher levels of psychological distress and lower quality of life (Balderson & Towell, 2003; Bisson et al., 2002; Visser et al., 2003; Zabora et al., 2001). Research also suggests that those with low levels of social support and insufficient support networks can be particularly vulnerable to suffering negative outcomes of the disease and treatment (e.g. Helgason et al., 2001).

### **2.3.2 Psychological impact of prostate cancer on partners**

Cancer diagnosis affects not only the psychological well-being of patients, but also impacts upon the lives of their partners and close family members who frequently become informal caregivers and a key source of support (Pitceathly & Maguire, 2003). It is important to note, that the majority of cancer caregivers are spouses or partners of the patient while adult children, parents, friends or other family members fulfil this role less frequently (e.g. Pitceathly & Maguire). This is particularly notable in prostate cancer research, where studies report that the vast majority of caregivers participating in research are wives or partners of the patients (e.g. Couper et al., 2006a, 2006b) and little is known about the experiences of other relatives caring for prostate cancer patients. Indeed, the existing literature portrays prostate cancer as a 'couples' disease' (Bottoroff et al., 2008) due to the profound effect it has on both spouses as well as the high level of effort the healthy partners put into supporting the patient and dealing with the disease. To reflect the unique role partners play in the patient's care and management of prostate cancer, treatment and post-treatment issues, and due to the majority of literature relating to partners of prostate cancer patients, rather than other relatives, the main focus of the following sections will be

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placed on this particular group of caregivers to prostate cancer patients rather than on other family members.

Partners, similar to the patients, experience worry and anxiety related to an uncertain future and fear of losing their partner (Osse, Vernooij-Dassen, Schade & Grol, 2006). Increased levels of psychological distress, including depression and anxiety as well as lower quality of life in partners who care for a spouse with cancer have been noted in recent research (e.g. Carter & Chang, 2000; Cliff & MacDonagh, 2000; Bennett & Badger, 2005).

Becoming a caregiver to a cancer patient often brings a dramatic change to a person's lifestyle, such as, for example, the necessity to give up employment, temporarily or permanently despite the physical ability to work (Rivera, 2009). This can add to financial difficulties already experienced due to loss of the patient's earnings and can lead to increased social isolation and a decrease in status. Informal caregivers also often miss out on their social activities and time with other family members (Rivera, 2009). Although many adjust well to the role of a caregiver, a notable minority suffer from psychological morbidities (Pitceathly & Maguire, 2003).

### **2.4 Treatment decisions**

As outlined in the earlier part of this chapter, treatment choices in prostate cancer are numerous (see 2.2.5.). Although most treatments offer a good chance of cure or progression-free life, especially in localised disease, the side-effects and recovery vary between treatment modalities, and outcomes depend on factors such as the experience of the health care professional as well as patient's individual characteristics. Consequently,

making decisions regarding treatment in prostate cancer is a complex and difficult task, particularly considering the psychological vulnerability of the newly diagnosed patients.

#### **2.4.1 Models of treatment decision-making**

Several models of medical decision-making have been discussed in the existing literature. According to the paternalistic model, medical treatment decision-making is the domain of the health care professional, while the patient's role is often reduced to giving consent to the health care professional's final choice (Emanuel & Emanuel, 1996). Recently, however, trends have shifted towards greater patient involvement in medical decision-making.

As described by Charles, Gafni and Whelan (1997), the informed decision model assumes that two components of knowledge are necessary to make an optimal treatment decision. These are medical knowledge (which resides with the health care professional) and knowledge about preferences (which is attributed to the patient). This model assumes transference of medical knowledge from health care professional to the patient, theoretically resulting in the patient being equipped with all the necessary information to make an autonomous decision.

Shared decision model assumes that the responsibility for the final decision should be split between the individuals involved in the decision-making process. Charles and colleagues (1997) indicated that a shared decision-making process requires participation of at least two parties (patient and health care professional), but it can involve more people (other medical professionals, the spouse) who play various roles in the process. Each side must be willing to participate in the process to some degree and information sharing between the parties is essential. Mutual agreement on the final choice is the desired outcome.



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Whitney (2003) proposed a theoretical model of medical decision-making based on two key characteristics: importance (the effect the decision has on the patient) and certainty (its degree of medical consensus). According to this model, decisions with high certainty and low importance can be made by the health care professional alone; however in decisions with low certainty and high importance the patient should be encouraged to participate in the decisional process. As outlined previously, treatment decisions in prostate cancer are of high importance to the patients, as their consequences may affect the man and his family for the rest of his life. However, the certainty of outcome is low as the likelihood of cure is similar for the majority of active treatments (i.e. not one of the treatments is obviously and significantly better than the rest). This suggests that the preferences of prostate cancer patients, particularly those with localized disease should be considered in the decisional process, and therefore a shared decision-making can be the most beneficial for this group of patients.

### **2.4.2 Treatment decision-making in prostate cancer**

Research confirms that the vast majority of men with prostate cancer wish to assume some level of active participation in the decisional process and those who feel included in the process are more satisfied with the treatment outcomes (Davison & Breckon, 2012; Davison & Degner, 1997; Fallowfield, Hall, Magure, Baum & A'Hern, 1994; Fisher et al., 2006; Steginga & Occhipanti, 2004). The National Institute for Health and Clinical Excellence (NICE) issued guidelines for the diagnosis and treatment of prostate cancer (NICE, 2008) which highlight the importance of allowing each man and his family to actively participate in the decisional process, in partnership with the health care professional. The complexity of the decision was noted; as was the possibility that men and their families may lack the necessary resources to confidently get involved in the decision-making process. The

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necessity to empower patients and their families through the provision of information and support from health care professionals became the main focus of the guidelines, which suggest that sufficient and appropriate information should be provided to the patient and his family in order to facilitate the treatment decision-making process. Studies support the fact that better informed patients who actively participate in the decision-making process have better adjustment post-treatment (e.g. Clark & Talcott, 2006). For example Clark and Talcott (2006) found that men who felt their decision regarding prostate cancer treatment was well-informed had lower levels of post-decisional regret.

A certain minority of patients, however, prefer to leave the decision to the health care professional. These are usually older, less educated men with more advanced disease (Davison et al., 2002; Davison & Breckon, 2012; Fisher et al., 2006; Steginga & Occhipinti, 2004). NICE (2008) recognises this and advises that patients' desired level of engagement should be respected. However Charles and colleagues (1997) point out that an in-depth assessment of the reasons why a patient wishes to withdraw from the process should be carried out, as this decision may be based on factors that can be improved (for example insufficient knowledge or sense of disempowerment in the context of health care) rather than on stable personal traits or disease characteristics.

One of the theories helpful in explaining the difficulties newly diagnosed men may have in making treatment decisions is Uncertainty in Illness Theory (Mishel & Braden, 1988). As mentioned previously (see 2.3.), uncertainty in prostate cancer can affect the psychological well-being of the patient at the screening stage. Some studies also indicate that uncertainty remains a major stressor throughout all the stages of illness trajectory which can have a negative impact on the prostate cancer patient's ability to make an optimal treatment decision (Denberg, Melhado & Steiner, 2006).

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According to Uncertainty in Illness Theory, uncertainty can be defined as ‘the inability to determine the meaning of events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes’ (Mishel & Braden, 1988, p. 98). Newly diagnosed men with localised prostate cancer have to make a treatment decision based on unfamiliar options with unpredictable outcomes, which can result in high uncertainty about the decision (Mishel et al., 2009). Mishel and colleagues (Mishel & Braden, 1988; Mishel et al., 2009) proposed that the uncertainty in treatment decisions can be reduced through social support from similar others, increased cancer knowledge and improved patient-health care professional communication.

### **2.4.3 Information needs of prostate cancer patients**

Past studies indicate that active participation in treatment decision-making requires a good level of knowledge about the disease, treatment options, outcomes and side-effects (e.g. Boberg et al., 2003; Davison et al., 2002; Davison & Breckon, 2012; Feldman-Stewart, Brennenstuhl & Brundage, 2008; Feldman-Stewart et al., 2010; McParland, 2009; Steginga et al., 2001). These studies report that a large majority of prostate cancer patients have a high need for information about their illness, treatment and side-effects management and that those needs are individual, complex and tend to change over time.

As mentioned previously, the NICE guidelines (2008) indicate that it is the role of health care professionals to provide sufficient and relevant information to prostate cancer patients and their partners during the treatment decision-making process and throughout recovery. Indeed, health care professionals have been identified by prostate cancer patients as the primary source of disease and treatment-related medical information

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(Ramsey et al., 2009; Finney Rutten, Arora, Bakos, Aziz & Rowland, 2005). There is however, a certain level of discrepancy between what health care professionals think constitutes useful information and patients' individual preferences for specific information. This can potentially diminish the usefulness and relevance of the information provided by the health care professionals (Capirci et al., 2005, Feldman-Stewart et al., 1998). For example, Capirci and colleagues (2005) found that although all main groups of health care professionals involved in prostate cancer care tend to have high levels of agreement regarding which information is important for the patients at the time of diagnosis, their beliefs do not highly correspond with the views of the patients. Furthermore individual patient's needs are not uniform (Feldman-Stewart et al., 2010) and therefore professionals must be careful when prioritising information disseminated to patients and work towards understanding the individual needs of each patient.

Despite this discrepancy men, overall, tend to feel satisfied with the information provided by health care professionals (Echlin & Rees, 2002), although many indicate that it can be difficult to utilise during treatment decision-making process. For example, some patients found it hard to recall the information provided during consultation, as they felt overwhelmed by the amount of detail provided, some found terminology and language in which it was delivered confusing, while others felt the important topics were not covered during their appointment in sufficient detail (McGregor, 2003; Oliffe & Thorne, 2007; Snow et al., 2007; Steginga et al., 2001).

Furthermore, the majority of the information exchange tends to take place during the initial consultation, when the patient is most likely to be given his cancer diagnosis (Echlin & Rees, 2002). Echlin and Rees (2002) found that men are unlikely to absorb or later accurately recall information provided at the time of diagnosis due to the initial shock. A

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few days later, however, throughout the period before a treatment decision is made, men display an increased need for information about the likelihood of cure, treatment modalities, and recovery. During this period they are less likely to have frequent contact with the physician and therefore alternative sources of information, such as other men/friends with prostate cancer, leaflets, media, and the Internet are likely to be consulted (Ramsey et al., 2009).

Furthermore, the need for information tends to change over time (Echlin & Rees, 2002). At the post-treatment stage there is an increased need for information about dealing with side-effects, such as sexual and urinary dysfunctions. Men frequently indicate that although information about the psychosexual and urinary dysfunctions is often offered as part of the package during treatment decision consultations, this information is not properly assimilated, as it may not be pertinent at the time (Feldman-Stewart et al., 2000; Steginga et al., 2001). Some studies also indicate that the communication with the practitioner is less frequent in the period of recovery and that the follow-up consultations do not always foster the opportunity to discuss psychosexual and urinary problems (O'Brien et al., 2011).

### **2.4.4 Information needs of the partners**

Although their involvement in treatment decision-making is not always direct, similar to the prostate cancer patients, their partners also report high levels of information needs and preference for active engagement in information gathering processes (Echlin & Rees, 2002; Gray, Fitch, Philips, Labrecque & Klotz, 1999; Mason, 2005, 2008). Spouses seek information to reduce anxiety, to help their partner in terms of care and to offer informational support to the patient during treatment decision-making processes (Feltwell & Rees, 2004). Partners most frequently report needs relating to the domains of treatment,

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diagnosis, coping, homecare of the patient, cancer, impact on the family, support and their relationship with the patient (including intimacy and sexuality) (Adams, Boulton & Watson, 2009). Many of these needs are unmet, including needs for information about homecare of the patient, relationship with the patient and practical help (Mason, 2005; 2008).

Prostate cancer patients' partners reported using a variety of sources to obtain information, including the health care professionals, the patient, family and friends, the Internet and a variety of printed materials (Feltwell & Rees, 2004). The women, however, often felt that their information needs were not being met by their partner's health care professional (Echlin & Rees, 2002; Feltwell & Rees, 2004). Some felt they had to be proactive and persistent to receive any information during consultation, while others felt disempowered and excluded by the health care professionals, who tended to direct all the communication to the patient. Lack of time during consultation has also been found to inhibit information-seeking during consultation. Furthermore, the women reported several barriers to accessing other sources of information, for example a lack of knowledge about printed materials or being too old to use the Internet (Feltwell & Rees, 2004). Some studies however indicated that the partners were more likely than the patients to explore alternative sources of information, such as the Internet, possibly because their information needs were not being satisfied by the health care professional (James et al., 2007).

### **2.5 The effects of treatment on the patients and their partners**

#### **2.5.1 Post-treatment side-effects**

As highlighted previously (see 2.2.5.6.), the majority of prostate cancer treatments result in significant levels of side-effects such as urinary and sexual dysfunction, which can have a

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negative impact on the man's physical and psychosocial well-being, gender identity, working and social life as well as intimate relationships (Filiault, Drummond & Smith, 2008; Harden et al., 2002; Helgason, Fredrickson, Adolfsson & Steineck, 1995; Powel, 2000; Weber & Sherwill-Navaro, 2005).

Men who undergo radical prostatectomy tend to experience greater levels of urinary incontinence than those who have other types of treatment, for example radiation therapy (Liu et al., 2005; Powel, 2000). Men can experience various levels of incontinence as a result of prostate cancer treatment; some may drip small amounts of urine continuously, others may have stress-related incontinence (for example when coughing or sneezing), whilst some may have total lack of control over their bladder function (Powel, 2000). Although men with mild incontinence have been found to cope well, those who experience moderate to severe incontinence reported the condition as a considerable problem in their daily lives, which impacted on their quality of life (Herr, 1997). Incontinent men report that their inability to control their bladder function impacts on many areas of their lives, from the clothes they wear (for example to conceal a pad), the physical activities they engage in, their working life and sleep patterns, to their relationships with other people; they found their condition to be embarrassing and stigmatising (Powel, 2000).

Sexual dysfunction, including impotence, erectile dysfunctions and loss of libido, which affect many men following prostatectomy as well as radiation therapy, have been found to impact on the man's psychosocial well-being. For example, Helgason and colleagues (1995) investigated sexual functioning and related quality of life in 53 men who underwent radiation therapy 1.5-2 years prior to data collection. The majority of participants reported that before treatment they used to engage in some level of sexual activity; had sexual thoughts or dreams; and 66% reported that their erections were sufficient for intercourse.

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After treatment, the sexual function, activities, dreams and fantasies diminished significantly, for example, only half of those previously capable of intercourse were achieving sufficient erections and 77% reported a decrease in one or more aspects of sexual desire. Half of the respondents indicated that these changes in their sexuality affected or highly affected their psychological well-being and quality of life.

Hormonal treatment can also result in an increased sense of emasculation, as patients often experience symptoms similar to female menopause, such as hot flushes or mood swings as well as breast enlargement, shrinkage of genitals, loss of libido and fatigue, effects difficult to accept for many patients (Navon & Morag, 2003). Navon and Morag (2003) reported that participants in their study who underwent hormonal treatment experienced strong feelings of loss and sadness, as they were unable to derive any pleasure from the activities they used to enjoy. This was not only relevant to activities of sexual nature, but also to pastimes, such as travelling with their spouse. Many also felt embarrassed of their emasculated bodies. The findings from this study suggest that prostate cancer treatment not only affects patient's sexual functioning, but also his psychosexual well-being.

The findings of the above mentioned research suggest that the post-treatment side-effects have a detrimental effect on many areas of the patient's life. Although there are counselling and treatments for erectile and urinary dysfunctions available, studies also suggest that men find it particularly difficult to seek help and advice in dealing with their physical impairment and psychological distress related to altered sexuality and urinary function (e.g. Clarke, Booth, Velikova & Hewison, 2006; O'Brien et al., 2011).



### **2.5.2 'The couple's disease'**

Prostate cancer also affects the intimate aspects of the life of a couple. Studies have found that both spouses and patients felt the shared experience of prostate cancer had drawn them together and helped them re-establish their relationship (e.g. Gray et al., 1999; Lavery & Clarke, 1999; Harden et al., 2002). On the other hand, the side-effects of treatment have been recognised as putting a strain on the sexual relationship between the partners. Men often report struggling with the loss of libido and the ability to achieve and maintain erections. As a result, many men start distancing themselves from their partners by avoiding physical contact associated with sexual activity, as they feel they should not start what they cannot finish (Harden et al., 2002). The women acknowledged that the altered sexuality was a problem for them as a couple as they could see their partners' distress at the loss of physical ability to perform sexually. For many female partners, however, the sexual issues were of secondary importance compared with the survival of their partners as they felt sexuality was a thing of the past for them even before treatment (Galbraith, Fink & Wilkins, 2011; Lavery & Clarke, 1999). Female partners often reported feeling more upset by the changes in the level of affection their partners were displaying than by the loss of intercourse.

### **2.6 Summary**

In summary, the experience of prostate cancer is challenging for the patients as well as for their partners and can lead to negative psychosocial outcomes such as impaired psychological well-being, poor quality of life and strain on relationships due to the distortion of traditional gender roles. It is also recognised, that those with low levels of social support are most vulnerable to these negative effects of diagnosis and treatment.

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The diagnosis often makes the couple feel closer and they greatly rely on each other for support; however social support from other sources is often lacking.

Furthermore, treatment decision-making is an important and complex challenge for the newly diagnosed men and their partners. The majority of prostate cancer patients wish to take an active part in their treatment decision-making while their partners often wish to support them in this task; therefore many patients and partners keenly engage in the pursuit of information. However, the information received from health professionals, although valuable, may not be sufficient for making a fully informed decision. The level of contact with health professionals is also limited by the constraints of the scheduled consultation time and the information provided is sometimes given at the wrong time. Partners often feel that the health care professionals are unprepared to recognize their informational needs.

The findings of studies discussed so far suggest that prostate cancer patients and their partners may benefit from seeking additional sources of emotional support and information. The following sections will review the role of social support networks in providing emotional and informational support to prostate cancer patients and their partners throughout the illness trajectory.

### **PART THREE: THE ROLE OF SOCIAL SUPPORT IN PROSTATE CANCER**

#### **2.7 The concept of social support**

Social support has been found to be helpful in improving psychosocial outcomes in cancer (e.g. Baidar, Ever-Hadani, Goldzweig, Wygoda & Peretz, 2003; Campbell, Phaneuf & Deane,

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2004; Mehnert, Lehmann, Graefen, Hulan & Koch, 2010; Oliffe & Thorne, 2007; Sapp et al., 2003; Walsh & Hegarty, 2010; Weber et al., 2004; Zouh et al., 2010). Social support has been defined as the 'provision of emotional, instrumental, informational and appraisal assistance that includes both the resources that meet individual needs as well as the social relationships through which these needs are met' (Clarke et al., 2006, p67). Three main types of social support have been identified: cognitive assistance, which consists of information and advice provision; emotional support, which includes reassurance, empathy, love, care and the opportunity to express feelings; and instrumental support, i.e. the provision of services or material aids which can help resolve practical problems (e.g. Cohen, 2004; Clarke et al., 2006). The key sources of social support available to cancer patients and their family members are health care professionals, family and friends. Those who struggle to obtain sufficient support from these sources may also turn to face-to-face support groups. The following sections will discuss the role of the key social networks in providing emotional and informational support to cancer patients and their family members, with a particular focus on prostate cancer patients and their partners. Barriers to accessing face-to-face support from family, friends, health care professionals and peer support groups will also be considered. After addressing these barriers, a novel source of support – the Internet and in particular online support groups will be introduced.

### **2.7.1 Informal social support – family and friends**

In the extant literature much attention has been paid to the effects of social support from family and friends on improving psychological outcomes for cancer patients (e.g. Baider et al., 2003; Mehnert et al., 2010; Sapp et al., 2003; Walsh & Hegarty, 2010; Zouh et al., 2010). Spouses, family members, friends and special confidants are frequently named as the primary (and particularly valuable) sources of social and emotional support for cancer

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patients (e.g. Kornblith et al., 2001; Sapp et al., 2003; Zouh et al., 2010). Studies involving prostate cancer patients are in line with the wider literature on informal support in cancer (e.g. Baider et al., 2003; Helgason et al., 2001; Mehner et al., 2010; Zabora et al., 2001; Zouh et al., 2010) and suggest that those who are married or live with a partner, have higher levels of positive social support, report lower levels of anxiety, depression and have better health-related quality of life post-diagnosis, treatment and throughout the duration of their prostate cancer journey.

Studies indicate that men with cancer tend to confide their main concerns and seek emotional support as frequently as women with cancer; however they typically use only one confidant, usually their spouse, while women turn to a wider circle of family and friends (Harrison, Maguire & Pitceathly, 1995). Research indicates that in the case of many prostate cancer patients even these minimal support needs are not always fulfilled. For example, Helgason and colleagues (2001) found that 30% of men who lived with a partner felt they could not confide in her, while 70% of those who did not have a partner had no one to talk to about their health, feelings and problems. This raises concerns about the level of emotional support available to prostate cancer patients, particularly those who do not have a partner. Furthermore, Taylor, Ford and Dunbar (1986) suggested that some cancer patients may experience ambivalent reactions from their close ones, who, despite their positive feelings towards their loved ones, experience negative emotions towards the cancer. The authors note that this dissonance can result in incongruent verbal and non-verbal messages which can in turn lead to feelings of rejection and abandonment in the patients.

Few studies have focused on social support provision for prostate cancer patients' spouses and the results of the existing research suggest that the levels of support are often

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insufficient to meet caregivers and spouses needs. For example, the larger support networks and a higher number of confidantes frequently reported by women in general and by female cancer patients (Harrison et al., 1995) are not necessarily predictors of better social support for women who care for prostate cancer patients. Glasdam, Jensen, Madsen & Rose (1996) found that although cancer patients' spouses report a high frequency of contact with relatives and friends, they perceive low levels of support from them.

### **2.7.2 Health care professionals**

As described previously (see 2.4.3) health care professionals are usually identified by prostate cancer patients as the primary source of disease-and treatment-related medical information. As reported by Clarke and colleagues (2006) health care professionals tend to be perceived by male cancer patients as a source of information rather than emotional support. In their study, female patients had a higher need for in-depth emotional support from medical staff and were more likely to both utilise available support and feel dissatisfied with the levels of support available. In contrast, male patients were found to be satisfied with very basic levels of emotional support from the healthcare professionals during hospital visits, such as being offered a cup of tea or polite small-talk, and they tended to report sufficient availability of emotional support, should they ever need it. They regarded in-depth emotional support from the medical staff to be inappropriate and considered information provision to be a suitable alternative to emotional support as it helped them improve their psychological well-being and reduce distress. The results of this study have also shown that although male cancer patients often dismiss their own support needs, they believe their spouses could benefit from higher levels of emotional support from medical staff. Indeed, prostate cancer patients' partners also indicate the need for

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emotional support from their husbands' health care team, but they often feel they are unable to obtain such support (e.g. Bottoroff et al., 2008). Caregivers are also often reluctant to seek professional support for their own caregiving, psychological and physical needs as they feel their own needs and well-being are secondary to those of the patient (Glasdam et al., 1996; Osse et al., 2006).

### **2.7.3 Barriers to seeking social support from health care professionals, family and friends**

#### **2.7.3.1 Barriers experienced by the patients**

Despite numerous health-related benefits of social support, research indicates that male cancer patients experience significant barriers to engaging in support-seeking behaviours (Clarke et al., 2006). Masculine representations have been recognised as one of the possible reasons for the diminished likelihood of male cancer patients to seek support during their illness. For example, some men diagnosed with prostate cancer report reluctance to disclose their diagnosis to family and friends in an effort to preserve their identity as healthy, strong men and maintain their pre-diagnosis 'normality' (Gray, Fitch, Fergus, Mykhalovskij & Church, 2002; Walsh & Hegarty, 2010). Similar tendencies were found amongst young men diagnosed with testicular cancer (Hilton, Emslie, Hunt, Chappelle & Ziebland, 2009), who often pre-empted empathy with humour and jokes about their illness. Some men diagnosed with cancer want to protect their family, and therefore either hide the diagnosis (for example from their children) or try to avoid conversations about their illness to minimise the strain on their spouses (e.g.: Walsh & Hegarty, 2010; Emslie et al., 2009). Avoiding disclosure and discussions about the hardships related to the disease, treatment and recovery diminishes men's chances to receive social and emotional support from their close ones.

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Furthermore, prostate cancer patients often report experiencing several barriers to seeking emotional support from their health care professional (Clarke et al., 2006). For example, asking another man for help was perceived as an atypical, non-masculine behaviour, which patients negotiated by engaging in the communication in a business-like manner (Olliffe & Thorne, 2007). Treatment-related side-effects, such as erectile dysfunction or loss of libido have also been perceived as 'embarrassing' and threatening to the sense of heterosexual masculinity, therefore men often feel uncomfortable seeking help for these issues from family, friends and health care professionals (Broom, 2005a; Gray et al., 2002; O'Brien et al., 2011; Weber, Roberts & McDougall, 2000).

Moreover, some treatments, such as for example radiation or surgery can require a prolonged stay at a hospital or temporary relocation nearer to the radiation therapy centre, and can result in physical isolation from established support networks during emotionally difficult times (Walsh & Hegarty, 2010; Steginga et al., 2001). As prostate cancer affects predominantly older men, the shrinking of their social networks due to retirement, relocation and death of friends and family members could also potentially limit the patients' access to traditional sources of face-to-face support (Weber et al., 2000).

Furthermore, although overall information gathering seems to be an acceptable help-seeking behaviour for men with prostate cancer and is often reported as the main reason for engaging in support-seeking by this group of patients (Gray et al., 2002; Thaxton, Emshoff & Guessous, 2005) men often experience difficulties in gathering sufficient and relevant information from the health care professionals, as they frequently struggle to process information provided during initial consultations, experience difficulties understanding the information, recalling it at the later date and using it during decision-making process (see 2.4.3.).

### **2.7.3.2 Barriers experienced by the partners**

Although female patients have been found to be more open about their emotional issues and better able to seek social and emotional support (Clarke et al., 2006), women in caregiving roles experience significant barriers to support seeking. In the process of diagnosis, treatment decision-making and post-treatment recovery, the focus of the health care professional and often family and friends is, understandably, on the patient. Unfortunately this means that the needs of the partners, albeit important and significant, are often overlooked (Bottoroff et al., 2008; Glasdam et al., 1996; Osse et al., 2006). Furthermore, their access to health care professionals as a source of information is also often limited and many prostate cancer patients' partners have reported that they felt they didn't have the same support from the health care professional that their husbands did (Bottoroff et al., 2008).

### **2.7.4 Face-to-face peer support groups**

The literature reviewed so far has highlighted the increased need for emotional and informational support after prostate cancer diagnosis. Research indicates, that both patients' and their partners' psychological and psychosexual well-being is challenged throughout the illness trajectory and the desire to actively participate in treatment-related decisions leads to a heightened need for information. These needs are often unmet by the traditional sources of support, such as family, friends and health care professionals.

Cancer-related face-to-face peer support groups have been developed as a means to deliver community-based support for the patients by the patients and survivors (Dunn, Steginga, Rosoman & Milichap, 2003). In these groups emotional and informational support is provided through shared experience with the disease. The first peer support groups for



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women with breast cancer were created in recognition of the increased need for emotional support in this patient group. In recent decades, however, a large number of male support groups have also emerged (Coreil & Behal, 1999; Dunn et al., 2003).

The existing studies suggest that reasons for joining support groups vary between female and male cancer patients with women being more likely to seek emotional support, while men most frequently name information seeking as their main reason for joining a group (Coreil & Behal, 1999; Thaxton et al., 2005). Learning from people who have experienced similar issues and have dealt with similar problems has been recognised as a unique and particularly valuable aspect of the information and emotional support exchange in peer support groups (Dunn et al., 2003; Thaxton et al., 2005). Stevinson, Lydon and Amir (2011) found that the main reasons for joining a peer support group, as reported by UK cancer peer support group members were: meeting similar others (64%), emotional support (13%), practical advice (8%) and, interestingly, only 3% named information seeking as the main reason for joining the group. Although the majority of participants in this study were female, a considerable proportion (32%) were male, which could suggest that both men and women who join cancer peer support groups do so primarily to exchange views and experiences with other patients in similar situation.

Although increasingly attention is being paid to the role of support groups in improving outcomes for cancer patients, it is noted that there is a paucity of studies systematically evaluating the outcomes of such programs particularly with regards to male support groups (e.g. Dunn et al., 2003; Thaxton et al., 2005). The results from the existing research suggest that participants in cancer support groups are highly satisfied with all aspects of the groups and experience a number of positive outcomes of participation (e.g. Coreil & Behal, 1999; Dunn et al., 2003). Prostate cancer patients have highlighted improved knowledge as the

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main and most important benefit of participation in the groups. Many also listed an improved outlook on cancer, a reduced sense of isolation, a greater sense of support, an improved ability to cope with the disease and increased hope for the future as the outcomes of participation in prostate cancer support groups (Adamsen, Rasmussen & Pedersen, 2001; Coreil & Behal, 1999; Steginga, Pincock, Gardiner, Gardiner & Dunn, 2005; Thaxton et al., 2005).

More recently researchers have started to explore the empowering aspects of participation in cancer support groups (e.g. Mok & Martinson, 2000; Ussher, Kirsten, Butow & Sandoval, 2006). Ussher et al. (2006) investigated the outcomes of participation in cancer support groups. They found that the processes experienced by the members, such as provision of emotional support, information exchange and encountering other people in a similar situation led to an increased sense of empowerment and agency in relation to self (i.e. feeling more in control and better able to cope), the cancer (i.e. normalisation of feelings and experiences and a shift in their sense of identity from 'cancer victim' to 'normal' person living with cancer) and in their communication with other people, for example health care professionals (i.e. greater ability, confidence and sense of agency in medical encounters and an increased ability to actively participate in treatment decision-making). Cancer support groups were positioned by the members in contrast to the outside world, where participants experienced isolation, rejection and a lack of knowledge. In the cancer support groups the members felt empowered through the unique sense of community, unconditional acceptance from other members and provision of experiential information and advice about the illness and treatment options.

Mok and Martinson (2000) also reported that Chinese cancer support group participants became empowered through experiencing a sense of interconnectedness ('being in the

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same boat', equality, connectedness through shared suffering and hope), mutual care, non-judgemental acceptance, experiential knowledge and social networking. In both these studies participants also reported feeling empowered by the ability to help other members within the group, through sharing experiences and offering support, which made them feel useful and increased their sense of mastery over the disease.

The prostate cancer peer support groups have also been recognized as promoting empowerment of the patients through education and support. For example, 'Man to Man' groups strongly advocate men's rights and responsibilities to expand their knowledge about new advances in treatment modalities and place particular emphasis on empowering men to take more active part in their own health care and decision-making processes (Coreil & Behal, 1999). Man to Man groups offer both educational talks by professional speakers as well as education through the sharing of experience with others in a similar situation, thus providing multifaceted learning opportunities.

Although there is a notable scarcity of studies investigating the role of support groups for caregivers, and particularly for female partners of prostate cancer patients, the existing studies indicate that participation in caregiver support groups can also be useful for their members. Gilbar (1997) reported that spouses of cancer patients benefited from the ability to openly share their emotions and mutual support. Finding others who experienced similar issues helped participants feel less alone and reduced their emotional suffering. Caregivers of people with mental health issues, who attended support groups reported lower levels of depression and caregiving burden as well as better social outcomes and psychological well-being (Chien et al., 2011; Chou, Liu & Chu, 2002).

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Spouses of prostate cancer patients' who participated in a prostate cancer support group operating alongside the patients' groups, indicated low levels of social and emotional support outside of the group (Bottoroff et al., 2008). The women missed sharing their feelings about cancer with someone who would understand their problems. They believed that family and friends found it hard to comprehend the cancer and felt uneasy talking about it or simply got tired of the subject. The participants found the support group to be a valuable alternative source of social and emotional support, where they could openly share their emotions, receive useful information, advice and reassurance from other women. Further research is needed in order to fully understand the role support groups can play in improving psychological outcomes and knowledge in prostate cancer patients' caregivers.

### **2.7.4.1 Barriers to accessing face-to-face support groups**

Despite the benefits of participation in face-to-face peer support groups, relatively few cancer patients are aware of this source of support and fewer yet take advantage of it (Eakin & Strycker, 2001; Kirazek, Roberts, Ragan, Ferrera & Lord, 1999). Overall, male patients, especially those who are non-white and are from lower socio-economic and educational backgrounds, are poorly represented amongst support group members (e.g. Deans, Bennett-Emslie, Weir, Smith & Kaye, 1988; Eakin & Strycker, 2001; Kirazek et al., 1999; Stevinson et al., 2011) Furthermore, many prostate cancer patients report joining support groups post-treatment, and thus missing out on a valuable source of knowledge and support during their decision-making process (Coreil & Behal, 1999). The main barrier to accessing the group at the time of diagnosis was reported as lack of knowledge about this opportunity and lack of a physician's referral (Coreil & Behal, 1999; Ussher et al., 2006). Furthermore, participation in face-to-face support groups requires weekly or monthly attendance, which can be inconvenient for individuals who are too ill to attend, are in full

time employment, have caregiving duties or live in areas where there are no local groups available (e.g. Braithwaite, Waldron & Finn, 1999, Finn, 1999; Salem, Bogart & Reid, 1997).

## **2.8 Summary**

In summary, family, friends, health professionals and face-to-face support groups can be perceived as valuable sources of social support. Both emotional and informational support can help prostate cancer patients and their partners to achieve positive outcomes in terms of psychological well-being, knowledge, active participation in health care and empowerment. Participation in face-to-face support groups has been found to be particularly valuable as they provide access to large groups of people in similar situations, whose experiences with disease and treatment serve as a unique source of first-hand knowledge and inspiration to other patients. Despite these benefits, several barriers to engaging in active support seeking have been recognised, such as embarrassment, poor physical health, lack of access, time constraints and distance. Studies suggest that in recent years more patients and their partners have started to turn to a new source of social support, i.e. the Internet and in particular, online support groups, which can potentially offer similar benefits to those available from face-to-face support, with fewer barriers (Salem et al., 1997; Broom, 2005a).

## **2.9 New avenues for accessing social support: the Internet and online support groups**

Recent studies suggest that prostate cancer patients are becoming frequent Internet users, for example Paulter et al. (2001) reported that nearly 30% of prostate cancer patients accessed the Internet for prostate cancer specific information. More recent studies suggest that this number is rising, for example Ramsey et al. (2009) reported that 58% of men were

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using the Internet during their treatment decision-making process and 94% found this source to be helpful. Unsurprisingly, younger, better educated men with access to a private computer and with higher levels of computer literacy were more likely to use Internet for prostate cancer-related information seeking (Mayer et al., 2007; Paulter et al., 2001).

Prostate cancer patients and their partners reported using the Internet to retrieve a variety of medical information: to investigate the possible meaning of symptoms, seek information about the cancer staging, available treatments, side-effects, lifestyle changes and survival (Ziebland et al., 2004). Some studies, however, expressed concerns over the quality of health-related information online (Eysenbach, Powell, Kuss & Sa, 2002). Eysenbach & Diepgen (2001) pointed out that the majority of health-related websites are created and administered by lay health consumers without medical training and, as such, can contain information of varying credibility, accuracy and completeness. A review of 79 studies evaluating the quality of health-related websites (Eysenbach et al., 2002) confirmed this observation. For example websites relating to diet and nutrition were found to contain mainly incorrect information (up to 89% inaccurate information) while cancer-related sites were mainly correct (4-9% inaccurate information). A more recent study (Black & Penson, 2006) evaluated 39 prostate cancer-related websites and found that although many lacked the appropriate information necessary to evaluate credibility of the website, the prostate cancer-related contents were generally correct (only 1% of information was found to be incorrect). The authors concluded that the information within the websites was of 'sufficient quality' to help guide patients treatment decisions.

Prostate cancer patients and their partners were also found to seek information, advice and support from health-related online support groups (Blank & Adams-Blodnieks, 2007; Blank, Schmidt, Vangsness, Monteiro & Santagata, 2010; Seale, 2006). Online support

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groups can be regarded as the virtual equivalent of face-to-face support groups free from temporal, geographical and spatial limitations (Coulson & Knibb, 2007; Malik & Coulson, 2008a). Online support groups allow increasing numbers of patients from all disease stages and socio-demographic backgrounds to freely exchange information and emotional support with others in a similar situation (Coulson, 2005; Mo & Coulson, 2008). Certain specific features of online groups, such as anonymity, asynchronous communication and the ability to communicate with large groups of patients suffering from the same condition can be beneficial for prostate cancer patients, as they may feel less restricted in emotional expressions and seeking help. For example, Broom suggested (2005a, 2005b) that the anonymity of an online group can enhance men's ability and willingness to seek support in relation to their sexual and urinary dysfunction and encourage emotional disclosure. Although few studies have investigated this aspect of online communication, preliminary findings seem to confirm the usefulness of online support groups as a safe arena to discuss intimate issues (e.g. Blank et al., 2010; Broom, 2005a).

Health-related online support groups have been found to be a valuable source of social support, and studies consistently indicate that informational support is most frequently exchanged by the members; however other forms of support, such as emotional, esteem and network support are also present (Coulson, 2005; Coulson, Buchanan & Aubeeluck, 2007; Huber et al., 2010; Meier, Lyons, Frydman, Forlenza & Rimer, 2007; Mo & Coulson, 2008). The majority of studies to date concentrated on the social support processes taking place within online support groups, and little is known about the outcomes of participation. In recent years the focus has shifted towards understanding the effects membership of such groups can have on patients. Recent studies suggest that patients can benefit from participation in online support groups in terms of increased knowledge, reduced social

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isolation as well as greater sense of mastery and control over their lives and the disease (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009). To date, however, little is known about the effects participation in online support groups has on prostate cancer patients and their partners and other family members. The characteristics of online support group communication and the outcomes of participation will be described and discussed in greater detail in the following chapter.



## **Chapter Three: Health-related online support groups**

### **Chapter overview**

This chapter presents an overview of the literature concerned with online support groups. The potential advantages and disadvantages of online support groups which stem from the unique characteristics of this novel source of support and information are presented. The findings of current research regarding who accesses online support groups, what they talk about and what the patterns of participation are will be discussed. The main body of the chapter will focus on the processes that occur in online support and will highlight the potentially beneficial outcomes of participation in these groups. The literature reviewed in this chapter points towards the beneficial role online support groups may have for the participants, however several gaps in the existing research pertaining to online support groups are also acknowledged, particularly in relation to prostate cancer. The chapter identifies the need for further research into the experiences of prostate cancer patients and their family members within online support groups.

### **3.1 The growing popularity of the Internet as a source of information and support**

Since the popularisation of the World Wide Web in 1993 (Thomas & Wyatt, 1999), use of the Internet has been growing rapidly. Increase in day-to-day Internet use can be observed across a variety of activities, such as using email for private and official communication, getting news, checking weather, learning, trading, and information seeking (PEW, 2005). The Internet is also a growing source of health-related information, for example Health on the Net Foundation (HON, 2010) reported that 69% of the respondents to their 2010 survey engaged in online health-related information seeking activities at least twice 'in the past week'. Studies indicate, however, that there is a certain level of inequality in accessing the Internet, as health-related information seekers are more likely to be from well-developed countries, white, female, aged between 25-44, with a higher level of education and socio-economic status, with good or excellent Internet skills (Cohen & Adams, 2011; Fox & Purcell, 2010; Ybarra & Suman, 2006).

As well as seeking health-related information online, patients and caregivers can use the Internet for communication with other people dealing with the same health issue and with health care professionals (e.g. Coulson et al., 2007; Lu, Shaw & Gustafson, 2011). This can be achieved through a variety of channels, such as chat facilities, mailing lists or message boards within health-related online support groups. The remainder of this chapter will focus on the characteristics and nature of communication within health-related online support groups, a medium rapidly growing in popularity, which offers large groups of patients and their family members the opportunity to seek information about the disease and treatment and exchange social support with other people affected by a similar health concern (Eysenbach et al., 2004; Klemm, Repper & Visich, 1998).

### **3.2 Health-related online support groups**

Health-related online support groups (henceforward referred to as online support groups) are social networks existing on the Internet, and providing social, emotional and informational support to members who share a common disease, condition or health concern (Eysenbach et al., 2004; Klemm et al., 1998). In this respect, online support groups can be described as the virtual alternative to face-to-face support groups (e.g. Braithwaite et al., 1999, Finn, 1999; Salem et al., 1997). Communication within online support groups can occur in a number of ways, for example, asynchronously, i.e. when the sender and the recipient of messages are not online at the same time, through discussion boards (where members can post messages and respond to messages posted by other members) or mailing lists (where emails containing the messages are sent round to everyone in the group). Synchronous communication, i.e. when participants in the communication are present online at the same time and take turns to post messages, is also possible in some groups, for example via chat rooms.

There are many types of online support groups, depending on privacy levels (i.e. public, with no login required to access the messages, or private, where login is required); type of users (e.g. patients only, caregiver only, both); who moderates/facilitates the group (e.g. peer or professionally led, unmoderated); type of support (e.g. educational/informational, social networking, professional advice) (Im, 2011). The majority of communication in online support groups is public, i.e. visible to all members and, in public groups, to non-members as well. In some groups participants have an option to send a private message to another member and these messages are only visible to the sender and the recipient.

### **3.2.1 Unique characteristics of online support group communication**

Literature investigating online support groups has identified several unique characteristics of communication in online support groups, such as lack of spatial and temporal constraints; anonymity; asynchronous, text-based communication; and access to large groups of patients sharing common health concerns (Braithwaite et al., 1999). These characteristics have been linked to several advantages for the members; however concerns were also raised regarding potential disadvantages of this novel medium of communication (e.g. Coulson & Knibb, 2007; Malik & Coulson, 2008a; White & Dorman, 2001). The following sections of this chapter will discuss these advantages and disadvantages of online support group communication.

#### **3.2.1.1 Advantages**

##### ***3.2.1.1.1 Lack of spatial and temporal barriers***

As discussed in Chapter 2, face-to-face support groups have been found to be a valuable source of emotional and informational support to their members (Thaxton et al., 2005), who report high satisfaction with the groups and note many positive outcomes, such as improved social well-being and reduced isolation, increased optimism, improved relationship with their physician and increased knowledge about illness and treatment options (Dunn et al., 2003). Salem et al. (1997) and Braithwaite et al. (1999) pointed out, however, that participation in face-to-face groups requires time commitment as well as means of transportation and is often inconvenient for individuals who have other commitments or mobility issues. Participation in online support groups is free from those constraints, as patients and caregivers can access them at any time without the necessity to leave the house. Furthermore, 24 hours a day support is available from online support

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groups. Accessing emotional and informational support online, during times when conventional support is unavailable, i.e. at the weekends or late at night has been found to be beneficial for many participants (e.g. Coulson & Knibb, 2007; Klemm et al., 1998; Malik & Coulson, 2008a).

### ***3.2.1.1.2 Anonymity and lack of visual cues***

Anonymity has also been recognised as one of the characteristics of online support groups which can be beneficial to some members (e.g. Broom, 2005a). In the anonymous setting of online support groups people can communicate with other members revealing as much or as little information about themselves as they feel comfortable with. Members often report that the anonymous environment of online support groups facilitates disclosure, particularly on sensitive or painful subjects, as well as aiding active support seeking (Broom, 2005a; Malik & Coulson, 2008a; Pfeil, Zaphiris & Wilson, 2009; Suzuki & Calzo, 2004). Anonymity and lack of visual cues also facilitates participation of patients with illnesses/treatments that are causing physical disfigurement (e.g. loss of a breast or hair), are associated with social stigma (e.g. illnesses where patients are perceived as 'guilty' of their disease, such as HIV/AIDS) or embarrassment (e.g. prostate cancer, where treatment causes intimate side-effects which would be difficult to discuss face-to-face) (e.g. Davison, Pennebaker & Dickenson, 2000; White & Dorman, 2001; Wright & Bell, 2003). Some studies found that participation in online support groups facilitates disclosure, open expression of emotions in men (Malik & Coulson, 2008b) and discussions about intimate issues, such as sexual and urinary dysfunctions (Attard & Coulson, 2012; Broom, 2005a; Gooden & Winefield, 2007; Sullivan, 2003), issues traditionally recognised as difficult for men to discuss face-to-face.

**3.2.1.1.3 Advantages of asynchronous communication**

Asynchronous communication in online support groups occurs when messages are posted to a discussion board or mailing list, where they can be viewed and responded to at any time. The person sending a request and the person posting a reply do not need to be online at the same time. As the messages remain online for a considerable amount of time, and the pool of messages is usually large and covers a variety of topics, members who seek solutions to a specific problem are able to search through existing messages for answers. In this way they can access some level of support at any time of day or night, and to receive support without communicating their need for help. Members have also reported that the asynchronous nature of communication within online support groups gave them the opportunity to think through what they wanted to convey (Malik & Coulson, 2008a). Furthermore, in this format multiple responses to messages are possible, offering the recipient access to a variety of opinions and information sources. Time constraints are removed from the communication, and posters can decide when to engage in communication (Malik & Coulson, 2008a; Wright & Bell, 2003).

**3.2.1.1.4 Access to large groups of similar others**

One of the unique characteristics of online support groups is the fact that there is potentially no limit to the number of people who can join an online support group resulting in large populations of people who share common health concerns and who can contribute personal experiences and knowledge to the discussions (Wright & Bell, 2003). Researchers have reported that access to large groups of people in similar situations can help improve the sense of social well-being in members of online support groups (e.g. Im et al., 2007a; Sullivan, 2003; van Uden-Kraan et al., 2008c). For example, patients with breast cancer,

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fibromyalgia and arthritis felt that participation in online support groups helped reduce their sense of social isolation and 'being the only one' through communication with others who shared similar experiences and feelings (Hoybye, Johansen & Tjornhoj-Thomsen, 2005; van Uden-Kraan et al., 2008c). Online support group members have been found to gravitate towards and seek support from people most similar to themselves in terms of age, beliefs, disease and treatment characteristics as they felt that people in similar circumstances can understand them better, empathise with them and can help validate their experiences, opinions and decisions (e.g. Bunde, Suls, Martin & Barnett, 2006, 2007; Im et al., 2007a; Sillence, 2010).

Furthermore, the diversity of views, opinions and experiences encountered in large online support groups can increase members' chances of finding somebody who can help solve a specific problem or offer relevant advice, as well as chances of coming across new, useful information (Pfeil et al., 2009). Accessing online support groups can be particularly beneficial for those individuals suffering from rare conditions, who are unlikely to meet many people in a similar situation offline (Coulson & Knibb, 2007; Im et al., 2007a; White & Dorman, 2001).

### **3.2.1.2 Disadvantages**

#### ***3.2.1.2.1 Reduced credibility of information***

Eysenbach and Diepgen (2001) pointed out that the majority of health-related websites (including online support groups) are created and administered by lay health consumers without medical training and as such can contain information of varying credibility, accuracy and completeness. As practically anyone can post information to online support groups, the credibility of information provided is reduced (Coulson & Knibb, 2007; Pfeil et

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al., 2009). Lack of sufficient identifying information, about individual members, can also make it difficult to assess the level of expertise or qualifications the author of a message possesses (Feenberg, Licht, Kane and Smith, 1996). Some studies investigated the level of misinformation contained in the messages posted to online support groups, and the results suggest that the correctness of information varies between groups used by people with different health concerns. For example, Winzelberg (1997) found that a considerable proportion (12%) of messages posted to a group dedicated to eating disorders, offered information or advice that was outside the acceptable standards of medical care. Conversely, Esquivel, Merric-Bernstam & Bernstam (2006) found that only 0.2% of messages posted to breast cancer online support groups contained information that was not entirely correct or misleading. The majority of those postings were promptly corrected by other members, which could suggest that members of certain groups employ mechanisms for ensuring high quality of information contained within their site. It has been noted that in many of the groups where provision of factual information or 'teaching' is the primary objective, a greater rigour, with regard to ensuring quality of information, can be found (Gooden & Winefield, 2007; Klemm et al., 1998; Seal, Ziebland & Charteris-Black, 2006; Sullivan, 2003). In these groups members frequently quote sources of information, such as health care professionals, scientific publications or websites, to demonstrate the credibility of the information provided. In peer-led online support groups members also often emphasize that the information available within the group is not provided by health care professionals and that opinion or advice given should not replace consultation with a health care professional. Furthermore, Feenberg et al., (1996) observed that within peer-led online support group for amyotrophic lateral sclerosis the participants had the knowledge and ability to protect each other from making serious mistakes as a result of adhering to misleading or incorrect information exchanged within the group, such as



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undertaking 'faddish' and potentially dangerous treatments. When questions about unproven treatments such as mega-doses of B complex vitamins or ozone therapy were posted, members replied warning others off such therapies.

### ***3.2.1.2.2 Delayed feedback***

Asynchronous nature of communication within online support groups can result in delayed feedback and information provision. This can be confusing for members unfamiliar with online support group use and frustrating in times of urgent need (Pfeil et al., 2009). Winefield (2006) found, however, that group members recognise the delay in feedback as undesirable, and thus try to look after one another by ensuring messages are not left without a response for too long. She pointed out that the 'regular' members in a breast cancer online support group often took it upon themselves to reply to posts that had no replies. Van Uden-Kraan et al. (2008a) also noted that within breast cancer, fibromyalgia and arthritis the majority of questions have been answered within 24 hours.

### ***3.2.1.2.3 Depersonalisation and uninhibited, antisocial behaviour***

Early theories of computer-mediated communication, such as Social Presence Theory (Short, Williams & Christie, 1976) or the 'lack of social-context cues' hypothesis (Sroull & Kiesler, 1986) indicated that the absence of non-verbal cues, which are a rich source of socio-emotional and relational information and thus help communicators gauge the mood, status and social context during face-to-face encounters, can lead to depersonalisation of computer-mediated communication (Walther, Anderson & Park, 1994). According to these theories, lack of non-verbal cues can result in fewer socio-emotional expressions, and have a negative effect, leading to uninhibited, antisocial communication ('flaming'), status

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equalization, greater emphasis on task-orientation and general impersonality of electronic communication (Walther, 1992, 1994).

These early theories, often referred to as 'cues-filtered-out' theories (Culnan & Markus, 1987) were, however, widely criticised, for example Walther and colleagues (Walther, 1992, Walther et al., 1994) pointed out that the majority of the empirical literature supporting these theories was based on short-term, time-limited interactions, within groups created artificially in laboratory settings. Walther proposed an alternative approach to computer-mediated communication, taking a social information processing perspective (Walther, 1992), according to which communicators in online settings, like any other communicators, are driven by their desire to develop meaningful social relationships with other communicators. According to this model, linguistic and textual behaviours can be adapted to convey socio-emotional and relational information, however, the absence of non-verbal cues means that this process will take longer. Therefore the main difference between face-to-face and computer-mediated communication is the matter of *rate* rather than *capability*. Given sufficient time communicators can exchange social and emotional information online as effectively as face-to-face. Indeed, the majority of studies conducted in 'naturally occurring', on-going online groups whose main aim was to exchange social support suggested that the communication was rich in socio-emotional information and formation of interpersonal relationships was a natural part of the interactions (Coulson, 2005; Gooden & Winefield, 2007; Finn, 1999; Sharf, 1997; Sullivan, 2003, van Uden-Kraan et al., 2008c).

Furthermore, studies have also found little evidence of antisocial, aggressive or uninhibited behaviour in health-related online support groups, for example Finn (1999) found no messages that could be classified as aggressive or hostile in the pool of messages

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downloaded over a period of three months from an online support group for individuals living with a physical or mental disability. In an analysis of 1500 messages posted to breast cancer, fibromyalgia and arthritis online support groups van Uden-Kraan et al. (2008a) found that only 1% of messages contained negative remarks directed at other participants. The above mentioned findings suggest therefore, that the initial concerns about impersonal or uninhibited nature of online communication are largely unfounded and irrelevant to online support group setting, where members have the time and inclination to get to know each other, develop meaningful interpersonal relationships and exchange social and emotional support as well as task-oriented information.

### ***3.2.1.2.4 Misinterpretation of messages***

Lack of non-verbal cues can also lead to another disadvantage for the members who have to rely solely on textual information when interpreting the meaning of messages exchanged within online support groups. In a study investigating the attitudes of older adults to online support groups (Pfeil et al., 2009), the participants highlighted that not being able to hear the tone of voice or see facial expressions can lead to misunderstanding of messages, for example messages intended as sarcastic or humorous. This could potentially lead to misinterpretation of the sender's intention behind posting the message, tone or meaning of messages, which could in turn result in upset or provision of irrelevant information.

The literature on online communication suggests that in order to overcome the lack of non-verbal cues in the textual communication, Internet users developed an electronic 'paralanguage', which can help convey the non-verbal elements of communication typically observed in face-to-face interactions, such as facial expressions, body language, tone of

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voice or emotions (Carey, 1980). Carey (1980) identified several paralinguistic features used in early computer-mediated communication, such as intentional misspellings or 'vocal spellings' such as 'weeeeeell' or 'noooooo'; lexical surrogates, such as description of tone of voice ('she says happily') or vocal segregates such as 'uh-huh!' ; and manipulation of grammatical markers, such as capital letters (e.g. using capital letters only depicts shouting: 'DON'T DO IT') or punctuation marks ('?!?!?!?!?!'). More recently the use of emoticons and abbreviations became a widely acceptable way of depicting emotion, such as for example :- ) or :-( meaning 'happy' or 'sad', and 'LOL' meaning 'laugh out loud' (e.g. Malik & Coulson, 2008a).

Examples of paralinguage use were described in several studies on online support group communication. For example van Uden-Kraan et al. (2008a) noted that members of breast cancer, arthritis and fibromyalgia groups compensated for the lack of non-verbal cues by using emoticons, capital letters, punctuation and by creating specific online support group vocabulary (for example word 'marmot' was used instead of word 'wig'). Similar use of paralinguage within online support groups for people with disabilities was reported by Braithwaite et al. (1999). Nevertheless, paralinguage has been developing for some years and is now quite complex, and can therefore be difficult to understand or to adopt, particularly for people who are new to computer-mediated communication. For example Pfeil et al. (2009) reported that older participants often found paralinguistic expressions to be confusing or inappropriate, and many reported feeling uncomfortable using this virtual 'equivalent' to face-to-face gestures or facial expressions. In recognition of this problem, many groups have started to provide dictionaries and term glossaries to help new members understand the online support group language (e.g. van Uden-Kraan et al., 2008a).

**3.2.1.2.5. Negative impact of online support group communication**

Several studies have investigated the potentially negative impact communication within online support groups can have on participants (e.g. Finn, 1999; van Uden-Kraan et al., 2008a) and the findings suggest that online support group communication appears to have few detrimental effects on the members (Finn, 1999; van Uden-Kraan et al., 2008a). For example, Finn (1999) found only two messages which indicated that members felt negatively affected by something that happened within the group. Van Uden-Kraan et al. (2008a) reported similar findings in breast cancer, fibromyalgia and arthritis online support groups. It is important to note, however that the majority of the studies typically employed a content analysis of messages, a method that does not provide a sufficient insight into the views and feelings of the members or how interaction with others in the group or the topics of conversations affects them. The impact of communication within online support groups on people who do not post messages, i.e. 'lurkers' or people who left the group also cannot be explored through content analysis of messages.

One study that explored the negative effects communication within online support groups had on members was an interview study by Sandaunet (2008). She interviewed 29 women who discontinued their use of a breast cancer online support group and identified several factors that had led the women away from their group. One of the main reasons, related to the topics of conversations within the group, was the need to protect themselves from the information about negative aspects of the disease, such as recurrence, metastases and death. The participants reported that they needed to remain hopeful and believe they could be cured, and such messages reminded them that not everyone survives. Van Uden-Kraan et al. (2008a) also found that participants were uneasy reading about disease progression, while Malik and Coulson (2008a) reported that members of infertility groups

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felt deeply upset when reading about other couples' fertility treatment failure. Interestingly, some of them also felt upset when reading about other members' pregnancies, as it evoked negative emotions such as jealousy and sadness that it wasn't them. Conversely, some women in Sandaunet's study (Sandaunet, 2008) also felt uneasy when posting 'sunshine stories', which, they believed, could have been upsetting for members in a worse situation. Some members, on the other hand, feared being perceived as complainers, as they felt that others had worse problems and one should not 'go on' about their own issues (Sandaunet, 2008). Indeed, some members reported that they found people who talked about themselves too much, or complained frequently, to be irritating (van Uden-Kraan et al., 2008c).

The findings of these studies (Malik & Coulson, 2008a; Sandaunet, 2008; van Uden-Kraan et al., 2008c) indicate that some aspects of online support group conversations may be inappropriate or emotionally upsetting to other members, especially topics relating to happy or sad events and may therefore have a negative effect on the participants. As it is apparent that these effects can only be fully understood through direct exploration of participants' experiences, further research into the negative aspects of online support group communication is necessary.

#### **3.2.1.3 Summary**

The literature discussed thus far suggests that the unique characteristics of online support groups, which distinguish them from face-to-face sources of support, can lead to several advantages for the members, offering them more convenient access to social support. Although some potential drawbacks of online participation have been noted within the literature, members have demonstrated the ability to overcome many of these

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disadvantages. Few studies, however, have investigated prostate cancer patients and their partners' perceptions regarding the advantages and disadvantages of online support groups, warranting further research within this area.

### **3.3 Nature of online support communication**

In order to fully understand the nature of online support group communication, it is important to also discuss who uses online support groups, what they talk about, how they talk about it and what they gain from participation. In recent years a growing body of research has investigated the nature of communication within online support groups. The majority of studies investigated the content of the messages posted to the groups in order to describe the topics of conversations (e.g. Blank & Adams-Blodnieks, 2007; Chen, 2012) and the processes occurring within the groups (e.g. Coulson, 2005; Coursaris & Liu, 2009; Mo & Coulson, 2008). Other studies used interviews and surveys to examine the perceptions and experiences of the members regarding the processes occurring within online support groups (e.g. Mo & Coulson, 2010; van Uden-Kraan et al., 2008c). Several of the survey studies, as well as studies analysing the content of the messages, provided information about the demographic make-up of the online support group users (e.g. Im, Chee, Tsai, Bender & Lim, 2007b; Owen et al., 2010; Seale, 2006) and patterns of online support group use (e.g. Nonnecke & Preece, 2000; Winefield, 2006). More recently, researchers have also explored the effects participation in online support groups has on members (e.g. Mo & Coulson, 2012; van Uden-Kraan et al., 2008c, 2009).

The following sections of this chapter will therefore review the literature investigating the characteristics of online support group users; the patterns of online support group participation; the topics of online support group conversations; the processes that occur

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within online support groups; and the outcomes of participation, with the particular focus on the prostate cancer online support groups.

### **3.3.1 Characteristics of online support group users**

Research indicates that a relatively small proportion of patients access online support groups. For example, Owen and colleagues (2010) found that only 1.8% of Americans living with chronic conditions have ever used online support groups, while Fox & Purcell (2010) reported that around 8% of their US study sample had experience with online support groups. Similar to the general population of Internet users and those who seek support in face-to-face groups, online support group participation levels vary according to members' gender, age, education and socio-economic status (Dutta & Feng, 2007; Im et al., 2007b; Owen et al., 2010). Other individual characteristics such as disease characteristics and level of computer skills have also been associated with differences in online support group use (Davison, Pennebaker & Dickerson, 2000; Gooden & Winefield, 2007; Pfeil et al., 2009; Seale, 2006). In addition, differences between patients and caregivers in use of online support groups have also been identified (Seale, 2006).

#### **3.3.1.1 Access and computer skills**

Participation in online support groups requires access to a computer, Internet connection and a certain level of computer skills. Individuals from higher socio-economic backgrounds (i.e. who have a greater chance to own a computer and have an Internet connection) and those who are better educated and more comfortable using computers and the Internet are more likely to access an online support group (Ybarra & Suman, 2006; Pfeil et al., 2009). Some studies conducted with people lacking computer skills, who did not own a computer suggested that providing the participants with the hardware, software and computer



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training could help remove barriers to participation in computer-mediated communication (Kreps et al., 2007; McTavish et al., 1994; Dow et al., 2008). For example, McTavish et al., (1994) targeted African-American women from impoverished areas of Chicago who were diagnosed with breast cancer. As a result of the intervention, all participants reported using the computer-based Comprehensive Health Enhancement Support System (CHESS) daily to communicate with other breast cancer patients and survivors. They had positive feelings towards using this system, such as acceptance, relief, motivation and understanding, and found it relatively easy to master.

The socio-economic barriers to computer and Internet access are, however, difficult to overcome. Although technological advances have spread rapidly through developed countries, the 'digital divide' between 'the rich' and 'the poor' is still apparent across the world. Even within Europe level of online participation varies dramatically between countries, with over 90% of Scandinavians accessing the Internet compared to just 20% of Kosovars (Internet World Stats, 2011). This indicates that large proportions of entire nations are currently missing out on the potential benefits of accessing information and support online.

#### **3.3.1.2 Age**

Generally, online support group members have been found to be younger than the general population they represent (Fox & Purcell, 2010; Owen et al., 2010). Although many older patients and caregivers embrace the opportunity to communicate with others over the Internet, the majority of older adults do not engage in online activities (Office of Communications, OFCOM, 2006). Some simply reject the use of computers and the Internet and are happy to exclude themselves, while many non-users feel they are missing out due

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to their lack of computer skills. Pfeil et al. (2009) found that many older adults, who did not use online support groups, felt that this type of communication was more suited to the younger generation and that they did not feel comfortable using such groups. Conversely, older adults who did use online support groups reported many benefits in terms of information support and in-depth emotional connections with other group members. Prostate cancer patients, who are typically older men, have also been found to actively engage in communication with other patients within online support groups (e.g. Blank et al., 2010; Huber et al., 2010; Sullivan, 2003). It is also worth noting that the Internet has been available for nearly two decades now, and the Internet users' population is aging, with increasing numbers of older adults who would have encountered Internet earlier in their life.

### **3.3.1.3 Gender**

Early studies have suggested that a similar proportion of men and women use online support groups (e.g. Salem et al., 1997; Klemm et al., 1998; Klemm et al., 2003). In recent years, however, women, who are frequently reported to be the primary support seekers offline (see Chapter 2), recently became the majority within online support groups as well, and groups dedicated to breast cancer outnumber those aimed at prostate or testicular cancers (Im et al., 2007b; Ybarra & Suman, 2006). Even in groups dedicated to male-only diseases, such as prostate cancer, female partners tend to make up a significant proportion of participants (Seale, 2006).

### **3.3.1.4 Disease characteristics and health motivation**

Certain health characteristics are also associated with online support group use. Dutta and Feng (2007) found that intrinsic and extrinsic motivation to seek health-related information

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were significant predictors of the level of engagement in online support groups. Individuals, who had higher health information orientation, i.e. were more interested in seeking information related to health issues (intrinsic motivation), were also more likely to access online support groups. Being at risk of cancer or having cancer was described as extrinsic motivation and the authors also found that people with cancer or those who perceived themselves as being at higher risk of contracting cancer, were more likely to access online support groups.

Davison, Pennebaker and Dickerson (2000) also suggested that individuals living with diseases associated with higher stigma, are embarrassing, poorly understood or overlooked by health professionals are more likely to engage in online support group use. They found that individuals living with HIV/AIDS, alcoholism, as well as breast and prostate cancer patients are most frequent users of online support groups. They also noted that acute conditions are more likely to prompt online support seeking, for example, patients living with hypertension were amongst those less likely to seek support online, but if their condition worsened (i.e. resulted in a heart attack) they tended to turn to online support more frequently.

#### **3.3.1.5 Use of online support groups by caregivers**

The majority of research to date has focused on the use of online support groups by patients and few studies have investigated the use of this source of information and support by partners, family members, friends and other informal caregivers (Kinnane & Milne, 2010). The existing literature suggests that caregivers of people living with a variety of diseases and health concerns such as Alzheimer's disease (Mahoney, 1998; Yoo, Jang & Choi, 2010), asthma (Sullivan, 2008), lung cancer and chronic Lymphocytic leukaemia (CLC)

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(Ginossar, 2008), pancreatic cancer (Nolan et al., 2006) and various other cancers (Klemm & Wheeler, 2005; Schultz, Stava, Beck & Vassilopoulou-Sellin, 2003) are frequent participants in online support groups. Few studies, however, have explored the levels of caregivers' participation in prostate cancer groups (Blank & Adams-Blodnieks, 2007; Blank et al., 2010; Seale, 2006).

Research suggests that overall patients are more frequent and more active members than caregivers in mixed patient/caregiver online support groups (Ginossar, 2008; Schultz et al., 2003; Seale, 2006). For example, Schultz and colleagues (2003) found that in an online support group for people affected by various types of cancer, 60% of members were patients and 40% caregivers. Seale (2006) reported that in a breast cancer online support group 76% of members were patients, who posted 92% of messages while 15% were relatives, who posted 6% of messages (9% were health professionals or moderators). He reported, however, that in a prostate cancer online support group the levels of caregiver participation were considerably higher: 43% of members were patients, who posted 44% of messages; 39% were caregivers, who contributed 52% of messages. Interestingly, Nolan and colleagues (2006) found that only 11% of postings to a pancreatic cancer online support group were attributed to people with cancer, while the rest were posted by family members. These findings indicate that cancer type also affects the proportion of patients and caregivers posting to online support groups. In pancreatic cancer, as opposed to breast or prostate cancer, the progression is rapid, the prognosis poor and the symptoms frequently severe, which can hamper patients' ability and willingness to participate whilst increasing the caregivers' need for support.

Research suggests that the majority of caregivers posting to online support groups are female. For example, in online support group Life After Cancer Care investigated by Schultz

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and colleagues (2003), 76% of the caregivers posting messages were female. Seale (2006) also found that in the breast cancer group 66% of caregivers were female, while in the prostate cancer group nearly all caregivers were female. The proportion of male and female relatives taking part in online support groups reflects the cultural difference in the tendency of men and women to assume a caregiving role, with caring and providing support being recognised as a typically female trait (Ginossar, 2008). The fact that more female than male caregivers access online support groups is also in line with the general literature on support seeking among males and females; as was discussed in Chapter 2, women tend to seek social and emotional support more often, both face-to-face and online. The large proportion of female caregivers, who were predominantly spouses of the patients, in prostate cancer online support groups, corroborates the notion that prostate cancer is indeed the 'couples' disease' (Bottoroff et al., 2008).

### **3.3.2 Patterns of online support group use**

#### **3.3.2.1 Membership life cycle**

Members of online support groups fulfil a variety of roles within the groups, and these roles change and evolve throughout the membership life cycle (Kim, 2000; Sonnenbichler, 2010). Kim (2000) proposed that these roles, to a large extent, mirror the social roles observed within offline communities. She argues that usually new members enter the community as '*visitors*' who just observe the activity of other members (for example read the messages), familiarise themselves with the layout, contents and rules. Whilst many visitors will leave the community after first few visits, some will progress to become '*novices*'. Novices are members who decide to join the community, assume a nickname and start to actively participate in the activities within the group. At this stage members tend

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to introduce themselves to the group and contribute few messages to the discussion threads. They may post messages enquiring about the group rules or technical issues relating to navigating the site. As their activity within the group increases, some novices may progress to become '*regular members*', who frequently contribute to discussions and visit the groups regularly. Those who participate regularly may eventually take on the role of the group '*leaders*' who welcome new members, help resolve technical issues, answer questions and remind members of the group rules. Members, who enter the final stage of membership life cycle, i.e. become '*elders*', are in the process of leaving the community. They would have resolved their issues, for example in prostate cancer groups elder members may be those who had successful treatment and recovered from side-effects.

#### **3.3.2.2 Levels of engagement in online support groups**

Online support groups can have hundreds or thousands of members, however only a handful of participants in a group have been found to display high levels of activity (e.g. Huber et al., 2010; Salem et al., 1997; Winefield, 2006). For example Huber and colleagues reported that in a prostate cancer online support group, 5% of frequent posters (74 people) posted 70% of all messages (a staggering 23000 messages over 32-month study period). The top ten advisors contributed 36% of all messages (nearly 12000 messages during the study period). In comparison, the majority of active members ('posters') tend to contribute 1-10 messages during their membership (Winefield, 2006). Highly active members have also been found to adopt the role of informal group leaders, provide more support and post fewer requests (Salem et al., 1997; Winefield, 2006).

On the other hand, Nonnecke and Preece (2000) highlighted the importance of exploring the category of members referred to as '*lurkers*' – those who read messages posted by

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others but do not contribute any messages or only post occasionally. They noted that this group makes up a large proportion of all online support group members: on average 45% of health-related groups users did not post any messages and a further 35% posted on average one message per month. Although some authors perceived 'lurking' as a negative and selfish behaviour (Kollock & Smith, 1996, as cited in Nonnecke & Preece, 2000), Nonnecke and Preece (2000) postulated that 'lurking' is an acceptable and appropriate behaviour within online communities and causes no harm or strain on resources. In fact, they argued that there are manageable levels of 'traffic' within each online support group, with too many messages being difficult to cope with on a daily basis. Therefore 'lurking' allows large groups of people to benefit from the knowledge imparted within the messages without adding to the already large volume of postings.

The literature suggests the existence of some differences in the experiences with online support group participation between 'posters' and 'lurkers'. For example, some studies found that 'posters' and 'lurkers' vary significantly according to the level of beneficial processes they experience during their participation in online support groups (Mo & Coulson, 2010; van Uden-Kraan et al., 2008b). These authors found that 'lurkers' had lower levels of satisfaction with their relationship with other members, and reported receiving less social support, which could be explained by the fact that 'lurkers' generally do not post messages to the group and thus they have no means to express their need for support; in fact other members may be unaware of their presence. Furthermore, in both studies (Mo & Coulson, 2010; van Uden-Kraan et al., 2008b), the 'lurkers' reported receiving less useful information than the 'posters'. The authors speculated, that as 'posters' were actively seeking answers to their specific problems by asking questions, the information they received in response was a better match to their unique situation. 'Lurkers' on the other

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hand, were only reading existing messages, and therefore received more generic information, that may not be applicable to their situation (Mo & Coulson, 2010; van Uden-Kraan et al., 2008b).

Despite the differences in the processes experienced by 'posters' and 'lurkers' during their participation in online support groups, van Uden-Kraan and colleagues (2008b) found no significant differences in terms of empowering outcomes such as 'feeling better informed', 'feeling more confident in relationship with the physician', 'improved acceptance of the disease and confidence with treatment' or 'improved optimism and control'. The only statistically significant difference related to lower sense of improvement in social well-being in 'lurkers'. These findings are not surprising, as gaining new social contacts, building relationships and engaging in exchange of social support may require at least some level of reciprocal communication.

### **3.3.3 Topics of communication in online support groups**

Research suggests that the majority of conversations taking place in online support groups relates to illness and treatment (Blank & Adams-Blodnieks, 2007; Blank et al., 2010; Gooden & Winefield, 2007). Members of online support groups have been found to frequently exchange medical information and personal experiences relating to symptoms interpretation, diagnosis, treatment modalities, medication, long-term side-effects and health care professionals (Blank et al., 2010; Chen, 2012). Female members, for example in breast cancer groups, have also been found to exchange high levels of emotional support, express emotions and discuss their relationships with their close ones (Blank et al., 2010, van Uden-Kraan et al., 2008c). Van Uden-Kraan and colleagues (2008c) also found that female members of online support groups engage in off-topic conversations about family,



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hobbies and everyday events. Although some level of emotional support was noted in prostate cancer online support groups, the men are more likely to focus on treatment, treatment decision-making and dealing with the side-effects of treatment, with fewer examples of 'off topic' conversations and discussions of emotions (Gooden & Winefield, 2007; Huber et al., 2010; Sullivan, 2003). Discussions about sexuality, sexual dysfunction and sexual performance have also been frequently noted in prostate cancer online support groups (e.g. Blank et al., 2010)

### **3.3.4 Processes occurring in online support groups**

#### **3.3.4.1 Social support**

Recently, studies investigating the content of messages posted to online support groups suggest that the majority of communication occurring within these groups could be classified in terms of social support categories. As discussed in Chapter 2, social support can be perceived as the provision of emotional, tangible and informational assistance and it includes both the resources that meet individual needs as well as the social relationships through which these needs are met (Clarke et al., 2006). Cutrona and Suhr (1992) proposed the existence of five main categories of social support available to individuals from traditional, face-to-face support networks. These categories include informational support (including advice, factual input and feedback on actions), emotional support (including expressions of caring, concern, empathy, sympathy and reassurance), network support (which entails a sense of belonging in a group of similar others), esteem support (including communication of regard for one's skills, abilities or personal qualities) and tangible assistance (including offers to provide goods or services) (Cutrona & Suhr, 1992). A number

of studies to date have investigated the existence of these support categories in online support groups (e.g. Coulson, 2005; Coulson et al., 2007, Mo & Coulson, 2008).

#### ***3.3.4.1.1 Informational and emotional support in online support groups***

Studies suggest that informational and emotional support are most frequently exchanged within online support groups. For example, Coulson et al. (2007) reported that provision of both informational and emotional support were present in 56% and 52% of messages posted to a Huntington disease group, respectively. Several studies have investigated gender differences in information and emotional support exchange within male and female online support groups (e.g. Blank et al., 2010; Klemm, Hurst, Dearholt & Trone, 1999; Meier et al., 2007; Owen, Klapow, Roth & Tucker, 2004). In prostate cancer, the most prominent has been the exchange of informational support, while emotional support has been observed less frequently. According to these studies, the male patients tend to focus on cancer- and treatment-related information and advice exchange, and emotional support was often brief and coincidental. These authors reported that the opposite could be observed in breast or ovarian cancer online support groups, where female patients tend to offer each other emotional support and discuss emotions more often and exchange cancer-related information less frequently. Conversely, Gooden and Winefield (2007) suggested the main difference in male and female communication is not related to the quantity of informational vs. emotional support exchanged by men and women (each group in this study exchanged around 60% of messages containing informational support and 40% messages containing emotional support), but to the gender style in which support was communicated. For example, women offered encouragement through expression of affection and nurturing support, while men did so through 'battle-like' language and promotion of strength. Women were also more open in their expression of emotions, they

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explicitly communicated their fears and anxieties, while the men were more likely to intellectualise their feelings and use indirect, implicit descriptions.

These findings suggest that to a large degree the exchange of informational and emotional support in male and female online support groups mirrors the offline gender communication styles (e.g. Clarke et al., 2006; Harrison et al., 1995; Keller & Henrich, 1999). This is particularly evident in single-gender online support groups (Mo, Malik & Coulson, 2009). It is however important to note, that the majority of studies investigating social support exchange in single-gender online support groups mainly focused on typically male or female cancers, such as prostate or breast/ovarian cancer (e.g. Gooden & Winefield, 2007; Sullivan, 2003). Mo et al. (2009) speculated that the differences in communication within these groups could therefore be explained by the individual needs of the people living with those particular types of cancer, rather than by gender alone. The authors highlighted some important differences between breast and prostate cancer, such as in prostate cancer the treatment choices are less well defined than in breast cancer, and thus prostate cancer may require more information to make their treatment decision than the breast cancer patients.

Conversely, other studies on single-gender online support groups for men affected by infertility (Malik & Coulson, 2008b) or fathers of children with spina bifida (Nicholas, McNeill, Montgomery, Stapleford & McClure, 2003) suggest that participation in single-gender online support groups could help remove the gender differences in communication styles. For example, Nicholas et al. (2003) found that the men in their study frequently engaged in highly emotional discourses and openly shared their feelings of anger, hurt, frustration as well as joy and happiness. Malik and Coulson (2008b) found that men in single-gender infertility groups often openly communicated their feelings of helplessness

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within the group. As they often felt neglected and alienated from the treatment process they perceived the group as the only place where they could express their fears and frustrations and find emotional support they much needed.

The differences between prostate cancer patients and the men in the above mentioned studies by Malik and Coulson (2008b) and Nicholas et al. (2003) could be partially explained by Cutrona and Suhr's theory of social support (Cutrona & Suhr, 1992). Cutrona and Suhr found that those dealing with a controllable stressor tended to appreciate more action-facilitating support, such as information and advice, while those in an uncontrollable situation valued emotional support more. Arguably, prostate cancer patients are in a situation where they have some level of control over their treatment choice, but they need a significant amount of informational support in order to make the best possible decision. Men in online support groups described by Nicholas et al. (2003) and Malik and Coulson (2008b) had less control over their situation and suffered from high levels of emotional distress, and thus information support might have been of a lesser value to them than emotional support.

Interestingly, Mo et al. (2009) have reported that in the majority of studies on mixed gender online support groups in their review, such as online support groups for people with depression, diabetes or bereaved parents, found few gender-related differences in social support communication. The authors have suggested the communication style of the predominant gender is adopted by the entire group, for example, men in predominantly female groups have been found to exchange emotional support as frequently as the women.

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The majority of studies have focused on the processes that occur in messages posted by patients, and few studies to date have provided insight into how, if at all, the exchange of information within online support groups differs between patients and caregivers (e.g. Blank et al., 2010; Ginossar, 2008; Seale, 2006). For example Ginossar (2008) hypothesised that since caregivers' informational needs are frequently unmet by the health care professionals, they would be more likely than the patients to seek information from alternative sources, such as online support groups. The results of her analysis confirmed this hypothesis, indicating that family members in lung cancer and chronic lymphocytic leukaemia (CLL) online support groups accessed these groups for information seeking purposes twice as often as the patients. Patients, on the other hand, were more likely than family members to provide information, further suggesting that they indeed had higher levels of knowledge about their disease and treatment options than the caregivers.

While both patients and caregivers tend to seek information and support within online groups, the patients have been found to gather these resources for themselves, while caregivers accessed online support groups to aid their own knowledge and psychological well-being as well as to be better able to provide help for the patient (Kinnane & Milne, 2010). Caregivers to prostate cancer patients have been found to seek information and advice on behalf of the patient, for example to aid their treatment decision-making processes (James et al., 2007).

#### ***3.3.4.1.2 Encountering similar others in online support groups***

Research also points to the benefits of encountering social support from similar others within online support groups (Sillence, 2010; van Uden-Kraan et al., 2008c). Many cancer patients, their partners and close relatives report experiencing a sense of isolation from

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their family and friends, as they feel their peers lack the empathy and understanding of their situation necessary to provide optimal support (Bottoroff et al., 2008; Ussher et al., 2006). Conversely members of cancer-related face-to-face support groups were found to offer unique understanding, empathy, sense of community and unconditional acceptance based on the shared experience of living with cancer or caring for cancer patients (Bottoroff et al., 2008; Ussher et al., 2006). Studies investigating social support online also found that the ability to communicate with others in a similar situation is an important feature of online support groups (e.g. van Uden-Kraan, 2008c). Several studies reported that aspects of emotional support which stem from commonality of experiences and feelings, such as empathy, understanding, and validation of feelings and experiences were most frequently exchanged within online support groups (Attard & Coulson, 2012; Coulson, 2005; Coursaris & Liu, 2009; Mo & Coulson, 2008). Sharf (1997) described connectedness in online support groups as one of the central themes in breast cancer patients' experiences of empowerment. She found it provided validation of feelings previously ignored by the health professionals, reassurance and hope and helped the women to prepare for the unexpected. Van Uden-Kraan et al. (2008c, 2009) reported similar findings from the interviews with members of breast cancer, fibromyalgia and arthritis online support groups.

#### ***3.3.4.1.3 Esteem support in online support groups***

Meier et al. (2007) described provision of esteem support in online support groups as the exchange of messages that aim to increase another person's sense of self-value, worth and competence. Overall, esteem support was less frequently reported in the majority of studies than informational or emotional support; it was found in 6-22% of messages posted to HIV/AIDS and Huntington disease online support groups (Coulson et al., 2007; Coursaris

& Liu, 2009; Mo & Coulson, 2008). Members most often expressed esteem support through gratitude, compliments and praise for the activities they performed within the group, such as open sharing of experiences, or for their personal characteristics, such as courage or positive attitude. They often noted that others were an inspiration to them; they thanked them for their help and information they provided.

#### ***3.3.4.1.4 Tangible assistance in online support groups***

Studies suggest that offers of tangible assistance are rare in online support groups and can be observed in only 0.5-10% of messages (Coulson et al., 2007; Coursaris & Liu, 2009; Mo & Coulson, 2008). As tangible support refers to offers of practical help, such as babysitting, lending money or performing domestic tasks, this could be explained by the fact that members of online support groups may not be in the same area or even country, and thus are unable to do jobs for each other or to easily exchange goods. Tangible assistance offered in online support groups is usually related to performing tasks over the Internet, such as emailing useful resources (for example website addresses or diet plans).

#### **3.3.4.2 Self-help mechanisms**

A number of studies also investigated the extent to which therapeutic mechanisms previously associated with participation in face-to-face support groups or group therapy (e.g. Yalom, 1995) can be observed in online support groups (e.g. Finn, 1999; Malik & Coulson, 2010; Perron, 2002). For example, Finn (1999) examined communication in an online support group focusing on issues of living with a disability. He identified 14 mechanisms which he termed 'helping mechanisms'. His classification included nine socio-emotional ('expression of feelings/catharsis'; 'providing support or empathy'; 'chit-chat'; 'universality'; 'friendship'; extra-group relationships'; 'taboo topics'; 'damaging

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statements') and five task-oriented helping mechanisms ('requesting information'; 'providing information'; 'problem solving'; 'computer talk'; 'group cohesion'). The results suggested that many of these mechanisms were present in the messages and 'providing support and empathy', 'providing information' and 'problem solving' were most frequently exchanges by the members of this group.

Perron (2002) investigated the extent to which what he referred to as 'self-help mechanisms' could be found in online support group for caregivers to people living with mental illness. He found that members could benefit from the majority of the processes associated with face-to-face support groups, such as 'disclosure', 'providing information and advice' and 'empathy or support'. Malik and Coulson (2010) noted that members of infertility online support group could benefit the most from 'empathy or support', 'sharing personal experiences' and 'information provision'. In addition, studies investigating the prevalence of self-help mechanisms in online support groups also indicated that 'negative statements' were particularly rare in these groups (Finn, 1999; Malik & Coulson, 2010; Perron, 2002). It could, therefore, be concluded that members of online support groups can potentially benefit from a number of self-help mechanisms, previously described in the context of face-to-face support groups, mainly in terms of support, empathy and information sharing.

#### **3.3.4.3 Personal disclosure in online support groups**

Personal disclosure, one of the therapeutic mechanisms associated with participation in face-to-face self-help groups, has received particular attention in the online support group literature (Bar-Lev, 2008; Lieberman, 2007; Salem et al., 1997; Shaw, Hawkins, McTavish, Pingree & Gustafson, 2006; Tichon & Shapiro, 2003). Salem et al. (1997) defined online



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disclosure as messages in which the author reveals some personal information about themselves or someone close to them; these messages can contain descriptions of feelings, desires or non-public behaviours. Several studies noted that personal disclosure occurs in online support groups more frequently than in face-to-face self help and support groups (Joinson, 2001; Perron, 2002; Salem et al., 1997) and the authors speculated that various characteristics of online communication can facilitate personal disclosure in online support groups. Salem and colleagues (1997) argued that anonymity, lack of visual cues and identifying information within online support groups can increase perception of similarity between members, which, in turn, can increase personal disclosure. Pfeil, Zapiris and Wilson (2009) also found that members of online support groups for older adults felt more comfortable 'opening up' in front of 'strangers', particularly when the topic was sensitive or painful. Attard and Coulson (2012) also noted that sense of commonality within online support groups as well as empathy and understanding from other members improved trust and helped people with Parkinson's disease disclose sensitive, personal information. Braithwaite et al. (1999) pointed out that the asynchronous communication in online support groups can also facilitate personal disclosure as it allows members to write longer and more revealing accounts of their experiences and gives others the opportunity to read them in their own time.

Studies suggest that personal disclosure can serve several roles in online support groups. For example, new members use it to introduce themselves and to outline their health issues and the challenges they are facing (Perron, 2002). Several authors (Bar-Lev, 2008; Salem et al., 1997; Tichon & Shapiro, 2003) also suggested that emotional self-disclosure can create a sense of intimacy between the members and thus helps elicit empathy and emotional support by conveying a story others can easily relate to. Perron (2002) found

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that online disclosure can serve a cathartic function, particularly disclosure of negative emotions or emotionally traumatic events difficult to disclose in face-to-face situations. Klemm and Wheeler (2005) also found that cancer caregivers in their online support group disclosed negative emotions towards the patient or the cancer, such as anger, fear, frustration and sadness, which could be difficult to express in front of family and friends.

As well as being useful to the author, personal disclosure can be used to help other members. Messages containing disclosure of personal feelings or experiences can also be used to provide support to other members (Tichon & Shapiro, 2003; van Uden-Kraan et al., 2008c). Sharing personal experiences and feelings can be used to help reassure other members and to validate their own feelings and experiences (van Uden-Kraan et al., 2008c). By describing how they dealt with a particular situation, members can also provide indirect advice to others facing similar challenges (Pfeil et al., 2009). Personal experiences with treatment modalities, outcomes and side-effects have been frequently used by members of prostate cancer online support groups to help other members make a more informed decision about treatment and to better prepare for future treatment and recovery (e.g. Gooden & Winefield, 2007; Huber et al., 2010). Not surprisingly, studies suggest that disclosure of personal experiences with cancer is more common amongst prostate cancer patients than emotional self-disclosure (e.g. Owen et al., 2004).

#### **3.3.4.4 Summary**

A large body of research indicates that the members of online support groups can experience similar beneficial processes to those observed within face-to-face supportive interactions. Provision of informational and emotional support and personal disclosure have been particularly frequently noted as therapeutic processes within the majority of

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online support groups. Encountering other people who share a common health concern has also been found to be valuable to online support members, allowing them to find unique understanding as well as compare experiences and feelings, which might have been ignored or misunderstood by family, friends and health care professionals. The majority of studies to date have been conducted within predominantly female or mixed gender online support groups and prostate cancer online support groups have been typically investigated in the context of informational and emotional support sharing, with the findings pointing towards informational support as the main process observed within these groups (Blank et al., 2010; Sullivan, 2003). There is therefore limited evidence available to fully evaluate the therapeutic potential of the processes occurring within prostate cancer online support groups and further research into this matter is necessary.

#### **3.3.5 Psychosocial benefits of participation in online support groups**

More recently, research has focused on the potentially beneficial outcomes of participation in online support groups and some authors have attempted to link participation in online support groups to improved psychosocial outcomes for the patients. The majority of these studies have used cross-sectional or qualitative designs, some used pre-post-test design and few randomised trials have been conducted to date (see Hong, Pena-Purcell & Ory, 2012 for a review). The majority of these studies have investigated outcomes for breast cancer patients or mixed cancer groups. At the time of writing, no studies have explicitly investigated outcomes for prostate cancer patients or their caregivers.

Some of the recent studies have indicated a link between participation in online support groups and psychological outcomes for patients. For example Lieberman and Goldstein (2005) observed significant improvement in levels of depression, post-traumatic growth

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and psychosocial well-being after six months of participation in a breast cancer-related online support group. The authors did not, however, employ a control group and therefore it was impossible to ascertain if participation in the group was in fact the main factor influencing this change. Conversely, the majority of randomised trials indicated no main effect of the intervention (participation in an online support group vs. waiting list) on any of the outcome variables, such as health-related quality of life and psychological and physical well-being of cancer survivors (Hoybye et al., 2010; Owen et al., 2005). Winzelberg et al. (2003) found a moderate positive effect of participation in a breast cancer-related group on depression, perceived stress and cancer-related trauma, but no significant effect on anxiety or coping was detected.

Barak, Boniel-Nissim and Suler (2008) argued, however, that participation in online support groups should be evaluated in terms of 'support' and not 'treatment'. As such, taking part in online support groups should not be expected to produce psychological, distress-related outcomes but general emotional relief and an increased sense of control, which the authors described as the two central components of empowerment.

#### **3.3.5.1 Helper-therapy principle online**

Some studies investigating psychosocial benefits of participation in online support groups utilised the 'helper-therapy principle' theory, according to which helping others offers psychosocial benefits to the helper as well as the person who requires help. Reissman (1965) proposed the 'helper-therapy principle' which states that those who help others help themselves. Helping others was associated with increased feeling of competence and mastery, social value and usefulness (Roberts et al., 1999). Providing help, and especially advice, to other members of a face-to-face support group for individuals with major mental

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illnesses was found to be a better predictor of psychological adjustment than receiving help (Roberts et al., 1999). Helping others is deeply embedded in the theory and practice of many face-to-face support groups, such as those based on the 12-step principles (Pagano, Post & Johnson, 2010). The 12-step groups emphasize that constant engagement in helping other alcoholics is a key to one's own recovery.

Findings from recent studies indicate that the 'helper-therapy principle' is also applicable to online support groups. Salem et al. (1997) defined helping processes in online support group context in terms of provision of informational and emotional support, advice and personal experience sharing. Although members report that they join online support groups predominantly to seek information and support (Bunde et al., 2006; Meier et al., 2007; Setoyama, Yamazaki & Nakayama, 2011), analysis of messages posted to online support groups has demonstrated that instances of support provision by far outnumber help seeking behaviours in online support groups (Blank et al., 2010; Klemm et al., 1998; Meier et al., 2007; Salem et al., 1997; Winefield, 2006). Furthermore, members of breast cancer, fibromyalgia and arthritis online support groups reported that the ability to help other members was one of the main reasons they participated in the groups. They mentioned several ways of helping people in their online groups, such as providing useful information, advice, support and personal experiences (van Uden-Kraan et al., 2008c).

Helping others in online support groups tends to be achieved mainly through posting helpful or supportive messages; therefore it is not surprising that perceived helpfulness is associated with the level of participation. For example, studies indicated that 'lurkers' felt they were helping others to a much lesser degree than 'posters' (Mo & Coulson, 2008; van Uden-Kraan et al., 2008b). On the other hand, Salem et al. (1997) reported that highly active members provided more social support, contributed more to the positive climate in

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the groups and offered more knowledge. In turn, more requests were directed to these members than to anyone else in the group.

Although, as it was highlighted earlier, studies indicate that providing help to other members in face-to-face support groups can lead to several benefits for the helper (Roberts et al., 1999), and that helping behaviours are also frequent in online support groups (Blank et al., 2010; Klemm et al., 1998; Meier et al., 2007; Salem et al., 1997; Winefield, 2006), few studies have explored the benefits of helping others in online support groups. Winefield (2006) interviewed two of the most active members of a breast cancer online group and found that these women had high levels of satisfaction derived from their activity in the group, as they enjoyed feeling useful and helpful. Providing help appears to be the primary motivation for long-term, prolific users of the groups, who tend to sacrifice a significant amount of time answering the queries posted by new members (Winefield, 2006). Members of fibromyalgia, arthritis and breast cancer online support groups also reported that the ability to help other members by providing support and advice led to an increased sense of self-esteem and self-value (van Uden-Kraan et al., 2008c).

### **3.4 An integrated approach to researching online support**

Literature reviewed thus far has highlighted several theoretical perspectives and frameworks which have been utilised to interpret the findings of research on online support group communication. For example, some studies employed the social support framework (e.g. Coulson, 2005) or the self-help mechanisms framework (Malik & Coulson, 2010) to investigate the potentially therapeutic processes that occur within the messages posted to the groups. Other studies drew upon theories such as 'helper-therapy principle' to explain the beneficial outcomes of participation in online support groups (Winefield,

2006). Although each of these theoretical perspectives and frameworks has its merits and helps shed light on certain aspects of online communication, there is a notable paucity of integrative models and frameworks which could help us better understand the growing phenomenon of online support in its entirety and allow us to explore its different components and the intricate relationship between them (LaCoursiere, 2001). To date, two integrated approaches to online social support have emerged from the literature: the theory of online social support (LaCoursiere, 2001) and the empowerment framework (van Uden-Kraan et al., 2008c, 2009).

#### **3.4.1 Theory of online social support**

The theory of online social support was developed by LaCoursiere (2001) as a response to the lack of a holistic approach to understanding the online support phenomenon within nursing theory and practice. This multidisciplinary theory combines aspects of nursing as well as psychological, sociological/communication science and anthropological perspectives. It consists of four main interrelated components of online social support: initiating events, mediating factors, online social support processes and outcomes.

According to the theory of online social support, participation in online support groups starts with an *initiating event*. LaCoursiere (2001) describes two major factors that can prompt an individual to seek online support: a change in health status or a change in perceived health. These changes may occur on an acute or a chronic basis; for example in the context of prostate cancer, the initial cancer diagnosis or the diagnosis of metastatic disease can be perceived as acute factors leading to an increased support seeking behaviours. The initiating events can be further influenced by various *mediating factors*, such as demographic characteristics (age, gender, marital status, being a patient or a

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caregiver), health factors (diagnosis, stage of the disease or treatment), perceived individual factors (availability of social support, stress, uncertainty, coping) and Internet use factors (history of Internet use, computer skills).

Online social support *processes* are the focal concept of this theory and can be described as 'the processes of initiating, participating and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health and psychosocial processing ability' (LaCoursiere, 2001, p. 66). According to this theory, online social support occurs through three filters: perceptual, which relates to the feelings and emotional state of the support seeker; cognitive, which represents the intellectual processing of the information exchanged by the online support group members; and transactional, which represents the conscious and unconscious evaluation of the information obtained through the exchanges occurring within online support groups, in order to determine personal relevancy of this support.

Further, LaCoursiere (2001) describes three types of *outcomes* of online social support: quantitative, qualitative and linking. Quantitative, measurable outcomes occur as a result of perceptual and cognitive processes of online social support. These outcomes can include psychosocial variables such as decreased stress, anxiety or depression; outcomes related to health status, for example increased functioning or improvement in physiological status; and perceived health outcomes, such as, for example, increased sense of empowerment. Qualitative outcomes are the result of the evaluative processes of online social support which occur through the transactional filter. These outcomes refer to the individuals' perceptions of their interactions in cyberspace. LaCoursiere (2001) proposes that the final outcome of participation in online support groups is *linking* which can be defined as 'the conscious and/or unconscious process of relating and weaving emerging awareness to



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previously learnt thoughts or information' (LaCoursiere, 2001, p.67). Linking results from both the quantitative and qualitative outcomes and thus it is the representation of the fusion of the online experiences encountered by an individual.

This theory has been developed with the view to help guide empirical research and future theory building. LaCoursiere (2001) argues, that through the evaluation of the initiating events, mediating factors, processes, outcomes and the relationships between them, the researcher can gain a more comprehensive picture of online social support and how individuals seeking support online make sense of their experiences. She also proposes that in order to achieve fuller understanding of the phenomenon of online support, both quantitative and qualitative outcomes should be measured using appropriate methods. For example, to assess the extent to which an individual has been affected by participation in online support (quantitative outcomes), quantitative methods should be used. The specific means to measure these outcomes may vary depending on the focal concept of interest, and can include various questionnaires or scales assessing physical and psychosocial phenomena. On the other hand, qualitative outcomes can be studied through the use of qualitative methods, such as phenomenology, or ethnography. Content analysis of messages exchanged within online support groups can also offer a valuable insight into the qualitative outcomes as well as the processes that occur within these groups. Finally, linking can be measured through triangulation of the findings obtained from both the quantitative and qualitative methodology. For example the researcher may want to measure improvement in quality of life as a result of participation in online support groups. They can strive to do so by using a quality of life scale and also by means of narrative interviewing. Consistency between findings obtained through quantitative and qualitative

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research would suggest that linking has occurred, while inconsistency would indicate absence of linking.

Although no published studies have empirically tested this theory as yet, the theory of online social support offers a comprehensive basis for future research into the online support group experience, which can be applied within any conceptual framework in social sciences and nursing.

### **3.4.2 The empowerment framework**

Another framework, offering a comprehensive approach to the exploration of the experiences of individuals who access online support groups, has emerged from the empirical work conducted by van Uden-Kraan and colleagues (e.g. van Uden-Kraan et al., 2008a, 2008b, 2008c, 2009). This framework links participation in online support groups to an increased sense of empowerment in patients living with somatic diseases.

In recent years there has been a shift from a traditional, paternalistic model of medical care towards greater involvement and empowerment of patients and their family members (NICE, 2008). For example, for prostate cancer patients and their partners, informational and social support have been recognized as the key resources required to increase their sense of empowerment and agency in relation to self (e.g. enhanced ability to cope, sense of control and self-esteem), other people (e.g. increased confidence and agency in communication with health care professionals and improved relationships with family members) and the cancer (e.g. increased ability to make informed decisions about treatment, acceptance of the treatment outcomes and ability to cope with the side-effects)(e.g. NICE, 2008).

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Past studies reported findings which suggested that participation in online support groups could have an empowering effect on the members. For example, Sharf (1997) has found that members of breast cancer online support groups reported experiencing several empowering outcomes of participation in their online support group, such as being better informed or having more hope for the future. Broom (2005a, 2005b) has noted that prostate cancer online support group members felt empowered to openly discuss their intimate problems with other men within the group. Dental phobia online support group members reported feeling empowered to tackle their fears and had increased confidence during dental appointments (Buchanan & Coulson, 2007). Although the findings of those studies highlighted the potential empowering effects of online support group participation, their main focus was not on patient empowerment, nor did they endeavour to present a comprehensive picture of the online support group experience.

The empowerment framework suggested by van Uden-Kraan and colleagues (2008c, 2009), offers a more holistic and focused approach, as it incorporates the two central components of the online support group experience, previously identified by LaCoursiere (2001): the processes occurring within online support groups and the outcomes of participation; and positions them within the concept of patient empowerment (Gibson, 1991; Rappaport, 1987). The authors propose that the empowering processes and outcomes are interrelated, and that the extent to which members experience empowering processes within their groups can help explain the levels of empowering outcomes of participation. This framework has emerged as a result of a 'bottom-up', mixed methods research process, which incorporated content analysis of messages posted to online support groups for arthritis, breast cancer and fibromyalgia patients; narrative interviews with the group members; and quantitative study in which the extent to which members experienced the

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empowering processes and outcomes was measured. Mixed methods approach has been previously identified as conducive to obtaining a fuller picture of the online support phenomenon (LaCoursiere, 2001).

The following sections of this chapter will describe in detail the components of the empowerment framework, including the concept of empowerment, empowering processes and outcomes and the possible relationships between the two.

### **3.4.2.1 Empowerment as a concept**

The concept of empowerment was introduced in 1981 by Rappaport who described it as a complex, multidimensional construct (Rappaport, 1987). Empowerment can be broadly understood as a process through which individuals, organisations and communities gain control and mastery over issues that concern them (Rappaport, 1987; Zimmerman, 1995). Patient empowerment was described in terms of enhanced communication between the patient and the health care professionals (Gibson, 1991), greater ability to self-manage the condition as well as patients' autonomy and right to take responsibility for their own care and treatment-related decisions (Anderson & Funnel, 2009). In the concept of patient empowerment the emphasis is placed on patients' need to obtain information about their disease and available treatment options and other aspects of health care, which is necessary to enable their active participation in treatment decision-making. Increased knowledge and participation in making important decisions about their health-care can in turn enhance patients' sense of control over their illness and life in general (Ouschan, Sweeney & Johnson, 2000).

Some authors propose that empowerment should be considered as both a process and as an outcome (Gibson, 1991; Zimmerman, 1995). The empowering processes refer to *how*

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people become empowered while the empowering outcomes reflect the consequences of those processes (Zimmerman, 1995). Empowering processes can be described as a series of experiences through which individuals create or receive an opportunity to gain mastery and control over their lives and increase their ability to participate in making decisions that affect them. They allow people to have a better awareness of their goals and ways to achieve them as well as provide those lacking an equal share of valued resources to gain access to and control over those resources (Cornell University Empowerment Group, 1989, as cited in Zimmerman, 1995). According to Zimmerman, empowering processes may lead to a variety of empowering outcomes, such as enhanced communication with health care providers, improved ability to actively participate in decision-making and increased control over one's life, disease and treatment regime. Empowering processes can also lead to other positive outcomes, such as improvement in mental and physical health, adoption of certain health behaviours, such as diet or exercise and greater quality of life.

#### **3.4.2.2 Empowering processes in online support groups**

In their initial work, van Uden-Kraan et al. (2008a, 2008c) conducted a content analysis of online messages and interviewed a number of women accessing breast cancer, fibromyalgia and arthritis online support groups, to identify which of the processes occurring within online support groups were perceived as empowering by the members. The content analysis suggested the existence of several empowering processes within the messages posted to the groups and the interviews confirmed that the members perceived these processes as contributing to the increase in their sense of empowerment. The authors identified the following empowering processes: information provision, encountering emotional support, finding recognition and understanding, sharing experiences and helping others. In the subsequent studies, the authors tested the extent to

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which members experienced each of those processes (van Uden-Kraan et al., 2009). These processes reflect many of the processes discussed previously (see 3.3.4), which were described in past studies as beneficial or therapeutic for the members and identified as frequently occurring within online support group communication (e.g. Coulson, 2005; Gooden & Winefield, 2007; Malik & Coulson, 2010; Sullivan, 2003).

'Information provision' was found to be the most frequently experienced empowering process, and members rated the information exchanged as understandable and valuable, albeit not always new. The process of 'finding recognition and understanding' was the second most commonly experienced by online support group members. It refers to the process of finding others in similar circumstances, relating to or recognizing oneself in the stories of others, and sharing empathy and communicating understanding of another person's feelings or experiences. 'Encountering emotional support' was described by all the women interviewed by the authors as a process of comforting and reassuring one another, sharing friendship and love. 'Sharing experiences' and 'helping others' were also experienced by the members, albeit to a lesser extent, and these processes mainly involved sharing their own stories of dealing with the disease or treatment, offering useful information and advice (van Uden-Kraan et al., 2008c).

#### **3.4.2.3 Empowering outcomes of online support group participation**

According to the empowerment framework, the second central component of the online support group experience includes empowering outcomes of participation (van Uden-Kraan et al., 2008c, 2009). The outcomes reported by female members of arthritis, breast cancer and fibromyalgia online support groups include 'being better informed', 'enhanced social well-being', 'improved confidence in communication with health care professionals',

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'improved acceptance of the disease', 'increased confidence in treatment' and 'increased optimism, control and self-esteem' (van Uden-Kraan et al., 2008c, 2009). Other authors also reported that these outcomes are commonly experienced by members of online support groups dedicated to various types of cancer (Bartlett & Coulson, 2010). No studies to date, however, specifically focused on the empowering effects of online support group participation on individuals affected by prostate cancer or indeed male members of online support groups.

#### ***3.4.2.3.1 Being better informed***

Studies have reported that the most frequently experienced empowering outcome of participation in online support groups was 'being better informed' (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). Members of fibromyalgia, arthritis and cancer online support groups reported having greater sense of cognitive mastery over their disease due to being better informed as patients and understanding their illness better, as an outcome of participation in online support groups (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2008c; 2009). Van Uden-Kraan et al. (2008c) have found that the patients who joined online support groups soon after their diagnosis reported benefiting the most in terms of improved knowledge. Those who joined the groups later in their illness trajectory had already gathered a lot of knowledge from other sources, such as their health care professionals, books and other websites. Nonetheless, they also noted that the information exchanged within the groups helped them make sense of the knowledge they had. Furthermore, some of the women in a Scandinavian breast cancer group SCAN-BC-LIST interviewed by Hoybye et al. (2005) have reported that being better informed about their cancer helped them regain 'power over their bodies', which they felt they lost as a result of the disease. Information and support offered within the group also empowered these

women to take active action in situations, where they previously thought that nothing could be done.

#### ***3.4.2.3.2 Enhanced social well-being***

While some women, for example breast cancer patients and prostate cancer caregivers, reported that cancer diagnosis resulted in significant loss of support from their existing social networks which led to an increased sense of loneliness and social isolation (Bottoroff et al., 2008; Hoybye et al., 2005), online support groups has been found to be a useful medium through which new social networks can be forged (van Uden-Kraan et al., 2008c). Indeed 'enhanced social well-being' has been found to be the second most commonly experienced empowering outcome amongst fibromyalgia, arthritis and cancer online support group users (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). Building personal relationships with other women within online support groups has been found to be particularly important within fibromyalgia, arthritis, breast and ovarian cancer online support groups, where members were able to find others in a similar situation to their own and, as a result, they felt less lonely and less isolated. Some members reported continuing their online relationship offline, via telephone or arranging personal meetings (Sullivan, 2003; van Uden-Kraan et al., 2008c).

#### ***3.4.2.3.3 Improved confidence in communication with health care professionals***

Some members have suggested that information, advice and support obtained within online support groups can lead to an increased ability to effectively communicate with health care professionals (van Uden-Kraan et al., 2009). Members of fibromyalgia, arthritis and breast cancer groups felt that they learnt new, useful strategies for preparing for the consultation; they felt more confident in asking questions and less shy to approach the



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physician. Some also learnt to be less dependent on their physician and consult group members in all minor issues and only engage in communication with the doctor if really necessary (van Uden-Kraan et al., 2008c).

Sullivan (2003) reported that prostate and ovarian cancer patients used their online support groups to become better educated and thus be more active and equal partners in their own healing. They believed that having the necessary knowledge increased their sense of control in their encounters with health professionals and thus improved their chances of getting the best care possible. Some members indicated in their messages that the knowledge obtained within the group helped them weigh the pros and cons of their doctors' decisions and they felt confident to challenge these decisions if they didn't think they were appropriate.

Conversely, some studies (e.g. Kirschning & von Kardorff, 2008; Malik & Coulson, 2008a) indicated that patients who brought information obtained from the Internet to the consultation often encountered a negative reaction from their physician. Kirschning and von Kardorff (2008) reported that although the majority of patients openly discussed online information with their doctors, only 50% of them had positive experiences in their endeavours. A third of male participants and a fifth of the women experienced rejection and irritation from their health care professional. Bartlett and Coulson (2010) reported that 82% of respondents shared online information with physician, out of which 16% felt dissatisfied with the reaction. Kirshing and von Kordoroff (2008) speculated that women suffered negative reactions less frequently as they used more acceptable ways of conveying the information to the doctor. This was reflected in the findings of the study by Malik and Coulson (2008a), which suggested that women tended to present online information as something they have learnt from a friend.

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Broom (2005b) and van Uden-Kraan et al. (2010) investigated the health professionals' perceptions of patients 'empowered via the Internet'. Findings of the studies conducted by Broom (2005b) with a group of Australian prostate cancer specialists indicated that physicians find online information to cause confusion, information overload, disruption to the doctor-patient relationship and to be a general waste of time. They worried that vulnerable patients may lose their trust in their medical team and seek treatments that are not appropriate for them. Van Uden-Kraan and colleagues (2010), however, found that majority of doctors were moderately positive about their patients' use of online sources of information, but the majority were not familiar with the health-related sites available on the Internet and rarely or never referred patients to health-related websites or online support groups.

### ***3.4.2.3.4 Improved acceptance of the disease***

Participation in online support groups has also been found to have a positive effect on how participants feel about their disease (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). They were better able to accept it and deal with it more effectively and calmly. Knowing there were others suffering from similar or worse problems helped members feel less alienated and put their situation into perspective. Some members learnt to be more positive about their disease and learnt new coping strategies from other participants in the group (van Uden-Kraan et al., 2008c).

### ***3.4.2.3.5 Feeling more confident about the treatment***

Research also suggests that the experiences of other members who have undergone similar treatment helped participants feel more confident about their own treatment decision (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). Some members indicated that

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reading about others' experiences with similar treatment helped them feel more at ease, while others felt that it led them to realising their prescribed treatment was not appropriate for their needs and they ended up changing it (van Uden-Kraan et al., 2008c). Furthermore, research suggests that cancer patients tend to access online support groups before treatment (Setoyama et al., 2011) and that a large proportion of communication within online support groups relates to treatment, particularly in groups dedicated to prostate cancer (Huber et al., 2010). Participation in these groups could therefore potentially help inform newly diagnosed patients' decisional processes. Further research is needed, however, to fully understand the impact participation in online support groups has on treatment decision-making in prostate cancer patients.

#### ***3.4.2.3.6 Increased optimism, control and self-esteem***

Enhanced psychological well-being, increased optimism, hope for the future and control were mentioned as some of the effects of participation in online support groups by patients with breast cancer, fibromyalgia and arthritis (Hoybye et al., 2005; Sharf, 1997; van Uden-Kraan et al., 2008c). Members appreciated the ability to read personal stories of other survivors who lived many years post cancer diagnosis; they felt these stories were reassuring and gave them hope for their own survival. Some felt knowing that others were doing well helped them regain control over their lives.

Recent studies indicate that esteem support is exchanged within online support groups; members often pay each other compliments and praised each other's skills and abilities as well as expressed thanks and gratitude (e.g. Coursaris & Liu, 2009; Mo & Coulson, 2008). As a result, members experienced increased self-esteem, as they felt more useful and appreciated by other members (van Uden-Kraan et al., 2008c).

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The existing studies report, however, that increased optimism and control as well as enhanced self-esteem were experienced to the lowest extent by the fibromyalgia, arthritis and cancer online support group members (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009).

### **3.4.2.4 Relationship between the processes and outcomes**

Finally, the empowerment framework suggests, that the empowering processes and outcomes are interrelated, however few studies to date have investigated the relationship between the processes occurring in online support groups and the outcomes experienced by the members (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). The existing research suggests that the empowering outcomes can be significantly predicted by one or more of the processes experienced within the groups.

Empowering processes helped explain around 30% of the variance in outcomes 'being better informed' and 'enhanced communication with the health care professionals', suggesting a significant relationship between participation in online support groups and increased knowledge and agency in medical encounters (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). Processes that most significantly explained these outcomes were 'provision of information', 'encountering emotional support' (van Uden-Kraan et al., 2009) and 'encountering similar others' (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). As previous studies indicate that exchange of expert information and experiential knowledge is the main process occurring within the prostate cancer online support groups, it could be speculated that prostate cancer patients also benefit in terms of 'being better informed' and having 'enhanced communication with health care professionals', however further research is necessary to confirm this.

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Both studies by Bartlett and Coulson (2010) and van Uden-Kraan et al. (2009) indicated that processes significantly predicting levels of 'enhanced social well-being' were 'encountering emotional support' and 'sharing experiences'. This confirms findings from the past qualitative studies which suggested that forging new relationships, learning from the experiences of others and emotional support within online support groups can help members achieve reduced social isolation and improve their social well-being through promoting a sense of empathy and mutual understanding as well as commonality of feelings and experiences (Hoybye et al., 2005; van Uden-Kraan et al., 2008c). Although experience-sharing was commonly observed in prostate cancer online support groups, men tend to share their experiences with cancer and treatment rather than disclose their emotions or personal experiences. Emotional support is also less frequently observed in prostate cancer online support groups than information exchange and communication in these groups is focused on education and enhancing treatment decision-making (Huber et al., 2010; Sullivan, 2003). Therefore further research into the role of prostate cancer online support groups in enhancing their members' social well-being could shed additional light on this issue.

According to Bartlett and Coulson (2010), 'encountering similar others' and 'encountering emotional support' significantly predicted members' 'acceptance of illness', and these predictors explained 23% of the variance. Van Uden-Kraan et al. (2009), however, found no significant predictors of this outcome, indicating that participation in online support groups affects perceptions of illness only to a small degree.

Processes occurring in online support groups explained the smallest proportion of variance (16-18%) in outcomes 'increased optimism and control' and 'enhanced self-esteem' (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). 'Increased optimism and control'

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were significantly predicted by the process of 'encountering similar others', which confirmed that improved mental well-being can be linked to the fact that online support groups offer patients the chance to meet others like them, who are doing well and are successfully managing their disease for many years. Not surprisingly, 'encountering emotional support', a concept which incorporated items measuring esteem support, such as receiving compliments and being chosen as a confidant by another member, was found to be the only significant predictor of enhanced self-esteem (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009).

A recent study by Mo and Coulson (2012) has suggested there is a relationship between online support group use, the empowering processes within online support groups and improved psychosocial outcomes. The authors found that participation in online support groups for individuals living with HIV/AIDS can result in participants experiencing empowering processes such as receiving information and social support, finding positive meaning and helping others. These processes were in turn related to improved psychosocial outcomes for the members, as measured by self-care self-efficacy, coping and quality of life.

It is, however, necessary to point out that only a small number of studies have explored the relationships between the processes and outcomes and although overall their findings support the notion that empowering outcomes can be partially predicted by the processes, some differences between various online support groups have also been highlighted. This suggests that the findings from the existing research should be generalised onto prostate cancer online support groups with caution. Further research involving prostate cancer online support groups is needed to better understand the processes, outcomes that occur within these groups and the relationships between them.

### **3.5 Summary**

The existence of potentially beneficial processes within online support groups has been well documented in the extant literature, which suggests that online support groups provide a venue for the exchange of social support, helping others and personal disclosure. Although relatively few studies have investigated participation in male online support groups, several studies suggest that the exchange of factual and experiential knowledge is one of the most frequently observed processes within prostate cancer online support groups. Little is known about the online experiences of partners and family members of prostate cancer patients.

Few theoretical perspectives and frameworks have been applied to research on online support groups, and the scarcity of integrated models or frameworks is particularly notable. The empowerment framework proposed by van Uden-Kraan et al. (2008c, 2009) offers a comprehensive approach to exploring the online support group phenomenon, by integrating its key components, such as the potentially empowering processes, empowering outcomes and the possible relationships between the two. Despite the growing interest in the empowering qualities of participation in online support groups, few studies to date have investigated the empowering outcomes of participation. Nonetheless the findings of the existing literature suggest that as a result of online support group participation, members can achieve a number of empowering outcomes, such as 'being better informed', 'enhanced social well-being', 'improved confidence in communication with the health care professionals', 'improved acceptance of the disease', 'increased confidence in treatment' and 'increased optimism', 'increased control' and 'enhanced self-esteem'.

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In recent years, following the shift towards greater involvement of patients and their families in treatment decision-making, growing numbers of prostate cancer patients and their partners have been turning to online support groups for information and support. The literature to date, however, has focused on the outcomes of participation in predominantly female or mixed gender groups for patients and there is a particular paucity of studies specifically investigating the role of online support groups in enhancing the sense of empowerment in prostate cancer patients, their partners and family members. The literature on online support suggests that improved access to information, experiential knowledge and social support in online support groups could also potentially help improve empowering outcomes in prostate cancer patients, their partners and family members; further empirical research into this issue is, however, necessary.



## **Chapter Four: Research rationale and aims**

### **Chapter overview**

Based on the literature reviewed in the introductory chapters of this thesis, the current chapter identifies gaps in our understanding of the online support group experience and presents a rationale for undertaking the research into the experience of individuals affected by prostate cancer who access online support groups. The philosophical foundations underpinning the choice of a mixed-methods approach employed are discussed and the overarching aims guiding the research process are also presented.

### **4.1 Research rationale**

In recent years, a novel and promising opportunity for accessing social support by individuals affected by a variety of diseases and conditions has been identified: online support groups (Finn, 1999; Sharf, 1997). As discussed in Chapter 3, participation in online support groups is free from the spatial and temporal barriers typically associated with face-to-face support and offers a safe and anonymous environment in which members can share feelings and experiences difficult to disclose face-to-face (Klemm et al., 1998; Broom, 2005a). A growing body of research has also reported the existence of a number of therapeutic processes within online support group communication, such as exchange of informational and emotional support; opportunity to communicate with others in similar situation; self-disclosure and sharing personal experiences (Mo & Coulson, 2008; Malik & Coulson, 2010; Tichon & Shapiro, 2003). Recent studies have suggested that the processes observed in online support groups can help foster empowerment in members and the authors have also pointed towards the possible relationships between these processes and

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empowering outcomes of participation, such as increased knowledge or reduced social isolation (van Uden-Kraan et al., 2008c, 2009).

The literature presented in Chapter 3 has, however, identified some gaps in our understanding of the online support group experience, particularly in the context of prostate cancer. The majority of the existing literature has focused on predominantly female or mixed gender groups; research pertaining to online support group use amongst individuals affected by prostate cancer is largely limited to the issues of gendered communication, informational/emotional support and decision-making (e.g. Blank et al., 2010; Gooden & Winefield, 2007; Huber et al., 2010; Seale, 2006; Sullivan, 2003). Few studies have investigated other beneficial processes occurring in prostate cancer online support group communication (Broom, 2005a, 2005b) and there is a particular paucity of studies investigating the effects participation in prostate cancer online support groups can have on the members. Furthermore, little is known about the potential limitations of online support groups as a source of support and information, both in general and for individuals affected by prostate cancer in particular.

The following empirical chapters of this thesis will therefore aim to address some of the gaps in our understanding of the nature of communication within prostate cancer online support groups by presenting the findings of novel and in-depth research, exploring the experiences of the individuals accessing prostate cancer online support groups.

As there is limited literature in the area of online support groups in the context of prostate cancer, an exploratory approach was considered to be appropriate for the research undertaken in this thesis. Exploratory research is not concerned with testing predetermined hypotheses but rather with gaining a broader understanding of a particular

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phenomenon, issue or problem from the perspective of the participants themselves. However, as Bryman (2004) points out, even a researcher engaging in an exploratory investigation should consider the theoretical and conceptual frameworks that guide their research process. As discussed in detail in Chapter 3, the empowerment framework proposed by van Uden-Kraan and colleagues (2008c, 2009) offers an integrated approach to the investigation of online support group communication. This framework encompasses the two main components of the online support group experience – the processes occurring within the groups and the outcomes of participation; it also allows for the exploration of the relationships between the processes and the outcomes.

Furthermore, the context of patient empowerment is particularly applicable to the experiences of individuals affected by prostate cancer, as it taps into all the main challenges and desired outcomes pertinent to this group of patients and their family members. As discussed in previous chapters, there has been a shift in health care towards greater involvement and empowerment of patients and their family members. Empowering outcomes such as increased knowledge about disease and treatment, improved communication with health care professionals, involvement in treatment decision-making, mastery and control over disease, treatment and recovery as well as reduced social isolation are the desired outcomes for prostate cancer patients and their family members, as described within recent policy guidelines (e.g. NICE, 2008). Research suggests that these outcomes can be achieved through informational and social support from family, friends, health care professionals and support groups, however the literature discussed in Chapter 2 highlighted several barriers reported by prostate cancer patients and their family members to accessing the traditional sources of support. It was considered to be of particular importance, when investigating the communication in prostate cancer online

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support groups, to explore their potential to foster empowerment in members. Therefore the empowerment framework (van Uden-Kraan et al., 2008c, 2009) was deemed to provide an appropriate context for the investigation of the experiences of the individuals affected by prostate cancer who access online support groups.

LaCoursiere (2001) pointed out that online support is a complex phenomenon, and therefore, in order to get a more comprehensive understanding of the experiences of online support group members, researchers exploring this phenomenon could benefit from employing a mixed-methods approach. Qualitative methodology, such as narrative interviews and content analysis of messages posted to the groups could offer an in-depth understanding of the empowering processes and outcomes experienced by the individuals accessing online support groups. Quantitative methodology, on the other hand, could help examine the extent to which these processes and outcomes are experienced by the group members.

### **4.2 Philosophical foundations and the rationale for a mixed-methods approach**

There are two main research strategies in social science research, qualitative and quantitative, each underpinned by different ontological and epistemological positions that lie at the opposite ends of the spectrum (Johnson & Onwuegbuzie, 2004). Quantitative research is underpinned by the philosophical position of positivism and thus is concerned with facts, causal relationships and confirmation or falsification of hypotheses. Social phenomena, according to this perspective, are independent from the observer and, much like physical phenomena, can be studied using objective, scientific methods, which can produce time- and context-free generalizations (Johnson & Onwuegbuzie, 2004). According to the positivist paradigm, researchers should eliminate personal biases, remain

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neutral and uninvolved with the research objectives, and test or empirically justify research hypotheses. Thus positivist researchers employ scientific, quantitative methods to investigating the phenomena in question (Al-Hamdan & Anthony, 2010; Johnson & Onwuegbuzie, 2004).

Qualitative approaches, on the other hand, are underpinned by the relativist/social constructionist philosophy. In contrast to the realist perspective, from this epistemological position, no one objective reality exists and people construct and communicate meaning for both self and the social world, through language. According to the relativist position the researcher (observer) and the phenomena are intertwined and cannot be separated (Al-Hamdan & Anthony, 2010; Johnson & Onwuegbuzie, 2004).

Although some purists on each end of the spectrum argue these approaches should not be mixed, as they come from different philosophical positions and are not compatible (Johnson & Onwuegbuzie, 2004), there are several limitations to using single approach research designs, which arise from the limitations of each methodology. For example, quantitative methods do not allow for an in-depth exploration of human behaviours and feelings, their underlying motives, perceptions and experiences and therefore can provide only a superficial picture of the phenomenon under investigation. Furthermore, quantitative research does not take into consideration the complexities of the social world in which the phenomena occur. Conversely, qualitative methodology provides opportunities for an in-depth exploration of motives and experiences; however it is susceptible to major methodological flaws, such as researcher bias, lack of concern with generalizability of findings and low reliability (Al-Hamdan & Anthony, 2010; Johnson & Onwuegbuzie, 2004).

### 4.3.1 Triangulation in social science research

Considering the strengths and limitations of each of the two approaches, Johnson and Onwuegbuzie (2004) argue the necessity to introduce an alternative paradigm which would lie in the middle of the spectrum and could help bridge the schism between the two opposing paradigms, by offering a workable solution for combining quantitative and qualitative approaches to investigating the same phenomena (Johnson & Onwuegbuzie, 2004). They further argue, that combining methodologies has several advantages, as it can help elicit a fuller description and understanding of the phenomena in question as well as maximise validity and rigour of the enquiry, by drawing on the strengths and minimising the shortcomings of different methodologies (Johnson & Onwuegbuzie, 2004).

The classic type of combining quantitative and qualitative methods in studying the same phenomenon is triangulation (Hussein, 2009). Hussein (2009) describes several types of triangulation identified in the literature, including *data source triangulation*, which refers to the use of data from multiple sources, for example diverse groups of service users; *theoretical triangulation*, which refers to using more than one theoretical perspective to interpreting data; *investigator triangulation* which refers to using two or more researchers to collect, analyse or interpret the dataset; analysis triangulation, which refers to using multiple methods of analysing the same set of data for validation purposes; and *method triangulation*, which refers to the use of various methods when studying the same phenomenon. Method triangulation can occur at the level of research design or data collection, resulting in two types of method triangulation: between-methods, where the researcher utilizes both qualitative and quantitative methods to explore a single phenomenon; and within-methods, where the researcher uses two different methods of data collection within qualitative or quantitative paradigm. Between-methods triangulation

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aims to increase convergent validity, while within-methods triangulation is concerned with improving the internal validity of the findings (Hussein, 2009; Jick, 1979).

Johnson and Onwuegbuzie (2004) describe several benefits of methods triangulation, i.e. employing both qualitative and quantitative methodologies to investigate a single phenomenon. First, they argue that qualitative data can add meaning to quantitative data, while quantitative data can add precision to qualitative data. Second, thanks to using a mixed-methods approach, rather than being confined to a single method of enquiry, the researcher can address a broader and more complete set of research questions. Third, the limitations of one method can be buffered by the strengths of another in mixed-methods design research. Fourth, through corroboration and convergence of findings, research using both quantitative and qualitative methodologies can provide stronger evidence for a conclusion. Fifth, mixing methods may help uncover a unique variance, which might have been missed when using a single method. Finally, it 'can produce a more complete knowledge necessary to inform theory and practice' (Johnson & Onwuegbuzie, 2004, p.21).

### **4.3.2 Triangulation in the current study**

As the phenomenon of online support is a complex one, it was considered appropriate to employ a mixture of methods to help us gain a more complete picture of its various components and the interplay between them. The research was therefore conducted from a subtle realist/pragmatist stance. Both between-methods and within-methods types of triangulation were employed. This approach could arguably help us gain a more in-depth knowledge of members' motives, perceptions and experiences within the groups, through the use of various qualitative methods of data collection such as analysis of the messages or open-ended, qualitative questionnaires as well as help quantify those experiences

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through the use of quantitative questionnaires. Triangulation of methods could also help uncover any potential similarities and/or difference between data obtained via different methods.

### **4.3 Research aims**

In summary, the current research adopts a mixed-methods approach to exploring the experiences of individuals affected by prostate cancer who access online support groups. The research, guided by the empowerment framework proposed by van Uden-Kraan and colleagues (2008c, 2009), intends to address the following overarching research aims:

**Aim one: To explore the potentially empowering processes occurring within prostate cancer online support groups.**

**Aim two: To explore the potentially negative aspects of participation in prostate cancer online support groups.**

**Aim three: To explore the empowering outcomes of participation in prostate cancer online support groups.**

**Aim four: To explore the relationship between the potentially empowering processes and outcomes.**



## **Chapter Five: Study One. Content analysis of messages posted to prostate cancer online support groups**

### **Chapter overview**

Research suggests that participation in online support groups can provide the members with an opportunity to experience a range of therapeutic processes which can help foster empowerment. Although individuals affected by prostate cancer are known to be frequent users of online support groups, little is known about the empowering processes that take place in prostate cancer online support groups. This chapter presents a qualitative study which undertook a content analysis of 631 messages posted to two prostate cancer online support groups. The main aim of the study was to establish which empowering processes could be identified within the naturally occurring conversations and to assess the extent to which these processes could be observed. The analysis pointed towards the existence of six processes. Most frequently observed were 'information provision' (in 45% of messages) and 'sharing personal experiences' (41.5%), followed by 'provision of emotional support' (37.6%), 'provision of esteem support' (18.2%) and 'universality' (9.4%). The sixth process identified in this study, 'discussion of sensitive issues', was found in 25.7% of messages. Some differences relating to the empowering processes observed in messages posted by the patients and family members were also identified. The results are discussed in the context of the existing research pertaining to online support and prostate cancer.

## **5.1 Introduction**

Chapter 3 has provided a detailed description of beneficial processes observed in online support group communication, which have been found to foster empowerment in members (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2008c; 2009). The majority of existing studies have concentrated on the communication within female or mixed-gender groups for patients and little is known about the potentially empowering processes that occur within prostate cancer online support groups, as research in this area has typically focused on the issues related to emotional and information support exchange. Furthermore, little is known about the use of prostate cancer online support groups by individuals other than the patients, such as the caregivers.

In past research, content analysis of messages posted to online support groups provided a valuable insight into the communication exchanged between members (Malik & Coulson, 2010; Mo & Coulson, 2008; van Uden-Kraan et al., 2008a). Therefore a thorough investigation of the naturally occurring conversations within prostate cancer online support groups was considered to be a useful method in the initial stage of the current research. This approach could help shed more light on the extent to which potentially empowering processes occur within the messages posted to prostate cancer online support groups. The current study was therefore undertaken to help address the first aim of the research programme, to explore the potentially empowering processes occurring within prostate cancer online support groups.

### **5.1.1 Aims**

The overarching aim of the current study was to examine the extent to which the potentially empowering processes, previously identified in female and mixed gender online

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support groups, are prevalent in the naturally occurring communication in prostate cancer online support groups. Specifically this study aimed to address the following research questions:

- To what extent are potentially empowering processes observed in naturally occurring communication in prostate cancer online support groups?
- Who uses prostate cancer online support groups?
- What are the similarities and/or differences in the messages posted by various groups of members such, as patients and family members?

## **5.2 Methods**

### **5.2.1 Data collection**

#### **5.2.1.1 Method of data collection**

Messages posted to online support groups have been found to be a rich source of naturally occurring qualitative data which can help the researcher understand how online support groups are utilised by their members and how the members engage in the discussions about their experiences with the disease or condition (e.g. Blank et al., 2010). Online researchers have noted that the anonymity of online support groups facilitates personal disclosure (Joinson, 2001) and that the messages posted to the online support groups offer a unique, in-depth insight into the feelings, thoughts and experiences of the members that is rarely available in face-to-face communication (Robinson, 2001). Furthermore, analysis of messages can allow us to observe the processes that occur between members, within the

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natural context of conversations (e.g. Coulson, 2005, Malik & Coulson, 2008a, Mo & Coulson, 2008) and provides the opportunity to assess the differences and similarities in communication exchanged by various member groups, for example male and female patients (e.g. Sullivan, 2003) or patients and caregivers (e.g. Seale, 2006). As noted by Huber and colleagues (2010), the majority of conversations about disease, such as prostate cancer, and the related treatment decision-making processes usually occur in private, between the patient and the physician or between family members. Messages posted to online support groups provide a unique record of such discussions within public spaces.

The analysis of naturally occurring messages was therefore deemed to be an appropriate method to address the aims of this study. Messages collected from prostate cancer online support groups could provide valuable data for an initial exploration of the potentially empowering processes within the groups. This type of data could also allow us to explore the similarities and differences between the processes that occur within messages posted by various groups of members, for example by the patients and family members.

### **5.2.1.2 Data collection procedure**

The search engine Google™ was employed to identify publicly available prostate cancer online support groups, using the search terms 'support group' or 'forum' or 'board' or 'chat' and 'cancer' or 'prostate' or 'prostate cancer'. Online support groups related to cancer in general were examined in order to establish if they had a separate board for prostate cancer patients. Only publicly available prostate cancer online support groups were eligible for the study (see section 5.2.4 Ethical considerations). Groups were deemed publicly available if they did not require a login to read messages, had over 100 messages posted each month and had 100 members or more. Five such groups were identified and two were

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selected for the study, based on the high volume of messages being posted to them and the large number of members contributing. From messages posted between 1 June and 31 October 2007 ( $N_{\text{Group1}}=594$  and  $N_{\text{Group2}}=1,271$ ), a random number generator was used to select a total of 100 threads containing 682 messages, which constituted a sample size similar to those found in past studies on online support groups (e.g. Coulson, 2005; Finn, 1999). Furthermore, during data analysis no new categories were discovered in the final 20% of the messages, therefore the decision was made that saturation of the data has been reached and no additional data collection was deemed necessary. A total of 50 threads from Group 1 (238 messages) and 50 threads from Group 2 (444 messages) were sampled. Entire threads were sampled, rather than individual messages, so that each message could be analysed in context.

### **5.2.2 Data analysis**

#### **5.2.2.1 Data analysis method**

The data were analysed using content analysis. Content analysis is a method of summarising large sets of qualitative data, allowing the researcher to generate generalizable conclusions about the phenomenon within the manifest contents of large dataset, rather than offering a detailed and in-depth picture of a particular case (Neuendorf, 2002). Neuendorf (2002) broadly defined content analysis as a systematic and objective method of describing and quantifying message characteristics. Content analysis is often employed in research concerned with developing an understanding of the meaning of communication, and has been previously used to analyse textual data, such as newspaper articles or transcripts of television shows (Neuendorf, 2002). A number of recent studies employed content analysis to explore the naturally occurring communication within

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messages posted to online support groups (e.g. Coulson et al., 2007; Malik & Coulson, 2010; Mo & Coulson, 2008; Coursaris & Liu, 2009). Content analysis was therefore considered an appropriate method for this stage of the current research, which was predominantly concerned with the extent to which beneficial processes occur within the messages posted to prostate cancer online support groups.

Elo and Kyngas (2008) suggest that a deductive approach to content analysis is useful in order to test an existing theory or framework, or to compare categories at different time points or within different datasets. As this study aimed to explore the prevalence of potentially empowering processes, which were previously identified in studies on online support (van Uden-Kraan et al., 2008c), a deductive content analysis was employed to analyse the data (Elo & Kyngas, 2008). The data were therefore analysed using a coding framework created on the basis of previous research concerned with potentially empowering processes occurring within online support groups (van Uden-Kraan et al., 2008c). Van Uden-Kraan et al. (2008c) described five categories of processes, identified as beneficial and potentially empowering by members of fibromyalgia, arthritis and breast cancer online support groups. These included two of the social support categories: 'information exchange' and 'encountering emotional support', as well as 'finding recognition'; 'sharing personal experiences'; and 'helping others'. Research exploring the empowering potential of online support group communication is relatively recent, and few studies to date have used the empowerment framework (Bartlett & Coulson, 2010; Mo & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009). Therefore, to improve content validity of the coding framework (Neuendorf, 2002), other studies on online support communication were reviewed in order to identify processes that could also have empowering potential for the members (Broom, 2005a; Coulson et al., 2007; Malik &

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Coulson, 2010). These studies applied various coding categories to online support messages, such as Cutrona and Suhr's social support categories (e.g. Coulson et al., 2007; Coursaris & Liu, 2009; Mo & Coulson, 2008) or self-help mechanisms (Malik & Coulson, 2010). Social support categories frequently occurring in online support groups included 'informational support'; 'emotional support'; and 'esteem support'. Categories relating to self-help mechanisms adapted for online support communication by Malik and Coulson (2010) included 'requesting information and advice'; 'provision of information and advice'; 'provision of social support and empathy'; 'sharing personal experiences'; 'universality'; 'friendship'; 'gratitude'; 'creative expressions'; and 'chit-chat'. In addition, Broom (2005a) recognised another potentially beneficial process: 'discussions of sensitive issues', which could be particularly pertinent in the context of prostate cancer. The coding categories for the current study were therefore chosen to reflect all aspects of the above mentioned processes (see Table 1). It is worth noting that 'helping others' has been broadly defined as provision of various types of support, including information provision, emotional support, personal experience sharing and advice (Salem et al., 1997), therefore no separate coding category was assigned for this process. Furthermore no 'creative expressions' were found within the data, therefore this category was removed from the coding frame.

Each message was coded for the presence of each of the seven coding categories. Any one message could contain more than one category, for example provision of information, followed by an expression of emotional support; therefore messages in which several categories were present received multiple codes. Several instances of any one category within one message were coded only once. Each message was coded in the context of the thread it belonged to, to increase the researchers' ability to gain better understanding of the processes occurring within each message (e.g. Finn, 1999).

**Table 1 Coding categories for potentially empowering processes**

Category	Description
Requests for information or advice	<p>Messages asking for specific factual or experiential information, advice or guidance for dealing with a particular issue or problem.</p> <p><i>Example: 'Can anyone who has been through this tell me what to expect and what kind of prognosis are we looking at?'</i></p>
Information provision	<p>Messages containing provision of factual information, guidance and advice or personal experiences, relating to all aspects of prostate cancer, treatments for prostate cancer, recovery and health care.</p> <p>Subcategories: factual information provision; advice.</p> <p><i>Examples: 'Radical prostatectomy excises the prostate gland and the seminal vesicles.'; 'You should ask your urologist about this.'</i></p>
Sharing personal experiences	<p>Messages in which members describe personal experiences, thoughts or feelings related to prostate cancer and surrounding issues. <i>Examples: 'I am almost three months post op and having issues with incontinence. I feel that I am improving slowly, but it does get discouraging at times (...) I am doing the biofeedback and it has helped'</i></p>



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Category	Description
Provision of emotional support	<p>Messages containing communication of friendship, love, care and concern, aimed to console and comfort the recipient without focusing on solving the problem.</p> <p>Subcategories: empathy; sympathy; reassurance; encouragement; virtual affections (emoticons, hugs, kisses); prayer; personal interest.</p> <p><i>Examples: 'I am sorry to hear you had a bad night.'; 'This must be very frustrating for you'; '😊'</i></p>
Provision of esteem support	<p>Messages containing communication of respect and confidence in one's ability.</p> <p>Subcategories: praise; gratitude.</p> <p><i>Examples: 'You really have an enormous wealth of information that you share so well though your posts. You share such details and this is what I come to these boards to learn. Hope you'll continue sharing.'</i></p>
Universality	<p>Messages containing notification of similarity of experience or assurance of normalcy of one's experiences.</p> <p><i>Examples: 'We're all in the same boat.'</i></p>
Discussing sensitive topics	<p>Messages containing discussions on sensitive topics such as incontinence or sexual issues.</p> <p><i>Examples: 'My erections take a little longer to happen, but they get there.'</i></p>

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### 5.2.2.2 Data analysis procedure

Messages were read and re-read in order to become familiar with the data and to assess suitability of the coding frame for the dataset. Initially, all messages posted to one of the groups were coded using the existing framework and examples of quotes for each coding category were noted. The results were discussed with two researchers experienced in coding online messages to identify any potential problems with the coding categories, their descriptions or examples of each category. As a result, several subcategories were included in the following categories: 'information provision' (two subcategories); 'provision of emotional support' (seven subcategories); 'provision of esteem support' (two categories) (see Table 1). This aimed to provide a more detailed picture of the processes occurring within the messages.

Subsequently, all the data from both groups were coded using the final coding framework presented in Table 1, consisting of seven categories and eleven subcategories reflecting potentially empowering processes. Once the process of data analysis was completed, a random sample of 150 messages was coded by a second independent rater in order to establish the inter-rater reliability of the coding framework. The second rater was a doctoral student of psychology, not involved in the current research. She received the coding framework and was trained to use it on a different sample of messages. Cohen's Kappa was calculated for each category and subcategory. Cohen's Kappa for the categories and subcategories ranged from .86 to 1.00, indicating an excellent inter-rater reliability.

In addition, all available demographic information about the individuals assessing the online support groups was collected, including gender, status (patient/caregiver) and relationship to the patient (spouse/child etc.), to help address research questions 'who

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uses online support group'. Neuendorf (2002) argued that statistical analysis such as crosstabulation can be conducted in content analysis to test relationships between two variables. In the current study chi square was used to assess the relationship between the distinctive member groups (i.e. patient/family member) and the number of potentially empowering processes found in the messages posted. This was done to address the research question 'to what extent can the potentially empowering processes be observed in the messages posted by various groups of members?'

### **5.2.3 Ethical considerations**

Ethical issues in Internet mediated research are subject to much debate amongst researchers. There is a particular controversy in relation to the collection of naturally occurring data in cyberspace, such as messages posted to online support groups, bulletin boards and mailing lists. Pfeil and Zaphiris (2010) highlighted three main ethical issues that should be considered when designing research with human participants on the Internet: the necessity to obtain informed consent; determining the distinction between public and private domain; and preservation of participants' privacy.

Informed consent requires the researcher to notify the participant about their intention to collect data, to explain the purpose and nature of the research they intend to conduct and to highlight the participants' right to withdraw from the study. It is beyond doubt that informed consent must be collected when conducting research where participants are asked to perform a task or answer specific questions; it is, however, debatable if informed consent is necessary when analysing existing messages retrieved from the Internet (Pfeil & Zaphiris, 2010).

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In general, researchers are not required to seek informed consent to use data freely available in the public domain, such as data observable on the street or featured on the television, and some authors argue that the same rule should apply to the data publically available within cyberspace (Frankel & Siang, 1999). Messages posted to the majority of the online support groups are visible to anyone and, if archived, they can be accessed years after being posted. Nonetheless, participants in such groups may not be aware of the possibility that their interactions can be observed for research purposes. The British Psychological Society's 'Guidelines for ethical practice in psychological research online' (BPS, 2007) suggest that researchers should refrain from collecting data without informed consent in such online spaces, where participants could reasonably expect to maintain privacy.

This raises the issue of distinction between public and private domain within cyberspace. Eysenbach and Till (2001) suggest that several characteristics of the data available online can be examined in order to assess the perceived level of privacy. Firstly, the level of security when accessing the groups should be considered, for example in some online support groups access to messages is password protected and members are 'vetted' by the moderators before they join the group. In other groups, however, no login is required to read or post messages. The authors argue that members of the former groups could reasonably perceive their groups as 'private', whilst the latter type could be considered public (Eysenbach & Till, 2001). Secondly, the number of users can also help researchers establish if a group could be considered private or public, for example members of a group with ten subscribers can perceive their group as more intimate and exclusive than participants in groups where hundreds of people post messages. Finally, the 'terms and conditions' of each group should be examined, as some groups' rules state that a group

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cannot be observed by non-members (Eysenbach & Till, 2001; Flicker, Haans & Skinner, 2004), for example the rules of a discussion group for ill children, 'SickKids', clearly state that adults are not allowed within the group. On the contrary, some groups' rules highlight the fact that information shared within the group is publically available and members should refrain from sharing personal information. Therefore groups that require no login to read messages, have a large number of members and their rules and regulations do not contain disclaimers forbidding non-members from reading the messages can arguably be considered to be in the public domain and informed consent can be deemed not necessary.

Even when the online support group can be reasonably considered to be in the public domain, precautions should be taken to protect participants' privacy and right to remain anonymous (Pfeil & Zaphiris, 2010). In offline research, the identity of participants is usually concealed and the same should be observed when conducting online research. Names, addresses and all other identifying information should be removed from all quotes. Although online support group members usually use pseudonyms instead of their real names, these pseudonyms can become part of a members' identity and individuals can be recognisable by their online pseudonym. Therefore all names used in online support groups should be concealed during data dissemination and publication, regardless if they reflect 'real' or 'assumed' identity (Frankel & Siang, 1999).

In light of the abovementioned debate, in the current study several measures were undertaken to identify online support groups that could be reasonably considered to be in the public domain. Only groups which did not require a login to read messages were included in the study. Small groups with less than 100 members and 100 messages posted monthly were excluded from this study. In addition, only groups whose rules and regulations did not contain statements explicitly precluding observational research but did

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contain statements reminding members of the private nature of the communication within the group were considered. As a result of this process, data were obtained from online support groups that could have reasonably been considered to be in the public domain and therefore informed consent was not deemed necessary. Nonetheless ethical approval from departmental Ethical Committee at the Institute of Work, Health and Organisations, University of Nottingham was obtained. In order to protect participants' privacy all identifying information was removed from quotes, spelling mistakes have been corrected and verbatim quotes have been kept to a minimum or paraphrased without changing their essential content, in order to decrease the chances of each quote being traced back to the group and the individual who posted it. The decision was also made not to disclose the names and website addresses of the online support groups investigated in this study to further protect members' privacy.

### **5.3 Results**

#### **5.3.1 Sample characteristics**

The sampled threads contained a total of 682 messages, posted by 153 individual members. The characteristics of the members and number of messages posted by each group of members are presented in Table 2. The majority of the members (68.6%) could be identified as prostate cancer patients/survivors and they contributed the most messages (76.3%). A total of 29.4% of members could be identified as family members, and they posted 16.3% of the messages and the three individuals (2%), who identified themselves as health care professionals posted 7.5% of the messages. As this study focuses on the experiences of individuals affected by prostate cancer, the messages posted by health care professionals were excluded from analysis. The majority of family members were female

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(73.3%), 8.9% were male and in case of 8 members there was not enough information to identify their gender. The family members were mainly wives (48.9%) or children (40%) of the prostate cancer patients, 4.4% were siblings of prostate cancer patients and one person identified themselves as a friend. Two of the wives also had a father in law with prostate cancer.

**Table 2 Characteristics of the members who contributed messages to the sampled threads and number of messages posted**

	Members	Messages
	N=153	N=682
	N (%)	N (%)
Patients	105 (68.6)	520 (76.3)
Caregivers	45 (29.4)	111 (16.3)
Female	33 (73.3)	89 (80.2)
Male	4 (8.9)	8 (12.6)
Unknown	8 (17.8)	14 (7.2)
Doctors	3 (2.0)	51 (7.5)

### **5.3.2 Processes occurring within the messages posted to the prostate cancer online support groups**

Nearly five times as many messages containing offers of support, as opposed to messages requesting support, were posted to the two prostate cancer online support groups. All of the potentially empowering processes identified in previous research on online support groups, such as 'information provision', 'sharing personal experiences', 'provision of emotional support', 'discussion of sensitive issues', 'provision of esteem support' and

'universality' were identified in the messages within the current study. The frequency of all processes identified within the messages in this sample, are presented in Table 3.

### **5.3.2.1 Requests for information**

A total of 112 (17.7%) messages contained requests for information. Messages posted by family members were significantly more likely to contain a request than messages posted by the patients ( $\chi^2(1)=25.07$ ,  $p<0.001$ ). Both patients and family members posted requests for information, advice, personal experience and opinion relating to various aspects of diagnosis, treatment options and health care providers, side-effects and disease progression. Understandably, the patients posted requests relating to their own disease and treatment. Some sought advice or personal experiences that could supplement the information they obtained from their doctors or other sources, such as medical publications. Some family members sought information with the view to help the patient, while others needed information for themselves, so that they could understand the situation and to prepare for the future.

### **5.3.2.2 Information provision**

'Information provision' was observed in 45.8% of the messages. It was the most frequently observed process within the messages overall and particularly within messages posted by the patients. Patients posted more factual information ( $\chi^2(1)=21.51$ ,  $p<0.001$ ) and advice ( $\chi^2(1)=10.37$ ,  $p<0.01$ ) than family members.



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**Table 3 Frequency of the processes identified within the messages**

	Patient	Family	Total
	N=520	N=111	N=631
	N(%)	N(%)	N(%)
Requests for information***	74 (14.2)	<b>38 (34.2)</b>	112 (17.7)
Offers of support (total)***	<b>456 (87.8)</b>	89 (80.2)	545 (86.4)
Information provision***	<b>263 (50.6)</b>	26 (23.4)	289 (45.8)
<i>Factual information</i> ***	<b>221 (42.5)</b>	21 (18.9)	242 (38.4)
<i>Advice</i> **	<b>98 (18.8)</b>	7 (6.3)	105 (16.6)
<i>Sharing Personal Experience</i>	216 (41.5)	46 (41.4)	262 (41.5)
Provision of Emotional Support**	<b>211 (40.6)</b>	26 (23.4)	237 (37.6)
<i>Empathy</i>	12 (2.3)	1 (0.9)	13 (1.9)
<i>Sympathy</i> **	9 (1.7)	<b>8 (7.2)</b>	17 (2.7)
<i>Reassurance</i> *	<b>42 (8.1)</b>	2 (1.8)	44 (7)
<i>Encouragement</i>	18 (3.5)	2 (1.9)	20 (3.2)
<i>Virtual affection</i> **	<b>137 (26.3)</b>	14 (12.6)	151 (23.9)
<i>Prayer</i> ***	10 (1.9)	<b>10 (9)</b>	20 (3.2)
<i>Personal interest</i> *	<b>59 (11.3)</b>	4 (3.6)	63 (10)
<i>Discussion of sensitive issues</i> *	<b>144 (27.7)</b>	18 (16.2)	162 (25.7)
Provision of Esteem Support*	86 (16.5)	<b>29 (26.1)</b>	115 (18.2)
<i>Praise</i>	33 (6.3)	4 (3.6)	37 (5.9)
<i>Thanks</i> **	57 (11)	<b>28 (25.2)</b>	85 (13.5)
Universality	46 (8.8)	13 (11.7)	59 (9.4)

\*\*\*p<0.001, \*\*p<0.01, \*p<0.05; significance levels for  $\chi^2$  tests

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The information and advice exchanged pertained to all aspects of prostate cancer, including diagnosis, treatment options, health care providers, side-effects and disease prognosis and very few messages contained conversations unrelated to the subject of prostate cancer. In the few cases where off-topic conversations were evident, members discussed issues such as hobbies – for example bike riding. These conversations, however, nearly always occurred in the context of prostate cancer, for example how bike riding can affect healing post-surgery.

As many members appeared to be recently diagnosed, patients frequently exchanged information and advice relating to the diagnostic processes, helped each other interpret the test results and discussed how they can affect treatment choices. They also stressed the necessity to get the correct diagnosis before any decisions were made. One patient wrote:

*'A Gleason score of 9 is quite high. As someone else suggested, get another reading of the biopsy, because you want to know if the score is real, since the reading is somewhat subjective. Assuming that Gleason 9 is real, I would suggest surgery. That way the lymph nodes can be sampled to determine whether the disease is confined to the organ.'* (Patient)

There was also much discussion which focussed on helping others find a good specialist. Patients also shared personal experiences of the care they received, opinions about their doctors' skills, expertise and bedside manner. Patients emphasised the importance of choosing the most experienced treatment provider, as the skill of the physician could affect the treatment outcomes. They advised others to learn about the skill and track records of the available health care providers, messages such as this one were frequently posted:

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*'I wouldn't be too worried about which method is used. I would be looking for a surgeon with the most time doing the exact procedure. Extraperitoneal or intraperitoneal? Doesn't matter, as long as he can do it in his sleep!' (Patient)*

Treatment options were frequently discussed by both patients and family members. Members cited recent studies presenting information about effectiveness of various treatments, offered personal experiences with treatment modalities and post-treatment recovery. The majority of patients advocated informed decision-making and gathering in-depth knowledge prior to making the decision. Sometimes members encouraged others to challenge their physician's choice of treatment and explore other available options before making the final decision. Messages about treatment choices, such as this one, were commonly posted by the patients:

*'In the recent years the mainstream treatments have improved significantly. Both surgery and radiation indicate similar long-term results for early stage (prostate cancer). It really comes down to individual preference and issues with side-effects for each treatment. If you want to know more when considering a particular option, the book by (name) is very good, especially for someone interested in surgery, and (name) publication is also useful. He underwent (treatment type) himself. Most important thing is to find the best health professional available, regardless of the treatment you decide on. Having top doctor on your team could increase your chances of a good long-term prognosis.'* (Patient)

Messages that expressed strong preference towards a specific treatment options were treated with some level of distrust, however, and members at times accused authors of

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such messages of proselytising for a specific treatment option, or even of having financial interest in promoting a specific medical facility.

Although they contributed relatively few messages containing factual information and advice, family members, particularly the more active participants in the group, adopted similar style of information provision to that of the patients, they quoted experts and shared the findings of their own research into the subject, for example:

*'Not that we went with that choice due to timing, but I did a lot of research. The Head of a certain prostate cancer organisation, who has extensive knowledge about prostate cancer, went that route, which I found to be very interesting as he had access to all the top surgeons and had more data at his fingertips than most people.'* (Wife)

Overall, knowledge and information was perceived as the most effective 'weapon' in the 'battle with prostate cancer' and being an informed participant in the treatment decision-making process was of high importance. One member summed up the need for educating oneself in these words:

*'In my youth I often heard 'what you don't know cannot hurt you' – this does not apply when fighting cancer.'* (Patient)

### **5.3.2.3 Sharing personal experiences**

'Sharing personal experiences' was the most common process within messages posted by the family members and second most common within the messages posted by the patients, and overall it was observed in 41.5% of messages. No significant difference was found in

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the level of personal experiences contained in messages posted by patients and family members.

Patients and family members frequently provided personal thoughts and experiences with the disease and treatment, the patients told about their own experiences while the family members called upon the experiences of their close ones. Personal experiences were frequently used to support information provided or served as an overt way of advising other members. Patients also used their experiences with treatment and recovery to instill hope and reassure other patients. For example, one patient who had daVinci prostatectomy told his story of recovering continence, and urged others to do the same, to encourage those who may be struggling in the first weeks post treatment:

*'I thought it would be helpful for those who have had a 'very recent' surgery to see how things may progress in the months ahead. Maybe give these guys some encouragement? As for me, I am 7 months post-op and I am down to wearing one pad per day. Most of the time that one pad is virtually dry.'* (Patient)

Family members also provided similar accounts, for example:

*'My father in law had no nerves spared. He had zero issues with incontinence from day one. Did have severe issues with ED (erectile dysfunction). My husband had very fast recovery after 8 weeks and almost good as new.'* (Wife/daughter in law).

Sometimes personal experiences were presented to warn other members of the dangers of foregoing active treatment and to support guidance or advice:

*'My Father in law had his numbers rise in a similar fashion, 5 years after surgery. He began treatments awhile after that and has been battling PC (prostate cancer)*

*since. It is a horrible progression. He is in final stages now (...)Please encourage your husband to act as quickly as possible.’ (Wife/daughter in law)*

#### **5.3.2.4 Provision of emotional support**

Provision of emotional support was the third most frequently observed process within the messages and as it was present in 37.6% of messages; however the emotional content was brief and coincidental in the majority of cases. Messages posted by the patients contained significantly more emotional support than those posted by family members ( $\chi^2(1)=11.28$ ,  $p<0.01$ ). Virtual affections were most frequently observed type of emotional support. They were usually offered in the form of a short phrase or an emoticon, posted at the start or the end of the message, such as ‘good luck’, ‘best wishes’ or smiling/sad faces. No differences in the way emotional support was offered by patients and family members were observed.

#### **5.3.2.5 Discussion of sensitive issues**

Discussion of intimate or sensitive issues, such as urinary and sexual dysfunctions was observed within 25.7% of all messages. This process was significantly more frequently observed in the messages posted by the patients ( $\chi^2(1)=6.31$ ,  $p<0.05$ ). Patients disclosed very intimate information openly, often quite matter-of-factly and apparently without awkwardness. For example, several members took part in a long discussion about dry orgasms initiated by one of the patients:

*‘Here’s another controversial question for those of you who had a surgery. Can ‘dry orgasms’ be as pleasurable as the old ones with ejaculation? Do you miss the old*

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*ones? Do they feel any different? Your answers might help those contemplating having prostatectomy or considering a different treatment.'* (Patient)

*'I am missing the old orgasms a lot! I was expecting a drastic difference after surgery, and that's what I've experienced. Using a vacuum erectile device has been better than no sex, as the intimacy of that closeness cannot be replaced.(...)I am also very grateful for this forum. It finally allows me to gain some long overdue info that I would not have had otherwise.'* (Patient)

The last quote also illustrates that patients perceived their online support groups as a valuable and unique source of information about intimate issues.

The messages posted by family members also raised sensitive topics, albeit less frequently and in considerably less detail. The messages were more often related to urinary dysfunction than sexual issues, and in most cases pertained to post-treatment experiences of the patients or their fears before treatment. For example one wife reported her husband's progress after open radical prostatectomy:

*'My husband had a nerve bundle removed and he is now nine weeks post-surgery. He has almost no issues regarding incontinence, only occasional stress incontinence, and already his erections are back at 90% with the use of medication.'*  
(Wife)

### **5.3.2.6 Provision of esteem support**

Provision of esteem support was observed in 18.2% of all messages. Members provided esteem support by offering praise, respect and appreciation for other members'

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knowledge, efforts put into research and disease management, strength, bravery, honesty and openness in sharing their experiences. They also expressed gratitude for the information and support provided. Esteem support and particularly expressions of gratitude were significantly more commonly observed in the messages posted by family members ( $\chi^2(1)=5.64$ ,  $p<0.05$  and  $\chi^2(1)=15.97$ ,  $p<0.01$  respectively).

Many members offered praise and respect to patients who openly shared their detailed story of battling prostate cancer, researching and staying strong throughout the disease journey. Some members indicated that other patients and survivors were an inspiration to them. Those who shared personal experiences and knowledge, who endeavoured to become an active participant in their health management and tried to cope with dignity and good humour with the obstacles, were a particular source of encouragement to others. Some believed they helped them improve their outlook on the disease:

*'I love stories of winners! And yours is a great one. (...) Loved your story and your tremendous attitude.'* (Patient)

*'I followed your messages from when you first joined the group. (...) I never had the courage to join in at the time, but your journey really encouraged me. You always had such a great attitude despite of the setbacks after surgery.'* (Patient)

In general, all members most frequently offered gratitude and praise to those members who helped them learn about the disease and treatments and who supported them through hard times, for example:



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*'You have an enormous wealth of information that you share so well through your posts. You share such details and this is what I come to these boards to learn. Hope you'll continue sharing.'* (Wife)

### 5.3.2.7 Universality

'Universality', i.e. messages containing notification of similarity of experience or assurance of normalcy of one's experiences was observed in 9.4% of all messages. No statistically significant differences were found between patients and family members. In several messages members directly noted similarity of experience with other members or communicated to others that their situation and feelings were not unusual. Members described their own experiences or situation, which were often similar to what another member was experiencing at the time to help the other person normalise their experience. For example one patient, responding to a message posted by a member, whose father had blood in the urine after a biopsy, wrote:

*'Blood in the urine after biopsy happened to me as well – after about two and a half weeks it cleared.'* (Patient)

Phrases such as 'you are not alone' or 'we are all in the same boat' were also used to express sense of universality within the groups.

## 5.4 Discussion

Past studies have identified the existence of various therapeutic processes within online support groups (Coulson et al., 2007; Mo & Coulson, 2008). More recently, researchers have begun to consider these processes within the broader context of patient

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empowerment (van Uden-Kraan et al., 2008c, 2009) and suggested that such processes occurring within online support groups have the potential to empower members to become more active, better informed participants in health management and enjoy greater social and psychological wellbeing (Bartlett & Coulson, 2011; van Uden-Kraan et al., 2009). The main aim of this study was to investigate which, if any, of these potentially empowering processes may be present within prostate cancer online support groups through an analysis of messages sampled from two groups. Deductive content analysis confirmed the existence of a range of potentially empowering processes which have been identified within previous studies (van Uden-Kraan et al., 2008c; Broom, 2005a). These included: 'information provision', 'sharing personal experiences', 'emotional support provision', 'discussion of sensitive issues', 'esteem support provision' and 'universality' (or noting similarity of experiences). 'Information provision' and 'sharing personal experiences' were found to be particularly prevalent across the two groups. 'Discussion of sensitive issues', a process that did not feature in the studies on empowerment in predominantly female online support groups (van Uden-Kraan et al., 2008c, 2009) but was recognised as pertinent to members of prostate cancer online support groups (e.g. Broom, 2005a) was also highly prevalent within the messages analysed in the current study. The potential of these processes to empower prostate cancer online support group members will be discussed in the following sections.

#### **5.4.1 Which potentially empowering processes could be identified within online support groups?**

##### **5.4.1.1 The empowering qualities of information exchange**

Provision of information and advice was the most frequently occurring process within the sampled messages posted by the patients. The family members, however, posted significantly fewer messages containing information and advice and mainly offered personal experiences. In general, the information exchanged was detailed and reasonably well-referenced, based on members' literature search or on the advice they received from their own physician. Members provided information and advice in order to help each other make more informed treatment decisions or cope with the effects of the treatment. It was apparent that the communication was focussed on the subject of the cancer, treatment, side-effects and treatment providers with very few messages containing off topic conversations. Although past studies suggested that members of predominantly female online support groups felt the light-hearted conversations about everyday life helped them relax and forget about the disease for a while (van Uden-Kraan et al., 2008c), in the current study even the topics that could be considered as a general chit-chat, such as bicycle riding, were discussed in the context of prostate cancer. The main objective of these conversations was usually to share experiences and educate others about resuming various physical activities post-treatment and the effects they may have on healing. The findings of the current study are in line with the results obtained by Meier et al. (2007) and Sullivan (2003), and confirm that prostate cancer online support group members are highly focused on either gathering information about their situation or educating other members and rarely use the groups to simply socialise or unwind.

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Information, advice and personal experiences relating to treatment decision-making were prevalent in many messages in the current study. Choosing a treatment is an important part of disease management for prostate cancer patients (e.g. Litwin et al., 2007). Indeed, studies have found that shared decision-making is particularly beneficial for the patient (e.g. Frosch & Kaplan, 1999) and that most patients prefer a collaborative or active style of decision-making (e.g. Charles et al., 1997). Conversely, some studies (Aujoulat et al., 2007) suggest that patient empowerment should encompass the possibility that the patient may prefer to leave the responsibility for the final treatment choice to their health professional. In the current study members often described and discussed the processes through which they, or in case of the family members, their close ones, had reached their decisions. Although they represented different ways of reaching a decision, it is apparent that a higher value was assigned to active and informed decision-making whilst surrendering the autonomy in treatment decision-making process was discouraged. Members frequently encouraged others to take control of their health care. They provided each other with useful ideas on how to better prepare for consultations with treatment providers and urged newly diagnosed members to explore treatment options and challenge the treatment choice suggested by the physician if it was not optimal for them. In addition, members often praised those who sought knowledge and actively participated in their decision-making processes.

These findings suggest that information and advice exchanged within prostate cancer online support groups can potentially empower members to become better informed participants in treatment decision-making, which can in turn lead to greater acceptance of the treatment outcomes (Davison & Degner, 1997). Information and advice obtained from other members can also potentially help individuals be more active and confident in their

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communication with their healthcare professional (Bartlett & Coulson, 2011; van Uden-Kraan et al., 2009), which can be particularly valuable for the female caregivers, who often find communication with their partner's physician problematic (Meier, 2005; 2008).

Although as highlighted in Chapter 3, analysis of messages is not an appropriate method for investigating the negative effects of participation in online support groups, it is worth noting that some potentially negative aspects of information sharing were found within the messages analysed in the current study. For example, some level of distrust was observed towards members who advocated for certain treatment or diagnostic options. Other members, at times, accused them of having financial interest in promoting these options and questioned their status as a prostate cancer patient; these instances were, however, very rare. Further investigation of members' perceptions regarding potentially deceptive information in the groups is necessary.

### **5.4.1.2 Empowerment through emotional support**

Clarke et al. (2006) reported that men with cancer found information and advice about their disease and treatment to be helpful in reducing anxiety and a more valuable and acceptable form of support than display of emotions. Sullivan (2003) suggested that creating a sense of caring within an online community and sharing emotional support was more typical for female cancer groups, and indeed in the current study the exchange of emotional support was less evident than information sharing. Sullivan (2003) hypothesised that while women were empowered and felt supported through sharing emotions, men were empowered and supported through the exchange of information. Gooden and Winefield (2007) speculated that for men the exchange of detailed, reliable, well-referenced information could be comforting and in fact serve the function of emotional

support. This seemed particularly true in the current study, as the men showed apparent signs of caring through the way they volunteered their time to share their knowledge and intimate experiences to help others through their cancer journey. More importantly, the recipients appeared to feel supported by the information and advice provided, a notion they conveyed through the praise and gratitude they expressed. Interestingly, in the current study the female participants offered emotional support to an even lesser degree than the males. This could possibly be due to the fact that they were in a minority and the men were dominating the discussions, setting the 'biomedical tone' of conversations, and the emotional expressions were reduced to a minimum.

#### **5.4.1.3 Similar others as a source of empowerment**

As a result of cancer diagnosis, many patients report experiencing a diminished sense of connectedness with their family, friends and colleagues; they often feel rejected or misunderstood (Im et al., 2007a; Ussher et al., 2006). Prostate cancer patients' spouses have also reported lack of understanding and support from family and friends (Bottoroff et al., 2008). Studies suggest that participation in support groups, both face-to-face and online, can help reduce these feelings and help people be a part of a community based on mutual acceptance and understanding (Bottoroff et al., 2008; Im et al., 2007a; Ussher et al., 2006; van Uden-Kraan et al., 2008c). Cancer support group members also reported that, through access to people who had similar experiences, participation in their group increased their sense of empowerment and agency by helping them validate their own experiences and feelings which they previously perceived as abnormal or unusual (Ussher et al., 2006; van Uden-Kraan et al., 2008c). Their sense of control and ability to cope with the disease were also enhanced through learning about the experiences of others, with a similar or worse diagnosis, who coped well and led fulfilling lives despite their illness

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(Ussher et al., 2006). Indeed, within the present study, there was ample evidence of members sharing their experiences with others and in so doing reassuring and supporting them during this difficult time. Members often posted messages containing their own stories, aimed to validate and normalise feelings and experiences that other members found worrisome or difficult to accept. Further research is however necessary to explore the effect these messages had on the readers and their empowering potential, as it is impossible to assess through message analysis to what extent the members recognised themselves in the stories posted by others. The evidence found within the messages in the current study, however, suggests that, as a result of encountering others in a similar situation in online support groups, prostate cancer patients and their family members can potentially experience the empowered outcomes described in past studies, such as increased sense of normalcy, reduced social isolation and improved ability to cope with the disease (Ussher et al., 2006; van Uden-Kraan et al., 2008c).

### **5.4.1.4 Empowering men to openly discuss sensitive issues**

Although side-effects of an intimate nature are a common and often debilitating issue in prostate cancer (Penson et al., 2005), patients have reported difficulties in discussing them with their peers and health care professionals either due to lack of opportunity or embarrassment (O'Brien et al., 2011). Broom (2005a, 2005b) suggested, however, that the anonymity of online support groups could facilitate discussion of such sensitive topics. Findings of the current study support this view, as the messages posted in this study often contained very detailed information, advice and personal accounts of incontinence and impotence, with the men appearing to value the opportunity to exchange views on these sensitive topics. The threads about erectile and urinary side-effects were lengthy and many members contributed to them. Some men indicated that the online conversations with

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other similarly affected patients were an extremely valuable, and often the only, source of information and advice on dealing with erectile and urinary dysfunctions. It could therefore be argued that prostate cancer online support groups provide patients with a unique opportunity to safely share experiences, coping strategies and useful knowledge about this important, yet sensitive, part of their lives. Furthermore, through reading about other members' experiences, newly diagnosed members may gain a unique insight into the potential post-treatment side-effects and therefore be better able to make a more informed treatment decision or be prepared for treatment outcomes. The female participants were less involved in the conversations about sensitive issues and rarely joined threads specifically dedicated to erectile dysfunctions. The lack of female involvement could potentially further enhance the sense of safety men can experience while discussing sensitive issues in online support groups.

### **5.4.1.5 Helping others can empower the helper**

While receiving support in prostate cancer online support groups, particularly in the form of information and advice, can be beneficial for the recipient of help, many authors argue that offering help can also have positive effect on the help-provider (Gredianus & Everall, 2010; Roberts et al., 1999; Salem et al., 1999). Helping others, broadly defined as offering emotional support, direct advice, encouragement and information (Salem et al., 1997) has been associated with several empowered outcomes such as increased sense of competence and mastery, independence and perception of importance to others (e.g. Roberts et al., 1999). Studies of online support groups have noted that in those groups, messages offering help vastly surpass the requests for assistance (e.g. Blank et al., 2010; Salem et al., 1997). This was also true in the current study, where the majority of messages contained some form of potentially helpful behaviour, such as provision information,



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advice, esteem and emotional support. Gredinaus and Everall (2010) also found that one of the potentially helpful behaviours amongst the members of an online suicide prevention community was sharing of personal stories that could instil hope and offer reassurance to other members. In the current study many instances of members disclosing personal experiences with the disease, treatment and side-effects were observed. Several of these messages were clearly aimed to reassure other members and others served as an indirect offer of advice and guidance. Therefore the findings of the current study suggest that helping others is an important part of participation in prostate cancer online support groups. Through the process of helping one another members can not only receive useful information, but also may potentially experience positive psychosocial effects such as increased self-esteem, greater sense of mastery and competence in the context of prostate cancer knowledge and feeling important to other members. Further research is necessary to gain better understanding of the empowering effect helping others may have on the members of online support groups.

### **5.4.2 Use of prostate cancer online support groups by patients and family members**

To date few studies have examined family members' participation within the prostate cancer online support groups (Seale, 2006), therefore the second aim of the current study was to investigate to what extent patients and their family members engage in communication within prostate cancer online support groups. The similarities and differences in the messages posted by patients and family members were also explored.

#### **5.4.2.1 Who uses prostate cancer online support groups?**

The findings of the current study indicate that a considerable number of family members engaged in the exchange of messages within the prostate cancer online support groups in

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this study. The family members who contributed messages were most frequently female and spouses/partners of the patients, which is in line with past research indicating that female relatives of prostate cancer patients, most often spouses, are the ones seeking support in online support groups (Blank et al., 2010; Seale, 2006). Some recent studies have suggested that female family members were on the par with the patients within prostate cancer online support groups. Seale (2006) found that similar numbers of prostate cancer patients and female relatives took part in the conversations and that those relatives posted as many messages as the patients (Seale, 2006). In the current study family members were part of the online support group but they did not 'overpower' the patients with their presence. In this sample, over twice as many members were patients and they also posted a significant majority of messages. These findings, compared to the findings of Seale (2006) could suggest that online support groups for prostate cancer differ according to levels of family member participation and involvement.

### **5.4.2.2 Are there any similarities/differences between the ways in which patients and family members communicate in prostate cancer online support groups?**

Family members were more likely to access the online support groups to ask for information and advice which, as they often indicated, could help them support and educate the patients. They posted twice as many requests as the patients; they also expressed gratitude for the help they received more often. On the other hand, the patients contributed significantly more messages offering help in the form of emotional support, information and advice on prostate cancer, treatment and side-effects such as erectile dysfunction. These findings are in line with past studies by Blank and colleagues (Blank & Adams-Blodnieks, 2007; Blank et al., 2010), which indicated that relatives of the prostate cancer patients contributed fewer messages offering support and were more likely to seek

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help within the groups. This could be explained by the fact that the caregivers, particularly spouses of prostate cancer patients want to actively engage in the management of the disease and treatment choices, but their informational needs are often unmet by the health care professionals (Mason, 2005; 2008) and therefore they seek alternative sources of information, such as online support groups (James et al., 2007).

As mentioned earlier, the female relatives in this study did not conform to female style of communication, which typically involves emotional, nurturing language and expressions of care (Sullivan, 2003). Female participants adopted similar biomedical language as did the male patients and exchanged fewer expressions of emotional support than the men. They took part in discussions of treatment options, advised others to educate themselves or to opt for active treatment, however their messages could indicate lower levels of mastery over the subject of prostate cancer and treatment, as they often sought information and their advice was more frequently experiential rather than factual. They also often acknowledged the men's expertise by praising their knowledge and thanking them for the useful information they provided. This further confirms findings from past studies, which suggested that caregivers' informational needs are significant, yet they are often neglected by the health care professionals (Mason, 2005, 2008). Family members' engagement in information exchange, rather than in interpersonal relationships or emotional expressions could, therefore, be explained by the fact that their participation in these groups was driven by their informational needs. Furthermore, the findings of the current study are consistent with the findings of the literature review conducted by Mo et al. (2009), which suggested that the gender differences seem to dissipate in mixed gender online support groups. Seale (2006) also found that caregivers who were in the minority tended to adopt the communication style of the majority, i.e. the patients. In the current study the

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messages were drawn from mixed patient/caregiver groups, which were used predominantly by the patients. It is possible that female caregivers of prostate cancer patients communicate in a different manner groups designated for caregivers only or in predominantly female groups dedicated to prostate cancer patients' spouses. Unfortunately, no such groups were publically available at the time of data collection for this study, precluding the chance to investigate communication occurring within these groups for ethical reasons. Further research investigating communication in single gender groups is needed.

### **5.4.3 Strengths and limitations of the study**

In recent years there has been a growth in the number of studies exploring a range of aspects pertaining to online support group experience. However, the majority of groups studied have been used mostly by women or both genders (e.g. Coulson et al., 2007; van Uden-Kraan et al., 2008a, 2008b, 2008c, 2009). Where male groups have been included, this has been done so in order to make comparisons or identify gender differences in online communication and the results presented most often only considered the levels of information and emotional support exchange (e.g. Sullivan, 2003, Gooden & Winefield, 2007). The current study is one of the few which have focussed on the male experience of online support and is done so in order to understand more fully how men living with prostate cancer may experience the potentially empowering effects of online group participation. Furthermore, the experiences of prostate cancer patients' family members in online support groups also have not been fully explored and this study offers quite unique insight into the ways in which this group engages in online communication.

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It is important, however, to note the limitations of this study. In the first instance the limitations relating to the data collection technique should be discussed. Certain disadvantages of the specific characteristics of data collected from online support groups have previously been noted (Pfeil & Zaphiris, 2010). Firstly, the content of messages collected from the Internet is mainly text-based and as such devoid of non-verbal cues. Although this type of data has many benefits, for example the researcher does not have to transcribe or take notes and therefore will not make mistakes or omit any information, this also means that text is the only data available to examine. This can be a disadvantage, as, for example, the researcher misses out on important clues, such as facial expression or tone of voice. This could impair their understanding of the emotional tone of the message or hamper their ability to distinguish between ironic and sincere statement and thus lead to misinterpretation of the data. Certain graphic expressions such as emoticons or punctuation marks (e.g. ;) or !!!) could help the reader understand the undertone of the message, however not all online support group members use them (Pfeil et al., 2009). Furthermore accidentally incorrect spelling, punctuation, typing and grammatical mistakes can also change the meaning of the messages. Although it is difficult to overcome this limitation, in the current study care was taken to maximise the researchers understanding of the messages' intended meaning. Messages were analysed in the context of the whole thread, which at times improved understanding of ambiguous messages. All non-verbal cues were also considered when gauging the tone of any ambiguous messages, such as emoticons, punctuation marks and interjections.

Secondly, some studies suggest that the anonymity of an online setting can promote dishonesty (Pfeil & Zaphiris, 2010). Individuals may pose as somebody they are not (for example a medical professional or a patient) or disclose details about themselves that are

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not true. Pfeil and Zaphiris (2010) suggest that the researcher should be aware of this issue and become familiar with the community they are researching in order to get to know the members and their stories; they acknowledge, however that it may not be possible to overcome this problem. In the current study considerable amount of time was devoted to familiarisation with the data, the members and their stories.

Thirdly, although analysis of the content of the messages allows the researcher a unique and in-depth insight into the processes occurring within online support groups, it does not allow the researcher to assess with certainty how, if at all, these processes affect the members. This study aimed to observe which potentially empowering processes occur within prostate cancer online support groups. Based on the findings of past studies a search for processes that were previously reported to have empowering effects on members of online communities, such as breast cancer or fibromyalgia online support groups was conducted (van Uden-Kraan et al., 2008c, 2009). Although all of the previously reported processes have been identified within the current data, it is impossible to conclude if any of these processes had an empowering effect on the members. It was also difficult to establish which, if any, of the empowered outcomes of participation previously identified in predominantly female online support groups (van Uden-Kraan et al., 2008c) were experienced by prostate cancer online support group members. Analysis of messages also offers a limited insight into the potentially negative aspects of participation in online support groups.

Furthermore, Nonnecke and Preece (2000) highlighted that a significant proportion of members who read messages within online support groups do not contribute postings. These members ('lurkers') are also affected by the information and support within the

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groups (Mo & Coulson, 2010), however their experiences are entirely hidden from the researcher who analyses existing online support group messages.

Finally, the nature of the groups from which messages were sampled in this study could have affected the generalizability of the findings. Firstly, messages from only two groups were included in the analysis. This could have resulted in a sample bias, as some issues may be more frequently discussed in some groups than in others and certain group norms could have affected the communication. Some differences between the messages posted to the two groups in this study were found, for example, difference in the levels of emotional support provided in each of the groups (data not presented), which could indicate that communication in various prostate cancer online support groups does not necessarily follow the exact same pattern. Comparison of peer-to-peer groups and groups where health care professionals post messages alongside patients and caregivers was not the focus of the current thesis, and further investigation into the differences in communication within different types of prostate cancer groups is necessary to fully understand the online experiences of members. Furthermore, recent research has suggested that perceived privacy may be an important factor in determining the levels of self-disclosure within online support groups (Malik & Coulson, 2011) and that different patterns of communication can be observed in single gender and mixed gender groups (Mo et al., 2009). In the current study both of these groups were used by patients and family members and both were publically available. The communication in private groups used by patients or female relatives only could further differ from the patterns observed in the current study.

## 5.5 Conclusions

The current study focused on the naturally occurring communication within prostate cancer online support groups. The findings confirmed the existence of the majority of potentially empowering processes previously identified in female and mixed gender groups, such as 'information exchange', 'provision of emotional support', 'provision of esteem support' and 'universality' (van Uden-Kraan et al., 2008a, 2008c). An additional process, 'discussion of sensitive issues' previously identified as pertinent for prostate cancer patients (Broom, 2005a) was also frequently noted within the messages posted to the prostate cancer online support groups in this study.

The majority of the processes identified within the messages in this study appeared to serve the purpose of educating and advising other members about the disease and available treatment options. These processes, particularly information exchange, esteem support, encountering similar others and discussions of sensitive issues could possibly contribute to a sense of empowerment in members, as they have the potential to encourage members to become more active participants in their own health care, be better able to effectively communicate with their physicians, make more autonomous and informed decisions about their treatment, and be better able to deal with the management of their post treatment recovery. Some dissimilarity in the use of prostate cancer online support groups by patients and family members were identified, the main difference relating to the fact that family members were more likely to seek help while the patients more often offered assistance to others.



### **5.6 Future research recommendations**

The current study indicates that there is a need to conduct further empirical research in order to fully understand how participation in prostate cancer online support groups affects participants, both active members and 'lurkers'. Research directly asking prostate cancer online support group members about their experiences within the groups could help shed more light on the subject of empowerment in prostate cancer online support groups, as well as investigate the outcomes (both positive and negative) experienced by the members. Research exploring prostate cancer online support group experiences directly from the perspective of the members could therefore build on the findings of the current study.

## **Chapter Six: Study Two. Members' perceptions of the online support group experience**

### **Chapter overview**

A range of potentially empowering processes was identified within messages posted to prostate cancer online support groups in Study 1; however the extent to which these processes can help foster empowerment in members remains unclear. The current chapter describes an exploratory qualitative study which aimed to further investigate, from the perspective of the patients and their family members the empowering qualities of participation in prostate cancer online support groups. An online open-ended survey was completed by 147 participants. The findings corroborated and expanded the results of Study 1, confirming that participants perceived the processes observed in the messages as highly beneficial; they also described a number of empowering outcomes of participation, including 'being better informed', 'increased ability to participate in treatment decisions', 'feeling more confident in relationship with health care professionals', 'reduced social isolation', 'positive personal reappraisal' and 'positive reappraisal of the situation'. The empowering processes and outcome vastly surpassed the negative aspects of participation, further suggesting that participation in prostate cancer online support groups may be beneficial for the patients and their family members. The results are discussed in the context of the wider literature on the subject of online support.

### 6.1 Introduction

The findings of Study 1 suggest that a range of empowering processes, previously identified in predominantly female and mixed gender online support groups (e.g. Malik & Coulson, 2010; Perron, 2002; van Uden-Kraan et al., 2008a), can also be observed within the messages posted to prostate cancer online support groups. The results suggest that information provision and sharing personal experience were the most commonly observed empowering process within these groups. Other processes, such as provision of emotional support and universality were also frequently noted. Furthermore, an additional process, discussions of sensitive issues, was identified, confirming the findings of a study conducted by Broom (2005a) which indicated that prostate cancer patients use the online support groups to discuss their sexual and urinary post-treatment issues difficult to disclose in face-to-face encounters (Weber et al., 2000). Although this study provided a unique insight into the processes that occur within prostate cancer online support groups, it did not offer the opportunity to explore which of these processes were perceived by the participants as empowering.

The majority of literature on gendered communication within online support groups suggests that female patients tend to engage in the exchange of emotional support to a greater degree than male patients (e.g. Sullivan, 2003) or use more affectionate and relationship-building language (Gooden & Winefield, 2007). The results of Study 1 were in contrast with these findings, as female family members offered little emotional support, rarely exchanged affections and seldom express their emotions. Mo et al. (2009) pointed out that in mixed gender groups the communication follows different patterns than in single-gender groups. As no publicly available groups for female caregivers were identified at the time of data collection, the communication within female only groups was not

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explored. Extant literature also does not offer sufficient insight into the communication in female only groups for prostate cancer patients' caregivers and family members.

Furthermore, content analysis of messages posted to prostate cancer online support groups offered a limited insight into the negative aspects as well as the positive outcomes of online support group participation, as it did not provide the opportunity to explore members' perceptions of participation in the groups. Past studies suggest that participation in health-related online support groups can have empowering effects on the members. The majority of research suggests that members experience an increase in knowledge about the disease and available treatment options, enhanced communication with health care providers and greater sense of control over their lives (Buchanan & Coulson, 2007; Hill, Weinert & Cudney, 2006; Powell, McCarthy & Eysenbach, 2003; van Uden-Kraan et al., 2008c). Similarly, some negative aspects of participation in online support groups have been noted by some authors, such as being unsure about the quality of information provided (van Uden-Kraan et al., 2008c) or being confronted with negative aspects of the disease/treatment (Malik & Coulson, 2008a; Sandaunet, 2008; van Uden-Kraan et al., 2008c). The abovementioned studies, however, have described the negative aspects and empowering outcomes experienced by members of female or mixed gender online support groups, and no studies to date have investigated the full extent of either negative aspects or empowering effects participation in online support groups may have on male cancer patients and their family members.

The previous study concluded that research exploring the empowering processes, outcomes and negative aspects of participation in prostate cancer online support groups from the members' perspective is necessary to gain further insight into the experiences of the individuals accessing prostate cancer online support groups.

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### 6.1.1 Aims

The current study aims to build on the findings of the previous study as well as the existing literature and explore, from the members perspective, the empowering processes, empowering outcomes and negative aspects of participation in online support groups for prostate cancer patients and family members. Furthermore the motives that lead the patients and family members to start using online support groups are also explored. The current study addresses the following research questions:

- What motivates prostate cancer patients and their family members to start accessing online support groups?
- Which empowering processes are experienced by the individuals accessing prostate cancer online support groups?
- Which negative aspects of participation are experienced by the individuals accessing prostate cancer online support groups?
- Which empowering outcomes of participation are experienced by the individuals accessing prostate cancer online support groups?

## 6.2 Methods

### 6.2.1 Selection of data collection method

As highlighted in Chapter 4, qualitative methodology is concerned with in-depth understanding of certain aspects of lived experience. Since this study aims to expand current knowledge of the experiences of individuals affected by prostate cancer who access

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online support groups, a qualitative research eliciting direct responses from the group members has been considered to be an appropriate method of data collection.

Traditionally, qualitative data from participants can be collected in many ways, for example via face-to-face or telephone interviews. Interviews have also been successfully employed in online research (e.g. Hunt & McHale, 2005). Two types of online interviews are commonly described in the literature: *synchronous online interviews* (which most resemble traditional interviews in the sense that the interviewer and the interviewee are online at the same time and take turns to communicate via a chat room or an instant messenger; Davis, Bolding, Hart, Sherr & Elford, 2004) or *asynchronous online interviews* (where the interviewer and interviewee are not online at the same time; the questions are sent, in a series of emails to the interviewee, who can respond at their own convenience; Hunt & McHale, 2005). *Open-ended online questionnaires* (which most resemble structured interviews, as they consist of a fixed set of open ended questions presented to the participant in a form of an online survey; Hunt & McHale, 2007) can also be used to elicit qualitative data from participants (e.g. Buchanan & Coulson, 2007; Malik & Coulson, 2008a). The merits and disadvantages of online qualitative data collection in general as well as in relation to each of these data collection modalities are discussed in the following sections.

### **6.2.1.1 Advantages and disadvantages of online qualitative data collection**

As compared with offline data collection, several benefits of online qualitative data collection, for both the researchers and the participants have been noted (Davis et al., 2004; Hunt & McHale, 2007). One of the frequently mentioned benefits, from the researcher's point of view, is cost and time saving, as online data collection can be

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conducted from a single location, without the necessity to travel to interview participants in various locations and does not require lengthy data transcription (Davis et al., 2004; Hinchcliffe & Gavin, 2008, 2009; Hunt & McHale, 2007). Participants have also highlighted that compared to face-to-face interviews online data collection is more convenient and puts less pressure on the interviewee (Hinchcliffe & Gavin, 2008, 2009). This method of data collection can be particularly beneficial for shy or apprehensive individuals who feel uncomfortable disclosing personal information in face-to-face situations (e.g. Davis et al., 2004). Some researchers also argue that the anonymous nature of online setting helps elicit more open and veracious responses (Hinchcliffe & Gavin, 2008; Joinson, 2001).

Some disadvantages of online qualitative data collection have also been reported, for example lack of visual and auditory cues can impair the process of building rapport between the interviewer and the interviewee, as well as make it difficult to express and interpret emotions (Hunt & McHale, 2007). Anonymity provides a potential opportunity for deception, for example participants can pose as someone they are not, such as a patient or a caregiver (Hunt & McHale, 2007). Lack of physical presence of the researcher can also lead to a lower level of participant's engagement in the research process, and result in shorter and less in-depth answers or skipped questions. The researcher is also unable to control the study environment, which can be affected by various interferences, such as speed of Internet connection, software, hardware, other websites or programs open on the participants' computer or presence of other people in the room (LaCoursiere, 2003). Furthermore, although some researchers argue that online data collection can enhance the breadth of the sample, others point out that it can lead to sample restrictions, as individuals recruited via the Internet are more likely to be younger, better educated, from

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higher socio-economic background and have higher computer skills than the general population they represent (Hunt & McHale, 2007).

Particular modes of online qualitative data collection are also associated with specific benefits and disadvantages. For example, synchronous interviews provide an opportunity for the interviewer and interviewee to communicate in 'real time' and thus offer a chance to explore issues of interest as they arise (Hinchcliffe & Gavin, 2008, 2009). The downside is that the communication often takes the form typical for chat room conversations, characterised by rapid, short, ungrammatical exchanges, rich in paralinguistic expressions, such as emoticons, abbreviations and acronyms. Therefore this method may not be as effective as other online qualitative methods in producing rich and in-depth data (Davis et al., 2004).

Asynchronous interviews, on the other hand, offer the respondents more time to reflect on the question and compose their reply (Hunt & McHale, 2007). The interviewer also has a record of the entire conversation, to which they can refer whilst formulating their next question (Hunt & McHale, 2007). However, they are often conducted over several weeks or even months; therefore they require long-term commitment from the researcher and the interviewee. The participants may lose focus or interest in the process and either significantly reduce the length and depth of their replies or drop out (Hunt & McHale, 2007). Conducting too many interviews at the same time can also be confusing for the interviewer and lead to information overload (Hunt & McHale, 2007). This method of data collection is therefore more appropriate for gathering in-depth information from small groups of participants.



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In the case of open-ended online questionnaires the lack of interaction between the researcher and the participant can be perceived as the main disadvantage, as this method does not provide the opportunity to clarify issues or ask additional questions. This can raise concerns over the depth and quality of data collected this way, however a number of studies effectively employed open-ended online questionnaire to exploring experiences of individuals accessing online support groups (e.g. Buchanan & Coulson, 2007; Malik & Coulson, 2008a). The findings presented in these studies offered an in-depth and rich insight into the phenomenon of online communication. This could be explained by the fact that, similar to asynchronous online interviews, the participants have the time to reflect upon the questions and compose their responses to best reflect their experiences (Hunt & McHale, 2007).

In addition, open-ended online questionnaires are quick to administer and are the least labour-intensive for the researcher. Unlike asynchronous interviews, which require considerable time commitment from the participant, the questionnaires only take 30-60 minutes and therefore more people may feel inclined to participate. As data is collected only once, there is a lesser chance that participants will drop out during the process. As there is no contact between the participant and the researcher, the increased sense of anonymity can encourage people who feel uncomfortable taking part in one-to-one interviews to take part in the research. In summary, this method enables data collection from large and diverse groups of participants and thus helps elicit data representative of the experiences of a broader population.

In consideration of the above issues in online qualitative collection methods, the decision was made to employ open-ended online questionnaires to gather data for this stage of the investigation.

### **6.2.2 Sampling procedure and recruitment of participants**

This study was concerned with the experiences of the individuals affected by prostate cancer, who access online support groups. Therefore the inclusion criteria were broadly established as (a) being affected by prostate cancer, either as patients, survivor or family member *and* (b) having experience of accessing prostate cancer online support groups, either as an active member or a 'lurker'.

As highlighted before, recruitment of participants via the Internet can result in restricted samples that may not be representative of the wider population (Hunt & McHale, 2005). However, considering the inclusion criteria for the current study, recruitment directly from prostate cancer online support groups was deemed to be the most effective and efficient way of reaching the target population (Buchanan, 2000; Buchanan & Smith, 1999).

In order to identify appropriate online support groups, a series of Internet searches, using the search engine Google™ was conducted. The searches were conducted using combinations of terms 'cancer' or 'prostate' or 'prostate cancer' and 'forum' or 'board' or 'message board' or 'bulletin board' or 'chat' or 'support' or 'group' or 'support group' or 'online support group'. Message boards relating to cancer in general were manually searched in order to determine the presence of standalone forums for prostate cancer. Only prostate cancer online support groups in English were included in the study. Since the study required informed consent from the participants, private groups as well as public groups were included (see the Ethical Considerations discussed in section 5.2.4). The 'terms and conditions of use' of each group were scrutinised to assess if recruitment of members for research purposes was allowed, and groups that did not allow research activity were

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excluded. Whenever possible, group activity was scrutinised to find 'active' groups only. Groups were considered 'active' if they had at least one message posted daily.

As a result sixteen eligible prostate cancer online support groups were identified and the gatekeepers (e.g. owners/moderators of the groups) were contacted via email at the beginning of April 2010. A reminder email was sent two weeks later. Eight gatekeepers agreed to participate, three declined and five did not reply. The groups participating in the study varied in size from 175 to 81000 members.

The main disadvantage of posting participation request directly onto websites, including online support groups, is the fact that it precludes the possibility to estimate the sampling frame and thus to assess the response rate and compare respondents and non-respondents (Hewson, 2003). It also decreases the chances of reaching infrequent members and members who no longer access the website or group (Hewson, 2003; LaCoursiere, 2003). Hewson (2003) suggests that emailing participation requests directly to the members may offer a greater insight into the population size and characteristics. Nevertheless, for practical and ethical reasons the researcher who wishes to recruit online support group users often has no choice but to post a link to the group, as access to members' email addresses tends to be guarded by the gatekeepers.

In the current study the gatekeepers were asked to either: email the invitation to the members; post it to the board on behalf of the researcher; or allow the researcher access to the board to post the invitation in person. Three gatekeepers posted the invitation to the group; three allowed the researcher access to post and two gatekeepers emailed the invitation to the members. The majority of the gatekeepers were able to provide the number of members registered; it was, however, impossible to estimate how many of the

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registered members still visited the group or accessed the email associated with their membership account. It was, therefore, not possible to accurately establish the response rate and non-response bias in the current study.

The participation request posted to the online support groups/emailed to members contained a short description of the study and a link to the online questionnaire (see Appendix A). Individuals who chose to take part in the research were redirected to a questionnaire hosted by SurveyMonkey®, where they were provided with further details of the study. The data were collected from April through to June 2010.

### **6.2.3 Data collection**

#### **6.2.3.1 Data collection tool**

SurveyMonkey®, a large web-based survey software provider, was used to host the online questionnaire. SurveyMonkey® software is a relatively inexpensive, flexible and easy to use tool. The responses are easily downloadable in various formats and the survey creator has the option to enable or disable multiple responses from a single IP address. Although disabling multiple responses from a single IP address has several advantages, such as avoiding repeated responses from the same participant, in case of the current study the decision was made to enable multiple responses. Since both patients and their family members were invited to participate, it was possible that more than one person would use the same computer to complete the survey. From the perspective of the respondents, the navigation around the survey is relatively easy, with all the major command buttons, such as 'next', 'previous' or 'exit survey' clearly labelled. The progress bar allows the participants to assess their advancement in the completion of the survey. Finally, SurveyMonkey® offers high levels of physical, storage and network security.

### **6.2.3.2 The survey**

The survey commenced with an introductory page, which contained brief information about the researcher and research project and outlined the inclusion criteria, the procedure and ethical issues, such as confidentiality and right to withdraw from the study. Affiliation and departmental contact to the researcher and the first Supervisor were provided. The participants were asked to read the consent page and separately indicate their consent (a) to take part in the research and (b) for the use of quotes from their responses in publications. It was not possible to proceed without indicating consent. They were also asked to create a password which could help identify their responses if they chose to withdraw from the study.

The survey consisted of the following sections:

#### *Demographic and health characteristics*

The participants were asked to provide information regarding their gender, age, country of residence, marital status, education and current employment status. They were also asked if they were visiting the online support group as a patient or family member/friend. The participants were also asked to provide details relating to prostate cancer, such as time since diagnosis, latest diagnosis details, time since treatment and treatment type. Patients were asked to answer these questions in relation to themselves whilst family members/friends were asked to reply in relation to the patient.

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### *Online support group use*

Participants were asked questions about their habits relating to online support group use, including length of membership, frequency of accessing the groups and duration of visits. Participants were also asked to specify if they have ever posted messages, and if so, how frequently they posted. Finally, members were asked if the online support groups helped them (responses 'yes they helped me a lot', 'yes they helped me to some extent', 'yes, they helped me a bit' and 'no, they did not help me at all'). Participants were also asked to describe their reasons for starting to access prostate cancer online support groups and specify if and how these reasons changed over time.

### *Experiences of online support group participation.*

This section consisted of a series of open-ended questions designed to help address the research aims. These questions related to the potentially empowering processes, empowering outcomes of participation and negative aspects of accessing online support groups. Empowerment is a complex concept, which has been 'inconsistently defined' within extant literature (van Uden-Kraan et al., 2008c, p 406), and it is conceivable, that different people may have a different understanding of this concept, be unfamiliar with it or uncertain of its meaning. McTavish et al. (1994) reported high item non-response rate, when they used the word 'empowerment' asking participants about the effects of participation in an online support groups. Therefore the decision was made not to use the word 'empowerment' in the current survey, as it might lead to confusion or alienate some participants. The questions aimed to explore empowering processes and empowered outcomes were therefore formulated in terms of 'helpfulness' (e.g.: 'What aspects of the prostate cancer online support groups did you find most helpful?'). Questions relating to

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negative aspects of participation were formulated in terms of being 'less helpful or unhelpful'.

Members, who in the previous section indicated that participation in online support groups helped them deal with the challenges of living with prostate cancer, were asked the following questions:

What aspects of your life or the life of your family were affected by your participation in the prostate cancer online chat groups?

What aspects of prostate cancer online chat groups did you find most helpful?

In what way did using prostate cancer online chat groups help you deal with the challenges of prostate cancer?

Was there anything that you found unhelpful or less helpful within the prostate cancer online chat groups? If yes, please tell us more about it.

Is there anything else about your experiences of using online chat groups that you would like to tell us?

Members, who in the previous section indicated that participation did not help them at all, were asked the following questions:

Why using prostate cancer online chat was groups not helpful to you?

What aspects of prostate cancer online chat groups did you find the least helpful and why?

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Was there anything at all that you found beneficial or helpful when using prostate cancer online chat groups? If yes, please tell us more about it.

Is there anything else about your experiences when using online chat groups you would like to tell us?

On completion of the survey the participants were redirected to the debriefing page, where they were thanked for their time. Contact details for the research team as well as for organisations offering help to people dealing with prostate cancer were provided. The contents of the survey are enclosed in Appendix B.

The clarity of the survey and relevance of questions were assessed through consultations with colleagues experienced in online research. The survey was also sent to the gatekeepers of the online support groups and they were asked to comment on the contents. Few minor changes were made as a result of these consultations. The first ten completed surveys were used as pilot and assessed for the relevance and depth of information provided by the participants. The quality of data was good and no further changes were made to the survey.

### **6.2.4 Ethical considerations**

This study was conducted in accordance with the British Psychological Society (BPS) guidelines for ethical conduct (BPS, 2009) and BPS Guidelines for Ethical Practice in Psychological Research Online (BPS, 2007). Ethical approval for this study was obtained from the departmental ethical committee at the Institute of Work, Health and Organisations, University of Nottingham.



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In the first instance the permission to recruit members was obtained from the individual groups' gatekeepers, who were briefed on the purpose of the study. In order to obtain informed consent from the participants, the main objectives of the research were openly and without deception explained within the first page of the online questionnaire. The participants received an explanation of their right to confidentiality, privacy and withdrawal from the study. Once the participants had the chance to familiarise themselves with the purpose of the study and read their rights, they were asked to give an informed consent to participate in the study. The protection of the privacy of participants, their families and other group members is of paramount importance when conducting psychological research with human participants, therefore all identifying information such as names and addresses were removed from all quotes, and further consent was obtained for the use of any extracts from the responses within future publications. Contact details for the research team were also provided, should anyone wish to discuss the research in further detail. Due to sensitive subject of the study, after completion of the questionnaire, the participants were directed to a debriefing page containing a list of contacts from charities or organisations offering counselling for prostate cancer patients and their families.

In order to further protect the privacy and confidentiality of the participants the data were stored securely, in accordance with the British Psychological Society Ethical Code of Conduct for Internet Research. The access to the electronic data was password protected and only available to the lead researcher.

### **6.2.5 Data analysis**

According to Braun and Clarke (2006) thematic analysis is a method that allows the researcher to gain an in-depth insight into the qualitative data through the identification of

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patterns that occur within the dataset. Unlike many other methods of analysing qualitative data, such as IPA or grounded theory, thematic analysis is not theory bounded and therefore it can be applied across a range of epistemological approaches. In this respect, thematic analysis offers the researcher greater flexibility. As highlighted in Chapter 4, current research is carried out within the subtle realist approach, and thus is concerned with reporting of the straightforward experience and reality of the participants, without theorizing the socio-cultural contexts underlying the individual accounts. The themes were therefore identified at a semantic level, within the explicit meaning of the data.

Authors, such as Braun & Clarke (2006) and Boyatzis (1998) differentiate between inductive (bottom up) and deductive (top down) thematic analysis. When adopting an inductive approach, the researcher approaches the dataset without preconceived ideas about the potential themes. They do not try to fit the data into a pre-existing coding frame and the themes identified are data driven. Deductive thematic analysis, on the other hand, stems from a specific research question, and can, therefore, provide a detailed description of a particular aspect of the data. According to the deductive thematic analysis, the data can be analysed within a specific theoretical approach (theory-driven approach) and previous research can serve as a basis for code development (prior-research-driven approach (Boyatzis, 1998). The scope of the current study stems from the specific research aims, and the analysis was based on the empowerment framework proposed by van Uden-Kraan et al. (2008c, 2009). Therefore a deductive thematic analysis was considered to be the most appropriate analytical tool.

Data were analysed in line with the guidelines set out by Boyatzis (1998) for prior-research-driven approach thematic analysis. Data analysis was conducted in two stages: 'developing themes and code' and 'validating and using the code'.

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According to Boyatzis (1998) in the stage 'developing themes and a code', the researcher faces the task of development of the themes and coding frame. In the prior-research-driven thematic analysis, the themes and coding frame are generated through the review of existing research on the subject of interest. Codes and categories used by other researchers, as well as the findings from their research, form the direct basis for the creation of the coding frame. In the current study three major, overarching themes were dictated by the research aims and the empowerment framework (van Uden-Kraan et al., 2008c) and included empowering processes, empowering outcomes and negative aspects of participation in online support groups. Within each of these themes, several sub-themes reflecting specific processes, outcomes and negative aspects of participation in online support groups, as discussed in past literature (e.g. van Uden-Kraan et al., 2008c) were included.

The coding frame was then applied to the raw data during a process of repeated reading and re-reading of the dataset. The applicability of the existing coding frame to the raw data was tested throughout this process. Boyatzis (1998) suggests that at this stage changes can be made to the coding frame, including re-labelling, redefining, collapsing, separating and expanding of the themes to better reflect the notion carried by the raw data. This stage resulted in the creation of a redefined coding frame appropriate for the new raw data, which was based on the initial themes. Boyatzis (1998) points out that although this process allows sufficient flexibility to adapt the existing codes to the raw data, the main disadvantage of the prior-research-driven code development is the fact that the researcher has to accept another person's assumptions, projections and biases. In order to overcome this disadvantage, elements of inductive analysis were incorporated in the process of code development. Any new ideas of the sub-themes relating to empowering processes,

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outcomes and negative aspects of participating in online support groups that emerged from the data themselves were noted during the process of reading and re-reading of the raw dataset.

In the second stage, labelled 'validating and using the code', the redefined coding frame was applied to the entire raw dataset in order to validate the code and interpret the meaning.

### 6.2.6 Sample characteristics

The participants were a self-selected sample of prostate cancer online support group members who responded to the participation requests posted to online support groups. A total of 207 individuals accessed the survey website but 42 did not proceed beyond the consent pages; 165 completed the demographic data questions and 147 completed one or more open-ended question. These 147 participants, 92 males and 55 females, were included in the study. Chi square and t-tests were conducted to compare participants who were included and those who dropped-out. No significant differences were found with respect to age ( $t(165)=0.47$ ,  $p=0.640$ ), gender ( $\chi^2(1)=0.06$ ,  $p=0.805$ ), employment ( $\chi^2(4)=3.96$ ,  $p=0.411$ ), education ( $\chi^2(3)=0.75$ ,  $p=0.862$ ) or country of residence ( $\chi^2(4)=6.96$ ,  $p=0.138$ ).

All male participants described themselves as patient/survivor, while the majority of female participants were partners/spouses of patients ( $n=51$ , 92.7%)<sup>1</sup>. The mean age of participants was 59.2 ( $M=59.2$ ,  $SD=8.3$ ) and women ( $M=55.9$ ,  $SD=8.2$ ) were significantly younger than men ( $M=61.2$ ,  $SD=7.7$ ) ( $t(145)=4.03$ ,  $p<0.001$ ). The majority of participants

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<sup>1</sup> Since all male participants in this study described themselves as patients, and all female participants were family members, the terms 'patients' and 'men' as well as 'family members' and 'women' will be used interchangeably in this chapter.

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came from the USA (n=94, 63.9%) or Great Britain (n=31, 21.1%), and the remainder came from Australia, Canada, Israel and European countries other than the UK. The majority of participants were married or in a relationship (n=123, 83.6%), in employment (n=90, 61.3%) and had tertiary education (college, university or postgraduate) (n=77, 79.6%). No significant differences were found between patients and family members according to country of residence, marital status, employment or education ( $p>0.05$ ).

When reporting health-related information, female participants provided information about their close ones' disease and treatment, while male participants reported upon their own health status. On average, prostate cancer has been diagnosed 3.2 years before data collection (M=3.2, SD=3.4). The women reported shorter time since diagnosis (M=2.7, SD=2.3) than the men (M=3.6, SD=3.8) ( $t(129.416)=2.05$ ,  $p<0.05$ ). They also reported that their close ones were in more advanced stages of the disease, i.e. had a more advanced tumour stage ( $\chi^2(3)=11.91$ ,  $p<0.01$ ), higher Gleason score ( $\chi^2(2)=12.69$ ,  $p<0.01$ ) and PSA ( $\chi^2(3)=8.02$ ,  $p<0.05$ ) and were more likely to have metastatic disease ( $\chi^2(2)=7.98$ ,  $p<0.05$ ). The majority of all participants (n=117, 55.8%) reported that the treatment underwent by the patient was surgery.

On average, participants have been accessing online support groups for 2.6 years (M=2.6, SD=3.0). The women had significantly shorter period of membership (M=1.6, SD=1.8) than the men (M=3.2, SD=3.4) ( $t(143.446)=3.65$ ,  $p<0.001$ ). Although the majority of all participant (men n=70, 76%; women n=26, 48%) started using online support groups before treatment, the men were significantly more likely to start using the groups early (i.e. before treatment) ( $\chi^2(2)=10.43$ ,  $p<0.01$ ). Participants reported that an average visit lasted 35.4 minutes (M=35.4, SD=34.7). The majority of all participants described themselves as frequent users; 78 participants (53.8%) reported visiting their online support group daily

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and further 35 (24.1%) weekly. Overall 12 people (8.2%) have never posted a message and 28 (19%) only posted once or twice. One hundred and seven participants (72.9%) posted messages regularly. The majority of active posters (n=95, 88.8%) posted questions and replies; 9 (8.4%) posted replies but never asked questions; and 3 (2.8%) only asked questions. Overall 82 participants (56.2%) reported that online support groups have helped them a lot; 52 (35.6%) indicated they helped them to some extent, and few felt they only helped a little (n=10, 6.8%) or not at all (n=2, 1.4%). No significant differences between patients and family members were found for any of the online support group use characteristics ( $p>0.05$ ), except for length of membership and time when they started accessing the group.

### **6.3 Results**

#### **6.3.1 Reasons for accessing prostate cancer online support groups.**

An open ended question ('Why did you start to use prostate cancer online support groups?') was used to identify participants reasons for starting to use prostate cancer online support groups. Participants were also asked if their reasons for accessing online support groups have changed over time, and if so, in what way.

The majority of participants named seeking information as the main reason for starting to use online support groups (n=99, 67.3%; patients n=67, 72.8%; family members n=32, 58.2%). Both patients and family members looked for information about the cancer, treatment options and recovery. Patients indicated that information was needed to inform their treatment decisions. Women sought information to better understand the disease and treatment options as well as help inform their partner's treatment decisions. Some

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also needed information to pass it on to their partners. Participants also indicated that they were looking for information to supplement or cross-check information provided by health care professionals. A third of all participants (n=49, 33.3%; patients n=29, 31.5%; family members n=20, 36.4%) indicated that they wanted to get access to other people in similar situation, either to seek understanding and support which they considered unavailable elsewhere or to learn from their personal experiences.

Over twice as many family members as the patients stated that they started to use online support groups to seek emotional support (n= 20, 36.4% and n=13, 14.1% respectively). Some members also listed seeking validation of feelings and experiences (n=10, 6.8%), safe place to talk openly (n=7, 4.8%) and providing information to other members (n=7, 4.8%) as the initial reasons for accessing online support groups.

Fifty eight participants (39.5%) indicated that their reasons for accessing online support groups had changed over time. For those participants the main changes involved a shift from being an information and support seeker to providing information and support to others (n=16, 27.6%), decrease in informational or emotional support needs (n=15, 25.9%) and a shift from information seeking towards experiencing greater sense of community and mutual support (n=13, 22.4%).

### **6.3.2 Empowering processes**

During analysis of the data six recurring themes relating to empowering processes were identified:

Encountering similar others

Information exchange

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Encountering emotional support

Finding a safe place to talk

Helping others

Chit-chat

### 6.3.2.1 Encountering similar others

For many participants, both men and women, the online support groups provided a unique and valuable opportunity to exchange experiences, information and support with individuals whose situation closely resembled their own. The majority of participants indicated that meeting other people who ‘walked the same road’ helped to reassure them, offered them hope and comfort in knowing they were not alone. The following quotes illustrate common responses from both men and women:

*‘I now have a group of men who are going thru the same problems as me. It is reassuring to be able to post a problem or concern and have somebody with the same problem or concern to talk about it.’ (P154, Male, 63 years, USA)*

*‘All women walking the road as a PCa (prostate cancer) wife have or will encounter the basic same problems. There is always someone on the forum who can relate to my questions or issues when I need help.’ (P18, Female, 63 years, USA)*

Participants often praised other members for their exceptional knowledge, wealth of experience and willingness to share. The women, more often than the men, also



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emphasised the compassionate, caring and loving qualities of other female members. Some participants also indicated that they preferred to communicate with individuals most similar to themselves, for example the spouses found more in common with other spouses while patients preferred to exchange messages with other men. They were also seeking people with similar experiences, diagnosis, treatment or the medical centre they attended. For example one patient wrote:

*'Some time it seems that so called spouses of PCa patients write a lot on line. I feel more comfortable when working with men with similar values and medical history.'*  
(P72, Male, 59 years, USA)

Furthermore, encountering similar others in online support groups appeared to affect all the other processes occurring within the groups, as will be described in the following sections.

### **6.3.2.2 Information exchange**

Online support groups were perceived by many participants as a particularly valuable source of information and advice. The participants indicated that after diagnosis online support groups served as a valuable source of information about the available treatment options and potential outcomes, whilst during recovery they offered information with regards to coping with side-effects. Those, whose cancer recurred or metastasised, indicated that they used online support groups to explore treatment options available in advanced stages of the disease.

The information was particularly valued by the participants as it was based on lived experiences of other patients and their spouses, and thus offered an insider's perspective

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on what to expect in the future. Some participants also stated that they offered valuable practical and 'tested' tips and ideas for coping and improving health outcomes.

Participants often noted that experiential knowledge shared by others who were in a situation closely resembling their own was particularly relevant and helpful, as can be exemplified by this quote:

*'Friends and colleagues I knew who had PCa had stage 2 and surgery. Since I have stage 3 PCa I needed information from other men who had experienced what I was experiencing. (...) Having information from what other (members) were experiencing was invaluable.'* (P99, Male, 63 years, USA)

Online support groups were also perceived as a source of informational support that evolves alongside members' needs as they change through the stages of prostate cancer journey. For example, one patient stated that the most helpful thing about participation in online support groups was the fact that

*'EVERY aspect of every stage of the disease is discussed and available when you need it.'* (P113, Male, 57 years, USA)

Some of the female participants also stated that they benefited from information and support throughout the stages of their partner's disease as well as after his death, when they could learn from other widows how to cope after he is gone. One woman wrote:

*'I ask for advice based on experiences of others. Until recently it was always for advice on treatments or how to help my husband. Now I am a widow it is to ask other widows what to expect and how to cope.'* (P30, Female, 55 years, UK)

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While health care professionals were often considered to be the first port of call for technical information about treatment procedures, many participants felt they were biased towards their own specialism and underplayed the potential of negative outcomes. They also did not volunteer information about other possible treatment options. Many participants also felt health care professionals did not prepare them for post-treatment issues, especially sexual and urinary side-effects. Online support groups, on the other hand were perceived to be a more comprehensive and unbiased source of information about treatment options, outcomes and side-effects. This is illustrated by the following quotes:

*'Gathering information from others who also have my experience is helpful, especially as the information from health professionals is often too general. The focus of consultation is very much about initial intervention, there is little support following this other than chat rooms and charity based web sites.'* (P132, Male, 54 years, UK)

*'The accurate and detailed specific information about sexuality (was most helpful). We got much better information from the chat group than from the medical community which did not tell us the truth and was very unresponsive to us as a couple'* (P5, Female, 56, USA)

Gathering information from online support groups was also found to have several practical advantages. Participants felt that information provided within the groups was more understandable than information provided by health care professionals. Some participants also appreciated the fact that the information was quick and easy to obtain and available 24 hours a day, when needed the most. One woman wrote:

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*'Empathy, practical suggestions and responses 24 hours a day and over weekends and bank holidays when it is difficult to get advice. Problems always seem to happen at weekends and holidays and are usually not so significant as to want urgent advice but more urgent than we can deal with ourselves.'* (P31, Female, 55 years, UK)

The question and answer format of online support groups was also perceived as beneficial, as it helped save time and effort of going through large volumes of information:

*'I am glad that social media sites dedicated to PCa exist, since I would not have the energy to do traditional research in libraries, even assuming I could find a library with the appropriate resources.'* (P99, Male, 63 years, USA)

### **6.3.2.3 Encountering emotional support**

Both male and female participants reported encountering emotional support within online support groups; the women, however, put more emphasis on the caring, supportive and emotional aspects of their relationships with other members, whilst the men focused on information and experiential knowledge as the main source of comfort and support.

The women often stressed the value of having emotional support from other female partners, particularly during difficult times. Many women reported experiencing a great sense of community, 'sisterhood', friendship and 'special bond' with other women in the group. Some felt that having this support was 'a life-saver' for them. Many women spoke passionately about the unique support they experienced, particularly in female only groups:

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*'At this time my husband is going through chemotherapy and there are always new problems arising and with the mental and emotional toll this disease takes on us, thank God for my forum 'sisters' otherwise I have no idea what shape I would be in. We are a sisterhood who are all walking this horrid road together in one stage or another. My husband had widespread bone mets (metastases) from PCa and the future is not bright one at this time..... I need support and there is always someone on the forum all of the time if I need something. (...) If I didn't have someone to 'walk beside me' on this road, who understands where I am coming from as a wife, I'm not sure I could handle the stress, anger and responsibility.(...) (Group name) has been a gift from God.'* (P18, Female, 63, USA)

Online support groups, particularly the ones for females only, were portrayed by the women as a source of on-going emotional support throughout all the stages of the disease and after the death of their partner. One woman, who recently lost her husband, wrote about her experiences in these words:

*'I was becoming an emotional basket case! Overwhelmed by all that my husband and I were going through. It helped me with the final months/weeks/days of my husband's PAINFUL death. On my site there are also women who have 'gone ahead of me' in the loss of their men and can help guide me through this painful experience.'* (P20, Female, 54 years, USA)

The patients, on the other hand, spoke less explicitly about the emotional aspects of online support and tended to highlight the reassuring and comforting value of exchanging information and personal experiences with other men in similar situation. For example one man wrote: *'working with good information and experiences of others is calming'* (P108,

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Male, 71 years, USA). Several men indicated that they also experienced a sense of community or fellowship with other men in the groups, and that friendships were forged during the process of information gathering. For example one man described how his use of online support groups evolved from various stages of information seeking to information providing and finally providing a sense of community:

*'Originally (I was like) a 'deer in the head lights' with a tough diagnosis. Then fall-out with side-effects and injury from treatment. Then changing staging of the disease. Then support for others – there's more to life than being staked to cancer. Then fellowship and support unless an academic topic of interest arises.'* (152, Male, 57 years, USA)

Furthermore, many participants, both male and female, stated that they turned to online support groups because the support from family and friends was often insufficient or misplaced. Members of online support groups were able to offer support based on empathy and complete understanding which stemmed from the shared experience of living with prostate cancer, for example:

*'I needed psychological support from those who were in a similar position. I was unable to get this 'objective' help from family or anyone I spoke to.'* (P134, Male, 66 years, Ireland)

*'No one understands what I am going through. These ladies offer understanding, comfort and friendship along with a wealth of knowledge.'* (P12, Female, 58 years, USA)

#### 6.3.2.4 Finding a safe place to talk

Some participants indicated that online support groups provided space to openly discuss issues related to living with prostate cancer that may be difficult to talk about face-to face. The men predominantly focused on discussions of recovering potency and continence or adapting to the physical changes post-treatment. Many patients felt that the health care professionals did not prepare them for the side-effects and their impact on their lives. Conversely, open discussions with other, similarly afflicted men were very useful in preparing them for the future and improving coping. For example, one participant wrote that through participation in the group he felt:

*'more confident and prepared (for) what was ahead, which treatment to get, what side-effects would appear, how to deal with side-effects, medications for ED (erectile dysfunction), incontinence, etc.'* (P144, Male, 59 years, USA)

Whilst men focused on the physical functioning, women also highlighted the ability to talk about intimacy and relationship as beneficial. They often found the change in their relationship difficult to accept and understand. Many of them believed that family, friends and doctors did not appreciate the extent to which the loss of intimacy affected them as individuals and as a couple. The unique support they found from other wives and partners offered them comfort and helped them open up about their relationship problems:

*'I felt alone, depressed and desperate. I could not find understanding from our physician or even my therapist. Both of them, though professionals, seemed to minimize the suffering that I felt due to the loss of intimacy with my husband. I wondered if there was something wrong with me until I 'spoke' to other women on the forum. I think it really makes a difference to talk to others who are walking the*

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*same road as you are. Nothing compares to experience and real empathy. The ladies forum has made a world of difference to me and to my husband.’ (P21, Female, 48 years, USA)*

Some of the women also found online support groups to be a particularly useful venue for open expression of feelings and emotions. They could ‘vent’ their anger, frustration and anxiety as well as admit to feeling forlorn, down and vulnerable in a safe, non-judgemental and supportive environment, without burdening their partner and family:

*‘The group I use is composed of females only so I feel the freedom to say anything. The site is split into categories and I post in the ‘After He Is Gone’ area...it is a safe and comforting place to be...I can talk about being ‘down’ and the ‘sisters’ will help pick me up...’ (P20, Female, 54 years, USA)*

### **6.3.2.5 Helping others**

Both male and female participants highlighted the reciprocal nature of informational and emotional support exchange within online support groups. Many participants indicated that they were keen to share their own experiences to help inform other members. They also noted the importance of providing emotional support to newly diagnosed or recently widowed members. Overall, participants indicated that once they received help for themselves, they were able to ‘give back to the community’:

*‘It (reason for using online support groups) has changed over time from searching for information and obtaining people’s experiences to now giving back my experiences and support to others and the belief that you are not alone, you can get through this and that there are people here to give you all the advice, support, as*



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*little or as much as you need. In essence I am now giving back what I took in the early days.'* (P137, Male, 48 years, UK)

### 6.3.2.6 Chit-chat

The benefits of having off-topic conversations with other group members were very rarely brought up by the male participants and only a few men mentioned that they appreciated the fact that other members kept their sense of humour despite of the disease. The women occasionally mentioned enjoying light-hearted conversations about grandchildren, hobbies or exchanging recipes with other members. They felt that off-topic conversations helped lighten the mood and add personal depth to the relationships between the members, for example:

*'I feel connected to others in a very special and personal way. I look forward to 'talking' to friends about all sorts of issues, not just PCa but everything from pets to gardening.'* (P33, Female, 55 years, Canada)

### 6.3.3 Empowering outcomes

During data analysis six recurring themes relating to empowering processes were identified, including.

Being better informed

Increased ability to actively participate in treatment-related decisions

Feeling more confident in the relationship with health care professionals

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Reduced sense of isolation

Positive personal reappraisal

Positive reappraisal of the situation

### **6.3.3.1 Being better informed**

Many participants indicated that as a result of information and personal experience exchange with other members, they felt 'better informed' and 'more knowledgeable' and that they gained better understanding of the disease, treatment options and potential side-effects. Some participants reported an increased sense of expertise and mastery over the subject of prostate cancer, for example one patient felt he had more knowledge than his doctor:

*'My urologist claims I knew more than he did about PCa, in the last two years he has gotten much more informative.'* (P72, Male, 59 years, USA)

Increased knowledge appeared to have a positive effect on other empowering outcomes, such as ability to effectively communicate with health care professionals and to actively participate in treatment decision-making processes. Being better aware of all aspects of the disease and treatment also helped participants to be better prepared for the future. One patient summarised that increased knowledge helped him gain sense of mastery over his disease:

*'Knowledge is power – the chat groups went a long way in helping me own the cancer rather than the other way around.'* (P99, Male, 63 years, USA)

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Also, as a result of being more educated, some participants felt more confident and better equipped to pass the information and experiences on to their family as well as new members within the group, for example:

*'As I've become more knowledgeable, I've been better able to respond to questions from others and to offer advice.'* (P80, Male, 60 years old, UK)

*'(I now post more messages than I used to, because) self confidence in own knowledge has improved, so less fear of confusing newer users or giving incorrect advice.'* (P52, Female, 46 years, UK)

### **6.3.3.2 Increased ability to actively participate in treatment-related decisions**

Active participation in treatment-related decisions was particularly important for the male participants. Many patients who joined online support groups prior to their treatment decision being made reported that through the process of exchanging information with other members their ability to make informed treatment choices increased significantly. For example, some men felt that they have been better able to understand risks and benefits as well as possible outcomes of the available treatment options. Others indicated that they have learnt about new treatment or diagnostic options, which affected their treatment decisions

*'Information from posts led me to have an endorectal MRSI at (hospital's name) and a color Doppler ultrasound scan by (doctor's name). The results of these imaging exams were major factors in pursuing Active Surveillance rather than immediate treatment.'* (P86, Male, 67 years, USA)

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Others also indicated that as a result of participation in online support group they had more technical knowledge about treatment options and outcomes at their disposal and therefore they felt empowered to make independent choices or even oppose the physician or go against their advice:

*'(As a result of participation in online support groups) I became able to discuss potential treatments with my GP and family with good knowledge of the likely outcomes, specifically including the likelihood of the side-effects from treatment. I became more likely to reach my own conclusions (not just do what I was told was 'best'). (...) Main thing is that I was able to opt for active surveillance against the advice of specialists.'* (P131, Male, 59 years, UK)

Similar to the men, many women felt that making an informed treatment decision was a crucial part of the battle against prostate cancer. Some female participants also reported increased sense of agency, although their role almost always came down to supporting their partners through the process of treatment decision-making. They most often reported performing supportive tasks, such as gathering information about treatment options, which helped inform their partners' decisions. Learning about prostate cancer and treatment options was particularly important for women whose partners were unwilling to educate themselves, as one participant wrote:

*'I wanted to gather information regarding the process of this awful journey that we were pushed into. My husband was in complete denial and was refusing to look at options/gather information. This site allowed me to 'see into the future' so that I could direct our discussions and help to guide my husband's journey.'* (P32, Female, 61 years, USA)

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Some participants, both male and female, described the beneficial role of online support groups in treatment decision-making as a joint process involving both the man and his wife, for example:

*'Well initially upon diagnosis I posted a lot to help us decide the right treatment options.'* (P24, Female, 48 years, USA)

*'Most importantly (participation in online support group) gave my wife a better understanding of all the relevant issues confronted during the early decision-making process. Her knowing how much time and effort I put into exploring all the options prior to making our joint decision not to have medical treatment gave us both immeasurable comfort.'* (P81, Male, 71 years, Australia)

### **6.3.3.3 Feeling more confident in relationship with health care professionals**

Being better informed about the disease and possible treatment options allowed some patients to have a more effective communication with their health care professionals and become more confident and active participants in the medical encounters. They felt they could understand their test results and the information divulged during consultations. Some male participants reported feeling more able to 'ask more intelligent questions' about treatment and take more active part in discussing potential treatment options.

At times the patients also indicated that online support groups allowed them to cross check the information and advice obtained from their doctor. One man said that the members in the group '*validated what my doctor said.*'(P93, Male, 80 years, USA) Another man wrote that he *used online support groups to find 'information on treatment options, side-effects, etc. – mostly confirming what my urologist tells me.'* (P160, Male, 65 years, USA)

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Some women also felt that being better informed affected their ability to take a more active part in communicating with their partners' doctors. They felt empowered to attend the consultations, ask questions and bring new ideas they read about within the groups to discuss during the appointments, for example:

*'I was feeling very lonely when he was first diagnosed but have found 'friends' on the forum who understand and have helped empower me. I have also become proactive by visiting doctors with my husband and supporting him at appointments which I probably would not have done otherwise.'* (P7, Female, 62 years, Australia)

*'When I learn something new or interesting on the forum, I share it with my husband and at times, even bring something to the oncologist's attention.'* (P18, Female, 63 years, USA)

### **6.3.3.5 Positive personal reappraisal**

A number of male and female participants indicated that through participation in online support groups they managed to achieve greater sense of normalcy and accept feelings, such as anger or frustration, which they previously had difficulties dealing with. Several participants reported that realising how many other people were dealing with similar problems was a source of comfort and reassurance for them:

*'By reading along in these groups, I was able to accept and understand better what I was going and what I had been through. As I was going through my journey, from pre-, during and post-treatment, it let me see that I was ok for feeling the way that I was feeling throughout my various stages of PCa.'* (P71, Male, 53 years, USA)

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Several participants, particularly women, indicated that they experienced an increase in self-esteem as a result of participation in online support groups. For example, some indicated that participation in the online support groups helped them positively re-evaluate their own role in the process of dealing with the prostate cancer. Some indicated that they realised they had the ability and skill to research the subject of prostate cancer and related treatments and thus be able to contribute to their husbands' decisional processes. This is illustrated in the following quotes:

*'It made me feel I was doing something useful, a form of research, a means by which I could educate myself about the disease and support my spouse. I was able to ask questions about his treatment.'* (P34, Female, 55 years, UK)

Some female participants also noted that through increased knowledge, ability to talk openly and support from other members they were able to become calmer and more relaxed about the situation and thus provide more emotional support for their partners:

*'(Online support group) provided a safe place to vent frustrations without betraying the privacy of my partner. This made it easier to maintain a calm attitude to help support him during his own stressful times. It also provided knowledge of other couples experiences of what is 'normal' which helped lessen fear.'* (P15, Female, 41 years, USA)

*'I feel support from everyone in the group, and with that support I am better able to support my husband.'* (P43, Female, 64 years, Canada)

#### **6.3.3.4 Reduced sense of isolation**

Many participants reported that one of the major positive outcomes of exchanging support, information and experiences with similar others in online support groups was a reduced sense of isolation. Both male and female participants indicated that they experienced a strong sense of togetherness and community within the online support groups. The women put particular emphasis on the importance of being a part of the 'sisterhood' and having their online 'friends' or 'sisters' with whom they shared mutual support based on a unique bond and understanding, for example:

*'As I have come to know the women on the site more, I feel closer to them and we discuss our situations and concerns and support each other through the difficulties of facing a life threatening situation. I have come to regard many as friends, even sisters, as we can speak of things others outside the PCa world don't fully understand.'* (P33, Female, 55 years, Canada)

Many participants, both male and female, felt comforted and 'less alone' realising that others were 'walking the same road':

*'Having information from what others were experiencing was invaluable. It helped me feel less alone knowing that others had undergone what I was undergoing.'*  
(P99, Male, 63 years, USA)

#### **6.3.3.6 Positive reappraisal of the situation**

Several participants reported that through participation in online support groups they managed to positively reappraise their situation. Their outlook on the disease, treatment and recovery became more positive; many reported that their sense of control and mastery



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over the disease increased and that they felt better prepared for and less anxious about the future. Several participants also reported being calmer and having more hope for the future.

Some participants, especially the men, noted that encountering other patients who were in a similar or worse situation than themselves, either due to worse prognosis or more severe side-effects, was a source of inspiration and made them realise that their situation was not as bad as they initially thought, for example:

*'I was able to appreciate how common the disease was and, in some respects, how lucky I was that my own PCa was caught early.'* (80, Male, 60 years, UK)

*'It was morale-boosting to know there were other guys out there in the same straights I am –and to know that they were 'soldiering on' helped me soldier on as well.'* (99, Male, 63 years, USA)

Men and women alike reported that as a result of participation in online support groups they felt better informed about the possible treatment outcomes and disease trajectory and thus felt more in control of the situation. As a result, they felt they could deal with the disease, treatment and side-effects calmly and with less anxiety. For example one male participant said that the group *'helped me enormously to learn about PCa and about some of the options for treatment, thus reducing some of the worry and uncertainty'* (P70, Male, 67 years, UK). Another participant noted: *'I am the kind of person who has less fear the more I know.'* (P142, Male, 53 years, Israel)

Some participants also noted that through learning about other members' successful treatments and recovery they started to feel more positive about the disease and had more

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hope for the future. Patients with localized disease started to believe that the cancer was treatable or even curable and for those in more advanced stages hope for long-term survival was instilled:

*'I found out that it was curable, not just a treatable condition. I am now cancer free and after 6 mo. have only minor ED(erection dysfunction) problems, which I now know can take up to 1 yr. to recover.'* (P149, Male, 65 years, USA)

Depending on their situation, some women felt inspired not to give up hope for positive outcome, while others were comforted in the knowledge, that 'the end can be peaceful'. One daughter of a patient summarised that online support groups can help change attitude towards life and the disease through the process of *'learning that it's not about quantity of life but quality of life at any stage of prostate cancer, and how to deal with the course of the disease, learning to live one day at a time.'* (P56, Female, 44 years, Canada)

### **6.3.4 Negative aspects of accessing prostate cancer online support groups**

Overall, male participants reported experiencing more negative aspects of participation than the women. Three major recurring themes relating to negative aspects of accessing prostate cancer online support groups were found within the data:

Disempowering interpersonal relationships within the group

Negative aspects relating to contents of messages

Being confronted with the negative aspects of the disease

#### **6.3.4.1 Disempowering interpersonal relationships within the group.**

Several participants, particularly the patients, indicated particular dislike towards members dominating the discussions and taking on the role of health care specialists. One man explained how such posters affect the dynamics within the group:

*'It is easy for posters to be consumed by the mechanics of the disease, to become mini-MDs in an effort to help and to be really uncivil pains in the neck. A few uncivil or know-it-all posters can take all the life and energy out of a group, as can the loss of even a single helpful poster.'* (P102, Male, 81 years, USA).

Another man added that such attitude can be detrimental to the quality of patient-doctor relationship outside of the group:

*'I feel that the opinions of the 'know alls' can sometimes undermine the important and sometimes delicate relationship that exists between the patient and his urologist.'* (P133, Male, 69 years, Italy).

Lack of tolerance and criticism of other members' beliefs also contributed to people feeling less at ease using online support groups. This was particularly apparent in case of members who were interested in alternative treatments or active surveillance. Some participants reported occurrences of heated arguments between members. One participant summed it up in these words:

*'Condemnation of others by folks with differing beliefs, affiliations, knowledge base or opinions (was unhelpful). Cancer is challenging even without personal attacks by other members.'* (P152, Male, 57 years, USA).

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Overall, few women reported encountering disempowering interpersonal relationships, particularly in ladies only groups. One woman, however, who was using a mixed gender group, reported instances of female participants being bullied by a male member. These experiences led her to withdraw from the group:

*'I stopped posting after a particularly nasty period on the message board. There was a particularly obnoxious poster who upset many people. (...) When the Board became used by a poster as an offensive tool to belittle and bully the female posters, my family were very concerned and urged me to withdraw.'* (P34, Female, 55 years, UK)

### 6.3.4.2 Negative aspects relating to the contents of messages

Some participants noted that high volume of information can cause difficulties in sorting through the messages and separating relevant information from irrelevant. They noted that this was time and labour consuming:

*'Sifting through messages can be hard work. Subject lines may not be useful, threads can drift away from the topic, there may be lots of non-PCa specific junk.'* (P131, Male, 59 years, UK)

Some members pointed out that members' signatures (short description of the disease and treatment appearing at the end of each messages) can be useful, as they can help identify members who are in a similar situation and thus reduce the number of messages read/members followed.

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In addition, some participants, especially those who identified themselves as long-term users of the group, found the repetitive nature of information exchange tiresome, as one man put it:

*'After 14 years I find that the discussions are the same and boring.'* (P78, Male, 70 years, Israel)

Some members, albeit not many, mentioned that sometimes incorrect information posted by 'non-medical members' could be found within the groups. One patient described online support groups as 'unreliable source of information' and some also noted that members must learn to discriminate between incorrect and correct information. One person suggested that a presence of a moderator with medical qualifications could help improve the quality of messages containing information about disease and treatment. Two men also pointed out that they benefited from the presence of experts in the field of prostate cancer who offered their advice in the early 1990s.

Advocating for a particular treatment path was found to be particularly problematic. Patients perceived such messages as biased and therefore unhelpful and untrustworthy. Some even suggested that people posting such messages could be doctors covertly advertising their own business:

*'I suppose there must be misinformation available through these groups, but I did not come across it. With one possible exception: a 'poster' seemed to be very vociferous in advocating a particular line of treatment. I suspect he was a doctor with a commercial interest.'* (P75, Male, 64 years, USA)

#### **6.3.4.3 Being confronted with negative aspects of the disease.**

Some members pointed out that reading about the negative aspects of the disease, such as severe side-effects, cancer spread and death of other patients' was upsetting and could lead to a greater fear of the future. One participant wrote:

*'It is difficult, at times, to read emotional responses to questions or hear of a treatment which has not proceeded well. There are days where I cannot read the material because it can be depressing and all consuming.'* (P101, Male, 47 years, USA)

Female participants also found reading about cancer progression and death very emotional and painful, as it made the possibility of their own partner's death more real. They did, however, feel guilty for not reading or not responding to such messages, as if they were letting a friend in need down:

*'I feel after reading everyone's post for months, I got to know them!! At the moment one of the ladies on the forum husband is dying....I find it hard to post on her page. I believe it has become real (dying & pain) for me..... Kinda like looking in crystal ball. I feel guilty for not responding.'* (P22, Female, 59 years, USA)

#### **6.4 Discussion**

The main purpose of this study was to investigate the experiences of prostate cancer online support group members within the groups, with particular focus on perceived empowering processes and outcomes of participation. To obtain a fuller picture of members'

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experiences, motives for accessing the groups and negative aspects of participation were also considered.

The current study sample mainly consisted of long-term, active members of prostate cancer online support groups, who felt highly satisfied with the level of support they received within their groups. Many of them described their experiences within the groups as very positive and empowering; however some negative aspects of participation were also highlighted. The majority of respondents were patients; a significant proportion of the study sample, however, was made up of female family members. This is in line with the past studies, which indicated that overall women tend to care for the patient and therefore may be more involved in dealing with the disease and require more information and support (e.g. Ginossar, 2008; Jansma, Schure & de Jong, 2005; Pitceathly & Magiure, 2003). Similar to the sample of member who posted messages to prostate cancer online support groups described in Study 1, a large majority of the family members were spouses or partners of patients. This further corroborates the notion that prostate cancer could be perceived as a 'couples' disease', which affects the healthy partner as well as the patient (Bottoroff et al., 2008). In this study, both the patients and their female partners often described dealing with the disease as a joint process involving both partners. Many women were intently involved in the process of information seeking with the view to better understand the disease and to help support their partner; prostate cancer also had an effect on the relationship between some partners, for example some women felt deeply affected by the loss of intimacy.

#### **6.4.1 Empowering processes perceived by the prostate cancer online support group members**

Participants in this study confirmed experiencing all the major empowering processes reported in past studies (e.g. van Uden-Kraan, 2008c) and observed in the naturally occurring messages posted to prostate cancer online support groups in Study 1. The processes reported by the participants included 'encountering similar others', 'information exchange', 'encountering emotional support', 'helping others' and 'chit chat'. The existence of the additional process identified in Study 1, i.e. 'finding a safe place to talk' was confirmed from the participants' perspective. Overall, many participants indicated that the support available outside of online support groups, either from family, friends or health care professionals, was often insufficient or not applicable to their specific needs. In contrast, they perceived online support groups as a source of invaluable and highly relevant informational and emotional support based on the unique understanding and bond between the members which stemmed from the shared experience of dealing with prostate cancer.

##### **6.4.1.1 Sharing information, advice and personal experiences with similar others as a source of empowerment**

As described in Chapter 2, literature suggests that prostate cancer patients and their family members experience increased need for information throughout the illness trajectory (e.g. Boberg et al., 2003; Davison & Breckon, 2012; Mason, 2005, 2008) and that this need is often unmet by health care professionals (Echlin & Rees, 2002). A number of recent studies investigating contents of messages posted to prostate cancer online support groups (e.g. Blank & Adams-Blodnieks, 2007; Blank et al., 2010; Huber et al., 2010), including Study 1, suggest that prostate cancer patients and their family members most often access online



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support groups to seek answers to specific questions relating to cancer management and that informational support is most prominent within these groups. The results of the current study further confirm that from the perspective of the members, that information, advice and personal experience seeking is indeed the primary motivation for accessing prostate cancer online support groups, and provision of informational support is a commonly experienced process within these groups.

Participants in this study highlighted that high volume of experiential knowledge in prostate cancer online support groups contributes to the fact that online support groups are perceived as a valuable source of knowledge, over and above the information provided by health care professionals. Whilst doctors were often perceived as inclined to promote their own specialism, information from members was perceived as largely free from such bias and therefore more trustworthy and useful in the process of treatment decision-making. This is in line with the findings of other studies on online support (e.g. Malik & Coulson, 2008a; van Uden-Kraan et al., 2008c) which suggest that experiential knowledge is a particularly valuable source of informational support for patients.

Past studies also highlighted the fact that the informational needs evolve throughout prostate cancer journey and that information from health care professionals can be provided too early to be processed (Feldman-Stewart et al., 1998, 2010). In the current study, many participants indicated that online support groups were a much more flexible source of information due to the large number of people posting messages. The diversity of members ensured that appropriate information and advice was available at every stage of the disease and treatment trajectory.

Similar to the other studies on online support groups (e.g. Malik & Coulson, 2008a; van Uden-Kraan et al., 2008c) participants found the instant availability of information and

advice to be both convenient and comforting. Many participants indicated that it helped them resolve problems quickly, and was particularly valuable during out of office hours, late at night or at the weekends, when medical help was unavailable or the fear and anxiety became overwhelming.

#### **6.4.1.2 Encountering unique emotional support from similar others**

Research suggests that the second most often observed process occurring within online support groups is exchange of emotional support (Braithwaite et al., 1999; Salem et al., 1997), this process is, however, more often observed and most pronounced in online support groups used predominantly by women, as compared to male cancer groups (e.g. Blank et al., 2010; Sullivan, 2003). The findings of this study expand current knowledge suggesting that female family members of prostate cancer patients also engage in the exchange of emotional support to a higher degree than the male patients themselves. In the current study seeking emotional support was more often noted as the primary motive for accessing online support groups by the female participants and women also focused on the emotional aspects of communication with other members much more than the men. This was particularly apparent in single gender groups where many women felt comforted and reassured by the unique bond and sense of understanding shared with other 'sisters', which resulted in greater ability to open up, express feelings, complain and talk about their fears and sorrows without worrying about being judged or rejected. Similarly, Im et al (2007a) reported that female cancer patients prefer single gender groups as they feel safer and less embarrassed to discuss their feelings and problems with other women.

Past studies have suggested that men in prostate cancer groups tend to exchange information and personal experiences more often than emotional expressions. Some authors argued that for this group of members, informational support helps reduce fears

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and sense of isolation as well as improves mental wellbeing and sense of community (e.g. Gooden & Winefield, 2007; Sullivan, 2003). Similarly, in the current study fewer men than women specifically referred to the benefits of exchanging emotional support with other members. Conversely, the majority of men focused on the exchange of experiential knowledge and many suggested that learning about other patients' successful recovery, long-term survival and their ability to deal with the disease calmly and with dignity, helped comfort them, reduce their fears and led to a more positive outlook on life with prostate cancer. Therefore the current findings lend support, from the participants' perspective, to the notion that men feel comforted as well as informed through the process of information and experience sharing (Gooden & Winefield, 2007; Sullivan, 2003).

### **6.4.1.3 Discussions of sensitive topics**

Broom (2005a) suggested that masculine representations inhibit prostate cancer patients ability to discuss sexual and urinary issues face-to-face, thus, he suggested that the anonymity of online support groups could facilitate more open communication. The results of the current study, however, suggest that prostate cancer patients tend to seek information about intimate problems online due to lack of such information elsewhere; many participants suggested that health care professionals provided limited and often too general information about possible side-effects. Conversely, online support groups were often perceived as the only place where these issues could be discussed with people who had similar experiences and could offer practical advice and information. Notably, the current findings indicate that men are more likely to discuss sexual and urinary function online, whilst some women tend to benefit from conversations about problems related to the loss of intimacy and deterioration of the relationship with their partner. This confirms past findings from online support groups used by male and female patients (e.g. Gooden & Winefield, 2007) and extends them to female family members.

#### **6.4.1.4 Helping other members – giving back to the community**

Several participants, both male and female, indicated that their reasons for participation in online support groups changed over time. Many indicated that they started as inexperienced 'novices' in a desperate need to learn as much as possible about the disease, treatment options and chances for survival and cure. As they learnt more from other members and gathered experiences of their own, they became more confident in their knowledge and keen to 'give back what they got at the beginning'. Many recognised that mutual support forms the foundations of online support groups and they stayed on in the groups, mentoring and supporting newly diagnosed patients and their family members. Some indicated that they enjoyed sharing their own experiences with other members. Others reported that they felt responsible for other members and visited the groups to offer on-going support to those who were going through difficult times. This process of change closely reflects the membership life cycle (e.g. Kim, 2000; Sonnenbichler, 2010) described in Chapter 3. In the current study many participants indicated that they have been accessing prostate cancer online support groups for many years which could suggest that they derive satisfaction from the ability to share their own story and provide help and support to other members. Few members, however, described in detail the effects ability to help others had on them, therefore further research, possibly employing in-depth interviews with the long-term members as well as members who left the groups when their need for support subsided, could help us understand this issue better.

#### **6.4.2 Empowering outcomes of participation perceived by prostate cancer online support group members**

The current study indicates that participation in online support groups has considerable positive effects on both prostate cancer patients and their family members. Many

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participants reported that as a result of encountering the empowering processes described in the previous section they felt more knowledgeable about the disease and available treatment options; their ability to communicate with their health care professionals increased; they experienced reduced sense of isolation; and they were better able to positively reappraise themselves and the situation they were in. These findings are in line with the results of past studies which reported similar effects of participation on female patients accessing online support groups (van Uden-Kraan et al., 2008c, 2009). In addition, similar to prostate cancer patients in a study conducted by Broom (2005a), a large proportion of participants in the current study reported being better able to actively participate in treatment decision-making.

### **6.4.2.1 Being better informed and active participation in health care**

Being better informed was the most commonly mentioned empowering outcome of participation in online support groups. This was not an unexpected finding, as past studies also indicated that increased knowledge was most frequently reported by online support group users affected by a variety of diseases (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009). Furthermore, as discussed earlier, the majority of participants in this study started to use online support groups to seek information and, overall, they were satisfied with the facts and experiential knowledge they have obtained. The participants also frequently reported that being better informed and more confident in their own knowledge positively affected other empowering outcomes, such as increased ability to actively participate in treatment-related decisions and an improved relationship with the health care professionals.

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As it was discussed in Chapter 2, there is an expectation towards individuals living with cancer and other chronic diseases to become 'expert patients' and actively participate in their own health care (NICE, 2008). Treatment decision-making is an important yet difficult task for many newly diagnosed prostate cancer patients, which requires a considerable amount of knowledge about treatment options and their potential outcomes (e.g. Davison et al., 2002; Feldman-Stewart et al., 2008; McParland, 2009;). Making an informed decision was associated with greater satisfaction with the chosen treatment (Clark & Talcott, 2006) and some studies indicated that information obtained from other patients is often most valuable in this process treatment decision-making as it offers a unique insight into lived experiences of those, who experienced a particular treatment modality (Berry et al., 2003). In the current study the patients also suggested that the experiential knowledge shared by other men was most beneficial in their process of making a decision about treatment, as it helped them weigh all pros and cons of each option and as a consequence make an optimal choice for themselves.

Past studies also suggested that patients who access online support groups soon after diagnosis could benefit the most in terms of knowledge and informed decision-making (Broom, 2005a; van Uden-Kraan et al., 2008c). The current study confirms this and also suggests that men who seek information about prostate cancer online tend to do so sooner rather than later, however a notable minority of participants in this study did not reach this source of informational support till after the treatment commenced. Therefore educating newly diagnosed men about availability of online support at time of diagnosis may be beneficial.

Some men also indicated that participation in the groups empowered them to oppose the decision made by their doctor. Past studies, however, have indicated that introducing

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treatment-related information from the Internet can cause some animosity within the patient-health care professional dyad (Broom, 2005b) especially if the patient rejects health care professional's opinion on this basis (Sullivan, 2003). Broom (2005b) reported that health care professionals often found the information from the Internet irrelevant and sometimes harmful for the patients, for example when they became focused on a certain course of treatment that was not necessarily appropriate for them. Although in the current study few ill-effects of participation in online support groups on the relationship with health care professionals were reported, it is necessary to point out that due to the nature of the sample, the results did not capture the experiences of individuals who were dissatisfied with the effects participation had on their lives, and therefore further research is required to fully understand the effects participation in online support groups may have on relationship with health care professionals.

Partners and family members in the current study also reported experiencing increased knowledge about prostate cancer and treatment modalities as a result of participation in online support groups. Indeed, past studies suggested that alternative sources of information, such as the Internet and online support groups, are often the only way caregivers can learn about the disease (Feltwell & Rees, 2004) and therefore family members may particularly benefit in terms of knowledge. They also reported increased confidence in their own ability to retrieve useful and valid information, which they could share with the patient and thus guide his treatment decision-making processes. This is in line with the findings reported by Feltwell and Rees (2004), which suggested that the main reasons for the female partners of prostate cancer patients to gather information, apart from reducing their own anxiety, was to become more active participants in their partners' care and treatment decisions.

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Some participants indicated that the informational and emotional support they have received within their groups helped them feel more confident in the relationship with their health care professionals. For example, some patients felt that they could use online support groups to clarify or check the information they received during consultations. Ziebland et al. (2004) suggested that the ability to covertly check information provided by health care professionals can help build trust and prevent threats to the relationship between the patient and the doctor. Seeking information online was also found to enhance patients' ability to ask more appropriate questions during the consultation and thus elicit more relevant responses (Ziebland et al., 2004). Being better prepared for the consultation and ability to ask 'more intelligent questions' was often reported in the current study. Furthermore, some family members, particularly spouses of the patients indicated that through their participation on online support groups they felt empowered to take part in their husband's appointments and be more assertive in communication with the doctor. This is an important finding, as female partners of prostate cancer patients often feel disempowered in the relationships with their partners' health care professionals and excluded from the dialogue (Echlin & Rees, 2002; Feltwell & Rees, 2004).

### **6.4.2.2 Reduced sense of isolation and positive reappraisal**

Cancer diagnosis can lead to an increased sense of social isolation for both the patients and their family members (Bottoroff et al., 2008; Jansma et al., 2005; Taylor et al., 1986). Recent research suggested that online support groups can serve an important role in improving social well-being and reducing isolation in female patients (van Uden-Kraan et al., 2008c, 2009). The current study confirms these findings and extends them to the prostate cancer patients and their female family members. Participants frequently noted building personal relationships with other members, making new and valuable social



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contacts and even talking on the phone and meeting in person. For many of the patients and their family members being part of the online communities was very important, some even credited them with saving their sanity and their lives. This was particularly apparent in the responses of the spouses of patients who were in advanced stages of the disease or have passed away, which could suggest that the need to belong to a supportive social network is particularly strong in times of psychological distress. Further research, however, is necessary to explore this in more detail.

Reduced isolation and realising that others are going through similar problems and experience similar emotions helped some participants validate their feelings which they previously perceived as undesired or difficult to accept. Other authors also noted that through comparing experiences with similar others in face-to-face or online support groups, patients and caregivers felt more at ease with their feelings of anger and frustration and were better able to re-evaluate them as 'normal' (Attard & Coulson, 2012; Sharf, 1997; Ussher et al., 2006; van Uden-Kraan et al., 2008c).

For many patients and family members, the ability to compare experiences with others in a similar situation led to a more positive outlook on their situation. Some participants reported sense of realisation that their situation was not as bad as they thought; others felt inspired by the bravery and positive outlook of others. This is in line with the findings reported by van Uden-Kraan et al. (2008c) who suggested that patients often engage in downward comparison (comparing themselves to people who are in a worse situation) for reassurance that they are in a better position than the other patients. Helgeson and Taylor (1993) also noted that cancer patients derive hope and inspiration from the stories of others who are doing well (upwards comparison).

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Having sense of control is one of the central components of the construct of empowerment (Barak et al., 2008; Zimmernam, 1995) and participation in face-to-face as well as online support groups has been previously associated with increased sense of control. Many participants in the current study indicated that learning about other members' experiences with various treatment modalities, recovery and side-effects they felt better prepared for the future and more in control over the disease and their own lives.

Finally, participation in online support groups helped many spouses of the patients to feel better able to support their partners throughout the trajectory of the disease and treatment. Some felt, that they were able to 'vent' their negative feelings in a safe environment and receive valuable emotional support from other women, which resulted in improved mental well-being and thus improved their ability to be supportive and positive around their partner. This is an important finding, as past studies indicate that caregivers often do not feel that they have the time, opportunity or right to put their own health and well-being first and seek medical attention, even though breakdown in their physical or mental health could have negative effects on their ability to care for the patient (Osse et al., 2006). The results of the current study point towards online support groups as a suitable venue where the caregivers can receive emotional and informational support which can improve their own mental well-being and through this also enhance their ability to care for their partner.

### **6.4.3 Negative aspects of participation in online support groups**

Overall negative aspects of participation were mentioned less often than the positive aspects by all participants, and particularly infrequently by the women. Commonly mentioned problems included 'disempowering interpersonal relationships within the

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groups', 'negative aspects related to the contents of messages' and 'being confronted with negative aspects of the disease'.

Past studies indicated that online support group members felt unsure of the correctness of information shared by other people (e.g. van Uden-Kraan et al., 2008c). In the current study some members also mentioned the fact that sometimes information was incorrect, but the majority felt able to deal with this, as they usually double checked information obtained from the groups with other sources, such as their health care professionals. Some members suggested that involvement of health care professionals in the communication in online support groups could help improve the standard of information provided. This information could be useful for individuals who create and moderate prostate cancer online support groups, as securing the help of a well-known expert in the field could potentially enhance members' experiences in the groups. Potentially biased information and inability to assess the genuineness of some members' motives in proselytising for certain treatment options was found to be more problematic. Feenberg and colleagues (1996) pointed out that anonymity within online support groups can lead to decreased ability to assess authors' expertise and credibility; they raised concerns that lay-members may be posting as experts. In the current study, participants were also concerned with the possibility that experts may be posting as lay-members. As many participants joined online support groups with hope to find unbiased information based on real-life experiences of other members, they found such messages problematic.

Disempowering relationships between members were mentioned mainly by male participants who often felt irritated by dominant or intolerant members who forced their opinions and beliefs upon others. Some participants felt that such members could infringe upon the rights of others to express opinions or explore alternative options of treatment as

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well as negatively affect doctor-patient relationship. Interestingly, other authors investigating negative aspects of participation in health-related online support groups from the female participants' point of view (e.g. Malik & Coulson, 2008a; Sandaunet, 2008; van Uden-Kraan et al., 2008c) did not report similar problems within predominantly female groups. Similarly, in the current study female participants did not mention encountering dominant or intolerant members in female only groups, a few women, however, felt that some interpersonal problems occurred in mixed gender groups between male and female members. Herring (1993) found that male academics taking part in online discussions were more likely than the females to put other participants down, use self-promotion, overly long entries and sarcasm. This finding and the results of the current study could potentially suggest that male groups are more likely to witness aggressive discussions where opinions are presented more vehemently and with less regard for other members' views.

Similar to other studies (e.g. van Uden-Kraan et al., 2008c), some participants noted that being confronted with the negative sides of the disease, such as metastases, failed treatment or death of a member (or a partner of a member in case of the caregivers) could lead to greater distress and fear, often reminding them of the seriousness of this disease. Van Uden-Kraan and colleagues (2008c) suggested grouping members according to the stage of the disease could offer a possible solution to this problem, diminishing members' exposure to negative aspects of the disease. The participants in the current study, however, highlighted the fact that conversing with people at various stages of the disease was one of the major benefits of participation in the groups. They felt that reading messages posted by people who were ahead of them allowed them to prepare for the future, while posting their own experiences was perceived as useful for newly diagnosed patients.

### **6.5 Strengths and limitations of the study**

This study is amongst the first exploring the full extent of empowering processes and outcomes as well as negative aspects of participation in prostate cancer online support groups from the members' perspective. The qualitative data collected via the online open-ended questionnaires allowed a novel and in-depth insight into the experiences of the patients accessing these groups, as well as the experiences of their female family members. Multi-site strategy was adopted for data collection, resulting in a large sample consisting of participants from across various types of prostate cancer online support groups, including private and public, single and mixed gender, large and small, British and American groups.

Some limitations of the study should, however, be noted. Firstly, the participants were a self-selected sample of current prostate cancer online support group users. Although two moderators emailed the invitation to the members, no responses were obtained from people who no longer used the groups. Furthermore, nearly all participants were satisfied or very satisfied with the help they received within the groups. Many participants were long-term users, who were well established within the communities, and the majority were regular posters. These characteristics of the current study sample affect the generalizability of the findings and suggest that the results may overestimate the positive aspects of participation and underrepresent the negatives.

Secondly, the study was cross-sectional and only captured the participants' perceptions of their online experience at one time point. The data collected could potentially be affected by various factors, such as participants' mood, health or a particularly friendly conversation within the group they experienced that day. A longitudinal study could potentially help members' experiences at various time points reducing the effects of confounding factors as

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well as establish how members' perceptions of participation in online support groups change over time.

Thirdly, as in most research conducted over the Internet, the researcher had no control over the conditions in which the surveys were completed (LaCoursiere, 2003). Individual responses could have been affected by the quality of Internet connection, participants using other applications at the same time or any other distractions. Furthermore, the anonymity of online research is problematic and makes it difficult to establish if the participants are who they claimed to be. In the current study certain measures were applied to maximise the authenticity of the responses, for example all data were screened for duplicate entries and any responses inconsistent with the rest of the sample. No duplicate entries (i.e. entries from the same IP address) or inconsistencies were detected.

Fourthly, the data were collected using online open-ended surveys, a method which does not offer the researcher the opportunity to further explore the responses or to expand upon issues of interest. Despite this limitation, few participants provided incomplete surveys and the majority provided detailed and in-depth responses reflecting a wide range of online experiences. Nevertheless, future research using face-to-face or online interviews could help explore online experiences of the members in greater depth.

Finally, the data collected were qualitative, and thus did not provide information about the extent to which various processes and outcomes were experienced by the participants. Although some differences between the responses of the patients and the family members were found, it was impossible to establish the statistical significance of these differences. Therefore a quantitative study measuring the extent to which participants experienced the processes and outcomes identified in this study is necessary.

## 6.6 Conclusions

This study offers a novel and in-depth insight into the experiences of prostate cancer online support group users, including their motives for accessing the groups, the empowering processes and outcomes as well as disadvantages of participation, presented from the point of view of the members.

In summary, a number of previously identified empowering processes and outcomes were reported by the participants in this study. Overall, both the patients and the family members used online support groups predominantly for information seeking and to exchange experiences and support with similar others. The women were more likely to seek and experience emotional support than the men, who in turn focused on the exchange of information and personal experiences with the view to make informed decisions about treatment. The most frequently reported empowering outcomes were being better informed and having a reduced sense of isolation. Experiencing these outcomes appeared to help empower both the patients and family members to become more active participants in treatment decisions and medical encounters as well as to positively reappraise the situation and their own feelings towards the cancer. The findings of this study suggest that participation in online support groups can be particularly beneficial for the family members of prostate cancer patients; a group whose support needs are often underestimated or overlooked by the medical community as well as family and friends.

Overall, the benefits of participation vastly surpassed the negative aspects. Few female participants reported any unhelpful aspects of participation, especially in relationship to single gender groups. The main disadvantages included disempowering relationships

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between members, quality of contents and messages about disease progression and death. One of the main limitations of this study was, however, the fact that it was based on a self-selected sample of members, who were, by and large, very positive about their experiences within online support groups and therefore should not be generalised onto the entire population of individuals who have accessed prostate cancer online support group.

Further quantitative research could help build on the findings of this study and help assess the extent to which various empowering processes and outcomes reported in this study are experienced by the members as well as evaluate the significance of the potential differences in the processes and outcomes experienced by patients and family members highlighted in this study.



## **Chapter Seven: Study Three. Analysis of quantitative survey data**

### **Chapter overview**

The results of Study 2 suggest that both patients and family members experience a range of empowering processes and outcomes as a result of participation in prostate cancer online support groups. The qualitative nature of the study did not, however, offer the possibility to measure the extent to which the members feel empowered by their participation in prostate cancer online support groups or which processes occurring in the groups contribute to the increased sense of empowerment. This chapter presents the results of a quantitative study, conducted with 197 members of prostate cancer online support groups. Participants completed an online questionnaire comprising measures of demographic characteristics, online support group use and satisfaction as well as empowering processes and outcomes. The results indicated that participants felt empowered in several ways by their participation in the groups and the most commonly experienced empowering outcomes were 'increased knowledge and ability to participate in treatment decisions' and 'improved relationship with the physician'. No significant differences in empowering outcomes between patients and family members were identified. Empowering outcomes could be predicted by the processes occurring in the groups to a varying degree; the highest percentage of variance was explained in outcomes 'increased sense of community spirit' and 'increased knowledge and ability to participate in treatment decisions'. The findings of this study suggest that participation in prostate cancer online support groups can help foster empowerment in members.

## 7.1 Introduction

The findings of the two qualitative studies presented thus far pointed towards the existence in prostate cancer online support groups of all empowering processes and outcomes previously identified in studies conducted within female and mixed gender online support groups (Bartlett & Coulson, 2010; Mo & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009). Furthermore, another empowering process ('finding a safe place to talk') and empowering outcome ('increased ability to participate in treatment-related decisions') were identified by the participants in Study 2. The findings of past research also suggest that in online support groups dedicated to various conditions the empowering processes and outcomes can be experienced by members to a different extent. For example, van Uden-Kraan and colleagues (2009) found that the process 'information exchange' was experienced most frequently by members of breast cancer, fibromyalgia and arthritis groups, while 'helping others' was experienced to the smallest degree in these groups. Conversely, Bartlett and Coulson (2010) found that in various cancer groups 'encountering similar others' was experienced most frequently, followed by 'helping others' and 'information exchange'. The empowering outcome 'being better informed' was experienced to the highest degree by members of all the above mentioned groups (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009), followed by 'enhanced social wellbeing', suggesting that online support groups tend to fulfil educational and social roles. Past studies suggest that the process most frequently observed in the messages posted to prostate cancer online support groups is provision of informational support, including both factual information and experiential knowledge exchange (e.g. Gooden & Winefield, 2007; Huber et al., 2010), however the extent to which members of these groups experience various processes and outcomes remains unexplored.

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Although the previous studies conducted within the empowerment framework found some interesting relationships between the processes and outcomes of participation, there is no consensus regarding the exact relationships in various groups. Furthermore, only a moderate proportion of variance in the outcomes could be predicted by the processes. For example, although both van Uden-Kraan et al. (2009) and Bartlett and Coulson (2010) noted that the highest proportion of variance was explained in the outcome 'being better informed', the former study indicated that the significant predictors of this outcome were 'information exchange', 'encountering emotional support' and 'finding recognition', while the latter found no relationship between 'being better informed' and 'information exchange' and emotional support.

These findings warrant further quantitative investigation of the extent to which members of prostate cancer online support groups experience the empowering processes and outcomes. The relationships between the processes and outcomes in this type of online support groups should also be investigated. As no studies focused on the extent to which family members experience empowering processes and outcomes, comparison between patients and family members could also help extend current knowledge regarding empowerment in online support groups.

### **7.1.1 Aims**

The overall aim of this study was to examine the extent to which individuals accessing prostate cancer online support groups experience each of the empowering processes and outcomes identified in the previous studies. The specific research questions included:

- To what extent do individuals affected by prostate cancer, who access online support groups, experience empowering processes within the groups?

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- To what extent do individuals affected by prostate cancer, who access online support groups, experience empowering outcomes of participation in the groups?
- Are there any differences between the patients and the family members in the self-reported level of empowering processes and outcomes experienced as a result of accessing prostate cancer online support groups?
- What is the relationship between the empowering processes that take place in prostate cancer online support groups and the empowering outcomes experienced by the members?

### **7.2 Methodology**

The current study was cross-sectional in design and utilised a self-administered online survey of individuals accessing prostate cancer online support groups, including patients, family members and friends. Similar to Study 2, online data collection, and specifically recruitment of participants from within prostate cancer online support groups was considered to be an effective as well as time and cost-efficient method of reaching the target population, i.e. individuals affected by prostate cancer who access prostate cancer online support groups.

Statistical analysis of the data was conducted using PASW Statistics version 18.0 (SPSS).

#### **7.2.1 Sampling procedure recruitment of participants**

Thirteen online support groups which did not decline the invitation to participate in Study 2 were included in the current study. In addition, a new search, following the criteria

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described in Study 2, and using the search engine Google™ as well as Google Groups and Yahoo Groups was conducted in order to identify new prostate cancer online support groups and groups that might have been overlooked in the past. As a result, a further eight online support groups were identified.

In total, 21 gatekeepers of prostate cancer online support groups were contacted with the invitation to take part in the study. The gatekeepers of 12 online support groups agreed to participate. A message containing an invitation to take part in the study was posted to the message boards of 11 groups and one moderator emailed the invitation directly to the members.

The invitation contained a short description of the study and a link to the online survey (see Appendix C). Individuals who chose to take part in the research were redirected to the questionnaire hosted by SurveyMonkey®, at the start of which they were provided with information about the aims of the study and the procedure. Participants' confidentiality, anonymity and right to withdraw from the study as well as the departmental contacts of the research team were also explained. Informed consent was collected electronically from each participant and they were asked to create a password allowing them to withdraw their responses at a later date. Once they indicated their consent, participants were asked to complete questions relating to demographic characteristics, health status and online support group use, followed by measures of perceived social support outside online support groups and empowering processes and outcomes (see 7.2.3). On completion of the survey the participants were redirected to the debriefing page, where they were thanked for their participation and provided with contact details for the research team as well as for organisations offering help to people dealing with prostate cancer. The contents of the survey are presented in Appendix D.

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Ethical approval for this study was obtained from the departmental Ethical Committee at the Institute of Work, Health and Organisations, University of Nottingham. The ethical guidelines were followed, as described in section 6.2.3 of the previous chapter.

### **7.2.2 Measures**

#### *Demographic and health characteristics*

The participants were asked to provide information regarding their gender, age, country of residence, marital status, education and current employment status. They were also asked if they were visiting the online support group as a patient or family member/friend. Family members/friends were asked if they considered themselves to be caregivers to the prostate cancer patient. The participants were also asked to provide details relating to prostate cancer, such as time since diagnosis, latest diagnosis details, time since treatment and treatment type. Patients were asked to answer these questions in relation to themselves whilst family members/friends were asked to reply in relation to the patient.

#### *Online support group use*

Participants were asked questions about their habits relating to online support group use, including the type of groups they used (single or mixed gender), length of membership, frequency of accessing the groups and duration of visits. Participants were also asked to specify if they have ever posted any messages, and if so, how frequently they posted.

#### *Satisfaction with online support group use*

To assess satisfaction with online support groups, the participants were asked to rate, on a 5-point Likert scale (ranging from 1-very satisfied to 5-very dissatisfied), their overall

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satisfaction with the group, as well as their satisfaction with information and support provided within the group. Similar measures were used to assess satisfaction with online support groups in past studies (van Uden-Kraan et al., 2009; Mo & Coulson, 2010).

### *Satisfaction with online support group as a forum to discuss sensitive issues*

The results of Studies 1 and 2 suggest that prostate cancer online support groups are often used by the patients and their family members for discussion of sensitive issues such as post-treatment sexuality and impotence. As these studies were both qualitative and exploratory in nature, the extent to which patients and their family members perceive online support groups as a safe place to talk remains unexplained. Therefore three items, based on past literature and findings of Studies 1 and 2, measuring satisfaction with the group as a place to discuss sensitive issues were included in the current study. Participants were asked to rate, on a Likert scale, ranging from 1-not at all true to 5-very true, the following statements: 'My group is a safe place to discuss intimate issues'; 'I feel more comfortable discussing sensitive issues with the group members than in face-to-face situations'; 'I find the ability to discuss intimate issues within the group beneficial'.

### *Medical Outcomes Study: Social Support Survey Instrument (MOS: SSSI)*

The literature reviewed in Chapter 2 and the findings of Studies 1 and 2 suggest that the level of perceived emotional and informational support outside of the groups may affect the online support group experiences of prostate cancer patients and their family members. The MOS: SSSI (Sherbourne & Stewart, 1991) was used to measure the level of social support outside the online support groups. It is a concise self-administered scale measuring four main types of social support – emotional/informational support, tangible support, affectionate support and positive social interaction. The authors reported very

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good internal-consistency reliability of the original subscales and overall support index (Cronbach's alpha ranging from .91 to .97) and the one year test-retest correlation was good (ranging from .71 to .78) (Sherbourne & Stewart, 1991). The tangible support subscale referred to practical support, such as giving lifts or cooking meals. This type of support was found to be practically non-existent within online communities (e.g. Mo & Coulson, 2008) and could not be substituted through participation in an online support group. It was, therefore, deemed irrelevant and this subscale was excluded from the current study.

Three of the original subscales were used: emotional/informational support (8 items, Cronbach's alpha calculated for the current study sample  $\alpha=.95$ ); affectionate support (3 items, current  $\alpha=.90$ ); positive social interaction (3 items, current  $\alpha=.90$ ) plus one additional item. The overall support index was calculated as a mean score of all 15 items, with Cronbach's alpha for the current study sample being  $\alpha=.95$ . The opening question was slightly altered to ensure that participants referred in their answers to the support outside online support groups: 'EXCLUDING people you know through the prostate cancer online support groups, how often is each of the following kinds of support available to you if you need it?' followed by various examples of social support, such as 'Someone who hugs you' or 'Someone who understands your problem'. The participants were asked to rate each item on a 5-item Likert scale, ranging from '1-none of the time' to '5-all of the time'. The higher score indicated higher levels of support. Scores for each subscale and the entire scale were calculated by adding scores for all relevant items and averaging them. To allow comparison with the scores obtained from the original sample (Sherbourne & Stewart, 1991) the scales were transformed so that the lowest possible score was 0 and highest was 100.

### *Empowering processes*



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The 39-item measure of empowering processes within online support groups was based on the scale developed by van Uden-Kraan and colleagues (van Uden-Kraan et al., 2009). The original 29-item scale measured five dimensions of empowering processes: 'receiving useful information' (9 items,  $\alpha = .88$ ), 'receiving social support' (13 items, Cronbach's alpha .95), 'finding recognition' (4 items,  $\alpha = .70$ ), 'helping others' (2 items,  $\alpha = .82$ ) and 'sharing experiences' (2 items,  $\alpha = .87$ ). Participants were asked to rate, on a 5-point Likert scale, ranging from 1-never to 5-often, the frequency of certain events occurring within online support group, for example 'How often does it happen that someone in your prostate cancer online chat group offers you sound advice?'

The original scale was adapted for the use with prostate cancer online support group members based on the findings of Studies 1 and 2. Several items were added to reflect the specific aspects of empowering processes identified within prostate cancer online support groups. These items related to encountering similar others; participants' perception of the group as a safe place to talk openly and chit-chat.

### *Empowering outcomes*

The 38-item scale measuring empowering outcomes of participation in online support groups was based on the scales devised by van Uden-Kraan and colleagues (2009) and Mo and Coulson (2010). Van Uden-Kraan and colleagues (2009) developed a 38-item scale, comprising of seven subscales, measuring the following empowering outcomes of participation in online groups: 'being better informed' (4 items,  $\alpha = .85$ ); 'feeling more confident in the relationship with their physician' (11 items,  $\alpha = .91$ ); 'improved acceptance of the illness' (5 items,  $\alpha = .90$ ); 'feeling more confident about the treatment' (5 items,  $\alpha = .89$ ); 'increased optimism and control over the future' (8 items,  $\alpha = .76$ ); 'enhanced self-esteem' (3 items,  $\alpha = .93$ ). Mo and Coulson added another dimension to the empowerment

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scale entitled 'finding positive meaning' ( $\alpha=.95$ ). All items were formulated as statements beginning with 'Participation in prostate cancer online chat groups helped me...' followed by examples of possible outcomes of participation, such as '...feel better informed'. Participants were asked to rate each statement on a Likert scale, ranging from 1-completely disagree to 5-complitley agree.

Nineteen of the original items from van Uden-Kraan's scale and 6 items from the subscale added by Mo and Coulson's were adopted for the current study. A further 13 items based on the findings of Studies 1 and 2 were created to reflect other aspects of empowering outcomes discussed by the members of prostate cancer online support groups.

An exploratory factor analysis was conducted in order to investigate if the original and new items loaded meaningfully onto factors.

### **7.2.3 Sample characteristics**

The participants were a self-selected sample of prostate cancer online support group members who responded to the participation requests posted to online support groups. The link to the survey website was followed 290 times. A total of 247 individuals gave their consent while the remaining 43 left the survey without proceeding to the consent page. A further 50 people did not complete all of the measures, resulting in a final sample of 197 participants. T-tests and  $\chi^2$  test were conducted to establish if any differences existed between the completers and non-completers. Those who completed the questionnaire ( $n=197$ ) did not differ significantly from those who dropped-out ( $n=50$ ) according to gender, age, country of origin, marital status, education, time since diagnosis, or length of membership. The non-completers were, however, significantly more likely to be 'lurkers'

( $\chi^2(1)=3.89$ ,  $p<0.05$ ) and in employment ( $\chi^2(2)=8.88$ ,  $p<0.05$ ) than those who completed the survey.

### 7.2.3.1 Demographic and health information

Out of the 197 participants the majority were male ( $n=149$ , 76%). All men identified themselves as prostate cancer patients and the majority of women as partners/spouses ( $n=41$ , 85%) followed by daughters ( $n=6$ , 13%) and one identified herself as a friend (2%)<sup>2</sup>. Nearly all family members ( $n=44$ , 92%) perceived themselves at some point to be caregivers to the person with prostate cancer. The average age of respondents was 59.5 years ( $SD=9.2$ ), and the family members were significantly younger ( $M=54.1$ ,  $SD=9.8$ ) than the patients ( $M=61.3$ ,  $SD=8.3$ ) ( $t(193)=4.96$ ,  $p<0.001$ ). The majority of participants were married or in a relationship ( $n=164$ , 83%). Most participants lived in the USA ( $n=143$ , 73%), followed by the British Isles ( $n=19$ , 10%) and Canada ( $n=12$ , 6%). The majority had tertiary education (college, university or postgraduate) ( $n=169$ , 81%) and just over half ( $n=101$ , 51%) were employed<sup>3</sup>.

Similar to Study 2, when reporting cancer-related information, family members provided information about their close ones' cancer, while the patients reported upon their own health status. The average time since diagnosis was 4.1 years ( $SD=3.8$ ), ranging from 1 month to 19.5 years. The majority of family members reported that their close ones were in more advanced stages of prostate cancer, i.e. had a significantly higher tumour stage ( $\chi^2(4)=12.4$ ,  $p<0.05$ ), PSA ( $\chi^2(4)=12.5$ ,  $p<0.05$ ) and Gleason score ( $\chi^2(6)=27.3$ ,  $p<0.001$ ). They were also significantly more likely to report metastases ( $\chi^2(2)=11.1$ ,  $p<0.01$ ). The majority

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<sup>2</sup> As there were no male relatives and no female patients in the current sample, the terms 'patients' and 'men' as well as 'family members' and 'women' will be used interchangeably throughout this chapter.

<sup>3</sup> Only significant differences between groups are reported. When not stated, no significant differences were detected for the particular variable.

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of participants (n=175, 89%) reported that the initial treatment had already been administered.

A significant difference was observed in the type of treatment that had been administered to the patients and the close ones of the female participants ( $\chi^2(7)=30, p<0.001$ ); although surgery was the most popular choice of treatment reported by both the patients and the family members, the patients reported significantly more cases of surgery (n=89, 60%) than the family members (n=16, 33%). Conversely, the family members reported more cases of hormonal treatment (n=12, 25%), as compared to the patients themselves (n=7, 5%).

### **7.2.3.2 Online support group use**

On average, the length of membership in online support groups was 3.2 years (M=3.2, SD=3.1), ranging from 14 days to 16 years. The patients tended to have a longer membership period (M=3.5, SD=3.3) than the family members (M=2.4, SD=2.1) ( $t(195)=2.17, p<0.05$ ). An average visit to the group lasted 48.9 minutes (M=48.9, SD=57.3). There was a significant difference between the type of groups used by male and female participants ( $\chi^2(2)=18.1, p<0.001$ ). Women were more likely to use single gender groups (n=15, 32%) or a combination of mixed and single gender groups (n=18, 38%), while the majority of men used mixed gender groups only (n=95, 64%). Men and women also significantly differed with regards to the time they first started using the groups ( $\chi^2(5)=22.1, p<0.001$ ). Although the majority of both male and female participants first accessed the groups before treatment (men n=95, 64%; women n=21, 44%), far more women than men reported starting to use the groups during the initial treatment (n=10, 7% males and n=11, 23% females), whilst more men accessed online support after the treatment was completed (men n=35, 24%; n=7, 15%). The majority of all participants

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identified themselves as frequent online support group users; most participants (n=126, 64%) indicated that they visited their group daily and a further 54 (27%) logged on at least on a weekly basis. Similarly, the majority reported being active users of the groups (posters; n=144, 73%) while the remainder reported never posting a message or only having posted once or twice (lurkers; n=53, 27%). The majority of the women reported that their partners/fathers did not use online support groups (n=32, 68%).

### **7.3 Results**

#### **7.3.1 Distribution of the data**

In order to achieve normally distributed data, the sample should be randomly selected from the population (Field, 2005). Due to practical and ethical reasons access to the online support group members is restricted. The groups invited to take part in the current study were given the choice of emailing all members or placing an invitation on the message board. Only one group used the email method. The sample in this study, similar to Study 2, could therefore be described as self-selected, consisting mostly of people who were currently accessing online support groups. To minimise the selection bias, multiple prostate cancer online support groups were contacted, private and publically available, as well as mixed and single gender, however, access to individuals who ceased online support group use was largely restricted.

The Kologomorov – Smirnoff tests were employed to assess the distribution of the current data. The results indicated that the data collected were not normally distributed ( $p < 0.001$ ), however statistical textbooks (e.g.: Statsoft Inc, 2011) suggest that in large samples ( $N > 100$ ) normality of the data is less of an issue and parametric tests should be used, as they are more sensitive and have greater statistical power than non-parametric tests. As

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the current sample consisted of 197 participants, parametric tests were used throughout the analysis; however the results should be generalized onto a wider population with caution.<sup>4</sup>

Missing data in the three psychosocial scales were uncommon (0.8%) and were most frequently identified in the empowering processes scale (n=78, 1.3%), followed by MOS: SSSI (n=25, 1%) and the empowering outcomes scale (n=22, 0.3%). Missing values in background variables were even more infrequent (n=6, 0.2%), with the exception of information about disease, which had a considerable amount of missing data (tumour stage n=66, 33.5%, Gleason score n=35, 17.8%, PSA n=9, 4.5%; including responses 'not known'). It was however recognised that in order to provide this information participants had to be aware of the Gleason score, PSA and tumour stage. The majority of the missing cases could potentially be accounted for as 'not known'.

Missing data in the three psychosocial scales were replaced by the mean score for the variable. Field (2005) cautions that replacing missing values with means for factor analysis can result in non-significant results appearing as significant and is therefore not advisable in cases where excluding missing values would not significantly reduce the sample size. As the amount of missing data was small, for the purpose of factor analysis, missing values were excluded pairwise.

### **7.3.2 Factor analysis**

Before the analysis of the data commenced, an exploratory factor analysis using principal axis factoring extraction method with direct oblimin rotation was conducted in order to

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<sup>4</sup> Non-parametric tests (Mann-Whitney U) were also conducted and produced similar results to the parametric tests reported in this chapter.

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investigate how variables clustered onto meaningful factors reflecting various dimensions of empowering processes and outcomes. Factor analysis is a technique which allows the researcher to reduce the data from a large set of inter-correlated items to a set of fewer, uncorrelated factors underlying the responses. Each factor should consist of a set of items that correlate highly with each other but poorly with the other items in the dataset (Field, 2005).

There are two main methods of factor extraction: principal components analysis and factor analysis. While principal component analysis does not differentiate between the shared and unique variance of the variables, and therefore could result in an overestimation of the amount of variance accounted for by the components, factor analysis separates the shared variance from the unique and error variance, and produces the solution based on the shared variance only (Costello & Osborne, 2005). The author reasoned that all being equal, factor analysis would produce the same solution but without overly inflated variance accounted for. Therefore, in the current study, factor analysis was chosen over principal components analysis.

Furthermore, there are several methods of factor extraction, and whilst the majority require normally distributed data, principal axis factoring is appropriate in cases where multivariate normality of the data is 'severely violated' (Costello & Osborne, 2005). Since the current data were not normally distributed (Kologomorov-Smirnoff test  $p < 0.05$ ), and univariate normality of the data is considered essential for the multivariate normality to be assumed (Field, 2005), principal axis factoring was deemed appropriate for the purpose.

There are also two main rotation methods in factor analysis: orthogonal and oblique (Costello & Osborn, 2005; Field, 2005). Orthogonal rotation allows the researcher to rotate

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the factors whilst ensuring they remain uncorrelated. Oblique rotation, on the other hand, allows the factors to correlate. Although it is the object of factor analysis to extract factors that are independent, it is possible that in social sciences individual aspects or dimensions of a concept such as empowering processes and outcomes influence one another, for example feeling better informed can potentially influence the relationship with health professionals. Therefore direct oblimin, a form of oblique rotation, was employed in the current study.

Finally, factor analysis can be conducted either as an exploratory analysis or with a forced factor solution. If the analysis aims to test an existing scale on a new population or to test a theory, a number of factors should be predetermined to match the theory or previous findings (forced factor solution). In exploratory analysis, the number of factors is not predetermined, and the decision of how many factors to retain is made on the basis of eigenvalues, item loadings and analysis of the scree plots (Field, 2005). As new items and subscales were added to the original empowering processes and outcomes scales, an exploratory factor analysis was deemed more appropriate, as it allowed the researcher to investigate how the items clustered into meaningful factors and if any new constructs would emerge.

Diagnostic statistics indicated that factor analysis was appropriate for these data. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was high for both empowering processes (.907) and outcomes (.928), indicating that factor analysis should produce 'distinct and reliable factors' (Field, 2005, p455). Bartlett's test of sphericity was highly significant ( $p < 0.001$ ), indicating that the matrices were not identity matrices. The determinants for empowering processes and outcomes scales were  $> 0$  indicating lack of singularity within the data, although they were relatively low ( $8.60E-013$  and  $6.43E-014$



respectively), suggesting some level of multicollinearity. On closer inspection of the correlation matrices, however, no variables were found to correlate above .9 and removing variables correlated above .8 and .7 did not sufficiently improve the determinant (Field, 2005). Therefore, no changes were made to the pool of items at this stage.

### ***7.3.2.1 Exploratory factor analysis: empowering processes scale***

All 39 items measuring aspects of empowering processes were entered into the analysis, using data from 197 participants. Factor analysis suggested a 7-factor solution. Variables were included in a factor if their factor loadings were significant (above .40) and they did not load onto another factor above .40. Two items which did not load above .40 onto any one factor were excluded and the analysis was conducted again.

The second analysis also produced a 7-factor solution. Eigenvalues and scree plot were scrutinised and in accordance with Keiser criterion only the factors with eigenvalues  $>1$  were retained (Field, 2005). The seventh factor had an eigenvalue of .93 and was therefore excluded (three items excluded). Analysis was run again, suggesting a 6-factor solution, where the sixth factor had an eigenvalue of .93, and also was excluded (two items excluded). In addition, one item did not load above .40 onto any of the factors and was also excluded. The final analysis of the remaining 31 items produced a 5-factor solution, with all factors having eigenvalues  $>1$ . The scree plot confirmed the 5-factor solution. Items were inspected for their conceptual coherence with the factors and final labels were assigned to the factors.

Eleven items loaded significantly onto Factor 1. All these items were in line with the concept of 'receiving emotional support'. Eight items loaded onto Factor 2 which was consistent with the concept of 'receiving useful information'. Three items loaded onto

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Factor 3 which was consistent with 'helping others', six items loaded onto Factor 4, which was consistent with the concept of 'encountering similar others' and three items loaded onto Factor 5 which was tapping onto the dimension of 'finding a safe place to talk'. Cronbach's alphas for the factors ranged from .89 to .95 indicating excellent internal consistency of each factor. The score for each item loading onto individual factors were added up and averaged to obtain a total score for each dimension of empowering processes.

Items' loading onto the five factors relating to empowering processes, and Cronbach's alphas for each factor, are presented in Table 4.

### **7.3.2.2 Factor analysis: empowering outcomes scale.**

All 38 items measuring empowering outcomes were entered into the analysis, using data from 197 participants. Factor analysis suggested a 5-factor solution. Five items which did not load above .40 onto any one factor and one item which loaded significantly onto two factors were removed, and the analysis was conducted again with the remaining 32 items, yielding a 5-factor solution again.

All factors had eigenvalues  $>1$  and scrutiny of the scree plot confirmed the 5-factor solution; therefore all five factors were retained. Eight items loaded significantly onto Factor 1 and were consistent with the concept of 'improved relationship with the physician'. Five items loaded onto Factor 2, tapping into the dimension of 'positive personal reappraisal'. Seven items loaded onto Factor 3. Three of these items related to an improved sense of community and reduced social isolation, while the other four to increased ability to help others. This factor was labelled 'increased sense of community spirit' to reflect both of these aspects. Seven items loaded onto Factor 4, tapping into the

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dimension of 'positive reappraisal of situation'. Five items loaded onto Factor 5 and were consistent with the concept of 'increased knowledge and ability to take part in treatment decisions'. The Cronbach's alphas for the factors ranged from .90 to .92, indicating excellent internal consistency of all factors. The score for each item loading onto individual factors were added up and averaged to obtain a total score for each dimension of empowering outcomes.

Items' loading onto the five factors relating to empowering outcomes, and Cronbach's alphas for each factor, are presented in Table 5.

**Table 4 Empowering processes scale: an exploratory factor analysis**

<b>Factor</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Eigenvalues</b>	<b>12.1</b>	<b>3.8</b>	<b>1.9</b>	<b>1.6</b>	<b>1.2</b>
<b><i>Factor 1 - Receiving emotional support (<math>\alpha=.95</math>)</i></b>					
Someone in the group reassures you?	0.83				
Someone in the group is interested in you?	0.81				
Someone in the group consoles you?	0.80				
Someone in the group pays you a compliment?	0.77				
Someone in the group gives you encouragement?	0.75				
Someone in the group points out your strengths?	0.75				
Someone in the group pays particular attention to you in special cases, such as illness or moving house?	0.74				
Someone in the group is there for you when you need them?	0.73				
Someone in the group offers you sound advice?	0.66				
Someone in the group confides in you?	0.66				
Someone in the group is empathic?	0.66				
<b><i>Factor 2 - Receiving useful information (<math>\alpha=.89</math>)</i></b>					
Information and advice exchanged is reliable		0.87			
Information and advice exchanged is correct		0.85			
Information and advice exchanged is new		0.75			
Information and advice exchanged is usable		0.73			
Information and advice exchanged is valuable		0.69			
Information and advice exchanged is relevant to my situation		0.61			
Information and advice exchanged is of added value		0.59			

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Factor	1	2	3	4	5
to the information provided by the doctor					
Information and advice exchanged is in line with the information provided by the doctor		0.51			
<b>Factor 3 - Helping others (<math>\alpha=.91</math>)</b>					
You feel that your experiences can inspire other members?			0.82		
You feel that your experiences can give hope to other members?			0.82		
You feel that you can offer advice and support to someone in the group?			0.73		
<b>Factor 4 - Encountering similar others (<math>\alpha=.90</math>)</b>					
Thanks to someone in the group or through reading messages you...					
...find a unique support from people who understand exactly what you are going through?				0.86	
...feel comforted by the knowledge that other people deal with the same problems as you?				0.86	
...realise that your emotions and/or what you are going through are not unusual?				0.75	
...experience a sense of 'all being in this together'?				0.73	
...realise that you are not so bad off after all?				0.59	
You recognize yourself in the stories of other group members?				0.54	
<b>Factor 5 - Finding a safe place to talk (<math>\alpha=.91</math>)</b>					
You feel that you are able to openly share your feelings with other members?					0.95

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<b>Factor</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
You feel that you are able to openly discuss sexual or other intimate issues with other members?					0.77
You feel that you are able 'get things of your chest' within the group?					0.76

**Table 5 Empowering outcomes: an exploratory factor analysis**

<b>Factor</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<b>Eigenvalues</b>	<b>14.4</b>	<b>3.3</b>	<b>1.5</b>	<b>1.1</b>	<b>1.01</b>
<b><i>Factor 1 – Improved relationship with the physician</i></b>					
<b><i>(<math>\alpha=.92</math>)</i></b>					
Participation in the group helped me...					
...have more courage to raise matters with the physician	.822				
...be more able to oppose the physician	.785				
...feel better prepared for a doctor's appointment	.751				
...better able to explain my needs to the physician	.734				
...be more knowledgeable about which questions to ask the physician	.721				
...better understand the information provided by the physician	.671				
...improve my relationship with the physician	.559				
...feel less dependent on the physician.	.466				
<b><i>Factor 2 – Positive personal reappraisal (<math>\alpha=.92</math>)</i></b>					
Participation in the group helped me...					
...have greater sense of self-worth		.801			
...feel more positive about myself		.792			
...find new and worthwhile goals		.731			
...value life more		.707			
...understand the meaning of life better		.683			
<b><i>Factor 3 – Increased community spirit (<math>\alpha=.90</math>)</i></b>					
Participation in the group helped me...					

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Factor	1	2	3	4	5
...share useful information with other members of the group			.833		
...feel more confident about the quality of the information I share			.741		
...take a more active role in helping people affected by cancer			.739		
...find new, valued friends			.701		
...meet new people I enjoy communicating with			.670		
...feel like a part of a community I can depend on			.594		
...provide my close ones with useful information about prostate cancer/treatment			.417		
<b>Factor 4 - Positive reappraisal of situation (<math>\alpha=.92</math>)</b>					
Participation in the group helped me...					
...have more hope for the future				-.733	
...feel less worried or anxious				-.712	
...accept this illness better				-.632	
...feel more relaxed				-.632	
...have more positive attitude towards the illness				-.615	
...feel better prepared for the future				-.537	
...feel more in control				-.478	
<b>Factor 5 – Increased knowledge and ability to participate in treatment decisions (<math>\alpha=.90</math>)</b>					
Participation in the group helped me...					
...understand prostate cancer better					.894
...be more aware of the available treatment options					.814
...feel better informed					.764



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<b>Factor</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
...be more aware of my own preferences regarding treatment					.566
...more actively participate in the decision-making process					.522

### **7.3.3 Descriptive statistics.**

Descriptive statistics were calculated for satisfaction with the group and social support outside of the online support group (measured by MOS: SSSI). Differences between patients and family members were also calculated, using  $\chi^2$  tests and t-tests.

Descriptive statistics were also calculated for each of the empowering processes and outcomes. Multivariate analysis of variance (MANOVA) and covariance (MANCOVA) were employed to assess differences between the groups across the scales measuring empowering processes and empowering outcomes.

#### ***7.3.3.1 Satisfaction with online support groups***

Participants were highly satisfied with their prostate cancer online support group overall (M=4.5, SD=0.7)<sup>5</sup>, both with the information (M=4.5, SD=0.7) and the support provided within the group (M=4.5, SD=0.7). The women reported significantly higher overall satisfaction with the group (t(195)=2.26, p<0.05), but no differences between the groups were found for satisfaction with the information or support provided.

Furthermore, the participants found their group to be a safe place to discuss intimate issues (M=4.21, SD=1.1). They also found the intimate discussions within the group beneficial (M=3.93, SD=1.2), and reported that they preferred to discuss such issues with group members rather than face-to-face (M=3.64, SD=1.23).

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<sup>5</sup> The scores for satisfaction were recorded on a scale ranging from 1 to 5.

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The majority of the family members indicated that as a result of participation in online support groups they felt better able to care for the patient (n=40, 78%; responses 'agree' or 'strongly agree').

### **7.3.3.2 Social support outside of online support groups**

The mean scores for affectionate support (M=68.4, SD=34.5), positive social interaction (M=65.4, SD=33.2) and emotional/informational support (M=56.6, SD=30.3) were somewhat lower than the scores obtained from the original sample of 2987 adult patients with 'prevalent and treatable chronic conditions' (Sherbourne & Stewart, 1991, p706) (M=73.7, SD=28.3; M=69.8, SD=26.0; M=69.6, SD=25.5 respectively). No differences between patients and family members were found for any of the social support subscales.

### **7.3.3.3 Empowering processes**

Mean scores and standard deviations for empowering processes are presented later on in the Chapter, in Table 8. The empowering process most frequently reported as occurring within the prostate cancer online support groups was 'encountering similar others' (M=4.0, SD=0.7). For example, as a result of participation in the group, 85% of participants regularly to often felt comforted by the knowledge that there were other people who were dealing with the same problems. Also, 83% of participants regularly to often felt that their emotions and circumstances were not unusual and 80% found unique support from people who understood exactly what they were going through (data presented in Appendix E).

The second most commonly experienced empowering process was 'receiving useful information' (M=3.9, SD=0.6). The majority of participants regularly to often found the information provided valuable (82%), usable (74%), reliable and correct (70%) or of added

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value to the information provided by health professionals (68%). Fewer people found the information to be new – for 46% the information was regularly or often new, while for 47% it was only new some of the time, and for 7% it was seldom or never new.

‘Finding a safe place to talk openly’ was also a frequently occurring empowering process ( $M=3.7$ ,  $SD=1.0$ ). The majority of the respondents felt that they could regularly or often openly discuss sexual and other intimate issues with their fellow members (62%). Just over half (57%) felt they were regularly to often able to openly share their feelings with other members and 52% of people found they regularly to often could ‘get things off their chest’ in the group.

A less frequently occurring empowering process was ‘helping other members’ ( $M=3.4$ ,  $SD=0.8$ ). For example, 45% of participants felt able to offer advice and support to others regularly or often. Furthermore, 34% of all the participants felt that their experiences could regularly or often help inspire other members.

The empowering process occurring least frequently within the groups was ‘receiving emotional support’ ( $M=3.1$ ,  $SD=1.0$ ). Over half of all participants felt that regularly or often someone in the group was empathic towards them (62%), that someone was there for them when they needed them (53%) and offered them sound advice (51%) and encouragement (51%). Nearly half of all participants, however, found that other members seldom or never confided in them (49%), paid particular attention to their special cases, such as illness or moving house (47%) or pointed out their strengths (46%).

#### **7.3.3.4 Empowering outcomes**

Mean scores and standard deviations for empowering outcomes are presented in Table 9. The empowering outcomes experienced to the highest degree by the participants were 'increased knowledge and ability to participate in treatment decisions' (M=4.3, SD=0.6) and 'improved relationship with the physician' (M=4.0, SD=0.7). Nearly all of the participants felt better informed as a result of participation in the prostate cancer online support group (94%) and had a better understanding of prostate cancer (93%). Overall, the majority of participants felt that as a result of participation in the group they were able to more actively participate in treatment decisions (80%). A large majority experienced the increase in knowledge of available treatment options (94%) as well as better personal awareness of their own treatment preferences (83%). Many participants also felt more knowledgeable about which questions to ask their physician (91%); were better able to understand the information provided by the physician (88%) and generally felt better prepared for their appointments (87%) (data presented in Appendix F).

Many participants also reported an increase in their sense of 'community spirit' (M=3.9, SD=0.9), with 77% of participants experiencing a greater feeling of belonging to a community. The majority of participants felt more confident about sharing useful information about prostate cancer with other group members (84%) and family (75%).

To a lesser degree, participants also experienced 'positive reappraisal of the situation' (M=3.7, SD=0.8) and 'positive personal reappraisal' (M=3.4, SD=0.9). The majority of participants felt better prepared for the future (77%) and more in control (73%), while 58% learnt to value life more and 51% felt more positive about themselves as a result of participation in the group.

### **7.3.3.5 Multivariate analyses of variance and covariance**

In order to assess the differences in the extent to which patients and family members experienced empowering processes and outcomes, multivariate analyses of variance (MANOVA) were conducted with the five dimensions of empowering processes and the five dimensions of empowering outcomes as dependent variables. Although one of the assumptions of MANOVA is multivariate normality of the data, Field (2005) suggests that MANOVA is 'relatively robust to violations of multivariate normality' (p399), particularly when sample sizes in each cell exceed  $n=30$ , however caution should be applied when generalizing the results onto a wider population. Another assumption of MANOVA is equality of covariance matrices; for the current data both the Levene's tests and Box's test were non-significant ( $p>0.05$ ), indicating that the population variance-covariance matrices were equal, and thus suggesting that this assumption had been met.

Multivariate analyses of covariance (MANCOVAs) were also conducted to control for the effects of potentially covariant variables. As only variables that are highly correlated with the dependant variables but independent of each other should be entered into MANCOVA as covariates (Field, 2005), Pearson's correlation coefficients ( $r$ ) were calculated for the background variables and both the empowering processes and outcomes<sup>6</sup>. Correlations between the background variables and empowering processes are presented in Table 6. Correlations between background variables and empowering outcomes are presented in Table 7.

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<sup>6</sup> Age was significantly correlated with the majority of all other covariates and therefore this variable was excluded from further analysis.

**Table 6 Correlations between background variables and empowering processes**

	Receiving information	Emotional support	Similar others	Helping others	Safe place to talk
Age	<b>-.191**</b>	<b>-.196**</b>	<b>-.153*</b>	-.100	-.034
Marital status	-.133	-.051	-.097	-.075	.030
Education	<b>-.160*</b>	.011	-.016	.113	-.011
Poster/Lurker	-.049	<b>.388***</b>	.000	<b>.186**</b>	<b>.314***</b>
Satisfaction with group	<b>.467***</b>	<b>.161*</b>	<b>.346***</b>	.116	<b>.175*</b>
Membership duration	<b>-.232**</b>	-.066	<b>-.172*</b>	.055	-.018
Support outside group	-.020	<b>.179*</b>	.073	<b>.196**</b>	.058

\*\*\*p<0.001; \*\*p<0.01; \*p<0.05

**Table 7 Correlations between background variables and empowering outcomes**

	Increased knowledge	Relationship w. physician	Community spirit	Situation reappraisal	Personal reappraisal
Age	-.127	-.046	-.095	-.055	.030
Marital status	-.091	-.059	-.051	-.097	-.011
Education	-.117	-.131	-.114	-.009	-.060
Poster/Lurker	.041	<b>.164*</b>	<b>.305***</b>	.058	-.055
Satisfaction with group	<b>.341***</b>	<b>.227**</b>	<b>.178*</b>	<b>.236**</b>	<b>.150*</b>
Membership duration	-.120	-.071	-.051	<b>.173*</b>	-.064
Support outside group	.019	-.069	.122	.114	-.006

\*\*\*p<0.001; \*\*p<0.01; \*p<0.05

#### **7.3.3.5.1 Multivariate analysis: empowering processes**

Multivariate analyses of variance (MANOVA) indicated that the patients and family members differed significantly across the scale measuring empowering processes  $F(5,191)=6.41$ ,  $p<0.001$ , Wilks'  $\lambda=.856$ . In order to investigate differences within each dimension of empowering processes, univariate tests (ANOVAs) were conducted as follow-up, applying Bonferroni correction and setting significance level at 0.01 (0.05/5). The



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ANOVAs suggested that the family members reported receiving significantly more emotional support and useful information than the men ( $p < 0.001$ ). Table 8 presents the differences between male and female participants on all five dimensions of empowering processes.

Adjusting for the covariates, the differences between patients and their close ones across empowering processes scale remained statistically significant  $F(5,183)=4.14$ ,  $p < 0.01$ , Wilks'  $\lambda = .898$ . Univariate tests revealed that the difference on individual scales remained significant for receiving emotional support only ( $p < 0.01$ ), applying Bonferroni correction and setting the significance level at  $p < 0.01$  ( $0.05/5$ ) (see Table 8).

### ***7.3.3.5.2 Multivariate analysis: empowering outcomes***

Multivariate analyses of variance (MANOVA) indicated that there was no significant difference between the patients and family members with regards to the empowering outcomes of participation within online support groups  $F(5,191)=2.15$ ,  $p > 0.05$ , Wilks'  $\lambda = .947$ . Univariate tests suggested, however, that the difference between groups on the 'increased community spirit' subscale was statistically significant after applying Bonferroni correction and setting the significance level at  $p < 0.01$  ( $0.05/5$ ) ( $p < 0.01$ ). Adjusting for covariates confirmed the lack of significant differences between the two groups across the empowering outcomes scale and the difference in community spirit also became statistically non-significant (see Table 9).

**Table 8 Differences in empowering processes between patients and family members**

	Total N=197	Male N=149	Female N=48	Difference between groups (MANOVA)	Difference between groups controlling for covariates (MANCOVA)(a)
	M (SD)	M (SD)	M (SD)	F(1,195)	F(1,191)
Encountering similar others	4.04 (0.8)	3.97 (0.8)	4.26 (0.7)	5.36*	1.96
Receiving useful information	3.90 (0.6)	3.83 (0.6)	4.17 (0.6)	<b>7.73**(b)</b>	2.63
Finding a safe place to talk	3.60 (1.0)	3.59 (1.1)	3.61 (1.0)	0.01	0.59
Receiving emotional support	3.09 (1.0)	2.92 (1.0)	3.60 (0.9)	<b>18.29***(b)</b>	<b>10.64**(b)</b>
Helping others	3.39 (0.8)	3.38 (0.9)	3.45 (0.8)	0.24	0.05

(a) controlling for education, poster/lurker status, satisfaction, membership duration, support outside the group;

(b) Results significant at  $p < 0.01$ , applying Bonferroni correction; \*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$

**Table 9 Differences in empowering outcomes between the patients and family members**

	Total N=197	Male N=149	Female N=48	Difference between groups (MANOVA)	Difference between groups controlling for covariates (MANCOVA)(a)
	M (SD)	M (SD)	M (SD)	F(1,195)	F(1,192)
Increased knowledge/ decisions	4.32 (0.6)	4.29 (0.6)	4.40 (0.6)	1.10	0.01
Improved relationship with the physician	3.98 (0.7)	3.94 (0.7)	4.10 (0.6)	1.83	0.34
Increased community spirit	3.87 (0.6)	3.80 (0.6)	4.10 (0.6)	<b>7.89**</b>	4.23*
Positive reappraisal of situation	3.69 (0.8)	3.67 (0.8)	3.76 (0.8)	0.425	0.05
Positive personal reappraisal	3.44 (0.9)	3.38 (0.9)	3.61 (0.8)	2.30	1.49

(a) controlling for poster/lurker status, satisfaction, membership duration;

(b) Results significant at  $p < 0.01$ , applying Bonferroni correction; \*\*\* $p < 0.001$ ; \*\* $p < 0.01$ ; \* $p < 0.05$

#### **7.3.4 Hierarchical multiple regressions: assessing the relationship between empowering processes and empowering outcomes**

Regression is a statistical method which allows the researcher to fit a model to the data that would help best predict how the change in predictor variable would affect the change in outcome variable. The current study aims to assess the extent to which, if at all, empowering processes can help predict each of the five empowering outcomes over and above the background variables, therefore the hierarchical multiple regression was deemed an appropriate method. Hierarchical multiple regression allows the entry of several predictors into the model in a step-by-step manner, entering the known predictors in the first step, and new predictors in subsequent steps. This method allows the researcher to assess what proportion of variance in the outcome variable is explained by the variables entered first, and if the new predictors can help explain a higher proportion of the outcome variable over and above the initial predictors.

Five hierarchical multiple regressions were conducted with empowering outcomes as the outcome variables. In the first step of the hierarchical regression all background variables that significantly correlated with any of the outcomes (see Table 7) were entered into the model. As previous research (e.g. van Uden-Kraan et al., 2009; Bartlett & Coulson, 2010) did not present a clear picture as to which process can best predict each outcome, in the second step all empowering processes that significantly correlated with the outcomes were entered all at the same time (using enter method). Finally, the analyses were run again, including only the significant predictors.

#### **7.3.4.1 Testing the assumptions of hierarchical multiple regression**

One of the main assumptions of multiple regression is lack of multicollinearity within the data. If multicollinearity in the data exists, i.e. two or more predictors are highly correlated, it can impair the model in several ways, for example by limiting the proportion of variance explained by the predictors ( $R^2$ ), as once the first predictor is entered into the model, the second, highly correlated predictor will account for very little of the remaining variance. It can also make it impossible to establish the importance of individual predictors, and cause the regression coefficients to become unstable. Multicollinearity can be assessed by several means – firstly the correlations between predictor variables should be investigated for any overly high coefficients ( $>0.9$ ); secondly collinearity diagnostics produced by the PAWS should be assessed. High variance inflation factors ( $VIF > 10$ ) indicate variables with a strong linear relationship with another predictor. On average the VIF should be as close to 1 as possible. Tolerances are a statistic related to VIF ( $1/VIF$ ), and tolerances below 0.2 should be considered problematic (Field, 2005). In the current study no correlations between predictor variables exceeded .6, all VIFs were well below 10 and average  $VIF=1.5$ . The tolerances were high, exceeding 0.2. Therefore no multicollinearity within the data was assumed.

Another assumption of regression is independence of errors, that is to say, that for any two observations the errors should be uncorrelated. Durbin-Watson statistic can help assess the level of error independence. This statistic ranges from 0 to 4, and values close to 2 mean that the residuals are uncorrelated. In the current study, the Durbin-Watson statistics for the regression analyses ranged from 1.84 to 2.05, confirming the independence of errors.

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It is also important to assess if the model fits the data well and is not overly affected by few highly influential cases as well as that it can be generalised onto other samples. In order to establish the existence of cases that could potentially exert undue influence on the model, the data should be checked for any cases with large standardized residuals (in an average sample, 95% of cases should fall within residuals of -2 and +2, and 99% within -3 and +3). Case wise diagnostics provide a list of cases with values that fall outside this range and therefore should cause concern. The effect of each case on the model as a whole should also be investigated. Cook's distance is a test statistic allowing investigating the effect a single case has on the model as a whole. Field (2005) reported that Cook's distance values >1 should be a cause for concern.

In the current study the case wise diagnostics were set to produce a list of cases with standardised residuals between -2 and +2. In all regression analyses conducted, the number of cases that fell outside of  $\pm 2$  did not exceed 5% and the number of cases exceeding  $\pm 3$  ranged from 0 to 1.5%. The Cook's distance values did not exceed 1 and were close to 0. These diagnostic statistics indicate that the model fits the sample well and is not unduly influenced by any single case.

One of the means of assessing if the model can be generalised onto different samples (cross-validation) is to examine if the observed  $R^2$  differs greatly from the adjusted  $R^2$ . Adjusted  $R^2$  indicates how much variance in the outcome variable would be predicted by the independent variables, if the model was derived from the population from which the sample was drawn. In the current study the differences between  $R^2$  and adjusted  $R^2$  ranged from 0.006 to 0.011, indicating that the cross-validity of the model is very good.

### 7.3.4.2 Relationship between the processes and the outcomes

Hierarchical multiple regressions using the enter method were employed to examine the extent to which the empowering processes could predict the outcomes, over and above the background variables. Firstly, Pearson's correlation coefficients were calculated in order to identify which background variables and which empowering processes correlated with each of the outcomes and therefore should be entered into the model. The results indicated that all processes were significantly correlated with all outcomes ( $p < 0.001$  to  $p < 0.01$ ), although the correlations were weak ( $< .30$ ) to moderate ( $0.30 - 0.60$ ) (see Table 10). All background variables which significantly correlated with the outcomes (i.e. length of membership, satisfaction with the group and 'poster/lurker' status; see Table 7) were entered into each model in the first block of the analysis and all empowering processes were entered in the second block.

**Table 10 Correlations between the empowering processes and outcomes**

	Increased knowledge	Relationship w. physician	Community spirit	Situation reappraisal	Personal reappraisal
Receiving emotional support	<b>.237*</b>	<b>.245</b>	<b>.541</b>	<b>.331</b>	<b>.241*</b>
Receiving useful info	<b>.569</b>	<b>.479</b>	<b>.458</b>	<b>.443</b>	<b>.350</b>
Helping others	<b>.348</b>	<b>.243*</b>	<b>.572</b>	<b>.302</b>	<b>.294</b>
Encountering similar others	<b>.413</b>	<b>.369</b>	<b>.452</b>	<b>.493</b>	<b>.280</b>
Finding a safe place to talk	<b>.297</b>	<b>.262</b>	<b>.470</b>	<b>.344</b>	<b>.224*</b>

All correlations significant at  $p < 0.001$ , except when marked \* $p < 0.01$ .

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The initial regression analyses indicated that 'poster/lurker' status was a significant predictor of 'improved relationship with the physician' ( $p < 0.01$ ) and 'increased sense of community spirit' ( $p < 0.001$ ). 'Receiving useful information' was a significant predictor of all empowering outcomes ( $p < 0.001$  to  $p < 0.01$ ). 'Helping others' was a significant predictor of 'increased sense of community spirit' ( $p < 0.001$ ), 'positive personal reappraisal' ( $p < 0.01$ ) and 'increased knowledge and ability to participate in treatment decisions' ( $p < 0.01$ ). 'Encountering similar others' was a significant predictor of 'positive reappraisal of the situation' ( $p < 0.001$ ) and 'improved relationship with the physician' ( $p < 0.05$ ). 'Receiving emotional support' was a significant predictor of 'increased community spirit' ( $p < 0.05$ ).

The regression analyses were run again, with the significant predictors only. The empowering outcomes were significantly, albeit partially predicted by the variables entered into the model and the proportion of variance explained ranged from 16.4% to 50.4% ( $R^2$  ranging from .164 to .504). The regression results are presented in Table 11.

The outcome with the highest proportion of variance explained (50.4%) was 'increased sense of community spirit' ( $F(3,196)=59.12$ ,  $p < 0.001$ ), with 'receiving useful information' being the most important predictor, followed by 'helping others', 'poster/lurker' status and 'receiving emotional support'.

A total of 36.2% of variance in 'increased knowledge and ability to participate in treatment decisions' was accounted for by the predictor variables ( $F(2,196)=55.08$ ,  $p < 0.001$ ), with the most important predictor being 'receiving useful information', followed by 'helping others'.

A total of 28.7% of variance was accounted for in 'positive situation reappraisal' and 28.1% in 'improved relationship with the physician'. 'Positive situation reappraisal' was



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significantly predicted by 'encountering similar others' and 'receiving useful information' ( $F(2,196)=39.08, P<0.001$ ), and 'improved relationship with the physician' was significantly predicted by 'receiving useful information', 'encountering similar others' and 'poster/lurker' status ( $F(3,196)=25.11, P<0.001$ ).

The smallest proportion of variance (16.4%) was explained by the empowering processes in 'positive personal reappraisal' ( $F(2,196)=18.97, p<0.001$ ). The most significant predictor was 'receiving useful information' followed by 'helping others'.

**Table 11 The extent to which empowering outcomes can be predicted by the empowering processes**

		Increased knowledge/ decision	Relationship w. physician	Community spirit	Situation reappraisal	Personal reappraisal
		B	$\beta$	B	$\beta$	$\beta$
<b>Step 1</b>	Poster/lurker status	-	.288**	.254**	-	-
<b>Step 2</b>	Receiving useful information	.465***	.441***	.297***	.296**	.406**
	Receiving emotional support	-	-	.131**	-	-
	Encountering similar others	-	.136*	-	.358***	-
	Helping others	.141**	-	.278***	-	.226**
	R <sup>2</sup>	.362	.281	.504	.287	.164
	R <sup>2</sup> change	-	.254***	.411***	-	-
	F(df)	(2,196) 55.1***	(3,196) 25.1***	(4,196) 48.7***	(2,196) 39.1***	(2,196) 19.0***

\*\*\*p<0.001; \*\*p<0.01; \*p<0.05

## **7.4 Discussion**

The main objective of the current study was to measure the extent to which prostate cancer patients and their family members experience the empowering processes and outcomes of participation in prostate cancer online support groups and to assess any potential differences between these two groups of members. The relationship between the processes and outcomes was also explored to assess which, if any, of the empowering processes could help predict the empowering outcomes of participation in prostate cancer online support groups. In addition, the patterns of use and satisfaction with the groups were also investigated.

### **7.4.1 Patterns of use and satisfaction with prostate cancer online support groups**

Similar to Study 2, the current sample consisted mainly of patients, although a significant proportion of the sample was accounted for by female family members. Similar to Study 2, no male family members took part. The majority of the family members who participated in this study were partners or wives of the patients; a large majority also indicated that they were caregivers to the patient. Past studies indicated that family members who are responsible for the care of cancer patients have high levels of important needs in the domain of patient care, information about treatment and disease as well as their own wellbeing, which are often unmet by health care professionals (e.g. Osse et al., 2006). Osse and colleagues (2006) found that many caregivers didn't seek help for their own problems, as they perceived them to be less important in comparison with the patient's needs. The fact that the majority of family members who access prostate cancer online support groups perceive themselves as caregivers could explain the particularly high level of informational and support needs displayed by this group of users in Studies 1 and 2. Furthermore, the

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findings of Studies 1 and 2 as well as the current study could suggest that online support groups are a suitable alternative source of emotional and informational support for caregivers, as they can access it without the necessity to disclose their needs to the health care professionals, the patient or other family members.

In the current study, women were more likely to participate in single gender groups (exclusively or alongside mixed gender groups). This corroborates the findings of Study 2, which suggested that female participants felt more at ease in ladies only groups, where they had more perceived freedom to express their emotions, worries and frustrations without the fear of upsetting any of the male members. Past research on spouses' participation in prostate cancer face-to-face support groups also indicated that women tend to experience a special bond with other female members of online support groups (Bottoroff et al., 2008).

### **7.4.2 Empowerment in prostate cancer online support groups**

The current study undertook the first quantitative investigation of the extent to which prostate cancer patients and their family members experience empowering processes and outcomes within prostate cancer online support groups. The results of the qualitative studies (Studies 1 and 2) suggest that patients and family members using prostate cancer online support groups experience a similar range of empowering processes and outcomes to those described in past literature (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009). The findings of the current study corroborate the findings of Studies 1 and 2 and add to the current knowledge by providing a unique insight into the extent to which members of prostate cancer online support groups experience the empowering processes and outcomes. Similar to the studies by van Uden-Kraan and colleagues (2009) and Bartlett and

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Coulson (2010) the results suggest that participation in online support groups has varying effects on the sense of empowerment in different areas investigated.

### **7.4.2.1 Empowering processes**

Factor analysis of items measuring empowering processes confirmed the existence of all the main empowering processes identified in past literature (van Uden-Kraan et al., 2009; Mo & Coulson, 2010) and reported by prostate cancer online support group members in Study 2. These included 'receiving useful information', 'receiving emotional support', 'encountering similar others' and 'helping others' and 'finding a safe place to talk'. Items reflecting the empowering process 'chit chat' were excluded during the factor analysis, which could imply that although some members perceive it as beneficial, 'chit chat' does not have the same empowering qualities as the other processes.

Similar to past research (Bartlett & Coulson, 2010; Mo & Coulson, 2010; van Uden-Kraan et al., 2009), the empowering processes most commonly reported by both patients and family members was 'encountering similar others'. The results of the current study indicated that the unique value of participation in online support groups was related to the fact that members were able to communicate with other people who were in a situation very similar to their own. Many participants were able to validate their feelings and experiences through comparison to other members; they also experienced a unique sense of support from other members who could offer empathy and understanding that was often unavailable from friends and family. These findings mirrored closely the results of Study 2 and were in line with past research (van Uden-Kraan et al., 2009).

'Receiving useful information' was also frequently experienced; the majority of participants found the information provided within the groups to be understandable, valuable and

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usable in real life. Past research suggested that the information from other patients is particularly valued by members, as it is presented in simple, lay terms, rather than in 'medical jargon' which can be difficult to comprehend (e.g. van Uden-Kraan et al., 2008c). The results of Study 2 also indicated that the fact that the information in the groups is largely based on real-life experiences of other patients also made it useful and applicable to members' own situation, as it helped to prepare for future treatment and recovery. Although in the current study the information exchanged in the groups was found to be highly valuable, it was not always perceived as new, which could be explained by the fact that the majority of members participated in the groups for a significant length of time. This was in line with the findings of Study 2, which revealed that long-term members often commented on the repetitive nature of information exchange, as some basic topics were continuously raised by new members.

In the current study, another frequently experienced empowering process was 'finding a safe place to talk'. This construct was incorporated into the empowering processes scale on the basis of the findings of Studies 1 and 2 which indicated that members perceive prostate cancer online support groups as an important forum for intimate discussions. As a result of the treatment, many prostate cancer patients experience changes in their potency and continence, issues men find particularly difficult to discuss with their close ones and even health professionals (Gray et al., 2002). In Study 2, patients also frequently noted that side-effects were rarely discussed in detail during medical appointments and that as a result they felt under-informed and unprepared for the effects of their treatment. Conversely, for many participants, prostate cancer online support groups were the only place where they could get some information and practical advice on the matter. The results of the current study confirmed that the majority of prostate cancer online support group members were

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able to openly discuss with other online support group users the intimate issues arising after treatment. Furthermore, the majority of participants in this study found their groups to be a safe forum for intimate discussions and found the ability to engage in such conversations highly beneficial. Over half of all participants indicated that they preferred to discuss intimate problems within the online group than face-to-face. This corroborates the results of the study by Broom (2005a), which indicated that prostate cancer patients value the anonymity afforded by the online setting. The majority of female participants also preferred to discuss intimate issues online rather than in person. This could be because many female partners of prostate cancer patients feel that family and friends often do not want to listen or are unable to understand what they are going through as a result of the diagnosis of prostate cancer (Botorroff et al., 2008).

Furthermore, the results of Study 2 also indicated that women frequently reported the benefits of being able to 'vent' their negative emotions, such as frustration, fear and anger within online support groups. Although past research indicated that the anonymity of the online setting could facilitate emotional disclosure in male patients (Broom, 2005a; Gray et al., 2002), this aspect of participation in an online support group was not mentioned by the male participants in Study 2. Study 2, however, was exploratory in nature and no specific questions about emotional expressions were asked. The current findings indicated that when specifically asked about this issue, a similar proportion of men and women reported feeling able to share emotions within the group and 'get things off their chest'.

'Helping others' was the process experienced to the lowest degree by the participants in past studies (van Uden-Kraan et al., 2009). In the current study this process was also experienced less frequently than most other processes. Helping others within an online community is associated with members' active participation in the group, as it can mainly

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be achieved through provision of information, support and personal experiences (van Uden-Kraan et al., 2009; Winefield, 2006). Van Uden-Kraan and colleagues (2009) hypothesized that a low score on the 'helping others' subscale could be explained by the fact that a high proportion of participants in their study were 'lurkers' and thus did not contribute to the community. They also found that 'lurkers' scored significantly lower on 'helping others' than 'posters'. Similarly, in the current study over a quarter of all participants indicated that they never posted messages or only posted once or twice, which could also explain the low score on the 'helping others' subscale.

In the current study the process experienced by the participants least frequently was 'receiving emotional support'; this was in line with the past studies (Bartlett & Coulson, 2010; Mo & Coulson, 2010; van Uden-Kraan et al., 2009), indicating that although emotional support plays an important role in empowering members of online support groups, it is of secondary importance to information exchange and sharing personal experiences. The results of Study 2 suggested that the members of prostate cancer online support groups, particularly the patients, reported a decrease in worry and found most comfort, reassurance and hope as a result of sharing personal experience, advice and information with other members. In the present study, the aspects of support most commonly experienced by prostate cancer online support groups members were 'empathy', 'sound advice' and 'encouragement'. Sound advice and encouragement relate to more practical aspects of support, which could help people deal with their situation better, much like sharing personal experiences or information, whilst empathy relates to the unique understanding that stems from shared experiences. Conversely, few participants reported that other members confide in them, point out their strengths or pay



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particular attention to special events in their lives. This could indicate that the relationships in the groups often do not go far beyond the support and advice related to prostate cancer.

In the current study patients reported significantly lower levels of emotional support in the groups than the female family members. This is in line with past studies which suggested that women tend to engage more actively in the exchange of emotional support in support groups, both face-to-face (Bottroff et al., 2008) and online (Sullivan, 2003). The results of Study 2 also indicated that female family members accessing prostate cancer online support groups were highly involved in the exchange of caring and emotional support. The patients, on the other hand, more often indicated that exchange of personal experiences and informational support helped reduce anxiety, restore serenity and instil hope for the future.

### **7.4.2.2 Empowering outcomes.**

Similar to past research (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009), the results of the present study indicate that, participation in prostate cancer online support groups can help increase participants' sense of empowerment in several areas of their lives.

Factor analysis suggested the existence of five dimensions of empowering outcomes relating to participation in prostate cancer online support groups. These were 'increased knowledge and ability to participate in treatment decisions', 'improved relationship with the physician', 'increased sense of community spirit', 'positive reappraisal of situation' and 'positive personal reappraisal'. These dimensions were similar to the empowering outcomes identified in past research (van Uden-Kraan et al., 2008c, 2009) and those described by prostate cancer online support group members in Study 2.

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The empowering outcome that was experienced to the highest extent was 'increased knowledge and ability to participate in treatment decisions'. Other studies investigating outcomes of participation in cancer support groups, both online and face-to-face, emphasised that many participants report feeling better informed about their illness and treatment as a result of the informational support they receive within the groups (e.g.: Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009, Campbell, Phaneuf & Deane, 2004, Sharf, 1997). This suggests that patients tend to benefit the most from peer support groups in terms of knowledge.

The findings of Study 2 also indicated that many prostate cancer online support group members felt empowered to take a more active part in their own (or their partner's) treatment decision-making processes. Some additional items reflecting this aspect of participation in online support groups were therefore included in the empowering outcomes scale. The results of factor analysis indicated that items measuring 'increased ability to participate in treatment decisions' loaded significantly onto the same factor as items measuring 'increased knowledge'. This is an interesting finding which suggests that participants felt that through participation in prostate cancer online support groups not only their knowledge has improved but also the ability to put this knowledge into action. Past research indicated (Clark & Talcott, 2006) that prostate cancer patients who believed that their treatment decision was well informed had significantly lower post-decisional regret and better post-treatment adjustment, regardless of the success of the chosen treatment. The current findings therefore suggest that participation in online support groups can lead to making more informed and autonomous treatment decisions. This outcome was experienced to a similar extent by the patients and their family members, indicating that participation in the groups can have equally empowering effects on the

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perceived levels of knowledge and participation in medical decision-making for both these groups of members.

Similar to the research conducted by van Uden-Kraan and colleagues (2009), the second most frequently experienced outcome was 'improved relationship with the physician'. This finding is particularly encouraging, as effective communication with the physician was found to be linked to better health outcomes and overall post-treatment adjustment (Arora, 2003). This is a notable finding, as prostate cancer patients tend to report disparity between their informational needs and the information provided by their health care professionals (Rozmovitz & Ziebland, 2004). This outcome was also experienced to a similar degree by the patients and family members, which is encouraging, as family members tend to experience particular difficulties in communication with their close one's health care team (Mason, 2005; 2008).

Increased sense of community spirit was also frequently experienced by the participants in the current study. Factor analysis suggested that this outcome was an amalgam of items tapping into two aspects of being part of a community. The first aspect referred to giving to the community, helping other people affected by prostate cancer, by providing them with useful and correct information that could help them deal with the disease. The other aspect related to experiencing benefits of being part of the community, such as reduced sense of isolation and sense of belonging. This lends support to the fact that online communities are built on reciprocal support and both aspects, giving to the community as well as receiving support, are intrinsically intertwined and equally important. The reciprocal nature of online support groups was strongly emphasised by the participants in Study 2.

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Past studies offered an insight into the empowering effects online support group participation has on patients, but the extent to which accessing these groups can affect family members, spouses and caregivers remained unclear (Bartlett & Coulson, 2010; Mo & Coulson, 2008; van Uden-Kraan et al., 2009). In the current study no differences were found in the extent to which prostate cancer patients and their family members experienced empowering outcomes as a result of participation in prostate cancer online support groups. Therefore the results of this study extend current knowledge and suggest that prostate cancer online support groups are a useful tool for fostering empowerment and improving psychosocial outcomes in family members as well as in patients.

### **7.4.2.3 Relationship between empowering processes and outcomes.**

Overall the processes that took place within the prostate cancer online support group helped explain a significant proportion of variance in the empowering outcomes. Processes that were explained to the highest extent were 'increased sense of community spirit' and 'increased knowledge and ability to participate in treatment decisions'.

The results of all the three studies presented in this thesis, as well as past research, indicate that the majority of communication in prostate cancer online support groups involves factual and experiential knowledge exchange (e.g. Blank et al., 2010; Huber et al., 2010; Sullivan, 2003), however, to date little has been known about how information exchange can empower prostate cancer patients and their family members. Furthermore, the findings of recent studies on the role of online support in empowering patients also did not present clear results about the role of information exchange. Van Uden-Kraan and colleagues (2009) reported that 'receiving useful information ' helped predict the two outcomes that logically require or can benefit from informational exchange, i.e. 'increased

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knowledge' and 'improved communication with the physician'. Interestingly, Bartlett and Coulson (2010) reported that 'receiving useful information' did not help predict any of the empowered processes in a sample of patients with various types of cancer.

Conversely, in the current study, 'receiving useful information' was consistently the most significant predictor of all the empowering outcomes. Understandably, 'receiving useful information' played the most significant part in explaining outcome 'increased knowledge and ability to participate in treatment decisions'. This could be explained by the fact that prostate cancer patients, especially in the early stages of the disease, have many treatment options which do not differ significantly in terms of potential disease control or cure, and the final choice often comes down to personal preference (see 2.2.5.). Therefore, in order to make an informed decision (and later to deal with the issues arising during recovery) patients require a significant amount of knowledge about the options, particularly about the post-treatment effects, which is not always provided by the health care professionals (e.g. Echlin & Rees, 2002; Feldman-Stewart et al., 2000; Steginga et al., 2001). As discussed earlier, many patients and their family members perceive prostate cancer online support groups to be an important source of information about treatment options and outcomes over and above the information provided by health care professionals.

Similar to past research (van Uden-Kraan et al., 2009) the results of the current study also suggest that the information exchanged within online support groups helps improve communication with health care professionals, which can be explained by the fact noted by many participants in Study 2, that information obtained in online support groups helped them to understand the information provided by the health care professionals as well as increased their ability to prepare for the consultation. The results also suggested that 'improved relationship with the physician' is also affected by 'encountering similar others'.

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Berry and colleagues (2003) reported that many prostate cancer patients felt the course of their health care was positively affected by learning of the experiences of another patient. The findings of this study confirm that the experiential knowledge obtained from others who personally experienced various treatments and dealt with their consequences, can further inform and encourage patients and their partners, enabling them to have a more effective dialogue with their doctor. Sullivan (2003) also reported that ovarian cancer patients felt empowered to become more assertive in their communication with the health professionals. Interestingly, the results of the regression suggested that 'lurkers' are less likely to benefit in terms of improved communication with the physician. This finding is in contrast with past research (van Uden-Kraan et al., 2008b), which indicated that 'lurkers' and 'posters' benefit equally in terms of improvement in communication with health care professionals. One possible explanation for this could be the fact that prostate cancer patients may need specific help when preparing for the consultation, and 'lurkers' may be at a disadvantage as they are more likely to find general information rather than specific answers to their questions. However, as considerably fewer 'lurkers' than posters participated in this study further research, with larger samples, is necessary to better understand this issue.

Furthermore, exchange of reliable and useful information also helped increase community spirit, as through improved knowledge participants were better able to support other members of the community by sharing information more confidently. In Study 2 several participants indicated that increased knowledge enhanced their ability to help others and be more self-assured about the quality of information they shared. 'Receiving emotional support' was also a significant predictor of increased community spirit, confirming previous findings reported by van Uden-Kraan and colleagues (2009), who noted that encountering

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higher levels of supportive communication with other members can lead to reduced social isolation and a stronger sense of community. Unsurprisingly, 'lurkers' were less likely to experience an increase in the sense of community, as they tend to have fewer opportunities to engage in personal relationships with other members and to offer help to other members (van Uden-Kraan et al., 2008b, 2009).

'Receiving useful information', together with 'encountering similar others', was also a significant and important predictor of the outcome 'positive reappraisal of the situation', indicating that comparing experiential knowledge with similar others, individuals can engage in upward comparison, which has been found to be a source of hope, inspiration and reassurance (Helgeson & Taylor, 1993; Taylor & Lobel, 1989). Downwards comparison, or comparison to those who appear less fortunate, can further help reappraise the situation as not as bad as initially considered (Helgeson & Taylor, 1993; Taylor & Lobel, 1989). Similar findings were reported by van Uden-Kraan and colleagues (2008c), who noted that online support group members frequently engaged in downwards comparison.

The empowering processes explained the smallest proportion of variance in the outcome 'positive personal reappraisal'. Past studies found that a vast array of factors contributes to posttraumatic growth, a concept similar to 'positive personal reappraisal', in cancer patients and their spouses. These factors included demographic characteristics, such as age, education or time since diagnosis; personality traits (e.g.: optimism and hope); attitudes towards cancer; availability of social support (Sears, Stanton & Danoff-Burg, 2003), coping strategies (Thornton & Perez, 2006) or cognitive and emotional processing (Manne et al., 2004). This could suggest that achieving positive personal reappraisal is a complex task for cancer patients and their family members and thus require mobilisation of

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resources reaching far beyond those available through participation in an online support group.

Literature described in Chapters 2 and 3 suggested that levels of perceived social support outside of the group may affect the outcomes of participation in prostate cancer online support groups. Many participants in Study 2 also indicated that they joined the online support groups as they were unable to get the necessary support from their family and peers. The findings of the current study suggested that the levels of perceived social support outside of the group were overall lower than in the sample of individuals with chronic disease (Sherbourne & Stewart, 1991), however, it is unclear how these levels compare to other individuals affected by prostate cancer who do not access online support groups. Interestingly, a positive correlation was found between the perceived level of social support outside the online support group and the process 'receiving emotional support' within the group, indicating that those who perceive higher levels of support outside of the group also experience social support in the group to a higher extent. One possible explanation could be that some individuals may have a tendency to perceive their online as well as offline relationships as generally more supportive. This correlation was, however, weak and further research is necessary to better understand the relationship between perceived social support outside and within online support groups.

### **7.4.3 Strengths and limitations of the study**

This study offers further insight into the online support group experiences of prostate cancer patients and their female family members. It presents unique and novel findings that expand the current knowledge about the extent to which individuals accessing prostate cancer online support groups experience the empowering processes and



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outcomes identified in past research (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009) and in Studies 1 and 2. One of the major strengths of this study is a relatively large sample, including a considerable proportion of family members, which is a unique advantage comparing to similar studies. This allowed for statistical comparison of the extent to which patients and family members experienced empowering processes and outcomes within prostate cancer online support groups.

Some methodological limitations should be noted. The main disadvantage of posting participation requests directly onto the message boards of online support groups, is the fact that it precludes the possibility to estimate the sampling frame and thus the ability to assess the response rate and compare respondents and non-respondents (Hewson, 2003). This recruitment strategy promotes targeting active and current online support group members and can lead to self-selection bias which can, in turn, result in a data that is not representative of the population. In the current study the data were not normally distributed, and although the sample size was relatively large, the results should be generalised onto the general population of online support group users with caution. Nevertheless, the sample consisted of participants with varying characteristics, i.e. males and females, patients and family members, new and long-term members, individuals with different levels of activity within the group, including daily posters and 'lurkers', single and mixed gender group users. The large majority of participants, however, reported high levels of satisfaction with the group, which was potentially a major source of bias within this sample. An alternative sampling strategy, involving targeting members who ceased online support group use and infrequent users could result in a more representative sample.

Furthermore, the current sample consisted mainly of individuals from Western Countries, with higher educational attainment and who were considerably younger than the majority

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of prostate cancer patients (OSN, 2011b). These characteristics are similar to the demographics of the wider Internet user population (Ybarra & Suman, 2006) and reflect the issues related to the 'digital divide' (e.g. Kreps et al., 2007). Similar sample characteristics were observed in past online support group research (e.g. Mo & Coulson, 2008, 2012), therefore the current sample may be, to a greater extent, representative of the population of avid prostate cancer online support users, than of the general population of individuals affected by prostate cancer.

Furthermore, the current study offered an interesting insight into the relationships between members' characteristics, the processes occurring in prostate cancer online support groups and the empowering outcomes. However, the study design was cross-sectional and thus establishing the directionality of the relationships is problematic. In order to help further understand the nature of the relationship between the processes that occur within the groups and the outcomes, randomised controlled trials and longitudinal studies are necessary. Such research designs would also allow easier access to members who stop using the groups and those who are less satisfied with participation.

### **7.5 Conclusions**

The results of this study expand our understanding of empowerment in health-related online support groups and extend current knowledge onto prostate cancer patients and their family members. The empowering processes predicted a significant proportion of variance in all empowering outcomes, indicating that participation in prostate cancer online support groups can contribute to a sense of empowerment in patients and family members. Information exchange appeared to be the most empowering process, and participation was found to be particularly beneficial in terms of increased knowledge about

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the disease, greater ability to become an active participant in treatment decisions and improved communication with health care professionals. The self-selected sample of members who were highly educated and highly satisfied with their group could be a source of bias in the results; however it can be concluded that participation in online support groups could be highly beneficial to those who choose to get involved in these groups

## **Chapter Eight: Overall discussion**

### **Chapter overview**

This chapter brings together the findings of all three empirical studies and discusses them in the context of the existing literature and theory. First the main findings of the research conducted and their role in expanding the current knowledge on the online support group experiences of individuals affected by prostate cancer will be discussed. Recommendations for future research and practice will then be outlined and the methodological issues pertaining to the current research will also be discussed before the final conclusions.

The literature reviewed in Chapter 2 suggested that prostate cancer patients and their partners may experience a number of psychosocial challenges as a result of prostate cancer diagnosis, treatment and recovery. Although the impact of these challenges can be greatly ameliorated through informational and social support, research points towards the existence of several barriers prostate cancer patients and their partners experience when seeking face-to-face support. The literature described in Chapter 3 further suggests that many of these barriers can be significantly reduced when accessing support online, and that online support groups can offer a valuable alternative source of informational and social support. More recent research also points towards the empowering potential of participation in online support groups (van Uden-Kraan et al., 2008c, 2009), which could be particularly pertinent in improving outcomes for individuals affected by prostate cancer, as highlighted in Chapters 2, 3 and 4. Chapter 3 identified several gaps in the current understanding of the online support group experience of the individuals affected by

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prostate cancer. Therefore the main aim of this thesis was to redress some of these gaps and expand current knowledge about the role of prostate cancer online support groups in empowering the members.

The triangulated research described in Chapters 5, 6 and 7 offered a novel and in-depth insight into the experiences of individuals affected by prostate cancer within online support groups. This is the first time that the full range and extent of the empowering processes experienced by members of prostate cancer online support groups and the potential empowering effects of participation have been described. The findings of these studies also helped to expand our current knowledge about who uses prostate cancer online support groups and about members' motivation to access these groups. Some interesting findings regarding the perceived negative aspects of participation were also described.

### **8.1 Summary of findings**

#### **8.1.1 Who uses prostate cancer online support groups?**

Previous research has provided limited knowledge about the characteristics of users of online support groups, and information on users of prostate cancer online support groups is particularly lacking. As discussed in Chapter 3, the majority of research has focused on patients' experiences within online support groups and few studies have explored the degree to which family members utilise this source of support (Kinnane & Milne, 2010). The existing research indicates that in the majority of groups, cancer patients are the most frequent users, followed by female family members (Ginossar, 2008; Nolan et al., 2006; Schultz et al., 2003). This is in line with the wider literature on cancer caregivers, which suggests that assuming the caregiving role is typically a female trait (Ginossar, 2008) and

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that close family members who care for patients often have high level of informational and support needs that may be insufficiently met by health care professionals, family and friends (Mason, 2005, 2008; Osse et al., 2006). Few studies to date, however, have investigated the levels of caregivers' participation in prostate cancer online support groups in detail (Seale, 2006). Nearly a third of the sample in Study 1 was made up of female family members of prostate cancer patients, which is in keeping with results of previous research. A similar proportion of the respondents to the surveys in Studies 2 and 3 consisted of female relatives. Furthermore, the findings of this research lend support to the idea that prostate cancer is 'a couples' disease' (Bottoroff et al., 2008), as the vast majority of the female members in these studies were partners or spouses of the patients, who fulfilled the caregiving role to the patient. Female partners are very likely to actively engage in treatment decision-making and information seeking (Mason, 2005; 2008), particularly as the specific effects of prostate cancer and its related treatments on sexual and urinary function of the patient can have a deep impact on the couple's relationship (Lavery & Clarke, 1999; Navon & Morag, 2003). The findings of this thesis suggest that online support groups can provide a valuable venue to help fulfil the needs of the female partners, as well as the patients.

### **8.1.2 What is the potential of prostate cancer online support groups to empower members?**

The empirical studies presented in Chapters 5, 6 and 7 support the usefulness of the empowerment framework in investigating the online support group experiences of the members (van Uden-Kraan et al., 2008c, 2009). The findings largely confirm the results of past research (Bartlett & Coulson, 2010; Mo & Coulson, 2012; van Uden-Kraan et al., 2008c, 2009) indicating that participation in online support groups can help foster empowerment

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in members. However, the majority of past research was conducted within female or mixed gender groups which were used predominantly by patients. The current research expands the existing knowledge by extending past findings to predominantly male online support groups used by prostate cancer patients. It also presents a novel and unique insight into the experiences of female family members, mainly partners, who fulfil a caregiving role to the prostate cancer patients.

The results of the studies presented in chapters 5, 6 and 7 point towards the existence of all the previously observed empowering processes, such as 'encountering similar others', 'receiving useful information', 'receiving social support' and 'helping others'. The results also suggest that members of prostate cancer online support groups experience the majority of empowering outcomes identified in past studies, including 'being better informed', 'improved communication with the physician', 'increased sense of community' and ability to reappraise the situation and own feelings towards the disease, outcomes that encompass improved self-efficacy, increased optimism, hope and control as well as increased acceptance of the disease. Some findings that appear to be unique to the population of online support group users affected by prostate cancer have also emerged as a result of the current investigation. For example, the findings suggest the existence of another important beneficial process, 'finding a safe place to talk'. The role of online support groups in improving treatment decision-making was also brought to light. Treatment decision-making and discussions of sensitive issues are particularly relevant in prostate cancer, as they relate to specific challenges and needs of this group of the patients and caregivers affected by this disease (e.g. Broom, 2005a; Huber et al., 2010). This suggests that the empowerment framework proposed by van Uden-Kraan and colleagues (2008c, 2009) can be expanded by processes and outcomes specific to the type of online

support group or disease characteristics of the members. This supports the need to employ exploratory research into specific online support groups, investigating members' perspectives and experiences, before drawing conclusions about the empowering potential of groups devoted to various diseases and conditions.

### **8.1.3 Why do individuals affected by prostate cancer choose to participate in online support groups?**

In recent years there has been a shift in health care towards greater involvement of prostate cancer patients and their family members in decisional processes (NICE, 2002). The literature reviewed in Chapter 2 also suggests the treatment decision-making process in prostate cancer is complex and requires a considerable amount of knowledge, however, the majority of communication with health care professionals tends to take place at the time of diagnosis, when the ability to process information effectively is diminished (Echlin & Rees, 2002). Partners' needs are typically fulfilled to an even lesser degree than the needs of the patients, as many women report feeling left out in the communication with their partner's medical team (Mason, 2005, 2008; Rivers et al., 2011). As past studies pointed towards prostate cancer online support being an easily accessible source of factual and experiential knowledge on the vast array of topics related to the disease, treatment modalities, medical facilities and recovery, it is not surprising that nearly all patients and over half of the partners in Study 2 indicated that their primary motivation to start using online support groups was seeking information and experiential knowledge from other patients and caregivers. Study 1 also suggested that requests for information were commonly posted to prostate cancer online support groups and mostly related to information that could aid decision-making processes. In this study, partners and family members posted significantly more requests, further confirming that this group has a



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particularly high level of unmet informational need (Mason, 2005, 2008) which they seek to fulfil through the use of alternative sources, such as online support groups (James et al., 2007).

The results of Studies 2 and 3 also indicate that patients were most likely to start using online support groups before their treatment decision was finalised and later on, during recovery, when the side-effects were most likely to arise. These could be perceived as times invoking particularly high levels of informational need, during which patients must learn to deal with new and difficult challenges. Conversely, a significant proportion of female partners started to access the groups during their partner's treatment, in the advanced stages of disease and after his death. Women were also more likely than the patients to report that they started to access online support groups to seek emotional support from similar others. These findings could be explained by the theory of optimal matching (Cutrona & Russell, 1990). This theory suggests that the type of required support depends on the type of stressor. That is to say controllable stressors tend to increase the need for informational support while uncontrollable stressors may result in a heightened need for emotional support and comfort. Arguably, the patients have greater control over the decisions regarding treatment and thus require high levels of informational support to remain in control of their situation. The women may play an important part in supporting their partner's decision, but ultimately they have less perceived and actual control over his final choice. Their sense of control may be further diminished and anxiety heightened in the times when there is nothing that can be done, i.e. during treatment and at the later stages when the disease becomes incurable. In those times the need for emotional support may be overwhelming and thus lead the partners and wives to seek new sources of emotional support, such as online support groups.

#### **8.1.4 What do we know about the empowering processes occurring within prostate cancer online support groups?**

##### ***8.1.4.1 Encountering similar others***

Literature pertaining to psychosocial issues in cancer suggests that both patients and their caregivers may experience some changes in their relationship with their family and peers as a result of cancer diagnosis (e.g. Glasdam et al., 1996; Taylor et al., 1986), which may result in an increased sense of isolation and decreased perceived social support (Taylor et al., 1986). More recent research suggests that connecting with others who share similar experiences when accessing support groups can help reduce the unwanted sense of isolation and perceived lack of support (e.g. Bottoroff et al., 2008; Ussher et al., 2006).

The findings of the empirical studies conducted as part of this thesis are in line with past research, which suggests that encountering large groups of individuals who share similar experience is one of the major benefits of online support groups (e.g. Bartlett & Coulson, 2010, Malik & Coulson, 2008a; Sullivan, 2003; van Uden-Kraan et al., 2008c, 2009). In Study 2 participants highlighted the fact that they experienced a lack of understanding from family, friends and health care professionals as a result of cancer diagnosis and the changes in their lives it imposed. On the other hand, the participants indicated that online support groups offered them a chance to find others who shared similar experiences. Results of Study 3 further confirmed, that 'encountering similar others' was the empowering process most frequently experienced by the participants. Furthermore, it became apparent from the responses of participants in Study 2, that encountering similar others enhanced the value of all other processes they experienced within the groups, particularly informational and emotional support. This was reflected in the fact that the information and advice

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received within the group was valued over and above the information provided by health care professionals, as it was based on lived experiences of people who underwent certain treatments or dealt with certain side-effects. Health care professionals were also perceived as biased towards their own specialism, and thus information about treatment options provided by them was treated by many patients as incomplete or favouring a particular treatment modality. Conversely, experiential information provided by other patients was believed to be largely free from this bias, and thus more useful in guiding an informed treatment decision-making process. Similarly, the emotional support experienced within the groups was perceived as more appropriate and relevant, as it stemmed from shared experience and unique understanding. These findings closely mirror the findings of studies conducted with members of face-to-face and online support groups, which also suggested that the experiential knowledge as well as the acceptance, empathy and unique understanding provided by other members of support groups are often positioned in contrast to the lack of knowledge and understanding reported outside of the support groups (Mok & Martinson, 2000; Ussher et al., 2006; Im et al., 2007a). Thus the results of the current research extend the existing knowledge suggesting that, similar to face-to-face support groups, the informational and emotional support encountered within online support groups, has several unique benefits for the members, over and above the support they receive from health care professionals, family and friends.

### ***8.1.4.2 Information exchange***

A significant finding of this thesis is the importance of information and experiential knowledge exchange for the members of prostate cancer online support groups. Informational support appeared to be the primary purpose of the communication in prostate cancer online support groups. Information and personal experience exchange

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were the most frequently observed processes within the messages analysed in Study 1. Participants in Study 2 frequently referred to the benefits of exchanging information with other members, which included access to practical, relevant and unbiased information based on lived experience of other patients. Furthermore, 'receiving useful information', coupled with 'encountering similar others' were the two empowering processes most frequently experienced by participants in Study 3, further confirming that the exchange of experiential knowledge between people sharing similar experiences in prostate cancer online support groups is of paramount importance. These findings are in line with past research on prostate cancer online support groups, which also indicated that informational support and exchange of personal experiences are commonly observed within these groups (Blank & Adams-Blodnieks, 2007; Blank et al., 2010; Huber et al., 2010). As past studies based their results predominantly on the analysis of messages posted to the groups (Blank & Adams-Blodnieks, 2007; Blank et al., 2010; Huber et al., 2010) this research extends current knowledge by providing the much needed members' perspective regarding the importance of information and personal experiences exchange within prostate cancer online support groups.

Similar to past research (e.g. Huber et al., 2010) the results of Studies 1 and 2 suggested that informational support exchanged by both the patients and the family members related most frequently to treatment options, outcomes and side-effects. Information was provided with the view to help newly diagnosed patients make informed decisions, and members often emphasised the necessity to become empowered with information in order to gain access to the best possible health care, communicate effectively with health care professionals and make fully informed decisions about treatment. Gooden and Winefield (2007) also noted that promoting freedom of choice and informed treatment decision-

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making was an important aspect of communication in prostate and breast cancer online support groups.

Past research suggests that patients choose to seek information from online support groups as they perceive them to be a convenient source of information available 'round the clock' and provided in simple, understandable terms (van Uden-Kraan et al., 2008c). This was also true for the prostate cancer patients in the current research, who often reported that they benefited from accessing informational support during 'out of hours' periods and often asked other members to clarify some information provided by the health care professionals.

One of the key findings of Study 3 is the fact that 'receiving useful information' was a highly significant predictor of all empowering outcomes, further confirming that information exchange is one of the most important processes within prostate cancer online support groups. The instrumental role of information exchange in improving empowering outcomes also transpired from the responses of participants in Study 2. These findings further support the paramount importance of informational support in prostate cancer and the role of online support groups in providing this support

### ***8.1.4.3 Finding a safe place to talk***

A relatively novel and unique finding of the current research is the emergence of an additional empowering process 'finding a safe place to talk'. This process was not previously included in the empowerment framework (van Uden-Kraan et al., 2008c, 2009). In the current research this process incorporates two key aspects of finding a safe place to talk within online support groups that may be particularly pertinent to individuals affected by prostate cancer, as discussed in Chapter 2: (1) the ability to discuss sensitive topics such

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as sexual or urinary dysfunction and (2) the ability openly express emotions difficult to voice in face-to-face situations. Items relating to discussion of sensitive issues and emotional expressions were included in the Study 3 survey since the findings from Studies 1 and 2 pointed towards the key role of prostate cancer online support groups in facilitating open disclosure and discussions of these subjects. The results of the factor analysis suggested that these items load together onto a distinctive factor that reflects the two main aspects of open discussions in prostate cancer online support groups highlighted in past research (Broom, 2005a; Gooden & Winefield, 2007; Klemm & Wheeler, 2005).

As discussed previously, sexual and urinary dysfunctions are particularly common side-effects of most treatments for prostate cancer. Literature suggests that these side-effects also have a profound impact on the female partners and their relationship with the patient (Lavery & Clarke, 1999; Navon & Morag, 2003). Broom (2005a) noted that men experience many barriers to engaging in face-to-face communication pertaining to these intimate issues and thus may feel more comfortable discussing them online. However the role of prostate cancer online support groups in enabling patients and their partners to discuss intimate side-effects has not been fully explored. The results of Studies 1 and 2 confirmed that prostate cancer online support groups are frequently utilised for discussions of sensitive nature. A large proportion of messages analysed in Study 1 contained in-depth and detailed conversations about sexual and urinary problems commonly experienced by prostate cancer patients. This was particularly common in the messages posted by the patients, which is understandable as they are the ones who physically experienced these side-effects and are affected by them to a greater extent than their spouses (Lavery & Clarke, 1999; Rivers et al., 2011). Furthermore, Study 2 confirmed from the participants perspective, that online support groups could be perceived as an appropriate venue for

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discussions of the post-treatment sexual and urinary problems. Although Broom (2005a) suggested that men may prefer to discuss sexual and urinary issues online due to the increased anonymity of this venue, the findings of Study 2 suggest that patients and their partners felt that information about altered sexuality, incontinence and relationship issues was simply unavailable from other sources, including health care professionals. Many participants in Study 2 indicated that health care professionals were not forthcoming with the information about side-effects, including how to prepare for them and how to deal with them when they arise. Some men speculated that health care professionals may be reluctant to discuss side-effects as this may discourage patients from choosing the treatment they provided; others suggested that doctors may not know the answers, as they did not experience these effects themselves.

Furthermore, past research suggests that patients who seek information about their disease online do so mainly for convenience, as they feel that the majority of information they need could also be obtained from other sources, such as health care professionals (van Uden-Kraan et al., 2008c). Conversely, the findings of the current research indicate that online support groups are perceived to be a unique source of information and advice about sexual and urinary side-effects.

The current research also offers a valuable contribution to our understanding of the members' perceptions of online support groups as a safe and appropriate venue for discussions of sexual and urinary issues. The results of Study 3 suggest that the majority of participants, both patients and their partners indicated that they preferred to discuss intimate issues online than face-to-face. They also found online support groups to be a safe place to discuss intimate issues, and the discussions were beneficial to them. Interestingly, a similar proportion of women and men chose online support groups over face-to-face

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settings for the discussion of sensitive issues. This could be because there is a notable scarcity of support services for prostate cancer spouses, and therefore a lack of information and support on the issues of sexuality (Rivers et al., 2011). As well as this, women report that family and friends are unable to offer them the same support and understanding as other partners and wives of prostate cancer patients (Bottoroff et al., 2008).

Furthermore, many cancer patients and caregivers experience negative emotions, such as fear, anger and frustration as a result of the diagnosis and treatment (Broom, 2005a; Klemm & Wheeler, 2005; Street et al., 2010). These feelings are often difficult to discuss face-to-face as they may be perceived as socially unacceptable and lead to an increased sense of guilt (Klemm & Wheeler, 2005). Past research suggests that online support groups can be perceived as a safe and appropriate venue for such discussions (Broom, 2005a; Klemm & Wheeler, 2005). Interestingly, few emotional expressions were noted in the messages analysed in Study 1, which could be explained by the fact that the messages were derived from mixed gender groups used predominantly by patients. Mo et al. (2009) pointed out that in mixed gender groups the communication style of the predominant gender is adopted by all members in the group. Overt emotional expressions are typically associated with female communication style, and thus are observed less frequently in predominantly male groups (Seale et al., 2006). Furthermore, only female participants in Study 2 indicated that they use online support groups to vent their frustrations. Interestingly, the findings of Study 3 revealed that similar proportions of both men and women felt able to disclose their emotions and 'get things of their chest' within the groups. The contrast in findings of Studies 2 and 3 could potentially be explained by the fact that emotional expressions are overall more common and acceptable in women (Broom, 2005a; Gooden & Winefield, 2007) and thus the women may be more likely to bring them up



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spontaneously. The differences and similarities between prostate cancer patients and their female partners in utilising online support groups to openly disclose emotions, however, remain unclear.

### **8.1.4.4 Helping others**

Helping others in online support groups is typically associated with posting messages containing informational and emotional support (Winefield, 2006). Messages analysed in Study 1 contained significantly more offers of help than requests and participants in Study 2 indicated that they found participation in online support to be very helpful. The results of Study 3, however, indicated that participants experienced the empowering process 'helping others' to a relatively low degree, that is to say participants didn't always feel that the information, experiential knowledge and advice they provided could be helpful to others. This is in line with past findings, which also indicated that participants in online support groups rate their ability to help other members relatively low (Mo & Coulson, 2010; van Uden-Kraan et al., 2009). One possible explanation, suggested by van Uden-Kraan and colleagues (2009) is that a high proportion of lurkers in the study sample lowers the overall score on 'helping others' subscale, as lurkers have fewer opportunities to help others. Mo and Coulson (2010) suggested that many active members post messages containing requests for help and use the groups to socialise, which could also reduce their perceived helpfulness. Another explanation emerged from the findings of Study 2, which indicated that new members tend to feel unsure about the information and support they can offer. Participants indicated that their perceived ability to help others increased significantly as they gained experience and information. In fact, some participants indicated that their main motivation to access online support groups changed from information and support seeking to providing help to other members. Overall, the proportion of 'lurkers', new

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members and those who access online support groups to socialise could potentially explain the consistently low levels of perceived helpfulness.

The finding of Study 2 described above is also interesting as it reflects the cyclical and reciprocal nature of support in online support groups and is in line with the membership lifecycle described by Kim (2000), which suggests that long-term members become mentors to the 'newbies' once their own need for information and support subsides and confidence in their knowledge increases.

### ***8.1.4.5 Receiving emotional support***

Previous studies (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009) suggest that 'receiving emotional support' tends to be much less prevalent in online support groups than the other empowering processes such as the exchange of informational support. The current study largely confirms and extends the past findings onto the prostate cancer online support groups. Expressions of emotional support in the messages analysed in Study 1 were brief and coincidental, mainly limited to 'good luck' wishes or smiley faces. 'Receiving emotional support' was also found to be the least frequently reported empowering process in Study 3. Past research suggests that expressions of emotional support are less frequent and less apparent in predominantly male online support groups and more typical for predominantly female groups (Blank et al., 2010; Sullivan, 2003). Interestingly, the findings of Study 1 suggested that the female participants posted even fewer messages containing emotional expressions and offers of support. This is in sharp contrast with the wider literature on gender communication (e.g. Clarke et al., 2006; Harrison et al., 1995; Keller & Henrich, 1999) and, as discussed earlier, could be explained by the fact, that the messages scrutinised in Study 1 were drawn from mixed

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patient/caregiver groups used predominantly by patients which could have affected members' communication style (Mo et al., 2009). In Study 2, however, many women described the in-depth emotional support they have experienced from other women, mainly within female only groups. They spoke with deep affection about the sense of community and sisterhood they experienced and about the friendship, unconditional acceptance and unique understanding given from one sister to another. Furthermore the results of Study 3 indicated that women experience significantly more emotional support than the male participants. Interestingly, the majority of women in Study 3 reported using single gender groups. This supports the findings presented by Mo et al. (2009) which suggest that communication in mixed and single gender groups differs considerably. The findings of the current research point to the possibility that women may benefit more in terms of informational support from the mixed gender groups, while single gender groups provide them with the opportunity to access social and emotional support. These findings are comparable to those reported by Bottoroff et al. (2008) within face-to face prostate cancer support groups for caregivers, which also suggest that female partners of prostate cancer engage in higher levels of emotional support in female only groups. The current research extends those findings onto online support groups.

Overall, the findings of Studies 2 and 3 are in line with the literature pertaining to gender communication which suggests that women, particularly in single gender groups, engage in emotional support and personal relationship building to a higher extent than the men (e.g. Sullivan, 2003). Nevertheless, the men in Study 2 also indicated that community and emotional support played an important part in their online support group communication, particularly after the need for information was satisfied. The in-depth, often affectionate and supportive relationships with other members described by the participants in Study 2

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are in contrast with some of the early computer-mediated communication theories, such as the cues-filtered-out theories described in Chapter 3 (Short, Williams & Christie, 1976; Sproull & Kiesler, 1986) which suggested that emotional and relational communication is unlikely to occur in computer-mediated communication due to the lack of non-verbal cues. Conversely, the experiences of the participants in the current research appear to lend support to the social information processing perspective (Walther, 1992) which suggests that lack of non-verbal cues does not preclude emotional expressions and relationship forming in computer-mediated communication, but may delay this process, as members have to put additional effort into transforming the rich socio-emotional messages typical to non-verbal cues into textual and verbal behaviours.

### **8.1.5 What do we know about the empowering effects of participation in online support groups?**

The results presented in this thesis provide strong evidence that participation in online support groups can help empower individuals affected by prostate cancer in several areas of their lives. This is reflected in the high prevalence of empowering outcomes reported by participants across Studies 2 and 3. The findings of Study 3 also suggest the existence of significant relationships between the processes and the outcomes experienced by the participants, which further corroborates the notion that prostate cancer online support groups have an instrumental role in empowering members, with informational support playing a particularly important role.

Past research suggests that participation in online support groups can help foster empowerment in patients (Bartlett & Coulson, 2010; Mo & Coulson, 2010, 2012; van Uden-Kraan et al., 2008c, 2009), but the benefits of caregivers' and family members' participation

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in online support remain largely unexplored. A novel and significant finding of this thesis is that both the patients and the caregivers appear to experience all the empowering outcomes of participation in online support groups to a similar degree. One recommendation from this thesis is that caregivers should be encouraged to participate in online support groups so that they can benefit from the informational and emotional support.

The increased ability to actively participate in important decisions is considered to be one of the key concepts of empowerment, as it instils in the individual a sense of control and mastery over important areas of life (Zimmerman, 1995). Notably, the findings of this thesis point towards the fact that prostate cancer online support groups may play an important role in improving members' ability to actively participate in treatment-related decisions. Although this outcome was not previously discussed within the empowerment framework (van Uden-Kraan et al., 2008c, 2009), it is not unexpected in the context of prostate cancer. As discussed in Chapter 2, choosing an appropriate treatment is an important and complex task for the majority of newly diagnosed prostate cancer patients, which requires considerable knowledge and understanding of the available treatment options. Research on prostate cancer online support groups also consistently points towards the fact that members frequently engage in communication focused on issues related to treatment options and often highlight the importance of becoming active and informed participants in making treatment decisions (Gooden & Winefield, 2007; Huber et al., 2010).

The findings of Studies 2 and 3 offer a participants' perspective on the fact that informational support in prostate cancer online support groups has a notable impact on treatment decision-making processes. Patients in Study 2 often reported that the informational support and encouragement from other members helped them better

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understand the potential advantages and disadvantages of available treatment options and thus improved their ability to make an independent and informed decision regarding treatment. The results of factor analysis in Study 3 suggested that items relating to 'increased knowledge' and 'improved ability to actively participate in treatment decision-making' load onto one factor. Furthermore, 'receiving useful information' was found to be the main predictor of this outcome. This further supports the close relationship between information obtained from online support groups and improved decision-making in prostate cancer. This is a particularly notable finding, as past research suggests that patients who believe their decision regarding treatment was well-informed had lower post-decisional regret and better post-treatment adjustment (Clark & Talcott, 2006).

The results of Study 3 indicate that members of prostate cancer online support groups, both the patients and their partners, benefit the most in terms of 'increased knowledge and ability to participate in treatment-related decisions', which is largely consistent with past research on empowerment in online support groups (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009), confirming that the role of online support groups is predominantly educational and helps promote active participation in health care and informed treatment decision-making. This suggests that prostate cancer online support groups can potentially be a valuable, cost-effective supplement to the information and support from health care professionals and help meet the guidelines set out by NICE (2008; see Chapter 2) which advocate the need to empower patients and their partners to become more active and informed participants in health care and treatment decisions.

The findings of this thesis also suggest that information and advice from other members can help participants to take more active part in the dialogue with their health care professionals. Participants in Study 2 indicated that they were better prepared for

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consultations, could ask more relevant questions and understand information provided by the health care professionals to a higher degree as a result of the information, support and encouragement they received from other members. This was further confirmed by the results of Study 3 which suggested that 'receiving useful information' and 'encountering similar others' were significant predictors of the outcome 'improved relationship with the physician'. This is a notable finding, as past research points out that effective communication with health care professionals can lead to improved outcomes and adjustment to treatment effects (Arora, 2003).

Another important and encouraging finding is the fact that participation in the groups appears to have similar effect on the caregivers as it does on the patients in terms of improving ability to communicate with health care professionals. Past research indicates that women feel particularly dissatisfied with the communication with their partners' physician and they feel disempowered during medical encounters (Feltwell & Rees, 2004). The findings of this thesis add to the extant literature, suggesting that information, experiential knowledge, advice and encouragement from similar others in online support groups can help empower partners of prostate cancer patients to become more confident and assertive in communication with health care professionals.

Improved social wellbeing and reduced isolation were also frequently mentioned by the participants in Study 2. Both the patients and caregivers reported feeling less alone as a result of participation in the groups, as they were able to read about the experiences of others who were going through similar issues. This finding is comparable to those reported by other authors (Bartlett & Coulson, 2010; Hoybye et al., 2005; Sharf, 1997; van Uden-Kraan et al., 2008c, 2009). Unwanted social isolation following cancer diagnosis can be a major stressor for the patients (Hoybye et al., 2005) and the results of the current research

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strongly suggest that this can be rectified to some degree by participation in online support groups.

In Study 2, improved ability to help other people affected by prostate cancer, including members and non-members of online support groups also emerged as one of the outcomes of participation. Items reflecting this potentially empowering outcome were incorporated into the empowering outcomes scale in Study 3. Factor analysis clustered these items together with items measuring 'reduced social isolation' (van Uden-Kraan et al., 2009) suggesting that ability to offer reliable and correct information with confidence is an important community building aspect of participation in online support groups, lending further support to the reciprocal nature of the support within the groups, highlighted by the participants in Study 2. Unsurprisingly, 'receiving useful information', 'receiving emotional support' and 'helping others' were the predictors of this outcome, supporting the importance of the mutual informational, experiential and emotional support in building community spirit within online support groups.

The findings of Study 3 also suggested a relationship between the level of activity within the group (poster/lurker) and sense of community spirit. According to these findings, 'lurkers' were less likely to experience high levels of community spirit than the posters. This is in line with previous studies (van Uden-Kraan et al., 2008a), and further confirms that at least some level of active communication is necessary to build relationships with other members and to feel part of the group. As noted earlier, 'lurkers' also have fewer opportunities to help other members, which may further preclude their chance to participate in the mutual help processes within the community.



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Furthermore, the results of Studies 2 and 3 suggest that participation in prostate cancer online support groups may also lead to positive reappraisal of the situation. Participants in Study 2 often noted that their hope for the future, acceptance of the disease and sense of control increased, while their worry and anxiety decreased. Learning about the experiences of others and the ability to compare with other group members was found to be a source of reassurance, hope and inspiration. Participants indicated that encountering other individuals who were doing worse than themselves (for example had more advanced disease) helped them positively re-evaluate their own situation and realise that it was not as bad as they initially thought. On the other hand, comparison with others who were doing well, for example those who survived for many years despite poor initial diagnosis, led to increased hope for the future and was a source of inspiration. The results of Study 3 further confirmed that 'encountering similar others' was in fact the most significant predictor of the outcome 'positive reappraisal of situation'. These findings can be interpreted in the context of social comparison theory, which assumes that individuals tend to look to other, similar individuals, in order to achieve accurate self-evaluation (Festinger, 1954). Wills (1981) proposed that comparison with others who are considered to be worse off than their self (downward social comparison) helps individuals feel better about themselves or their situation. Upwards social comparison (Taylor & Lobel, 1989), or comparison with others considered to be better off than their self, can lead to increased hope and inspire individuals to strive to achieve better results. In the past, beneficial effects of both downward and upward social comparison could be observed in cardiac patients attending rehabilitation programmes (Helgeson & Taylor, 1993). Conversely, van Uden-Kraan et al. (2008c) noted downward but not upward comparison in online support groups. They hypothesised that online support groups may not be the right environment for upward comparison due to lack of visual cues which can increase bias when considering

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comparison targets. The findings of this thesis suggest, however, that both downward and upward comparisons are common in prostate cancer online support groups and can lead to positive reappraisal of situation.

The empowering outcome experienced to the lowest degree by the individuals affected by prostate cancer who access online support groups was 'positive personal reappraisal'. This outcome encompassed concepts such as enhanced sense of self-worth and increased ability to find positive meaning in life. As highlighted in Chapter 7, personal reappraisal is a complex process that may require mobilisation of personal resources and support beyond those available in online support groups (Manne et al., 2004; Sears et al., 2003; Thornton & Perez, 2002). This is corroborated by the results of Study 3, which suggest that only a small proportion of this outcome can be explained by the processes occurring in online support groups. The most significant predictor was 'receiving useful information', followed by 'helping others'. These findings could be explained in the context of helper-therapy principle (Reissman, 1965), which suggests that the ability to help others can lead to various positive psychosocial outcomes, including increased self-efficacy and sense of self-worth. However, participants in Study 2 suggested that their ability to help others improved as a result of increased self-esteem and confidence. Therefore the true direction of this relationship remains unexplained. Furthermore, the role of online support groups in empowering members to achieve personal reappraisal can overall be perceived as questionable, as past research also suggests that empowering processes can only help explain a small proportion of variance in this outcome (Bartlett & Coulson, 2010; van Uden-Kraan et al., 2009).

### **8.1.6 What do we know about the negative aspects of participation in prostate cancer online support groups?**

The results of this thesis suggest that the participants' experiences in prostate cancer online support groups were overall positive and participants named significantly more empowering processes and outcomes than negative aspects of participation. Participants in Study 2 indicated that they accessed online support groups to fulfil specific needs, such as need for information, experiential knowledge or social support. Notably, a large majority of participants also reported that participation fulfilled these needs to a high degree. The findings of Study 3 have also shown that participants were highly satisfied with their group, both in terms of information and support they received from other members. This is in line with past research, which suggested that members who reply to online support group related research requests tend to report high levels of satisfaction with their groups (Mo & Coulson, 2010; van Uden-Kraan et al., 2009).

Nevertheless, some negative aspects of participation were also mentioned by participants in Study 2. The men tended to report more negative aspects of participation than the women, who appeared to be particularly satisfied with female only groups. The most notable negative aspect of communication within prostate cancer online support groups was encountering potentially biased information. As discussed earlier, the main advantage of participation in online support groups was access to unbiased information, provided without prejudice and hidden agendas by members who had first-hand experience of these treatments. In Study 1 some instances of patients accusing other members of advocating certain treatment modalities or medical facilities were noted. Patients in Study 2 confirmed that messages 'promoting' certain treatments were undesirable. In fact, some of the participants implied that members could potentially have some financial interest in posting

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such messages. This has not been reported in past studies (e.g. Malik & Coulson, 2008a; Sandaunet, 2008; van Uden-Kraan et al., 2008c) and could be specific to online support groups dedicated to conditions with multiple treatment options, such as prostate cancer. This could be explained by the fact that, there are several treatments of similar effectiveness currently available to prostate cancer patients, and the choice is often down to personal preference. Further investigation is, however, necessary to fully understand how this issue affects members.

The patients also mentioned interpersonal conflicts with other members, such as lack of tolerance for other members' views and arguments. This issue also did not rise in female only groups (Sandaunet, 2008, van Uden-Kraan et al., 2008c) nor was it brought up by female participants in the current research. This could suggest that predominantly male online support groups are more likely to witness disempowering communication and arguments than female groups. This is in line with findings reported by Herring (1993) who pointed out that male members of an academic discussion board were more likely to dominate the discussions and engage in arguments. Suler (2005) suggested that the anonymity in online support groups coupled with lack of socio-emotional cues can increase hostile communication. However, the findings from female groups suggest that increased levels of arguments and power struggle may be related to the male style of communication (Herring, 1993) rather than to the online environment itself.

Similar to past studies (Sandaunet, 2008; van Uden-Kraan et al., 2008c), members of prostate cancer online support groups also suggested that learning about negative aspects of the disease, such as failed treatment or death of another member was difficult and could evoke strong feelings of sadness and fear. This negative aspect was experienced by both the patients and the family members, suggesting that online support groups can potentially

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cause emotional harm to all members, as it makes the possibility of death seem more real. Sandaunet (2008) found that members' need to protect themselves from knowledge about negative aspects of the disease was one of the main reasons of leaving the groups. Many participants in the current research indicated that they protected themselves by avoiding such messages. However, as only current members participated in this research, it is possible that exposure to negative aspects of the disease might have equally profound effects on some individuals affected by prostate cancer, as described by Sandaunet (2008).

### **8.2 Discussion of methodological issues pertaining to research conducted on the Internet**

With the rise of the Internet, new opportunities for data collection have opened up for researchers across disciplines. Online surveys and online interviews are commonly used to gather quantitative and qualitative data on a variety of subjects within social sciences (e.g. Hunt & McHale, 2005; Malik & Coulson, 2008a) and the issues relating to online data collection receive growing attention in the literature (e.g. Hewson, 2003; Davis et al., 2004; Hunt & McHale, 2007). Online surveys are the most commonly used method of data collection in Internet mediated research, (e.g. Bartlett & Coulson, 2010; Malik & Coulson, 2008a; van Uden-Kraan et al., 2009) as they provide the opportunity to collect both quantitative and qualitative data.

As the current research was concerned with the exploration of online support group experiences of individuals affected by prostate cancer, online data collection via online support groups allowed the researcher quick and easy access to the target sample. This strategy resulted in a large and relatively diverse sample of individuals who were both online support group users and affected by prostate cancer. A key strength of the current research was the fact that a considerable proportion of participants were family members

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of prostate cancer patients, allowing exploration of issues experienced by this group of members. Although past studies suggest that the partners tend to be the most frequent users of online support groups, apart from the patients (Seale, 2006), the findings of Study 1 suggest that a significant number of children and siblings of prostate cancer patients took part in the discussions within the online support groups. The majority of family members who responded to the surveys were partners, however, which highlights the issues with recruiting children and other family members to research.

As highlighted in Chapter 3, only a small proportion of individuals affected by chronic conditions access online support groups (Fox & Purcell, 2010; Owen et al., 2010), therefore achieving a comparable sample size through recruitment via hospitals or doctor's surgeries would have been more time consuming and costly (Davis et al., 2004; Hinchcliffe & Gavin, 2008; Hunt & McHale, 2007), if not impossible within the means of the current research.

Some authors point out, that online researchers should be aware of the proliferation of online surveys posted to online support groups, which can result in survey fatigue in group members and subsequently reduce response rates (Witte, 2009). Nevertheless, past research concerned with the experiences of online support group users obtained relatively large samples (Bartlett & Coulson, 2010; Mo & Coulson, 2012; Van Uden-Kraan et al., 2009). In the current research the sample sizes were also considerable. Interestingly, the researcher has received several messages from moderators and group members, pointing out that research into the role of online support groups in the context of prostate cancer is much needed and that the current investigation was highly appreciated by the community. Positive responses about the relevance of the content of the survey to the experiences of the members were also included. This could suggest that placing surveys highly relevant to

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the members experience could help increase the response rate, especially in areas perceived by the members to be under-researched.

Furthermore, ensuring a positive relationship between the research team and the gatekeepers also appears to improve the chances of them posting participation requests on their website. For example, in the current research one group owner initially declined the invitation to get involved in the research, but became convinced through the dialogue with the researcher and through the overwhelmingly positive response from members of other groups. He then decided to post the request despite group rules prohibiting research activity within the group.

Another advantage of the current research relates to the fact that analysis of messages posted to the online support groups was incorporated into the research methodology. As discussed in Chapter 5, this allowed the researcher an original and unique insight into the naturally occurring communication between members. It also provided a more accurate idea about who uses mixed gender online support groups. No single gender groups were publically available at the time of data collection, which precluded the opportunity to compare the communication occurring within mixed and single gendered prostate cancer online support groups. This is regrettable, as the findings from Study 2 point towards potentially significant differences in the experiences of members in those two types of groups.

### **8.2.1 Disadvantages of online recruitment and of recruiting directly from online support groups**

Some disadvantages of online data collection have also been reported. The two main problems relate to sampling issues and researcher control (Hewson, 2003; LaCoursiere,

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2003), as they can pose a potential threat to the generalizability of online research findings (LaCoursiere, 2003).

Hewson (2003) points out that the characteristics of Internet users in general can affect the Internet sample characteristics. As it was discussed in Chapter 3, Internet users are more likely to be young, white, well-educated, from Western countries and higher socioeconomic background, which could lead to Internet samples being 'inherently biased' (Hewson, 2003). Indeed, many online studies report that participants tend to have higher education and be from the USA (Mo & Coulson, 2010; Mo & Coulson, 2012). This issue also transpired in the current research, where participants were highly educated and significantly younger than average prostate cancer patients (ONS, 2011b). The samples obtained via the Internet also may not be representative of the wider population they are meant to represent. That is to say that Internet samples consisting of people with a specific health concern, such as for example alopecia (Hunt & McHale, 2005), are not necessarily representative of all individuals living with alopecia, but only of people with alopecia who access specific websites (Hunt & McHale, 2007). Arguably, this is potentially somewhat less of a problem in research that specifically aims to recruit participants who are online support group users (LaCoursiere, 2003), for example in studies exploring the members' experiences in online support groups (e.g. Bartlett & Coulson, 2010; Malik & Coulson, 2008a; Mo & Coulson, 2010; van Uden-Kraan et al., 2008c, 2009). In fact, as online support groups often only collect email addresses of the members, the Internet may be the only way of accessing these communities. Nevertheless, the self-selection bias can be problematic in these studies, as long-term, active and highly satisfied online support group users are more likely to voice their opinions about their online support group than new, infrequent members



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who don't have strong feelings towards the group (Bartlett & Coulson, 2010; Mo & Coulson, 2010; van Uden-Kraan et al., 2009).

Furthermore, the majority of participants in the current research were recruited via an invitation posted to online support groups. The main disadvantage of posting participation requests directly onto websites and online support groups is the fact that it precludes the possibility to estimate the sampling frame and thus the ability to assess the response rate and compare respondents and non-respondents (Hewson, 2003). In research on online support groups this can also lead to further sample bias, as it decreases the chances of reaching infrequent and past members who no longer access the online support group (Hewson, 2003; LaCoursiere, 2003). Hewson (2003) suggests that emailing participation requests directly to the members may offer a greater insight into the population size and characteristics. It can also increase the potential chance to reach members who discontinued active participation in the group. As it became apparent in the current research, in reality, the researcher is restricted by the fact that access to email addresses is restricted and the mode of recruitment depends on the moderators preferences. In the current research only two moderators agreed to send messages, however, that did not seem to have increased the response from past or dissatisfied members.

Another important issue in online data collection is the lack of researcher control over the study environment, which can affect the quality of the data collected and thus further impact upon the generalizability of findings (LaCoursiere, 2003). This is particularly pertinent to experimental design studies, where difficulties may arise to control the experimental conditions; however the responses to surveys can also be affected by various inferences inherent to the online environment. LaCoursiere (2003) highlights the fact that the online environment is full of distractions, for example participants may be watching a

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video on the Internet or reading information on another website at the same time as they complete the survey. This can lead to incorrect entries or omissions. The hardware, software and Internet speed can further affect the quality of data; for example, particularly slow connection or incorrectly aligned screen view can irate the participant and thus affect his or her responses. This is particularly difficult to control, however in the current research the amount of missing data and incongruent responses to the open ended questions was minimal, suggesting that this was not a major issue. However, several instances of 'false-starts' were observed, where an individual entered the questionnaire and began to complete questions, only to abandon the research. Few of those members returned at a later time or date, but many did not complete the survey. It remains unclear if this occurred due to distraction or fatigue or whether it was due to the fact that some participants found the survey irrelevant.

### **8.3 Directions for future research**

This thesis describes an in-depth exploratory research into the online support group experiences of individuals affected by prostate cancer. The findings of the empirical studies have greatly expanded current knowledge relating to the processes and outcomes experienced in online support groups by prostate cancer patients and their family members, and particularly female partners. As highlighted in Chapters 5, 6 and 7, the current research unveiled new and interesting areas that warrant further investigation.

The research described in this thesis, and particularly in Study 3, has highlighted the existence of some interesting relationships between the processes encountered by the individuals within prostate cancer online support groups and the empowering outcomes. However, as the current research is cross-sectional, it does not offer the researcher the

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opportunity to fully explore the directionality of these relationships. Furthermore, data were collected at one time point only, and thus it remains unclear to what extent did other confounding factors, such as mood, mental and physical health or the environment in which surveys were completed affect the results. This points towards the need for randomised control trials and longitudinal studies, as this methodology could provide further insight in to the direction and strength of the relationships between the variables. Overall, there is a notable scarcity of studies on online support groups that employ prospective longitudinal research design or describe findings of randomised controlled trials (Hong et al., 2012). The majority of the existing randomised control trials and longitudinal studies have focused on the psychosocial outcomes of online support groups, such as levels of depression, stress or coping abilities (e.g. Winzelberg et al., 2003) and none have been conducted within the empowerment framework (van Uden-Kraan et al., 2008c).

Although the results presented in this thesis are encouraging and point towards the fact that prostate cancer online support groups can foster a sense of empowerment in patients and caregivers, the exact mechanism of this remains unclear. Research controlling for other potentially empowering factors occurring outside of the groups, for example information and support obtained from other sources, such as health care professionals, face-to-face support groups or other websites could provide a more accurate picture of the part played by online support groups. The current research included a general measure of perceived social support outside of the group, however no significant relationships were observed between the level of perceived support outside the group and the empowering effects of participation. Inclusion of more specific measures assessing level of support from different sources could help shed light on this issue.

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In addition, the research presented here has focused on the empowering effects of participation in prostate cancer online support groups. Future research, particularly longitudinal studies and randomised control trials should include measures of other potentially significant outcome variables, such as quality of life, coping (Mo & Coulson, 2012), depression, perceived stress or cancer-related trauma (Winzelberg et al., 2003). Incorporation of these outcomes could help further understand what impact the empowering processes identified in this research have on the lives of individuals affected by prostate cancer.

This research has provided a unique and interesting insight into the experiences of individuals affected by prostate cancer, who have mainly had positive experiences within online support groups. These members reported few negative aspects of participation; little is known, however, about the experiences of members who left the groups and those who were negatively affected by participation. Randomised controlled trials and longitudinal research could further help capture the experiences of members who drop out from the groups at various time points (Sandaunet, 2008).

### **8.3.1 Qualitative research**

Aside from the need for longitudinal studies and randomised controlled trials, the results of the current research has highlighted several areas in the online experience of individuals affected by prostate cancer, which warrant further in-depth qualitative investigation. Although the open-ended questionnaires produced rich data which offered a unique insight into the role of prostate cancer online support groups in empowering members, it became apparent that some of the issues raised by the participants require further investigation through e-mail, telephone or face-to-face interviews or focus groups. These methods can

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offer a much greater scope for probing and exploration of salient issues (e.g. Hunt & McHale, 2007).

For example, the findings of this research pointed towards some interesting differences in participation in single and mixed gender groups. These findings were most pronounced in the responses of the female family members in Study 2, and suggest that female caregivers to prostate cancer patients prefer to participate in single gender groups. These groups appear to offer them more freedom to express their feelings without upsetting the patients as well as provide them with more in-depth emotional support and result in greater sense of community. Conversely, there was a suggestion in the findings of Study 1 that mixed gender groups inhibit emotional expressions in women but promote informational support exchange, which was in line with other research (Bottoroff et al., 2008; Mo et al., 2009). Little is known about the effects participation in single gender groups may have on the patients as compared to participation in mixed gender groups. Further qualitative investigation targeting members according to their use of mixed and single gender groups, could shed additional light on these issues and provide foundations for quantitative research focused on exploring the differences in the role of mixed and single groups in empowering members.

Furthermore, other issues related to gendered communication, such as the differences between patients and female partners in discussions of sensitive issues and emotional disclosure in mixed and single gender groups require further attention. This could be achieved through both in-depth interviews and comparative analysis of messages posted to mixed and single gender groups.

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Another area that warrants further investigation relates to the role of the process 'helping others'. Current results indicate that members' motivation to help others increases as their confidence and knowledge improves. The findings of Study 3 also suggest that the process of offering help to members can aid positive personal reappraisal. As discussed earlier, the directionality of the relationship between level of engagement in helping behaviours in the group and the empowering outcomes is unclear. Furthermore, while the helper-therapy principle (Reissman, 1965) suggests that helping others leads to various positive psychosocial and empowering effects for the helper, participants in the current research did not elaborate on the effects that helping others had on their self-esteem, sense of mastery or sense of empowerment and the open-ended survey format did not offer the researcher the opportunity to further explore these issues (Hunt & McHale, 2007). Although the role of helping others appears to be important for the process of community building in prostate cancer online support groups, further in-depth qualitative research is necessary to gain greater understanding of this process. As mentioned earlier, the extent to which online support groups can promote positive personal reappraisal also requires further investigation.

### **8.3.2 Off-line research**

Previous research (e.g. Mo & Coulson, 2010, 2012) highlights the issue of sampling bias when recruiting from within online support groups. As noted in the discussion of Chapter 7, this problem also transpired in the studies presented in this thesis. Participants who responded to the research invitations in Studies 2 and 3 were considerably better educated and younger than average prostate cancer patients and caregivers (OSN, 2011b). Although the characteristics of the samples are consistent with the characteristics of the wider population of Internet users who tend to be better educated, younger and from higher

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socioeconomic background (Ybarra & Suman, 2006), the sampling bias can be perceived as potentially problematic, since the views of older and less educated patients and caregivers remain unexplored. Whilst the sample bias may be partially related to the fact that older and less educated patients may be less likely to access online support groups, there is an apparent need for an off-line research that would engage the general population of patients and caregivers of all ages and educational attainments, in order to explore their views on online support group and Internet use, their experiences with these media and their perceived barriers to seeking support and information online.

Furthermore, past research suggest that some older patients may be particularly reluctant to use the Internet, as they do not perceive this as a valid or appropriate venue for support-seeking, while others may feel excluded by the lack of skill, embarrassment and fear that they will 'break the computer' or do something inappropriate (Broom, 2005a; OFCOM, 2006; Pfeil et al., 2009). The reasons why some prostate cancer patients and caregivers may refrain from online support group use remain unexplained. Recruitment of patients and caregivers directly from doctor's surgeries, hospitals and treatment centres could therefore offer further insight into the reasons why some older patients and caregivers use online support groups while others do not.

### **8.4. Implications for practice**

#### **8.4.1. Implications of current research for health care professionals involved in prostate cancer-related care**

Accessing online support groups before a treatment decision is made has been found to be most beneficial to patients (van Uden-Kraan et al., 2008c). The current research also

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highlights the instrumental role of informational, experiential and emotional support obtained within prostate cancer online support groups in enhancing members' ability to take active part in making informed treatment decisions. Although the majority of participants in Studies 2 and 3, and particularly patients, reported accessing the groups before treatment, a notable minority did not start to use online support until after the decision was made. As the first port of call for newly diagnosed patients is usually their doctor who provides them with the details of diagnosis and potential treatment options, incorporating information about prostate cancer online support groups into the consultation could be beneficial for many patients. Some authors suggest that health care professionals are opposed to the idea of patients educating themselves online (Broom, 2005b) whilst others indicate that health care professionals have neutral or positive opinions of online support groups, but lack awareness of appropriate groups and thus rarely recommend this source of information and support to patients (van Uden-Kraan et al., 2010). Increasing health care professionals knowledge about available online support groups could increase their ability to recommend groups that provide high quality information and support, whilst at the same time are free from spam and advertisement.

The current research presented in this thesis as well as research of others (Malik & Coulson, 2008a, 2008b; van Uden-Kraan et al., 2008c) suggest that participation in online support groups is beneficial for patients and caregivers, with fewer negative aspects than advantages. Nevertheless, as highlighted in Chapter 3, only a small proportion of patients have been found to utilise this source of support and information (Im, 2011). This is particularly apparent amongst older patients (Pfeil et al., 2009), who are, in general, less likely to use the Internet, often due to perceived lack of confidence or skill (OFCOM, 2006). Recent research involving online support group members (e.g. Mo & Coulson, 2010, 2012),



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and the research presented here all highlight the fact that patients who are well-educated, and thus potentially have higher computer skills are more likely to access online support groups. Some training could potentially increase patients' and caregivers' confidence to access online support groups and reduce barriers to participation (Kreps et al., 2007; McTavish et al., 1994; Dow et al., 2008). This could be achieved, for example, through placement of computer terminals with Internet access and website addresses for some trusted online support groups in doctors' surgeries and other medical facilities. Availability of clear and concise user manuals and/or support from staff members or through volunteer-led computer clinics within face-to-face online support groups could also help encourage patients and family members to use the groups. Randomised controlled trials could help establish the cost and time effectiveness of such interventions.

The findings of Study 2 also suggested that the presence of health care professionals within online support groups could help control the quality of information provided by other members. Some participants also found the advice and information provided by well-known medical experts who offered their time to online support group members to be invaluable. This suggests that some involvement of health care professionals in the groups could enhance the trustworthiness of online support groups and potentially protect new and inexperienced members from following inappropriate advice. Participation in online support groups could also help the health care professionals to gain a better understanding of the needs of patients and caregivers.

Another important finding of this research that has practical implications for health care professionals is that prostate cancer patients and their partners often turn to online support groups as they perceive them to be the only available source of practical information about dealing with the side-effects of prostate cancer and related treatments.

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This is in line with past research which points towards insufficient availability of post-treatment care in prostate cancer (e.g. O'Brien et al., 2011; Rivers et al., 2011). This highlights the need to review the current provision of informational and support services aimed at improving coping and awareness of issues related to the treatment side-effects. This need is also recognised in the recent policy guidelines (NICE, 2008) which stresses patients' and family members' need for support and information throughout the illness trajectory.

Furthermore, the current research confirms previous findings (e.g. Mason, 2005, 2008) suggesting that family members and particularly partners of the patients have high informational supportive needs. Past research indicates that these needs are often unmet by health care professionals (Rivers et al., 2011). This highlights the need to increase availability of informational and psychological support for family members. Provision of information about prostate cancer online support groups, particularly single gender ones, could also be beneficial for many women affected by their partner's prostate cancer. The current study also points out that these groups serve a valuable supportive role for bereaved women.

In summary, the findings of this research indicate that prostate cancer online support groups can be perceived as relatively easily accessible and highly cost-efficient source of information and emotional support for prostate cancer patients and family members, who often struggle to access support offline. The beneficial processes occurring within the prostate cancer online support groups appear to vastly outweigh the potentially negative aspects, and can help foster empowerment in several areas important to prostate cancer patients and their family members. Raising awareness of these groups amongst patients and caregivers, as well as provision of practical advice and training on how to use them could

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lead to greater numbers of individuals benefiting in terms of knowledge, social well-being and improved communication with the health care professionals, with little additional cost to the health care providers.

### **8.4.2 Implications of current research for individuals creating and moderating prostate cancer online support groups**

The current research also points towards several practical implications for prostate cancer online support group owners and moderators. For example, participants in Study 2 suggested that the large amount of information available within the groups requires considerable time commitment to search through and can be confusing, especially for new and inexperienced members. This finding is consistent with past research, which suggests that a high volume of messages can be problematic in online support groups (Nonnecke & Preece, 2000; van Uden-Kraan et al., 2008c). Whilst the number of messages may be difficult to control without restricting membership numbers, some practices could potentially improve the accessibility of relevant information. For example, as discussed in Chapter 6, participants indicated that 'members' signatures' can be helpful when looking for information posted by those who share similar experiences or have the same diagnosis. Therefore introduction and reinforcement of rules relating to signature use could help streamline information retrieval. Long-term members also noted the repetitive nature of the information exchanged within the groups (van Uden-Kraan et al., 2008c; Study 2). Introduction and maintenance of Frequently Asked Questions sections or separate forums where newly diagnosed members could discuss basic issues relating to diagnosis and treatment with moderators and other members who are willing to help could potentially reduce the repetitive information exchange and overall volume of messages within the main sections of the group.

In order to reduce barriers to participation, moderators could also consider the layout of the websites and the ease of navigation, as well-designed online support groups may be simpler to use for less experienced patients and caregivers. Introductory pages, concise and clear user guides and technical support could also be helpful (van Uden-Kraan et al., 2008a).

### **8.5. Concluding remarks**

This thesis presents a novel and in-depth investigation into the online support group experiences of individuals affected by prostate cancer. The findings of the triangulated research provide a comprehensive insight into the range and extent of empowering processes that take place in prostate cancer online support groups and add to the current knowledge by describing the extent to which participation in these groups can foster empowerment in members.

The findings suggest that individuals who access prostate cancer online support groups tend to do so to seek others who have similar experiences with the disease, treatment and recovery and to gather information and experiential knowledge that could help inform their treatment decision. The informational and emotional support provided within the online support groups was often perceived as over and above support available from family, friends and health care professionals. The findings of the current research suggest that communication with similar others can provide a unique sense of empathy and understanding based on shared experiences, which is often unavailable offline. The experiential knowledge exchanged by patients and caregivers can also offer a unique and

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valuable insight into the lived experiences of people who underwent certain treatments. Furthermore, prostate cancer online support groups were perceived by participants to be a suitable venue for discussing problems pertaining to intimate issues such as erectile and urinary dysfunctions, which are common in prostate cancer patients. Information about intimate side effects was reported to be especially difficult to obtain from other sources, including health care professionals, and thus online support groups were particularly valued for the access they provided to other members who experienced similar issues.

The findings of current research also point towards the fact that participation in prostate cancer online support groups, and particularly the exchange of information and experiential knowledge, can lead to a wide range of empowering outcomes. The most commonly experienced outcome was improved knowledge about the disease, treatment and recovery, suggesting that these groups can be perceived as particularly valuable, easily accessible and cost effective tool for educating patients and their family members. Improved knowledge coupled with the support and encouragement from other patients and family members was in turn found to increase members' ability to actively participate in making important treatment-related decisions and improve their ability to effectively communicate with health care professionals. This is an important finding as these are the two areas highlighted in past research as challenging for prostate cancer patients and their family members.

Past research presents limited insight into the online support group experiences of caregivers and family members of prostate cancer patients. One of the key strengths of the current research is the considerable number of female family members who responded to the surveys, offering their views on participation in prostate cancer online support groups. An important and encouraging finding of this research is the fact that participation in

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prostate cancer online support groups appears to have similar benefits for the female family members, as it has for the patients. The findings relating to the role of these groups in improving knowledge, the ability to take part in health care encounters and treatment-related decisions, as well as in reducing the sense of social isolation, are particularly important as research suggests that the needs of cancer caregivers are frequently unmet.

Although some negative aspects of participation have been noted, for example interpersonal conflicts between members or being confronted by negative aspects of the disease; the positives appear to vastly outweigh the negatives. Nevertheless, it is important to point out that the main limitation of the current study lies within the sampling bias. That is to say that the majority of participants were highly satisfied current prostate cancer online support group users. Further research with members who dropped out or are infrequent users is necessary to fully understand the extent to which the processes occurring within the groups can negatively affect members.

Overall, the findings of the current research point towards the fact that prostate cancer online support groups can offer a valuable, easily accessible and cost efficient supplement to the informational and emotional support available to prostate cancer patients and their family members. They can help foster empowerment in both the patients and family members who choose to participate. Including information about trustworthy prostate cancer online support groups and easy to follow user guides to such groups in the informational packs provided at screening and diagnosis could help increase participation amongst the individuals affected by prostate cancer. Increased participation could in turn lead to greater sense of empowerment in patients and family members who embark on the prostate cancer journey.

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## **APPENDICES**

## Appendix A: Invitation to Study Two

My name is Kasia Campbell and I am a doctoral candidate at the University of Nottingham, UK. I would like to invite all prostate cancer patients, survivors, their families and friends, who have ever used ANY prostate cancer online support, chat or message boards to participate in this short survey. I would like to hear from those who post messages, and those, who only visit prostate cancer boards to read messages.

This survey is part of my PhD research project concerned with the ways participation in online chat groups and message boards influences the lives of men with prostate cancer, their families and friends. We would like to hear from you, to find out if and how your life has been affected by being part of an Internet Community.

The survey takes 15-30 minutes to complete, depending on how much you would like to write. It is anonymous – we will not ask you for any personal information, such as names, addresses, email addresses.

Your help is greatly appreciated – your responses will help us gain better insight into prostate cancer patients' and their families experiences with chat groups and message boards. We aim to publish the results in academic journals, to help health professionals better understand how Internet Communities can affect the lives of their members. Please feel free to forward this link to your family and friends.

To start the survey, please click on the link below. If you have trouble accessing this link, please cut and paste it or type it into your Internet browser.

[<<Link to Survey>>](#)

Survey will be open until 30 July 2010.

Thank you for your time

Kasia Campbell

## **Appendix B: Study Two Survey**

## Information Sheet

My name is Kasia Campbell and I am a doctoral candidate at the University of Nottingham, UK.

I would like to invite you to participate in this study, which is a part of my PhD project, exploring the role of online chat groups in the lives of prostate cancer patients and their families.

We would very much appreciate the help of all men who were at any point of their lives diagnosed with prostate cancer, their families and friends.

If you would like to take part in this study, please read the following information about the study.

### THE STUDY:

The purpose of this study is to examine how prostate cancer patients, their family and friends perceive the usefulness of the online chat groups and what are their experiences of using the chat groups. The results of this study will hopefully provide helpful information on the role of online chat groups in the lives of prostate cancer patients and their family and friends before, during and after treatment.

### PARTICIPANTS:

You are welcome to take part in the study if you meet both of the following criteria:

- You have suffered from prostate cancer at any point in your life OR are a spouse/partner, family member or a friend of a person who has or has had prostate cancer;
- You have at any point used or are currently using a prostate cancer online chat group or message board either to post messages or just to read messages.

### PROCEDURE:

You will be asked to complete an online survey regarding your experiences with online chat groups. The survey consists of some multiple choice questions and some open questions which you can complete at your own pace. The estimated time to complete the questionnaire is 15 – 30 minutes, depending on how much you would like to write.

### ANONYMITY AND CONFIDENTIALITY:

The data will be collected anonymously - we will not ask for any identifying details, such as email address or name, and will be password protected. It will be stored securely and only the research team will have access to your responses.

If you choose to participate, we will ask your permission to quote from your responses in publications, such as academic papers, doctoral thesis or books. However, you are still welcome to participate, even if you do not wish your responses to be used as quotes. Any information that could identify you or anybody else will be removed from all quotes.

### WITHDRAWAL FROM THE STUDY:

Although we much appreciate your participation in this study, it is entirely voluntary. Should you wish to withdraw from the study, you can do so at any time during completing the questionnaire, by clicking the "Exit this survey" on the top right, or by closing your Internet browser. You do not have to complete any questions that you feel uncomfortable with. There are however a few general questions that require an answer, as depending on your answer you will be directed to different sections (for example different questions for patients and for family members).

You will be asked to provide a unique password when completing the questionnaire. If you decide to withdraw from the study once your responses have been submitted, you can do so by emailing your password to [lwkc2@nottingham.ac.uk](mailto:lwkc2@nottingham.ac.uk). Your responses will then be removed from the study. Please note that we cannot guarantee the removal of responses after 6 months, as the results may have been published by then.

### ETHICAL APPROVAL:

Ethical approval for this study has been granted by the Ethics Committee of the Institute of Work, Health and Organisations at Nottingham University.

Should you have any questions about this study, please do not hesitate to contact

Kasia Campbell - [lwkc2@nottingham.ac.uk](mailto:lwkc2@nottingham.ac.uk)  
Principal Researcher

Neil Coulson - [lwznc@nottingham.ac.uk](mailto:lwznc@nottingham.ac.uk)  
Research Supervisor  
Telephone: +441158466642

Please read the following statements

1. I understand that participation in this study is voluntary and by clicking "Continue" button I agree to take part in the study.
2. I understand my right to withdraw from the study at any point without consequences.
3. I understand that any information I provide will be kept securely and confidentially and will only be accessed by the research team.

**1. I have read and understood the information sheet for participants and the consent form. By clicking "CONTINUE" I voluntarily agree to take part in this study.**

CONTINUE

**2. I give my consent for the research team to use quotes from my responses in publications, such as academic papers, books and thesis. I understand that any identifying information will be removed from all quotes used.**

YES, I agree for my responses to be quoted in publications.

NO, I do not agree for my responses to be quoted in publications.

**3. Please create a password. You will need this password should you wish to withdraw your responses from the study. Please make sure you remember your password, as this will be the only way to identify your responses. Please note we cannot guarantee your responses will be removed after 6 months, as the results may have been published by then.**



## About you.

First, we would like to know a bit more about you.

### 4. Gender

- Male  
 Female

### 5. Age

Your age in years:

### 6. What country do you live in

### 7. What is your marital status?

- Married/living with partner  
 In a relationship but living separately  
 Single  
 Divorced  
 Widowed  
 Other (please specify)

### 8. Education: What is your highest achieved education level?

- Primary education  
 Secondary education/High school  
 College or equivalent  
 University or equivalent  
 Other (please specify)

### 9. Current employment

- Working full time  
 Working part time  
 Unemployed  
 Retired  
 Student  
 Other (please specify)

**10. Are you visiting prostate cancer chat groups as...?**

- a prostate cancer patient/survivor
- a spouse or a partner of a prostate cancer patient/survivor
- a child of a prostate cancer patient/survivor
- a sibling of a prostate cancer patient/survivor
- a parent of a prostate cancer patient/survivor
- a friend or a colleague of a prostate cancer patient/survivor
- Other (please specify)

**Health status - Patients/survivors only.**

**11. How long ago were you diagnosed with prostate cancer?**

**If you do not remember the exact amount of time, please put number of years or months only.**

**If you have not been diagnosed, please put "0" in each field.**

Years

Months

Weeks

Days

**12. What was your most recent diagnosis? If you do not know please put "X" in the relevant field.**

Tumor stage - please state

PSA - please state

Gleason score - please state

**13. Has the cancer spread beyond the prostate gland?**

- Yes
- No
- I don't know

**14. Have you had your initial treatment for prostate cancer?**

- Yes
- No
- I have decided not to undergo treatment
- I have decided to take "watch and wait"/active surveillance approach

**15. How long ago did you have your initial treatment for prostate cancer?**

**(If you do not remember the exact time, please put number of years or months only.)**

Years ago

Months ago

Weeks ago

Days ago

**16. What was your main initial (primary) treatment for prostate cancer?**

**(e.g. traditional surgery, robot assisted surgery, radiation, seeds implants, HIFU etc.)**

## Health status - Family members/friends only

You have identified yourself as a family member or a friend of a person with prostate cancer, therefore the following questions will relate to THIS PERSON'S health status.

### 17. When was your close one first diagnosed with prostate cancer?

**If you do not remember the exact amount of time, please put number of years or months only.**

**If he has not been diagnosed, please put "0" in each field.**

Years	<input type="text"/>
Months	<input type="text"/>
Weeks	<input type="text"/>
Days	<input type="text"/>

### 18. What was his most recent diagnosis? If you do not know please put "X" in the relevant field.

Tumor stage - please state	<input type="text"/>
PSA - please state	<input type="text"/>
Gleason score - please state	<input type="text"/>

### 19. Has the cancer spread beyond the prostate gland?

- Yes  
 No  
 I don't know

### 20. Has he had his initial treatment for prostate cancer?

- Yes  
 No  
 He has decided not to undergo treatment  
 He has decided to take "watch and wait"/active surveillance approach

### 21. How long ago did he have his initial treatment for prostate cancer?

**(If you do not remember the exact time, please put number of years or months only.)**

Years ago	<input type="text"/>
Months ago	<input type="text"/>
Weeks ago	<input type="text"/>
Days ago	<input type="text"/>

### 22. What was his main initial (primary) treatment for prostate cancer?

**(e.g. traditional surgery, robot assisted surgery, radiation, seeds implants, HIFU etc.)**

## Online chat group use

The following questions relate to YOUR own usage of Internet chat groups, bulletin boards, message boards and similar sites, that relate to the issues of prostate cancer.

In the following questions, we will refer to all such groups as "prostate cancer online chat groups".

**23. How many prostate cancer online chat groups do you currently use, or have used in the past? This includes groups you visit or have visited just to read messages.**

Number of chat groups:

**24. Please name the prostate cancer online chat groups you use or have been using most often.**

1   
2   
3   
4   
5   
6   
7

**25. How long for have you been accessing prostate cancer online chat groups?  
(If you do not remember the exact time, please put the number of years or months only.)**

Years   
Months   
Weeks   
Days

**26. When you first started using prostate cancer online chat groups, were you (or your close one):**

**before the diagnosis of prostate cancer**  
**after the diagnosis of prostate cancer, but before treatment**  
**during the treatment**  
**after the treatment finished**

- before the diagnosis of prostate cancer  
 after the diagnosis of prostate cancer, but before treatment  
 during the treatment  
 after the treatment finished  
 Other (please specify)

**27. How often do you visit prostate cancer online chat groups to read and/or post messages?**

- several times a day
- about once a day
- several times a week, but not everyday
- about once a week
- several times a month but not every week
- about once a month
- less than once a month
- I don't use them any more
- Other (please specify)

**28. How much time, on average, do you spend or used to spend using prostate cancer online chat groups PER VISIT?**

**Hours**

**Minutes**

Hours

Minutes

**29. Have you ever posted a message to a prostate cancer online chat group?**

- Yes
- No

**30. How often do you tend to post messages to prostate cancer online groups?**

- I have only ever posted once or twice
- I post less than once a month
- I post once or twice a month
- I post several messages a month
- I post once or twice a week
- I post several messages a week
- I post once a day
- I post several messages most days
- Other (please specify)

**31. When posting to prostate cancer online chat groups, do you tend to ask questions or reply to messages posted by others?**

- I have asked questions, but I have never replied
- I have replied to other messages, but I have never asked a question
- I have asked questions and replied to other messages

**32. When posting messages to prostate cancer online chat groups, what subjects do you most frequently write about?**

**33. Has the frequency of your posts changed over time?**

- No
- Yes, I now post significantly less messages than I used to
- Yes, I now post significantly more messages than I used to
- Yes, the frequency tends to change periodically (e.g. depending on mood, health, pending appointments etc.)

**34. Please tell us more about why and how the frequency of your posts changes.**

## Your experiences of using prostate cancer online chat groups

**35. Why did you start to use prostate cancer online chat groups?**

**36. Do you feel your reasons for accessing prostate cancer online chat groups changed over time?**

- Yes
- No

**37. How did your reasons for accessing prostate cancer online chat groups change overtime?**

**38. Did the prostate cancer online chat groups help you in any way to face the challenges of dealing with prostate cancer?**

- Yes, they helped me a lot
- Yes, they helped me to some extent
- Yes, they helped me, but only a little
- No, they did not help me at all (\*skip the next section)



## Your experiences of using prostate cancer online chat groups

**39. What aspects of your life or the life of your family were affected by your participation in the prostate cancer online chat groups?**

**40. What aspects of prostate cancer online chat groups did you find most helpful?**

**41. In what way did using prostate cancer online chat groups help you deal with the challenges of prostate cancer?**

**42. Was there anything that you found unhelpful or less helpful within the prostate cancer online chat groups? If yes, please tell us more about it.**

**43. Is there anything else about your experiences of using the online chat groups you would like to tell us?**

**44. Please click "Continue" to finish and submit the survey.**

Continue

**Your experiences of using prostate cancer online chat groups (\*)**

**45. Why was using prostate cancer chat groups not helpful for you?**

**46. What aspects of prostate cancer online chat groups did you find the least helpful and why?**

**47. Was there anything at all that you found beneficial or helpful when using prostate cancer online chat groups? If yes, please tell us more about it.**

**48. Is there anything else about your experiences when using the online chat groups you would like to tell us?**

**49. Please click "Continue" to finish and submit the survey.**

Continue

## Thank you!

Thank you for taking the time to complete this questionnaire. Your help is much appreciated.

Should you have any questions about this study, please do not hesitate to contact

Kasia Campbell - [lwkc2@nottingham.ac.uk](mailto:lwkc2@nottingham.ac.uk).

Principal Researcher

Neil Coulson - [lwznc@nottingham.ac.uk](mailto:lwznc@nottingham.ac.uk)

Research Supervisor

Telephone: +441158466642

If you feel you need to discuss any issues relating to living with and managing prostate cancer, please refer to your online chat group or your doctor. You can also contact the following organisations:

The Prostate Cancer Charity

<http://www.prostate-cancer.org.uk/support/support.asp>

Free Phone in the UK: 0800 074 8383

We Are MacMillan Cancer Support

<http://www.macmillan.org.uk/Home.aspx>

Free Phone in the UK: 08008080000

Cancer Care

<http://www.cancercare.org/>

Telephone US: 1-800-813-HOPE

## **Appendix C: Invitation to Study Three**

My name is Kasia Campbell and I am a doctoral candidate at the University of Nottingham, UK. I am currently conducting research into the role of online support groups in the lives of prostate cancer patients and their families. Last year, thanks to the kind help and support of prostate cancer online support groups' members, I collected responses from over 200 prostate cancer patients, survivors and their families. This data has greatly contributed to our understanding of how participation in online groups affects members. However, the findings of this work have raised many other important questions and I seek your further support with this research.

Today I would like to invite you to participate in this study, which is the final part of my PhD project, exploring the role of online chat groups in the lives of prostate cancer patients and their families. The survey consists mostly of multiple choice questions exploring members' experiences with using prostate cancer online support groups. It takes approximately 15 – 20 minutes to complete. To find out more about this project and to take part in the survey, please follow this link below. If you have trouble accessing this link, please cut and paste it or type it into your Internet browser:

<<Link to Survey>>

The survey will be open until 1 August 2011. If you think any member of your family or friend who is affected by prostate cancer would like to help with this study – please do not hesitate to invite them.

Thank you very much for your help.

## **Appendix D: Study Three Survey**

## 1. Information Sheet

My name is Kasia Campbell and I am a doctoral candidate at the University of Nottingham, UK.

I would like to invite you to participate in this study, which is the final part of my PhD project, exploring the role of online chat groups in the lives of prostate cancer patients and their families.

Last year, thanks to the kind help and support of prostate cancer online chat group members, I collected responses from over 200 prostate cancer patients, survivors and their families. This data has greatly contributed to our understanding of how participation in online groups affects members. However, the findings of this work have raised many other important questions and I seek your further support with this research.

If you would like to take part in this study, please read the following information about the study.

### THE RESEARCH PROJECT:

The purpose of this research is to examine how prostate cancer patients, their family and friends perceive the usefulness of online chat groups and what their experiences of using chat groups are. The results of this project will hopefully provide helpful information on the role of online chat groups, particularly at different stages of their prostate cancer journey.

### PARTICIPANTS:

You are welcome to take part in the study if you meet BOTH of the following criteria:

- 1) You have suffered from prostate cancer at any point in your life OR are a spouse/partner, family member or a friend of a person who has or has had prostate cancer;
- 2) You have at any point used or are currently using a prostate cancer online chat group or message board either to post messages or just to read messages.

### PROCEDURE:

You will be asked to complete an online questionnaire regarding your experiences with online chat groups, which mainly consists of multiple choice questions. The estimated time to complete the questionnaire is 15 - 20 minutes.

### ANONYMITY AND CONFIDENTIALITY:

The data will be collected anonymously - we will not ask for any identifying details, such as email address or name, and it will be password protected. It will be stored securely and only the research team will have access to your responses.

### WITHDRAWAL FROM THE STUDY:

Although we much appreciate your participation in this study, it is entirely voluntary. Should you wish to withdraw from the study, you can do so at any time whilst completing the questionnaire, by clicking the "Exit this survey" link on the top right of the webpage, or by closing your Internet browser.

You do not have to complete any questions that you feel uncomfortable with. However, in order to make the questionnaire clearer, some of the questions are worded differently for patients/survivors to those for their family/friends. You will, therefore, be required to identify yourself as either patient/survivor or family/friend, in order to be directed to the relevant section of the questionnaire.

You will be asked to provide a unique password when completing the questionnaire. If you decide to withdraw from the study once your responses have been submitted, you can do so by emailing your password to [lwxc2@nottingham.ac.uk](mailto:lwxc2@nottingham.ac.uk).

Your responses will then be removed from the study. Please note that we cannot guarantee the removal of responses after 3 months, as the results may have been used in our analysis and dissemination.

### ETHICAL APPROVAL:

Ethical approval for this study has been granted by the Ethics Committee of the Institute of Work, Health and Organisations at University of Nottingham, UK.

Should you have any questions about this study, please do not hesitate to contact

Kasia Campbell - [lwxc2@nottingham.ac.uk](mailto:lwxc2@nottingham.ac.uk)  
Principal Researcher

Dr Neil Coulson - [lwznc@nottingham.ac.uk](mailto:lwznc@nottingham.ac.uk)  
Research Supervisor  
Telephone: +441158466642

## 2. Consent Form

Please read the following statements:

1. I understand that participation in this study is voluntary and by ticking "I consent" button I agree to take part in the study.
2. I understand my right to withdraw from the study at any point without consequences.
3. I understand that any information I provide will be kept securely and confidentially and will only be accessed by the research team.

**\* I have read and understood the information sheet for participants and the consent form. By ticking the "I consent" button, I voluntarily agree to take part in this study.**

I consent

**Please create a password. You will only need this password should you wish to withdraw your responses from the study. Please make sure you remember your password, as this will be the only way to identify your responses. Please note we cannot guarantee your responses will be removed after 3 months, as the results may have been used in our analysis and dissemination.**

## 4. About you.

First, we would like to ask a few general questions about you.

### Gender

- Male
- Female
- I would rather not say

### Age

Your age in years

### What country do you live in?

### What is your marital status?

- married/civil partnership/living with partner
- in a relationship but living separately
- single
- divorced
- widowed
- Other (please specify)

### Education - what is your highest achieved education level?

- primary education
- secondary education
- college or equivalent
- university or equivalent
- postgraduate
- Other (please specify)



**What is your current employment status?**

- working full time
- working part time
- homemaker
- unemployed
- retired
- student
- Other (please specify)

**\* Are you visiting prostate cancer online support group MAINLY as a:**

- Prostate cancer patient/survivor
- Spouse or partner of cancer patient/survivor
- Child of cancer patient/survivor
- Sibling of cancer patient/survivor
- Parent of cancer patient/survivor
- Friend of cancer patient/survivor
- Other (please specify)

**Would you describe yourself, currently or in the past, as caregiver to the prostate cancer patient/survivor?**

**(\*Family members/friends only)**

- Yes
- No
- Sometimes
- I am not sure

## Health status - Family members/friends only

PLEASE NOTE: You have identified yourself as a family member/friend of a person with prostate cancer, therefore the following questions relate to THIS PERSON'S health status.

**How long ago was your close one diagnosed with prostate cancer? If you do not remember the exact amount of time, please put the number of years or months only.**

Years	<input type="text"/>
Months	<input type="text"/>
Weeks	<input type="text"/>
Days	<input type="text"/>

**What was his most recent diagnosis? If you don't know, please enter 'X'.**

Tumor Stage - please state	<input type="text"/>
PSA - please state	<input type="text"/>
Gleason score - please state	<input type="text"/>

**Has the cancer spread beyond the prostate gland?**

- Yes  
 No  
 I don't know

**Has he had, or is he currently undergoing, his initial treatment for prostate cancer?**

- Yes  
 No  
 He decided not to undergo treatment  
 He decided to take the "wait and watch" approach  
 I don't know

**What initial treatment did he have? (e.g.: surgery, radiation, daVinci surgery etc)**

**Health status - Patients/survivors only.**

**How long ago were you diagnosed with prostate cancer? If you do not remember the exact amount of time, please put the number of years or months only.**

Years

Months

Weeks

Days

**What was your most recent diagnosis? If you don't know, please enter 'X'.**

Tumor Stage - please state

PSA - please state

Gleason score - please state

**Has the cancer spread beyond the prostate gland?**

- Yes
- No
- I don't know

**Have you had or are you currently undergoing your initial treatment for prostate cancer?**

- Yes
- No
- I decided not to undergo treatment
- I decided to take the "wait and watch" approach
- Not sure

**What was your initial treatment for prostate cancer (e.g.: surgery, radiation, daVinci surgery etc)?**

## Online Chat Group Use

The following questions relate to YOUR use of the prostate cancer online chat groups.

**How many prostate cancer online chat groups do you use or have used in the past?  
(This includes groups you visit just to read messages.)**

Number of groups

**What types of prostate cancer online chat groups do you usually use?**

- single gender groups (for ladies or for men only)
- mixed gender groups
- mixture of both

**How long for have you been accessing prostate cancer online groups?  
(If you do not remember the exact time, please state the number of years or months  
only)**

Years

Months

Weeks

Days

**When did you first start using prostate cancer online chat groups?**

- Before diagnosis of prostate cancer
- After diagnosis, but before the initial treatment
- During the initial treatment
- After the initial treatment
- When the need for additional treatment arose
- Other (please specify)

**In the recent 3 months, how often have you been accessing the prostate cancer online chat groups?**

- several times a day
- about once a day
- several times a week, but not every day
- about once a week
- several times a month but not every week
- about once a month
- less than once a month
- I don't use them anymore
- Other (please specify)

**How much time, per average visit, do you spend when accessing prostate cancer online chat groups?**

Hours

Minutes

**Have you ever posted a message to a prostate cancer online chat group?**

- No
- I used to post messages in the past, but not any more
- Yes, but I have only ever posted once or twice
- Yes, I tend to post once or twice a month
- Yes, I tend to post once or twice a week
- Yes, I tend to post several messages a week
- Yes, I tend to post about once a day
- Yes, I tend to post several messages a day

**When accessing the prostate cancer online chat group you use most frequently, how satisfied are you with:**

	very satisfied	satisfied	Sometimes satisfied sometimes dissatisfied	dissatisfied	very dissatisfied
the information provided	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the support provided	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
the group overall	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**On a scale from 1 to 5 ("1=not at all true"; "5=very true"), how true are the following statements for you:**

	1 - not at all true	2	3	4	5 - very true
My prostate cancer online chat group is a safe place to discuss intimate issues.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel more comfortable discussing intimate issues with the group members than in face-to-face situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find the ability to discuss intimate issues within the group beneficial.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Has your close one ever used any prostate cancer online chat groups?**

- Yes
- No
- I don't know

## Availability of social support in your everyday face-to-face life.

The next set of questions relates to the social support available to you OUTSIDE the online chat groups, in your everyday face-to-face life.

**EXCLUDING people you know through the prostate cancer online chat groups, how often is each of the following kinds of support available to you if you need it?**

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone you can count on to listen to you when you need to talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to give you information to help you understand a situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to give you good advice about a crisis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to confide in or talk to about yourself or your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone whose advice you really want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to share your most private worries and fears with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to turn to for suggestions about how to deal with a personal problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone who understands your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone who shows you love and affection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to love and make you feel wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone who hugs you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to have a good time with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to get together with for relaxation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to do something enjoyable with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone to do things with to help you get your mind off things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Processes occurring within prostate cancer online chat groups

Some online chat group members reported experiencing the following aspects of participation in the groups. Please indicate how often do you experience each of these aspects when using your prostate cancer online chat group. If you use more than one group, please answer with regards to the one you use most often.

### The information and advice exchanged in my prostate cancer online chat group is...

	never	seldom	sometimes	regularly	often
understandable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
valuable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
usable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
new	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
relevant to my situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
reliable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
correct	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
of added value to the information provided by the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
in line with the information provided by the doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### How often does it happen that someone in your prostate cancer online chat group...

	never	seldom	sometimes	regularly	often
invites you to have personal contact outside the group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
starts a private conversation with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is empathic?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
consoles you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
pays you a compliment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is interested in you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
pays particular attention to you in special cases, such as illness or moving house?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
reassures you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
offers you sound advice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
points out your strengths?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
confides in you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
gives you encouragement?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
is there for you when you need them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### How often does it happen, that thanks to someone in the group, or through reading messages, you...

	never	seldom	sometimes	regularly	often
experience a sense of "all being in this together"?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel comforted by the knowledge that other people deal with the same problems as you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
find a unique support from people who understand exactly what you are going through?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
realise that your emotions and/or what you are going through are not unusual?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
realise that you are not so bad off after all?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



**Within your prostate cancer online chat group, how often does it happen, that...**

	never	seldom	sometimes	regularly	often
someone in the group is an example or inspiration to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
you recognize yourself in the stories of other group members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
you feel you share a special bond with someone in the group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Within your prostate cancer online chat group, how often do you feel that...**

	never	seldom	sometimes	regularly	often
your experiences can inspire other members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
your experiences can give hope to other members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
you can offer advice and support to someone in the group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**How often, within your prostate cancer online chat group, conversations on topics unrelated to prostate cancer (pets, children, hobbies, jokes etc)...**

	never	seldom	sometimes	regularly	often
help you feel more relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
help take your mind of the disease for a bit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
help you get to know other members better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
annoy you or distract you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Within your prostate cancer online chat group, how often do you feel...**

	never	seldom	sometimes	regularly	often
able to openly discuss sexual or other intimate issues with other members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
able to openly share your feelings with other members?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
able "get things of your chest" within the group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Outcomes

Some online chat group members reported experiencing various outcomes of participation within these groups. The next questions aim to explore what outcomes you have experienced when accessing your prostate cancer online chat group. Please indicate how true are the following statements for you:

### Participation in the prostate cancer online chat groups helped me...

	Completely disagree	Disagree	Neither disagree nor agree	Agree	Completely agree
feel better informed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
understand prostate cancer better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more aware of the available treatment options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more aware of my own preferences regarding treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
more actively participate in the decision making process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more satisfied with the chosen treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more confident in my ability to deal with the disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have greater sense of self-worth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more positive about myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have more positive attitude towards life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have more positive attitude towards the illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
value life more	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
understand the meaning of life better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
find new and worthwhile goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel less worried or anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Participation in prostate cancer online chat groups helped me...**

	completely disagree	disagree	neither disagree nor agree	agree	completely agree
feel more in control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel better prepared for the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have more hope for the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
accept this illness better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more open about the illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel less lonely	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
meet new people I enjoy communicating with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
find new, valued friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel like a part of a community I can depend on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be better able to care for the person in my life with prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more positive around my partner and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
provide my close ones with useful information about prostate cancer/treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
share useful information with other members of the group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel more confident about the quality of the information I share	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
take a more active role in helping people affected by cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Participation in prostate cancer online chat groups helped me...**

	completely disagree	disagree	neither disagree nor agree	agree	completely agree
feel better prepared for a doctor's appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more knowledgeable about which questions to ask the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
better able to explain my needs to the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
have more courage to raise matters with the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
be more able to oppose the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
better understand the information provided by the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
improve my relationship with the physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
feel less dependent on the physician.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**\* Please click "Continue" to finish and submit the survey.**

Continue

## Thank you!

Thank you for taking the time to complete this questionnaire. Your help is much appreciated.

Should you have any questions about this study, please do not hesitate to contact

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If you feel you need to discuss any issues relating to living with and managing prostate cancer, please refer to your online chat group or your doctor. You can also contact the following organisations:

The Prostate Cancer Charity  
<http://www.prostate-cancer.org.uk/support/support.asp>  
Free Phone in the UK: 0800 074 8383

We Are MacMillan Cancer Support  
<http://www.macmillan.org.uk/Home.aspx>  
Free Phone in the UK: 08008080000

Cancer Care  
<http://www.cancercare.org/>  
Telephone US: 1-800-813-HOPE

Malecare  
<http://malecare.org/>

## Appendix E: Level of agreement with items of the empowering processes scale

Empowering processes scale item	% Scoring Never or seldom	% Scoring Sometimes	% Scoring Regularly or often
<b>Encountering similar others</b>			
<i>Thanks to someone in the group or through reading messages you...</i>			
...feel comforted by the knowledge that other people deal with the same problems as you?	5.1	9.6	85.2
...find a unique support from people who understand exactly what you are going through?	4.6	15.2	80.2
...realise that your emotions and/or what you are going through are not unusual?	5.1	11.7	83.2
...experience a sense of “all being in this together”?	6.1	16.2	77.7
...realise that you are not so bad off after all?	8.1	23.9	68.0
...you recognize yourself in the stories of other group members?	9.6	31.5	58.9
<b>Receiving useful information</b>			
<i>The information and advice exchanged in the group is...</i>			
...understandable	0.5	5.6	93.9
...valuable	1.0	16.8	82.1
...usable	1.0	24.6	74.4
...of added value to the information provided by the doctor	4.6	27.4	68.1
...reliable	1.0	29.4	69.5
...correct	1.0	29.4	69.5
...in line with the information provided by the doctor	4.1	36.2	59.6
...relevant to my situation	8.6	38.1	53.3
...new	7.1	46.7	46.2
<b>Finding safe place to talk</b>			
<i>You feel that...</i>			
...you are able to openly discuss sexual or other intimate issues with other members?	15.9	22.1	62.0

Empowering processes scale item	% Scoring Never or seldom	% Scoring Sometimes	% Scoring Regularly or often
...you are able to openly share your feelings with other members?	14.9	27.7	57.4
...you are able to “get things of your chest” within the group?	17.0	30.4	52.6
<b>Helping others</b>			
<i>You feel that...</i>			
...you can offer advice and support to someone in the group?	9.8	45.4	44.8
...your experiences can give hope to other members?	10.3	52.1	37.6
...your experiences can inspire other members?	11.9	54.6	33.5
<b>Receiving social support</b>			
<i>Someone in the group...</i>			
...is empathic?	16.1	21.9	62.0
...offers you sound advice?	18.2	30.7	51.1
...gives you encouragement?	20.0	28.9	51.1
...is there for you when you need them?	19.7	27.5	52.9
...reassures you?	29.5	27.5	43.0
...is interested in you?	27.9	30.5	41.6
...consoles you?	35.5	23.9	40.6
...pays you a compliment?	31.9	35.6	33.5
...confides in you?	49.0	23.4	27.6
...points out your strengths?	45.5	28.3	26.2
...pays particular attention to you in special cases?	47.3	23.9	28.7

## Appendix F: Level of agreement with items of the empowering outcomes scale

Empowering outcomes scale item	% Scoring Completely disagree or disagree	% Scoring Neither agree nor disagree	% Scoring Completely agree or agree
<hr/>			
<b><i>Increased knowledge and ability to participate in treatment decisions</i></b>			
<i>Participation in the group helped me...</i>			
...understand prostate cancer better	0.5	6.1	93.4
...be more aware of the available treatment options	1.0	4.6	94.4
...feel better informed	0.5	5.1	94.4
...be more aware of my own preferences regarding treatment	3.0	13.7	83.2
...more actively participate in the decision making process	3.0	17.3	79.7
<b><i>Improved relationship with the physician</i></b>			
<i>Participation in the group helped me...</i>			
...have more courage to raise matters with the physician	6.1	23.9	70.1
...be more able to oppose the physician	8.6	32.0	59.4
...feel better prepared for a doctor's appointment	2.5	10.7	86.8
...better able to explain my needs to the physician	3.5	12.7	83.8
...be more knowledgeable about which questions to ask the physician	2.5	6.6	90.9
...better understand the information provided by the	4.0	8.1	87.8

Empowering outcomes scale item	% Scoring Completely disagree or disagree	% Scoring Neither agree nor disagree	% Scoring Completely agree or agree
<hr/>			
physician			
...improve my relationship with the physician	10.1	35.0	54.8
...feel less dependent on the physician.	9.6	32.0	58.4
<b>Increased community spirit</b>			
<i>Participation in the group helped me...</i>			
...share useful information with other members of the group	2.0	13.8	84.2
...feel more confident about the quality of the information I share	2.5	15.3	82.1
...take a more active role in helping people affected by cancer	2.6	21.0	76.4
...find new, valued friends	14.3	44.4	41.3
...meet new people I enjoy communicating with	8.8	35.4	55.9
...feel like a part of a community I can depend on	3.1	20.4	76.5
...provide my close ones with useful information about prostate cancer/treatment	4.1	20.9	75.0
<b>Positive reappraisal of situation</b>			
<i>Participation in the group helped me...</i>			
...have more hope for the future	9.2	26.5	64.3
...feel less worried or anxious	14.3	30.1	55.6
...accept this illness better	9.8	20.5	69.7
...feel more relaxed	13.8	33.2	53.1
...have more positive attitude towards the illness	12.7	27.4	59.9



Empowering outcomes scale item	% Scoring Completely disagree or disagree	% Scoring Neither agree nor disagree	% Scoring Completely agree or agree
...feel better prepared for the future	5.6	17.3	77.0
...feel more in control	5.6	21.4	73.0
<b>Positive personal reappraisal</b>			
<i>Participation in the group helped me...</i>			
...have greater sense of self-worth	12.3	40.8	46.9
...feel more positive about myself	9.2	40.3	50.5
...find new and worthwhile goals	18.3	48.0	33.7
...value life more	13.8	28.6	57.7
...understand the meaning of life better	20.5	35.9	43.6