Understanding Lifestyle-Related Psychosocial Processes
After Prostate Cancer Diagnosis

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Thesis submitted for the award of Doctor of Philosophy (PhD)

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Statement of Originality

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Angelos Kassianos 24 of January 2014
Abstract

Prostate cancer diagnosis can result in patients losing control who then make efforts to cope by seeking information, social and medical support and changing their health behaviour. The objective of the Thesis is to investigate the psychosocial processes that influence prostate cancer patients’ coping process with an emphasis on dietary change. A mixed methods approach was used comprising of five studies. The first (Chapter 4) recruited 98 patients and significant others who completed an online survey. It found significant others to develop a need for treatment and interaction-specific information earlier than patients who were more in need for treatment and disease-specific information. Education predicted the time of information needs’ development. The second study (Chapter 5) recruited 126 GPs to an online survey and compared their responses to patients’ and significant others’. It found that GPs’ underestimate the time patients develop an interest in information whereas gender and years of practice can explain GPs’ perceptions of patients’ information needs. The third study (Chapter 6) systematically reviewed the literature to identify an association between dietary changes and quality of life identifying ten randomized-control trials and proposing that an association exists which needs further establishment on the pathways of the relationship. The fourth study (Chapter 7) recruited 95 patients on an online and paper survey and found that socio-demographic factors, cognitive functioning, external locus of control and cancer symptoms (dyspnea) can explain whether patients will change their diet after diagnosis but only cognitive functioning can explain changes after therapy has started. Finally, the fifth study (Chapter 8) used semi-structured interviews with eight patients and found that they develop an underlying mechanism that includes the determinants and the resulted evaluations of dietary change. Findings from the Thesis suggest that a holistic and patient-centred approach when targeting prostate cancer patients’ needs should be considered.
Acknowledgements

After years of effort, persistence and several obstacles, which I had to overcome, I am now in the great position of acknowledging the decisive contribution of many great people in my life. It is undeniable, that every each one of them has had a significant role on the completion of my PhD (whether they know it or not)!

A first thank you goes to my supervisor Prof. Monique Raats who had massive patience with me and guided me through a great experience – my PhD “journey”. A big thank you also goes to the researchers and scientists who contributed to my studies: Prof. Heather Gage, Prof Chris Fife-Schaw, Dr Adrian Coyle, Dr. Matthew Peacock, Prof. Margaret Rayman, Dr. John Nichols and John Vickers.

I would also like to thank the following: Maggie’s Centre London, the Prostate Cancer Charity, the Prostate Cancer Support Federation, the website Men’s Health, the Friends of Prostate Sufferers (FOPS) in Chorleywood and the Royal College of GPs (South West Thames Faculty) for helping me with recruiting participants for my studies.

A huge gratitude goes to the patients, significant others and GPs who completed questionnaires and/or were interviewed for my studies. Your experiences and responsiveness to research projects can make a difference.

Finally, I would like to express my love and appreciation to all the people close to me, that stood by me the last five years and really determined whether I would finish my PhD or not - my colleagues in Guildford, my friends, and finally (but not least) my truly unique family! All of you (mother, father, brother, uncles, grandparents, nieces etc.) defined my life and helped me emotionally and financially to complete my PhD. Therefore…it is partly yours!

This work is dedicated to my father, who lost the “battle” (I still hope I make you proud), and to my uncle, who will not lose his “battle”.
# Table of Contents

Statement of Originality…………………………………………………………………………………………..i
Abstract…………………………………………………………………………………………………………………ii
Acknowledgements………………………………………………………………………………………………..iii
Table of Contents……………………………………………………………………………………………………..iv

List of Tables........................................................................................................... x
List of Figures........................................................................................................ xv

Chapter 1: Introduction............................................................................................ 1
  1.1 The context of the Thesis ............................................................................... 1
  1.2 Research aims ................................................................................................ 3
  1.3 Epistemological stance of quantitative and qualitative methods ...................... 4
  1.4 Data collection in quantitative and qualitative research................................... 5
  1.5 Research Design used in the Thesis ............................................................... 6
  1.6 The structure of the Thesis ............................................................................. 7

Chapter 2: Theoretical Perspectives of Health Behaviour ....................................... 10
  2.1 Perspectives in Health Psychology ............................................................... 10
  2.2 Theories of Health Behaviour....................................................................... 11
  2.3 The Social Cognition Theoretical Models..................................................... 11
    2.3.1 Continuum Theories: the examples of The Theory of Reason Action and
         Theory of Planned Behaviour......................................................................... 12
      2.3.1.1 The role of perceived behavioural control ....................................... 13
      2.3.1.2 The role of self-efficacy.................................................................. 14
  2.4 Health-Belief Model..................................................................................... 15
  2.5 The Stage Theories....................................................................................... 16
  2.6 The Attribution Theory ................................................................................ 18
  2.7 The Self-Regulation Concept ....................................................................... 19
    2.7.1 Leventhal’s Self-Regulatory Model ....................................................... 20
  2.8 Models of Health Behaviour: Challenges and problems................................ 21
  2.9 Other Theoretical Perspectives of Health Behaviours ................................... 23

Chapter 3: Review of literature relevant to cancer patients’ lifestyle changes, with a
particular focus on prostate cancer and dietary changes.......................................... 25
  3.1 Prostate cancer ............................................................................................. 25
    3.1.1 Prostate cancer facts and figures.............................................................. 25
    3.1.2 Lifestyle as a cause of Prostate Cancer and Second Malignancies ....... 27
5.4.1 Limitations ...........................................................................................119
5.4.2 Clinical Implications ............................................................................119
5.4.3 Future Recommendations .....................................................................120
5.5 Conclusion ..................................................................................................120

Chapter 6: Study 3: Quality of Life and Dietary Changes among Cancer Patients: a Systematic Review
6.1. Introduction................................................................................................122
6.2 Methods ......................................................................................................123
6.2.1 Search Criteria......................................................................................123
6.2.2 Search Results ......................................................................................125
6.2.3 Data synthesis ......................................................................................126
6.2.4 Quality Assessment ..............................................................................126
6.3. Results .......................................................................................................127
6.3.1 Study descriptions ................................................................................127
6.3.2 Themes identified.................................................................................138
6.3.2.1 Association between HRQOL and dietary change..........................138
6.3.2.2 Cancer Type ..................................................................................139
6.3.2.3 Stage of treatment..........................................................................140
6.3.3 Quality appraisal ..................................................................................141
6.3.4 Limitations of included studies .............................................................144
6.4 Discussion...................................................................................................145
6.4.1 Limitations ...........................................................................................148
6.4.2 Future Recommendations .....................................................................149
6.5 Conclusions.................................................................................................149

Chapter 7: Study 4: Differences in psychosocial outcomes between those who change their diet and those who do not after prostate cancer diagnosis
7.1 Introduction.................................................................................................151
7.2 Methods ......................................................................................................154
7.2.1 Research Design...................................................................................154
7.2.2 Recruitment..........................................................................................154
7.2.3 Measures ..............................................................................................154
   “Demographic and Medical Information” ..................................................155
   “Dietary Changes” ....................................................................................156
   “Diet Quality” ...........................................................................................156
   “General Self-Efficacy” .............................................................................157
   “Perceived behavioural control” .................................................................157
“Health-Related Quality of Life (HRQOL)” ................................................................. 158

7.2.4 Analytic Plan .................................................................................................. 159

7.3 Results .............................................................................................................. 160

7.3.1 Data Screening ........................................................................................... 160

7.3.2 Participants ................................................................................................. 161

7.3.3 Predicting prostate cancer patients’ dietary change post-diagnosis .......... 163

7.3.3.1 Checking for Logistic Regression assumptions .................................... 163

7.3.3.2 Checking for residuals ......................................................................... 166

7.3.3.3 Main analysis ...................................................................................... 166

7.3.4 Socio-demographic factors and the level of dietary behaviour change after
diagnosis and therapy. ...................................................................................... 169

7.3.4.1 Checking for chi-square assumptions .............................................. 169

7.3.4.2 Main Analysis .................................................................................. 170

7.3.5 Comparing changers and non-changers ..................................................... 171

7.4 Discussion ....................................................................................................... 174

7.4.1 Limitations ............................................................................................... 179

7.4.2 Clinical Implications .............................................................................. 179

7.4.3 Future Recommendations ...................................................................... 180

Chapter 8: Study 5: An underlying mechanism of change: How prostate cancer
patients make sense of dietary changes .............................................................. 183

8.1 Introduction ................................................................................................... 183

8.2 Methods ......................................................................................................... 187

8.2.1 Research Design ..................................................................................... 187

8.2.1.1 Rationale for the Method ............................................................... 187

8.2.1.2 Thematic over other qualitative methods ....................................... 188

8.2.1.3 Analytic process .......................................................................... 189

8.2.1.4 Quality checks (“Confirmability”) .................................................. 190

8.2.1.5 Reflections before interviewing ..................................................... 191

8.2.2 Recruitment ........................................................................................... 192

8.2.2.1 Participant Characteristics ............................................................. 192

8.2.2.2 Interview Schedule ................................................................... 193

8.2.2.3 Interview process ....................................................................... 193

8.2.3 Ethics ....................................................................................................... 194

8.3 Results .......................................................................................................... 194

8.3.1 Participants ............................................................................................. 194

8.3.2 The analysis ............................................................................................ 197
List of Tables

Chapter 1

Table 1.1 Description of Research Methods Employed in Studies Included in the Thesis………………………………………………………………………………………………………6

Chapter 4

Table 4.1 Measures Included in the Study (Chapter 4)………………………………………………………………………………………………………………………………………………58

Table 4.2 Characteristics of respondents…………………………………………………………………………………………………………………………………………………………65

Table 4.3 Comparing Means Between Different Sources of Recruitment………………………………………………………………………………………………………………………………………………67

Table 4.4 Spearman’s Correlation coefficients Between Study Variables for Patients……………………………………………………………………………………………………………………………………………………………………68

Table 4.5 Differences Between Level of Education and Information Needs……………………………………………………………………………………………………………………………………………………………………71

Table 4.6 Mann Whitney Post-Hoc Tests Between Different Levels of Education and Information Needs……………………………………………………………………………………………………………………………………………………………………72

Table 4.7 Differences Between Level of Education and Information Need’ Development……………………………………………………………………………………………………………………………………………………………………73
Table 4.8 Mann Whitney Post-Hoc Tests Between Different Levels of Education and Time of Information Needs’ Development..............................74

Table 4.9 Frequencies of Participants’ Responses on Time of Information Needs’ Development..........................................................................................76

Table 4.10 Mann Whitney Test for Differences Between Patients and Significant Others on Type of Information Needs.............................................78

Table 4.11 Mann Whitney Test for Differences Between Patients and Significant Others on Time of Information Needs’ Development...........................................................................79

Table 4.12 Reliability Analyses for Tested Scales.................................................................................................................................80

Table 4.13 Mann Whitney Test for Differences Between Patients and Significant Others on Time of Information Needs’ Development...........................................................................80

Table 4.14 Wilcoxon Signed-Rank Post-Hoc Test Between Information Needs for Patients.................................................................................................82

Table 4.15 Perceived Causes of Cancer as Predictors of Lifestyle Changes After Diagnosis.........................................................................................83

Table 4.16 Diet as a Perceived Cause of Cancer as a Predictor of Diet as an Information Need.................................................................................................84
Chapter 5

Table 5.1 Measures Included in the Study (Chapter 5)…………………………………………………………………………………100

Table 5.2 Characteristics of Respondents………………………………………………………………………..102

Table 5.3 Mann Whitney Test for Differences on Perception of Patients’ Information Needs Development Between Male and Female GPs…………………………………………………………………………………103

Table 5.4 Kruskall Wallis Tests for the Effect of Gender and Years of Practice on GPs’ Perceptions of Patients’ Information Needs Development………………………………………………………………..……...105

Table 5.5 Mann Whitney Post-Hoc Tests for the Effect of Gender and Years of Practice on GPs’ Perceptions of Patients’ Information Needs Development……………………………………………………………………….106

Table 5.6 Kruskall Wallis Test for Differences in Perceptions of the Time of Information Needs Development Between GPs, Patients and Significant Others……………………………………………………………………………..108

Table 5.7 Mann Whitney Post-Hoc Tests for Differences in Perceptions of the Time of Information Needs Development Between GPs, Patients and Significant Others……………………………………………………………………………..110

Table 5.8 Crosstabulation Between GPs’ Years in Practice and Gender and Food Items……………………………………………………………………………..115

Chapter 6
Table 6.1 Criteria Used in Quality Checklist (Kmet et al., 2004)…………………127

Table 6.2 Included Studies with an Intervention Focused on Diet Only…………..129

Table 6.3 Included Studies with an Intervention Focused on Diet and Exercise……………………………………………………………………………131

Table 6.4 Included Studies with a Multifaceted Intervention……………………………………………………………………………………………136

Table 6.5 Quality Appraisals for Included Studies in the Systematic Review………………………………………………………………………………142

Chapter 7

Table 7.1 Measures Included in the Study (Chapter 7)…………………………………………………………………………………………155

Table 7.2 Reliability Analyses for Included Scales……………………………………………………………………………………156

Table 7.3 Characteristics of Respondents…………………………………………………………………………………………162

Table 7.4 Frequency of Reported Dietary Changes Among Respondents after starting Therapy and after Diagnosis………………………………………………163

Table 7.5 Spearman’s Correlation Coefficients Between Predictors…………………………………………………………………………165

Table 7.6 Logistic Regressions for Predicting Changes
Table 7.7 Logistic Regressions for Predicting Changes in Diet after Therapy

Table 7.8 Crosstabulation of Change in Diet after Diagnosis and Therapy and Marital Status

Table 7.9 Crosstabulation of Change in Diet after Diagnosis and Therapy and Educational Level

Table 7.10 Characteristics of Changers and Non-Changers

Table 7.11 Comparing Means of HRQOL Subscales Between Changers and Non-Changers

Table 7.12 Comparing Medians of HRQOL Subscales Between Changers and Non-Changers

Chapter 8

Table 8.1 Participant Demographics and Medical Information
List of Figures

Chapter 1

Figure 1.1 Conceptual Processes of the Thesis’ Studies ................................................................. 8

Chapter 2

Figure 2.1 The Theory of Planned Behaviour (Ajzen, 1991) .............................................................. 13

Figure 2.2 Health-Belief Model (Becker, 1974) .............................................................................. 16

Figure 2.3 The Transtheoretical Model of Change (Prochaska and Di Clemente, 1982) .................. 17

Figure 2.4 Leventhal’s Common Sense Model of Self-Regulation of Health and Illness (Leventhal et al., 1984) ......................................................................................... 20

Figure 2.5 Conceptual Model for Mechanisms Linking Social Relationships to Health Behaviours (Umberson et al., 2010) ................................................................................. 24

Chapter 3

Figure 3.1 Prostate Cancer Incidence Rates in the UK (1975-2010) from Cancer Research UK (2010) ..................................................................................................................... 26
Figure 3.2 Lazarus and Folkman Stress Appraisal and Coping Model
(1984) .................................................................................................................. 45

Figure 3.3 A Model of Psychosocial Processes after Cancer Diagnosis.............................................................. 50

Chapter 4

Figure 4.1 Chapter 4’s Analytic Plan .................................................................................................................. 63

Figure 4.2 Frequencies of Participants’ Responses on Time of Information Needs Development .......................................................... 77

Chapter 5

Figure 5.1 Proportion of Respondents Reporting Time of Information Need Development .............................................................. 111

Chapter 6

Figure 6.1 Study Selection for Inclusion in this Review ....................................................................................... 125

Chapter 7

Figure 7.1 Models for Logistic Regression Analyses ............................................................................................. 160

Chapter 8

Figure 8.1 Schematic Presentation of the Study’s Themes and Superordinate Themes ............................................................................ 198
Chapter 1: Introduction

1.1 The context of the Thesis

In recent years, the role of behaviour in health has been examined in depth. The establishment of Behavioural Medicine (Schwartz and Weiss, 1977; Pomerleau and Brady, 1979) and Health Psychology challenged the traditional beliefs of the Biomedical Model of Health (Annandale, 1998) and shifted the focus of health care from treatment only to prevention and intervention (Ogden, 2012). Within this context, behaviours, which related to health, are now referred to as health behaviours. Kasl and Cobb (1966) distinguished three types of health-related behaviours: health behaviours (preventative), illness behaviours (responsive) and sick role behaviours (coping). The change of health behaviours has been considered an important objective of healthcare for many years (Kaplan, 1990).

Kasl and Cobb (1966) define health behaviours as activities undertaken by healthy individuals to prevent a disease or detect it at an “asymptomatic stage”. This definition, however, does not take into consideration diseased individuals such as cancer patients who adhere to health behaviours for different reasons: to avoid recurrence and/or control their disease. Conner and Norman (2005) provide a broader definition of health behaviours as activities undertaken either to prevent/detect a disease or to improve health and well-being. This Thesis will deal with the latter part of this definition.

A number of theories have emerged which try to explain why some people adhere to health behaviours while others do not. They include the Learning and Cognitive Theories, Social Cognition Models and Stage Models. These theories, together with evidence from the literature, can inform evidence-based interventions targeting cancer patients’ well-being with an emphasis on their quality of life and coping with their illness. They will be discussed in greater detail in Chapter 2.
Gabhainn et al. (1999) found that men with cardiovascular disease are more reluctant than women to change their diet while Courtenay et al. (2002) found men in general to have unhealthier dietary habits compared to women. Ogden (2012) notes that men with prostate cancer illustrate “many of the issues relating to men’s health” (p. 458).

The importance of looking at dietary changes after cancer diagnosis is evident from prevalence in the literature: breast cancer patients who are overweight after diagnosis are more at risk of death and cancer recurrence than those who are not overweight (Chlebowski et al., 2002), while in a one-year follow-up trial (Maunsell et al., 2002) breast cancer patients reported dietary changes (41%) with most of them cutting down on meat (77%) and increasing their fruit and vegetable consumption (72%). The same study reports that those who changed their diet were more stressed younger and visited mental health services within one year of the follow up. Similar prevalence figures on dietary change by breast cancer patients are evident in Demark-Wahnefried et al. (2000). On the other hand, no prevalence figures exist for prostate cancer patients.

Chapman and Ogden (2009) suggest that the psychological processes involved in behavioural change are underexplored. The rationale of the Thesis investigating the constructs and processes surrounding dietary behaviour change is based on the concept of health as a continuum, which is one of the key perspectives of Health Psychology (Ogden, 2012). Specifically, aspects of patients’ beliefs and behaviours (sense-making of behavioural change, perceived causes of cancer) help seeking and doctor-patient communication (information needs, health professionals’ views), illness adaptation (dietary behaviour change, perspectives of significant others) and health outcomes (Health Related Quality of Life) are explored. These are integrated with the psychological processes used in Theories of Health Behaviour (perceived behavioural control, self-efficacy). The concepts of perceived behavioural control, self-efficacy and perceived causes of cancer are outlined in the Chapter 2 where the Theories that explain health behaviours are presented. The concepts of Health-Related Quality of Life (HRQOL), information needs and the roles of health professionals and significant others
on patients’ lifestyle changes and coping processes are outlined in Chapter 3 where the background literature is presented.

1.2 Research aims

The objective of this Thesis is to investigate the psychosocial processes around lifestyle changes after prostate cancer diagnosis, focusing on diet. The research aims to:

- Investigate the relationship between lifestyle changes after diagnosis and cancer-related information-seeking behaviour, cancer-related information needs, perceived behavioural control, healthy lifestyle prior to diagnosis and patients’ educational level (Chapter 4).

- Investigate whether perceived prostate cancer risk factors can predict lifestyle changes and information needs after diagnosis (Chapter 4).

- Compare the timing of information needs development after diagnosis in prostate cancer patients with that of significant others (Chapter 4).

- Compare GPs’ perceptions of prostate cancer patients’ timing of information needs after diagnosis with patients’ actual timing of information needs (Chapter 5).

- Assess the determinants of GPs’ a) perception of timing of patients’ information needs and b) beliefs about the role of diet in cancer aetiology (Chapter 5)

- Systematically review studies that investigate the association between dietary changes and health-related quality of life after cancer diagnosis (Chapter 6)

- Compare HRQOL, perceived behavioural control, self-efficacy, and the medical and demographic profiles of prostate cancer patients who do and do not change their diet after diagnosis (Chapter 7).

- Explore how prostate cancer patients make sense of, and account for, changes to their diet after prostate cancer diagnosis (Chapter 8).
1.3 Epistemological stance of quantitative and qualitative methods

The Thesis makes use of a mixed methods approach to reach the research aims, including quantitative, qualitative and systematic review methods. Quantitative methods are based on the idea that reality can be observed and the world can be understood in some form of mathematical (often statistical) relationship. In the early 20th century, the study of psychological phenomena focused on experimental studies (e.g. the work of Pavlov – 1849-1936 on conditional learning). Psychology, through the influence of positivism, has held a stance of quantifying phenomena for many years to this day (Howitt, 2010). The aim of quantitative research is to collect empirical data and it often uses statistical methods to answer hypotheses and generate models and theories. Chapters 4, 5 and 7 of the Thesis use quantitative methods.

On the other hand, qualitative methods are based on the idea that reality is not objective. Howitt (2010) argues that what distinguishes quantitative research from qualitative is that the latter is concerned with descriptive data and interpretation rather than hypothesis testing and it is based on one major assumption: that reality is socially constructed (social constructivism). Therefore qualitative research tends to reject positivism. Social constructivism is based on four assumptions: (1) knowledge is constructed through people’s interactions; (2) the way of thinking differs culturally and historically; (3) there is no objective observation of reality; and (4) social action is integrated with knowledge (Gergen, 1985). Nonetheless, researchers with a range of different epistemological backgrounds, from empiricism to social constructionism, who look for ways in which reality is constructed rather than reflected, use qualitative research methodology.

Also central to the qualitative methodology is the idea of critical realism, which challenges social constructivism. Critical realism proposes that, instead of independently constructed multiple realities; there are different perspectives on reality (Maxwell, 2012). Chapter 8 uses a qualitative approach.
1.4 Data collection in quantitative and qualitative research

For the collection of quantitative data, this Thesis has used online and paper surveys. A survey is defined as a method of gathering information from a sample of individuals and which provides an important source of basic scientific knowledge (Scheuren, 1980). Since the aim was to generate findings based on a sample of prostate cancer patients, significant others and GPs, data was collected through surveys. Surveys are one of the most common methods in psychological research because they are fast, cheap and easy. Surveys are useful in describing the characteristics of a large population. However, the survey method has also two major drawbacks. Firstly, it can be affected by an unrepresentative sample or poor survey questions and, secondly, the participants may affect the outcome. However, it is a method of scientific investigation in which a sample of people answers questions about their attitudes or behaviour in a relatively short time (Stangor, 2004).

Online recruitment has a number of benefits: they enable the recruitment of participants from a wide geographical area and are easy and cheap to use. The main drawback of online surveys is that they require computer literacy skills from participants and may therefore exclude participants from lower social classes or older individuals who do not own a computer or are not familiar with the Internet.

For the collection of qualitative data, this Thesis has employed semi-structured telephone interviews. Regarding data collection, Willig (2008) emphasizes the need to create a record of what participants do (or what they say they do) and, therefore, semi-structured interviews are the most common method used for data collection partly because of the flexibility they bring to data analysis. Yardley (2000) describes a set of criteria that encompass a good qualitative study which can be summarized as: a sensitivity to context, the completeness of data collection, analysis and interpretation, reflexivity and the question whether the research is important. Chapter 8 makes use of semi-structured telephone interviews to obtain data.
1.5 Research Design used in the Thesis

Chapters 4, 5 and 7 have a cross-sectional design. Any study’s design is based on the research questions that it aims to answer. Cross-sectional study design is an observational design that aims to describe certain phenomena. It is observational because it does not entail any intervention by the researcher. Since no intervention was required in this Thesis, a cross-sectional design was used.

Cross-sectional studies differ from longitudinal in that data is collected at once. Therefore causal relationships are difficult to derive. This drawback of the design is taken into consideration when interpreting findings (see Chapter 9, Section 9.3). On the other hand, cross-sectional studies are cheaper and less time-consuming.

The studies in the Thesis make use of both within- and between-subjects analyses. Within-subjects analyses are concerned with analysing data from the same sample (see Chapter 5 analyses within GPs and Chapter 7 analyses within patients) while between-subjects are comparative analyses that compare groups of individuals (see Chapter 4 patients-significant others and Chapter 5 patients-GPs).

Chapter 6 is a systematic review, the purpose of which is to synthesize the available evidence in the literature based on a specific research question. The quality of collected studies is also assessed so that findings can be combined.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Method of Analysis</th>
<th>Means of Data Collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter 4</td>
<td>Cross-Sectional</td>
<td>Between-participants</td>
<td>Online Survey</td>
</tr>
<tr>
<td>Chapter 5</td>
<td>Cross-Sectional</td>
<td>Within- and Between-participants</td>
<td>Online Survey</td>
</tr>
<tr>
<td>Chapter 6</td>
<td>Systematic Review</td>
<td>Narrative and Quality Assessment</td>
<td>Extraction of papers</td>
</tr>
<tr>
<td>Chapter 7</td>
<td>Cross-Sectional</td>
<td>Within-participants</td>
<td>Online and Paper Survey</td>
</tr>
<tr>
<td>Chapter 8</td>
<td>Qualitative</td>
<td>Thematic Analysis</td>
<td>Telephone semi-structured interviews</td>
</tr>
</tbody>
</table>
Overall, the Thesis makes use of a mixed-method approach, incorporating both the compelling, predictive and conclusive approach of quantitative research together with the in-depth and contextualized approach of qualitative research. Furthermore, a systematic review extracts evidence available in the literature. This approach offers comprehensiveness and rigour and tackles the aims and objectives of the Thesis from different points of view.

1.6 The structure of the Thesis

Chapter 1 introduces the topic and contextualizes the research area of the Thesis. It also explores the methodologies and the research aims of the Thesis.

Chapter 2 provides the theoretical context of the Thesis and the relevant theories that will inform the interpretation of findings. More specifically, it discusses the Theories of Health Behaviours and Behaviour Change and a Conceptual Theory of Social Relationships’ effect on Health Behaviours.

Having established the rationale, research aims, objectives as well as the theoretical and methodological context of the Thesis, the following Chapters will focus on answering its research questions and aims.

Chapter 3 reviews the relevant literature on lifestyle changes in cancer patients after diagnosis, focusing on diet and on two types of influence:

a) Intrapersonal, which includes the psychosocial processes that form either a prerequisite for change (information, perceived causes of cancer) or the characteristics or consequences of patients who change their dietary behaviour (Health Related Quality of Life) and

b) Interpersonal, which includes the role of health professionals and significant others in patients’ coping process after diagnosis. The Chapter then provides the rationale of the
current Thesis, gaps in knowledge and explains how the Thesis fits in with the wider research area.

<table>
<thead>
<tr>
<th>Prerequisites of lifestyle change: information needs, perceived cause of cancer (Chapter 4)</th>
<th>Dietary Changes, HRQOL, Quality assessment of available evidence (Chapter 6)</th>
<th>Sense-making of dietary changes (Chapter 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Issues of social support. GPs' perceptions of patients' information needs, GPs' awareness of prostate cancer diet (Chapter 5)</td>
<td>HRQOL, Self-efficacy, Perceived Behavioural Control (Chapter 7)</td>
<td></td>
</tr>
</tbody>
</table>

**Figure 1.1: Conceptual Processes of the Thesis’ studies**

Chapter 4 focuses on two prerequisites of change to diet, exercise and alcohol consumption (information needs and perceived cause of cancer) and investigates the time after diagnosis when patients are receptive to information and whether their perceived causes of their cancer predicts their lifestyle change and information needs. Finally, the patients’ information needs are compared with those of their significant others.

Chapter 5 focuses on the role of health professionals by assessing their perceptions of patients’ information needs and their awareness of prostate cancer diet.
Chapter 6 systematically reviews the literature for evidence that dietary change in cancer patients has an impact on their quality of life.

Having explored the interpersonal influences and the prerequisites of change, Chapter 7 investigates the differences between patients who change their diet after diagnosis and after starting therapy and patients who do not.

In Chapter 8 the patients’ perspectives on how they make sense of changes to their diet after diagnosis are assessed.

Chapter 9 discusses and synthesizes the findings, their implications and limitations. Finally, recommendations for future research are made while Chapter 10 summarises the Thesis.
Chapter 2: Theoretical Perspectives of Health Behaviour

“Without theory there is nothing to research” (Silverman, 1993)

2.1 Perspectives in Health Psychology

As seen in the previous Chapter, research has been undertaken in order to optimize the constructs included in theories that aim to explain and predict health behaviours. This Chapter will now focus on the different theories that have been used to explain health behaviours. The main perspectives that have contributed towards challenging the traditional Biomedical Model of Health (Annandale, 1998) are: a) the bio-psychosocial Model (Engel, 1977), b) the perception of health as a continuum, c) the direct and indirect pathways between psychological factors as determinants and health as an outcome, and d) the aspect of variability within health (Ogden, 2012).

The bio-psychosocial Model of Health and Illness (Engel, 1977) introduced the idea that social factors (i.e. social class, social values, education, etc.) integrate with biological and behavioural factors to determine health outcomes. Health outcomes can be directly and indirectly affected by psychological factors (Ogden, 2012). The direct pathway is concerned with the effect that a factor (e.g. depression) can have on health status while the indirect pathway is concerned with the intermediate effect of health behaviours (diet, smoking, etc.). Thus dietary behaviour and lifestyle in general can have an indirect effect on health (quality of life, mortality, longevity, etc.)

Finally, Health Psychology is concerned with the idea that different people act differently. For example, people may know that smoking is bad for their health but some continue to do so while others give it up. This variability among individuals can be explained by knowledge and the perception of the severity of the disease and also by the perceived cause of the disease and other cognitions.
2.2 Theories of Health Behaviour

Conceptualizing the underlying factors that can determine health behaviours has been the focus of psychology for over three decades (Winett, 1985; Adler and Matthews, 1994; Conner and Norman, 1995; Norman et al., 2000). In an effort to understand the “profile” of people who adhere to health behaviour as opposed to those who do not, the theories of health behaviour have been a focus of Health and Social Psychology for years. These theories use a social cognition approach in that they incorporate cognitive processes. They aim to make researchers and decision-makers understand how individuals make sense of social situations.

Social cognitive theories mainly deal with how an individual makes sense of him/herself (self-regulation). Fiske and Taylor (1991) define self-regulation as the “mental and behavioural processes by which people enact their self-conceptions, revise their behaviour, or alter the environment so as to bring about outcomes in it in line with their self-perceptions and personal goals” (p.181).

2.3 The Social Cognition Theoretical Models

There are two types of Social Cognition theoretical model: first the one that investigates aspects of an individual’s cognition to predict future health behaviours, and second the attribution theories (Conner and Norman, 2005). The first type is used to identify the predictors of future health behaviours. These include the Social Cognitive Theory (Bandura, 1982), the Theory of Reasoned Action (TRA) and Theory of Planned Behaviour (TPB) (Ajzen and Fishbein, 1980; Ajzen, 1991), the Health Belief Model (HBM) (Becker, 1974), the Protection Motivation Theory (Maddux and Rogers, 1983) and the Health Locus of Control (Wallston, 1992). The Implementation Intentions Theory (Gollwitzer, 1999) focuses on volitional variables. Social Cognition Theories have been extensively used the recent years to inform evidence-based interventions aiming to change health behaviours (Rutter and Quine, 2002). Generally, the theories that try to explain why certain people adopt several health behaviours and practices are
the TPB (Ajzen, 1991), the Health Belief Model (HBM) (Becker, 1974) and the Transtheoretical Model (Prochaska and Di Clemente, 1982).

2.3.1 Continuum Theories: the examples of The Theory of Reason Action and Theory of Planned Behaviour

The Theory of Reasoned Action (Fishbein and Ajzen, 1975; Ajzen and Fishbein, 1980) and its extension, the Theory of Planned Behaviour (Ajzen, 1991) have been used specifically to explain and predict eating behaviour (Ogden, 2012). The TPB is concerned with the predictors of health behaviours and describes the proximal determinants of health behaviours as intentions and perception of control (Figure 2.1). Intentions are predicted by subjective norms, attitudes towards behaviour, and perceived behavioural control. The TPB has been widely used to examine the predictors (cognitions) of health behaviours (Armitage and Conner, 2001; Hagger et al., 2002). A recent meta-analysis (McEachan et al., 2011) found the TPB to account for a variance of 44.3% of intentions and 19.3% of behaviour.

Perceived behavioural control includes internal (information, emotions etc.) and external (doctors, social pressure etc.) locus of control. Several studies have used the TPB to explain intentions to eat various foods (Raats et al., 1993; Arvola et al., 2008; Verbeke and Vackier, 2005) while Povey et al. (2000) explore the role of perceived behavioural control and other social influences on healthy eating. They found intentions to account for 42% of variance explained and behaviour to account for 15%.
2.3.1.1 The role of perceived behavioural control

Within the TPB (Ajzen, 1991), the concept of perceived behavioural control has emerged which is closely linked with self-efficacy and deals with the perceived confidence or difficulty in achieving a goal. The intention to achieve a behavioural change is a proximal factor, which conceptualizes future behaviour. Perceived behavioural control is a construct that has been added in the Theory of Planned Behaviour to explain behavioural change (Ajzen, 2002).

The motivations to exert lifestyle changes, such as dietary behaviour, and perceived behavioural control also have the capacity to enhance HRQOL. In their review of how lay people conceptualize health, Hughner and Kleine (2004) found that there are five lay themes of how health is defined, one of them being “health as freedom and the capacity ‘to do’”. Jensen and Allen (1994) note that “being healthy involves a sense of control; life can be coped with, challenges can be met. One feels motivated. There is a sense of power; one has the resources to meet the demands”.

Social support also has an impact on control (Umberson et al., 2010), which can be either direct (regulating health behaviours) or indirect (gradually establishing norms) and thus contribute to health behaviours (Umberson, 1992). It can enhance personal (or
internal) control by contributing to health knowledge but it can also reduce control by creating social pressure and stress (Mirowsky and Ross, 2003). It was also found to moderate the relationship between perceived behavioural control and behavioural intentions as well as the relationship between attitudes and behavioural intentions (Povey et al., 2000).

Nonetheless, a greater sense of control can be associated with dietary – and general – lifestyle change and this partially explains why people change their diets after diagnosis. But a greater sense of control may also be an outcome of habitual change (Chapman and Ogden, 2009) and thus people who change their diet and sustain it, have a higher sense of control because of the change.

2.3.1.2 The role of self-efficacy

Perceived behavioural control has been an addition to the TRA, resulting in the TPB (Bandura, 1982). In subsequent research, the concept of self-efficacy has been proposed as having similarities with perceived behavioural control. Schwarzer (1992) proposes that the two constructs are so similar that the one could replace the other. On the other hand, other studies (Trafimow et al., 2002; Ajzen, 2002) find distinct component differences between the two constructs and suggest they should remain separate.

Bandura (1997) defines self-efficacy as “the belief in one’s capabilities to organize and execute the courses of action required to produce given attainments”. Self-efficacy is found to be associated with behavioural change and behavioural change interventions and it is a central concept of theories that aim to explain behavioural change (Palmeira et al., 2007). Self-efficacy strongly predicts dietary behaviour (Aljasem et al., 2001; Bernal et al., 2000; Clark and Dodge, 1999).

Self-efficacy has been found to develop in different phases during changes to health behaviour and is thus a phase-specific self-efficacy that incorporates elements from the Stage Theories has been also suggested (Bandura, 1997; Luszczynska and Schwarzer,
A phase-specific self-efficacy incorporates the idea that maintaining a changed behaviour presupposes correcting a failed planned action. This concept initiates two types of phase-specific self-efficacy: coping self-efficacy (during the adoption or maintenance of a new behaviour) and recovery self-efficacy (after failing to adapt a planned action) (Schwarzer and Renner, 2000).

2.4 Health-Belief Model

The Health Belief Model (HBM; Rosenstock, 1966; Becker, 1974) is concerned with an individual’s perception of the illness threat based on two beliefs: the perceived susceptibility of the illness and the perceived severity of the illness’s consequences. These beliefs determine health behaviour change. Factors that counteract these beliefs are social pressure, personality and socio-demographic characteristics. Apart from the illness threat, the second aspect used by individuals to adhere to a health behaviour is the evaluation of behaviours that may affect the threat, such as alternative behaviours, costs and barriers, the efficacy and benefits of adopting a particular health behaviour. Another two factors commonly used by the model are cues to action – which can be external (i.e. advice from others, media campaigns) or internal (physical symptoms and health motivation). Thus the HBM is more a number of associated variables rather than a model itself (Conner and Norman, 2005).

The concept of perceived behaviour control used in the TPB (Ajzen, 1991) is not only associated with self-efficacy but also with cues to action found in the HBM (Becker, 1974). What links the two concepts is the assumption that external and internal factors can affect health behaviour change.
2.5 The Stage Theories

The Stage Theories aim to fill the “intention-behaviour gap” (Schwarzer, 2008) by focusing on behavioural maintenance and the role of planning in post-intentional phases. Behavioural change is a challenge and the Stage Theories try to explain this process in detail and provide a description of the underlying mechanisms when individuals proceed to change. The Transtheoretical Model (Prochaska and DiClemente, 1982) conceives change in different stages: pre-contemplation, contemplation, preparation, action and maintenance (Figure 2.2). Also, relapse is considered as a discreet stage. Patients lack an interest in behavioural change (pre-contemplation), consider change (contemplation), plan the change (preparation), adopt new behaviour (action), and are involved in the ongoing implementation of this new behaviour (maintenance). Each stage is different from the other and has obvious boundaries.

Mobility of cognitive resources is required to overcome old habits and achieve health behaviour change. The stage theories of health behaviour and self-regulation theories explain these processes. Within a stage, individuals make use of 14 constructs proposed...
by the model (Wright, Velicer and Prochaska, 2009): two decisional balance constructs, two self-efficacy constructs, five experiential processes of change and five behavioural processes. The process used refers to the way individual progresses from one stage to the other.

The Transtheoretical Model (Prochaska and Di Clemente, 1982) has been used in dietary-related research. Wright, Velicer and Prochaska (2009) evaluated how well the model predicted dietary fat intake. They found high degree of prediction confirmation for pre-contemplation (92%), contemplation (95%) and preparation (92%) stage.

Even though Stage Theories attempt to explain an adherence to behaviour change after diagnosis, they tend to focus on individual factors (beliefs, motivation, values, expectations, attitudes) and ignore social factors that might modify behaviour (Eertmans et al., 2001; Beagan and Chapman, 2004). On the other hand, conceptual theories of how
people choose what to eat (Furst et al., 1996; Story et al., 2002; Wetter et al., 2001) recognize the influential factors of environment, identity, the media, etc.

2.6 The Attribution Theory

The Attribution Theory is based on the idea that researchers need to seek for the origins of behaviour (Heider, 1958). According to the Theory, patients make efforts to seek for causal explanations for an illness. They have been used extensively to identify individual responses to various illnesses like coronary heart disease (Affleck et al., 1987), diabetes (Tennen et al., 1984) and cancer (Taylor et al., 1984). In their study Taylor et al. (1984) interviewed a number of breast cancer patients and concluded that the majority of women developed a causal explanation for their cancer (stress 41%, specific carcinogen 32%, heredity 26%, diet 17% etc.). They also found that 56% of women felt in control over their cancer.

Ogden (2012) argues that attribution theories have developed to distinguish between internal and external, stable and unstable, global and specific and controllable and uncontrollable. Consequently the attributions about a health condition can influence health behaviour. The dichotomous conceptualization of internal and external attribution has led to the development of the concept of health locus of control. Wallston and Wallston (1982) developed a relevant measure while Watson (1990) developed a Cancer specific Locus of Control Scale. The scale includes the following components: internal locus of control (the belief that health is dependent on own behaviour), external locus of control (the belief that health is dependent on others), chance (the belief that health is dependent on chance), control-others (the belief that health is dependent on other people) and control-doctors (the belief that doctors play a significant role in one’s health).
2.7 The Self-Regulation Concept

Self-regulation theories aim to explain the cognitive processes involved in overcoming habits to achieve behavioural change. Self-regulation is related to goal setting, cognitive preparations and the implementation and evaluation of goal-oriented activities and behaviours (Conner and Norman, 2005). While stage theories consider behavioural change as a process involving unique stages, self-regulation theories highlight the dynamic, which is evident between people involved in changing their behaviour and the actual behavioural change. It conceptualizes aspects of behaviour, such as goal pursuit, emotions and feedback control in the process. Cognitive and emotional processes are evident in the Scheier and Carver (2003) model of self-regulation, focusing on goal pursuit.

Theories of self-regulation take the perception of the processes of behaviour change a step forward. They propose a conceptualization of behaviour change as a dynamic process taking into consideration the active role of the individual in the pursuit of a goal, using feedback control as an evaluative element of effort. Additionally, they map the emotional processes that influence goal pursuit. Behavioural change has been described by self-regulation theory as a process of gaining insight into achieving, sustaining and repeating change.

Several theories of self-regulation have been postulated, some proposing the dialectical idea of goal achievement – goal avoidance (Scheier and Carver, 2003) and adding cognitive and emotional processes. Self-regulation theory combines habitual behaviour, goal pursuit with the stages of change and theories of willpower. Willpower is especially relevant in sustaining a behavioural change after achieving it. Exercise is proposed as a way of overcoming ego depletion (Muraven et al., 1999) and rest can help the restoration of resources (Baumeister, Heatherton and Tice, 1994).
2.7.1 Leventhal’s Self-Regulatory Model

The work of Leventhal and his Self-Regulation model (Leventhal et al., 1984) has been instrumental in explaining how people with chronic diseases cope with their illness and how they make sense of changes to their behaviour. There are three stages in this Model: at the first stage patients interpret the health threat using cognitive representations such as symptoms, social messages, cues and possible consequences. At this stage, they develop five dimensions of illness representation: identity, consequences, causes, timeline, and control/cure. At the second stage, patients develop an action plan seeking medical attention, prescribing, discussing with significant others, avoiding etc. The third stage incorporates the appraisal stage at which patients evaluate the success of their coping strategy and they develop strategies for maintenance. The self-regulation aspect of the model comes from the patients’ desire to return to a self-perceived normal stage (Figure 2.4).

![Diagram of Leventhal's Common Sense Model of Self-Regulation of Health and Illness](image)

*Figure 2.4: Leventhal’s Common Sense Model of Self-Regulation of Health and Illness (Leventhal et al., 1984)
Work on illness representations (Petrie and Weinman, 1997; Moss-Morris et al., 2002; Hagger and Orbell, 2003) has also used the Leventhal’s Self-Regulatory Model of behaviour to investigate patients’ reactions to disease. A meta-analysis (Hagger and Orbell, 2003) found that the control/cure dimension of the illness was only weakly associated with illness representations but found strong correlations between illness representations and physical and mental health.

The understanding of self-regulation processes has been instrumental in predicting how patients adapt to an illness (Hagger and Orbell, 2003; De Ridder and De Witt, 2006) and how patients’ coping strategies are related to their well-being (Leventhal, Diefenbach and Leventhal, 1992; Leventhal, Meyer and Nerenz, 1980).

The Model has also been used in cancer research. Stewart et al (2001) found that breast cancer patients who believed that stress was a cause of their cancer reported actions to reduce stress after diagnosis (causal belief). Rabin (2002) found breast cancer patientsto adhere to health behaviour change if they believed that the behaviour would help avoid cancer recurrence (controllability belief).

2.8 Models of Health Behaviour: Challenges and problems

Even though Health Behaviour Models have been used to inform interventions aiming at changes to health behaviours, they also share a number of problems. A major problem with the use of Social Cognition Models is the lack of clarity when it comes to the criteria for rejecting a theory (Ogden, 2003). It is also difficult to ascertain which Models and Theories work better than others because of the variability of findings in meta-analyses (see Armitage and Conner, 2001; Hagger et al., 2002; McEachan et al., 2011 for the TPB) and also the lack of comparative studies.
Recent reviews (Curran and Bauer, 2011; Hobbs et al., 2013) highlight that some structures such as attitudes are measuring processes that occur within individuals rather than between subjects. Therefore between subjects studies fail to establish a within individual variability of behaviour change (Molenaar and Campbell, 2009). N-of-1 and time series designs (Barlow et al., 2009) have been used recently (Hobbs et al., 2013) to establish the usability of the TPB (Ajzen, 1991) to predict physical activity with the TPB showing variable predictive utility.

There is a concern that many of the constructs used by Social Cognition Models overlap and researchers have not proved the differences in their underlying dimensions (Cummings et al., 1980). More specifically, controversy surrounds the differences between the concepts of perceived behavioural control and self-efficacy (Conner and Norman, 1995). Conner and Norman (2005) suggest self-efficacy as the strongest predictor of health behaviour.

Ogden (2012) has identified some further problems with Cognitive Models which aim to understand eating behaviour: meanings of food and body size, the role of affect and the social role of eating are often ignored while they have not been successful in predicting actual behaviour but rather intention instead. With regard to food, the problem is also that eating is a fairly habitual behaviour.

Not all Social Cognition Models consider the role of intention to engage in the health behaviour. Some Social Cognition Models like the TPB account for a variance in intention but only a small variance in target behaviour (see McEachan et al., 2011). Therefore the models have been criticized for the “intention-behaviour gap” and for failing to address behavioural maintenance (Schwartzer, 2008).

The Transtheoretical model and, generally, the stage theories have been criticized for being too descriptive and having low levels of prediction ability (Joseph, Breslin and Skinner, 1999). This problem with the theory was partly addressed recently in a study testing the \textit{a priori} prediction of the model (Wright, Velicer and Prochaska, 2009),
which found a high degree of confirmation regarding dietary predictors based on diet data.

Cameron and Leventhal (2003) identify the disadvantages of the stage theories of health behaviour in the theories’ nature and the processes they conceive as influential to behaviour. More specifically, they describe the theories’ nature as linear and they criticize the fact that they fail to describe the emotional processes of change and identify the societal role in change.

2.9 Other Theoretical Perspectives of Health Behaviours

A model has been proposed that aims to combine stage theories with other Social Cognition Models that view the process of behaviour change as a continuum. The Health Action Process Approach (HAPA) (Schwartzer et al., 2011) conceives behavioural change as a result of intentions that are transformed into clear instructions on implementing the behaviour.

Moreover, Umberson et al. (2010) in their review propose a theoretical context to explain the effects of social relationships on health behaviours. This framework is based on the work of early researchers who have provided evidence on the effect of social relationships on health behaviours (Berkman and Breslow, 1983; Resnick et al., 1997). These studies prove that social ties can promote healthy behaviours. Christakis and Fowler (2007) recently added evidence that risky behaviour can also be predicted by social relationships.

Social relationships (or ties) are generally conceptualized in terms of their structure and their content. The structural conceptualization of social relationships is related to social integration and social networks whereas content conceptualization is related to social support and stress.
The main constructs proposed by Umberson et al. (2010) as having a significant impact on health behaviours are: social support, stress, social and personal control, symbolic meaning, and mental health. These constructs are conceptualized as a holistic and single phenomenon. They work on an interpersonal, intrapersonal and social level to explain social relationships’ impact on health behaviours (Figure 2.4).

![Model for mechanisms linking social relationships to health behaviours (Umberson et al., 2010)](image)

*Figure 2.5: Conceptual Model for mechanisms linking social relationships to health behaviours (Umberson et al., 2010)*
Chapter 3: Review of literature relevant to cancer patients’ lifestyle changes, with a particular focus on prostate cancer and dietary changes

Having explained the Theories of Health Behaviour with an emphasis on concepts that will be used in this Thesis (behaviour change, perceived behavioural control, self-efficacy), the available literature surrounding lifestyle changes in cancer patients will now be presented, focusing on prostate cancer and dietary change. The concepts of information needs and HRQOL, as well as the role of significant others and health professionals, will be discussed.

The following databases where used for literature searches: PubMed, PsycInfo and Web of Knowledge. Furthermore cancer- and health- related journals were hand searched for relevant papers: Psycho Oncology, Lancet Onc, Psychology and Health, Patient Education and Counselling, Journal of Health Psychology, BMJ, Cancer. Combinations of the following keywords were used: “prostate cancer”, “dietary change”, “diet”, “HRQOL”, “control”, “lifestyle”, “social support”, “medical support”, “cancer diagnosis”.

3.1 Prostate cancer

3.1.1 Prostate cancer facts and figures

Cancer is a serious, life-threatening disease, which causes much concern and anxiety for patients and their families (“The Excess Burden of Cancer in Men in the UK”, 2009). The American Cancer Society highlights the fact that cancer treatments can be aggressive and unpleasant because of the changes in a patient’s life and because of its side effects (“Considering Prostate Cancer Treatment Options, 2013). Prostate cancer represents 12% of all cancers in the UK and in 2009, 10,382 men died of prostate cancer.
while one year earlier 37,051 were diagnosed with the disease. Furthermore lung, colorectal, breast and prostate cancer account for 47% of all cancer deaths in the UK. Survivors of breast, prostate and colorectal cancer have high survival rates and, if diagnosed early, they have good 5-year cure rates: 90% for localized colorectal, 98% for localized breast and 100% for localized prostate cancer (National Cancer Institute Office of Cancer Survivorship, 2008). Whilst prostate cancer is the most common cancer in men in the UK, survival rates have been improving (Cancer Research UK, 2010) (Figure 3.1).

Note: European Age-Standardised Incidence Rates per 100,000 Population, Males, Great Britain

*Figure 3.1: Prostate cancer incidence rates in the UK (1975-2010) from Cancer Research UK (2010).*

Prostate cancer is the most common cancer in men in the UK—25% (40,975 incidences in 2010) and the second most common cause of male cancer death—24% (19,410
incidences in 2010) (“The Excess Burden of Cancer in Men in the UK”, 2009). In general, men are 35% more likely than women to die from any type of cancer while the same report indicated that in 2011, the Cancer Research UK (2009) estimated that 45% of all types of cancers among men could be prevented if men had changed their lifestyle – drank less alcohol, stopped smoking, ate a healthier diet and weighed less. Evidence from an early study (Amler and Eddins, 1987) supports these figures. The authors have identified smoking, alcohol consumption, exercise and diet as the major lifestyle predictors of cancer diagnosis. It is also estimated that by 2030, prostate cancer will be the most common of all cancer types (Mistry et al., 2011).

3.1.2 Lifestyle as a cause of Prostate Cancer and Second Malignancies

It is important to address cancer patients’ behavioural and lifestyle changes after diagnosis because these patients are at risk of developing other conditions, such as osteoporosis and obesity (Salminen et al., 2004) which are related to lifestyle factors such as diet and exercise. Moreover, current research points to cancer survivor as having an increased risk of developing other chronic diseases (Jemal et al., 2008). Generally, three factors are believed to play a significant role in death rates and in the development of second malignancies (i.e. osteoporosis, cardiovascular disease and functional decline) in cancer patients and which result in a poorer HRQOL: genetic predisposition, cancer treatment and lifestyle factors (Demark-Wahnefried, Pinto and Gritz, 2006; Demark-Wahnefried et al., 2005; Jones et al., 2005). The lifestyle factors are the least mentioned and researched of the three (Demark-Wahnefried, Pinto and Gritz, 2006; Demark-Wahnefried et al., 2005; Jones et al., 2005).

There are some indications in the literature that cancer patients can have multiple benefits from changing their lifestyle. Lifestyle factors may contribute to reducing the risk of functional decline and the development of other chronic conditions (Doyle et al., 2006). Dietary changes, such as more fruits and vegetables and less meat consumption, are generally believed to be associated with lower levels of depression (Tangney et al., 2002) and psychological stress (Maunsell et al., 2002). There is also recent evidence
suggesting that there are indications that prostate cancer patients can have severe negative consequences by not changing their lifestyle if needed, with obesity affecting PSA monitoring (Oh et al., 2013).

3.1.3 Prostate Cancer Diagnosis and Control

Brockopp et al., (1989) were among the first to propose that post-diagnosis, cancer patients are generally inclined towards lifestyle changes, and they may benefit if they perceive that they can regain control by changing their dietary behaviour. The concept of perceived behavioural control has been widely used in cancer research to explain health post-diagnosis behaviours where patients are involved in a “process of action” (Maskarinec et al., 2001). They make attempts to cope with their situation and gain control over their condition. Also, many cancer patients are motivated to change their dietary behaviour after diagnosis, based on their desire to control their disease (Weitzman, 1998). Eyre (2001), moreover, observes that the feeling of losing control over one’s life is intense, and proposes that for cancer patients, the focus on diet is a way of regaining some control over their lives.

Patterson et al. (2003) suggest that lifestyle is an area in which cancer patients can regain a sense of personal control. Several studies have pointed out that cancer patients’ adherence to healthy lifestyle behaviour recommendations is related to gaining greater control over their lives (Taylor et al., 1984; Maunsell et al., 2002). Furthermore, Salminen et al. (2004) note that cancer patients show a desire to control their situation by modifying their dietary habits and their diet in general.

3.2 Coping with Prostate Cancer Diagnosis

3.2.1 Coping Strategies: Information Seeking

In order to change their lifestyle, patients first need to acquire information. This information may be relevant to their cancer, to relationship issues, lifestyle issues (diet,
exercise etc.), therapies, etc. The importance of information needs is reflected in studies that have associated needs with patients’ attempts to regain control over their lives (Asbring and Närvänen, 2004).

Several studies suggested that evidence-based information can reduce treatment-related anxiety (Hathaway, 1986; Suls and Wan, 1989; Krizek et al., 1999; Helgeson, Lepore and Eton, 2006) and concerns caused by side-effects (Johnson, Lauver and Nail, 1989; Johnson, 1996) and pain (Suls and Wan, 1989). Consequently, a lack of access to cancer-related information (Breau, McGrath and Norman, 2003) and of evidence-based information (Conn et al., 2001) can be major barriers to developing coping skills and, as a result, to changing health behaviour. Learning how to change health behaviour after receiving information has been found to enhance psychological well-being in a meta-analysis of 116 studies (Devine and Westlake, 1995) and also sense of control, treatment compliance and expectations (Carver, 2005; Doorenbos et al., 2005).

When are cancer patients susceptible to receiving information? One theory indicates that attempts to “take control” of their health succeeds a period of “blocking response” regarding information (McCaughan and McKenna, 2007) and this can be the period when patients develop information-seeking behaviour. Also, current research shows that men with prostate cancer have unmet needs at the time of diagnosis and during therapy (Sanson-Fisher et al, 2000; Steginga et al., 2001). A possible explanation for this is that treatment causes high levels of stress (Penson, Litwin and Aaronson, 2003).

Generally, cancer patients show difficulty in processing information given to them or information they collect themselves (Galloway and Graydon, 1996). The coping process after diagnosis is difficult and prostate cancer patients report barriers to gathering prostate cancer-related information and understanding their treatment (Boberg et al., 2003). At the same time, the information needs of patients are often not satisfied (McPherson et al., 2001; Sinfield et al., 2008). Needs related to support and knowledge of the recurrence and side effects of the illness were found to be the most unmet (Boberg et al., 2003). Another study (Carelle et al., 2002) found that prostate cancer patients
undergoing chemotherapy reported self-care information as the second highest unmet need.

Another study found that interest in diet and dietary changes in general has been found to increase with time since diagnosis and educational level also increases (Salminen et al., 2004). More educated people are considered to be able to better evaluate the benefits of modifying their behaviour in order to return to a “normal” life or not. There seems to be a stage during cancer patients’ journey at which they attempt to return to a “normal life” (McCaughan and McKenna, 2007).

The difficulty in processing information is also evident post-treatment. In general, following treatment, patients’ well-being is predicted by uncontrolled side effects (Helgeson and Lepore, 2004). A systematic review proposed that patients’ well-being was affected by their difficulty in understanding their treatment (Zeliadt et al., 2006). Furthermore, men with prostate cancer on radiotherapy were found in constant need of treatment-related information and information on side effects or the consequences of their illness such as those affecting sexuality (Miller et al., 2005; Wall and Kristjanson, 2005). However, despite all this evidence, little is known in general about the needs of prostate cancer patients following diagnosis and how they proceed in searching for cancer-related information. Even less is known about when they develop a need for cancer-related information.

Information-seeking behaviour can be beneficial for cancer patients. It may provide increased certainty and assistance in finding meaning in their experiences. At the same time, health professionals ought to tailor information-provision to patients’ needs (Rees et al., 2003). On the other hand, seeking information may also enhance patients’ stress by focusing on the negative parts of their stressors (Miller, 1983). Templeton and Coates (2003) emphasize the need for evidence-based educational interventions in order to address the information requirements of the prostate cancer population. Thus there are differences between patients in how they make sense of changes to their diet.
After diagnosis, patients are also confronted with the issue of making certain choices about their treatment. Roos (2003) suggests that obtaining information is linked to making certain treatment-related choices. Rees et al. (2003) introduce the idea that information needs are increased as information-seeking behaviour increases. Consequently, information needs and information-seeking behaviour are considered to be associated (Fallowfield, 1997; Rees et al., 2003). Moreover, Lee et al. (2004) note that post-diagnosis prostate cancer patients in China are interested in information related to treatment, to their body’s response and to possible side effects.

3.2.2 Coping Strategies: Seeking Social Support

Targeting significant others’ needs during the cancer trajectory is evident from studies indicating that psychological distress in female partners is higher than in patients (Cliff and Macdonagh, 2000; Eton and Lepore, 2002) with some indicating that 22% of partners can be clinically diagnosed with anxiety or depressive disorders (Couper et al., 2006; Street et al., 2010). Moreover, Schmidt et al. (2012) found that patients with a secure attachment relationship with their significant other have better coping and cancer management skills compared to avoidant-attached individuals.

Social support, which includes support from a partner, is important for prostate cancer patients as it leads to reduce distress (Lepore and Helgeson, 1998). Gray et al. (1999) found that patients are worried about the impact their diagnosis will have on their partners. Specifically, patients are concerned about the way cancer will affect their relationships and intimacy with their partner (Devins et al., 2006; Roberts, Lepore and Helgeson, 2006). Rees et al. (2003) also found prostate cancer patients’ partners to be highly interested when it comes to seeking information. More specifically, the partners of cancer patients were more interested in disease-specific information.

Findings from the literature suggest that patients and partners may have different needs and that targeting the quality of communication may not always be beneficial (Kershaw et al., 2008; Boehmer and Clark, 2001). They may also develop their needs earlier than
patients. It will be useful to identify at what time after diagnosis significant others develop their information needs in order to understand how and when clinicians can focus on providing the necessary information. This may have the capacity to benefit the quality of communication between patients and their significant others as well.

Several studies have pointed out the necessity of examining adaptation to illness not only as an individual process but also as part of the family and the roles of family members and partners (Franks et al., 2010; Hickman and Douglas, 2010). Karademas and Giannousi (2013) also found that a dyadic regulation approach exists between patients diagnosed with cancer and their partners. These findings are in line with previous ones (Badr et al., 2010; Dagan et al., 2011), which also highlighted the importance of a dyadic relationship when cancer patients adapt to their illness and cope with cancer. Another study (Sterba and de Vellis, 2009) highlights the importance of partners’ illness representations and control. Consequently, partners’ and other family members’ needs are also of importance when looking at patients’ therapeutic journey.

The importance of targeting significant others’ needs is evident in studies that have shown that patients’ adaptation to illness and the coping process is dependent on whether their partners show similar illness perceptions and needs to those of their partners (Figueiras and Weinman, 2003; Benyamini, Medalion and Garfinkel, 2007; Sterba et al., 2008; Benyamini, Gozlan and Kokia, 2009; Karademas, Zarogiannos and Karamvakalis, 2010) especially between prostate cancer patients and their partners (Merz et al., 2010). Furthermore, Chung et al. (2009) found that the dyadic adaptation to heart failure is associated with HRQOL. Finally Dagan et al. (2011) found that support from partners is important to cancer patients and their partners. This indicates that targeting the needs of significant others can benefit patients’ coping process. Collecting data on when patients’ significant others develop their needs for information will lead to more robust evidence on how clinicians can help the “dyadic” coping process after prostate cancer diagnosis.
3.2.3 Coping Strategies: Seeking Medical Support

There is evidence that breast and prostate cancers are considered “lifestyle cancers” (Anand et al., 2008). Thus lifestyle is a high risk factor for prostate cancer and can be a modifiable factor for patients, either through specialised advice or by choice. Salminen et al., (2000) found that only 11.8% of those who changed their diet after diagnosis did it because of healthcare professional advice while the same percentage (11.8%) changed their diet to cope with the symptoms of nausea and the majority (52.9%) to fight the disease and to be cured. These findings are in line with another study (Maskarinec et al., 2001) proposing that cancer patients change their dietary habits in order to avoid the probability of recurrence. However, findings from a recent systematic review (Gathirua-Mwangi and Zhang, 2013) found inconsistent results concerning the role of diet in prostate cancer prevalence, which can lead to confusion among health professionals.

Cancer patients constitute a high-priority health-care population with specific and distinct needs, which can benefit from identifying their needs after diagnosis and how different these are from those of their health care professionals as well as their significant others (Day, 1998; Nord et al., 2005). After diagnosis patients can also benefit from supportive care, which includes psychological, social and informational care, pain and symptom management, and other needs assessment (Fitch, 2000) and which may lead to a better HRQOL.

It is important for health professionals dealing with cancer patients to recognize that many patients seek advice outside the health care system (Helakorpi et al., 1999) and many are in need for more information regarding diet (Salminen et al., 2000; Boberg et al., 2003; McPherson et al., 2001; Sinfield et al., 2008) and other lifestyle-related behaviours such as exercise and smoking. Sinfield et al (2008) highlighted that this need is evident in patients’ partners as well.

The literature provides indications of how doctor-patient communication may improve health outcomes (Beck et al., 2002; Flach et al., 2004; Stewart et al., 2000) and specifically in cancer care (Mainous et al., 2004). Clinical information that patients can obtain from the Internet has led to patient empowerment, attempts to take control of their
health and their relationship with their health professional (Fox, Ward and O’Rourke, 2005).

Combining curative and palliative care with tailor-made and specific lifestyle interventions can benefit HRQOL and performance (Capra et al., 2001), increase treatment response and decrease co-morbidities, adverse cancer-related “sequelae” and disease complications (Brown et al., 2003; Nitenberg and Raynard, 2000; Stull et al., 2007). It can also enhance patients’ HRQOL when improving cancer-related symptoms (Segura et al., 2005; Roila and Cortesi, 2001; Stull et al., 2007).

Capra et al. (2001) emphasize in the need to accompany cancer treatment with nutrition-related interventions in order to improve physical functioning and general HRQOL. Nutritional support and counselling have the potential to increase the treatment response and reduce the number of complications (Brown et al., 2003) but also to improve clinical symptoms management associated with HRQOL (Segura et al., 2005; Roila and Cortesi, 2001).

Patients have a low expectation of their health professionals successfully palliating their loss of appetite (Hopkinson and Corner, 2006; Hopkinson et al., 2006). Consequently, health professionals and patients may also have different perceptions in terms of the patients’ lifestyle and information needs. Interestingly, Greiner et al (2008) found that patients and health providers even have different opinions on whether dietary issues are discussed during consultation in primary care, confirming previous studies that have shown discrepancies in health professionals’ diet-related discussions with patients during consultancies and nutritional counselling (Scott et al., 2004; Anis et al., 2004; Simkin-Silverman et al., 2005).

It has been suggested that patients are more likely to use direct and specific information on nutrition and diet and to take into account relevant recommendations (Potter et al., 2001). Also, they tend to focus on social and cultural context issues and doctor-patient communication barriers (Brown et al., 2006). Providing patient-centred information may be relevant to consultation and the health-professionals’ perceptions but if they are
patient-sensitive this may lead to share decision-making and greater patient satisfaction. One study reports patients’ preference for receiving person-centred nutritional counselling from their doctor (Parker, 2008).

For patients it is important to perceive behaviourssuch as a particular diet as a relevant medical issue in order to change it (Greiner et al., 2008). Wadden et al (2000) found that obese patients were prevented from looking for dietary-related information or from changing their behaviour if they perceived weight-related issues as unimportant during consultations. However, health professionals are reported as perceiving the media and not the consultation as the primary source of healthy diet recommendations (Pineiro et al., 2005). If patients’ and physicians’ perceptions get closer, doctor-patient communication may improve and as a result healthoutcome benefits are improved.

3.2.4 Coping strategies: Self-management and Behaviour Change

In broad terms, certain health (or lifestyle) behaviours refer to personal actions that can influence health, mortality and disability (Umberson et al., 2010). Some of these actions promote health and others undermine health. Several studies have found only small differences in health behaviours (diet, smoking, physical activity) and Body Mass Index (BMI) between cancer and cancer-free populations (Belizzi et al., 2005; Coups and Ostroff, 2005; Eakin et al., 2007; Mayer et al., 2007). On the other hand, two recent studies (Skeie et al., 2009; Karlsen et al., 2012) found that men with cancer change their health behaviour post-diagnosis and that they differ from cancer-free men. The first set of studies (Belizzi et al., 2005; Coups and Ostroff, 2005; Eakin et al., 2007; Mayer et al., 2007) used a cross-sectional design while the latter two (Skeie et al., 2009; Karlsen et al., 2012) used a prospective design. This can possibly explain the contradictory findings, given that cross-sectional studies are limited in identifying causal relationships.

The period after cancer diagnosis is referred to as a “teachable moment” (Demrak-Whanefried et al., 2005) because patients are motivated to adopt lifestyle changes in order to improve their well-being. Cancer patients are motivated to implement lifestyle
changes, especially in their first year after diagnosis (McBride et al., 2000; Eyre, 2001), in order to reduce the risk of death. The literature also provides evidence that dietary habits and lifestyle changes generally are associated with the progression of prostate cancer (Ornish et al., 2005), physiological changes of the telomere (Ornish et al., 2013) and even with the progression and aetiology of the dietary management of prostate cancer (Demark-Wahnefried, 2007).

On the other hand, adhering to a healthier lifestyle is not simple. For example, two studies (Demark-Wahnefried et al., 2000; Blanchard et al., 2004) found that 48% to 74% of cancer patients do not follow the American Cancer Society’s recommended diet (Doyle et al., 2006) and do not consume the advised 5-A-Day servings of fruit and vegetables. In a similar vein, current research indicates that even though the benefits of adjusting to a healthier behaviour are well known, cancer patients ignore the national diet and physical activity guidelines (Belizzi et al., 2005) or fail to meet the American Cancer Society’s 5-A-Day fruit and vegetable servings (Piece et al., 2007; Demark-Wahnefried et al., 2000). Wayne et al. (2004) suggest that after diagnosis there is a strong tendency among cancer patients to change their dietary habits. However, they suggest that these changes are modest at best.

There is not adequate research on patients’ interest in pursuing lifestyle changes and modifying their behaviour (Markman, 2001) or on how patients understand their dietary changes. Demark-Wahnefried (2000) found that the modification of dietary habits was associated with the extent to which patients believed that the habit was associated with their condition. These patients, and especially those who were newly diagnosed, also showed a great interest in diet-related interventions aiming at a healthier diet. Similarly, Moschen et al. (2001) propose that patients’ beliefs and health associations can predict dietary changes. Patients can change the behaviour they consider most related to their cancer diagnosis.

Because cancer patients are likely to pursue lifestyle changes they represent a group that could benefit from dietary interventions (Patterson et al., 2003). Demark-Wahnefried et
al. (2000) found a strong interest amongst cancer patients in health promotion programmes aimed at healthier diets.

Guiding patients to change their health behaviour is difficult to achieve and Andersen (2002) suggests in her review that health behaviour interventions have a major obstacle to overcome which is the fact that negative health behaviours are hard to quit while on treatment because of increased stress while positive health behaviours are abandoned due to lack of time or energy at the time of treatment. At the same time, patients often lack the readiness to change their behaviour (Dowswell et al., 2012).

Socio-demographic characteristics can also explain health behaviour change. Lemon et al. (2004) found that higher levels of education were associated with improvements in fruit and vegetable consumption 6 months post-diagnosis. Of course, a higher level of education might be correlated with higher class and higher income, which may explain these differences as well.

3.3 The Importance of Diet when Living with Prostate Cancer

Diet is interesting to investigate because it is modifiable (Wayne et al., 2006). Glanz (1997) proposed that the determinants of dietary behaviour and change processes are a priority area for behavioural research. Moreover, cancer treatment may result in changing food intake and nutritional status (Van Cutsem and Arends, 2005). Nutrition and dietary behaviour is related to oncology because it may influence treatment recovery, cancer-related symptomatology and disease development by modifying HRQOL.

One source that is used by cancer patients to obtain information related to their illness is diet-related brochures. Diet is underused in prostate cancer brochures and in one study (Rees at al., 2003) a patient notes that “it” – the leaflet – “mentions diet, no other mentions it” (Neil, aged 68). On the other hand, another patient notes the irrelevance of dietetic information noting that “…by the time you get to read the booklet it’s too late, it’s what you’ve eaten in your previous 60, 70, 80 years that counts” (Bob, aged 63). It is
a challenge, though, to investigate the time after diagnosis during which diet became of interest.

Even though nutritional interventions have positive biological outcomes – i.e. the maintenance of a neutral or positive protein and energy balance (Brown et al., 2003), maintenance of electrolyte, mineral, vitamin and trace element levels (Argiles, 2005) etc. – there may also be psychological benefits to cancer patients from maintaining a healthy diet or changing eating behaviour (i.e. by enhancing levels of control, physical function etc.). In particular Marin Caro et al. (2007) in their review highlight the importance of nutritional interventions in oncology and the critical importance of the relationship between quality of life and nutritional changes. The psychological constructs behind this relationship are critical and include the belief that nutrition may affect the anticancer therapy (Metz et al., 2005) and the patient’s confidence level (control).

There are mixed reports on the number of cancer patients that initiate changes after diagnosis (Demark-Wahnefried et al, 2006; Pinto and Trunzo, 2005) that could be a result of self-report bias, which is common in all survey-based research, as well as selection bias of participants highly interested in the researched health behaviours in some of these studies.

### 3.3.1 The Impact of Dietary Change on HRQOL

“The quality of life is more important than life itself”.

Alexis Carrel (1912), French surgeon and Nobel Prize winner

#### 3.3.1.1 What is Health-Related Quality of Life (HRQOL)?

In general, health is considered “a state of complex physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). Conclusively, it is important when conceptualizing health to understand the concept as something more than the absence of disease.
An issue of controversy is the actual definition of quality of life (King, 1998) because of different perceptions of health through time (i.e. health as the absence of disease or not) and different contexts of health (i.e. health influenced by social and spiritual factors). Ferrell, Dow and Grant (1996) provide an interesting definition: “a subjective multidimensional construct representing functional status, psychosocial well-being, health perceptions and disease/treatment-related symptoms”. Consequently quality of life can be a very broad term, which may include psychological, spiritual, physical, economic and social health, etc. (Galalae et al., 2004). Therefore, in clinical research, health-related quality of life (HRQOL) is used which constitutes “patients’ appraisals of their current level of functioning and satisfaction compared to what they perceive to be ideal” (Kuchler and Schreiber, 1989). It is also a construct that generally quantifies the psychological, social and physical aspects of therapy and the illness itself (Marin Caro et al., 2007). From a clinical perspective, psycho-oncologists focus on HRQOL as a behavioural outcome of the disease (Andersen et al., 1994).

The severity of a low HRQOL is highlighted in a study that showed its association with low response to anti-cancer treatments (Le et al., 2005). Sanders et al. (1998) and Gill and Feinstein (1994) have pointed out that HRQOL has been an important aspect of cancer treatment and prevention in the past two decades. Research on the impact of dietary changes on the HRQOL of various patient groups has been gradually increasing: women’s mental health status (Bowen et al., 1995), patients with cardiovascular metabolic disease (Hatton et al., 1996), patients after myocardial infraction (Barnes and Terry, 1991) and patients with Renal Disease (Coyne et al., 1995) have all been studied.

3.3.1.2 The Meaning of Health and HRQOL for Patients

Qualitative research has made an effort to explore what quality of life means to cancer patients. As highlighted by one qualitative study (Davies et al., 2008), HRQOL is important for cancer patients, with one of the interviewees stating that “There seems to be a sort of general assumption that for all [cancer patients] the objective will be to live
as long as possible… [but for some] it will be the quality of life, and the quality of life means being, or at least feeling, healthy – that’s the more important thing”.

Other researchers have suggested that alterations to diet may be beneficial when the patient lacks the social role of eating and it is limited to its functional role (Roberge et al., 2000). Various ways have been suggested (i.e. dietary modifications such as home enteral tube feeding) that may comfort the patient. The literature provides evidence that HRQOL has shown improvement or no change in 75-88% of patients as a result of home enteral tube feeding (Nelson et al., 1986; Sami et al., 1990; Roberge et al., 2000).

### 3.3.1.3 Cancer patients’ HRQOL

Baker, Haffer and Denniston (2003) found that cancer patients have significantly poorer HRQOL scores than non-cancer individuals using a large sample (22,747 cancer patients compared with an equal number of non-patients). These results suggest a functional decline among elder cancer patients after being diagnosed. The deterioration of HRQOL is also associated with biochemical and physiological changes due to cancer and its treatment (Marin Caro et al., 2007).

According to Visser et al. (2003), prostate cancer patients show a significant decrease in their HRQOL in several domains three months after diagnosis, while psychosocial factors (coping, distress and social support) contribute only in a marginal fashion to their HRQOL. Generally, prostate cancer patients are at an increased risk of functional decline and therefore health-related interventions may be of benefit (Moscher et al., 2009). Thus a lifestyle intervention may reduce the self-reported functional decline of cancer patients (Morey et al., 2009).

Cancer patients’ independent living is threatened by functional losses (Mosher et al., 2009). Individuals on diet-related intervention programmes have reduced functional decline compared to non-intervention individuals (Morey et al., 2009). Declines in physical functioning are also associated with a greater economic burden (Yabroff et al.,
which makes the promotion of a healthier lifestyle among this population even more challenging.

3.3.1.4 The Relationship between HRQOL and Lifestyle Changes, Diet in Particular

Much research is concerned with whether diet reflects or influences HRQOL (Wayne et al., 2006). The findings have been controversial and unclear. However if there is an association between dietary changes and HRQOL, then dietary-related interventions could have the capacity to enhance physical and mental well-being. Plaisted et al. (1999) found that hypertensive patients who consumed less fat and more fruits and vegetables improved their physical health. Moreover a review (McGrath-Hanna et al., 2003) found that modification from traditional to western diet negatively affects the mental health of circumpolar patients. Ravasco et al. (2005), who conducted one of the first intervention studies that investigated this association in a cancer population, found that dietary counselling during radiotherapy with people with colorectal cancer resulted in enhanced HRQOL. Conversely Tangney et al. (2002) found no association between diet quality and HRQOL among breast cancer patients.

Studies using a cross-sectional research design tried to identify a relationship between HRQOL and eating. Demark-Wahnefried et al. (2004) found a modest improvement among elderly breast and prostate cancer patients’ physical functioning scores when decreasing fat intake or increasing fruit and vegetable consumption. On the other hand Blanchard et al. (2004) found no significant association between HRQOL and healthy eating (fruit and vegetable intake) and Stephenson et al. (2009) found a non-significant relationship between HRQOL and dietary change among cancer patients. Another cross-sectional study (Ashing-Giwa et al., 2010) designated a significant relationship between physical functioning and diet quality among cervical cancer patients while results from breast cancer patients in the same study designate a significant relationship between physical well-being and exercise but not diet.
Several studies (Tymchuk et al., 2001; Ornish et al., 2005) have used diet-related intervention trials to test the association between dietary changes and prostate cancer progression and/or growth. However, the association between dietary changes and HRQOL is at a primary stage. Also Blanchard, Courneya and Stein (2008) hypothesize that multiple psychological constructs (including depression, functional decline and control) may interact to induce or reduce HRQOL. A randomized clinical trial (Kronenwetter et al., 2005) found that the prostate cancer patients who contributed to the study reported that the intervention, which aimed to change their lifestyle, had benefited them by increasing their optimism, hope and “fighting spirit”.

Corle et al. (2001) argue that studies that associate HRQOL with dietary changes should focus on the non-“health” aspects of HRQOL as well, including the cost of food, the impact on one’s social life, the difficulty in preparing food and changes to food’s taste. In their study they investigated 2,079 men and women with (non-cancerous) bowel polyps and the impact of a low fat, high-fibre and high-fruit and vegetable diet on health and non-health aspects of HRQOL, such as self-perceived emotional and physical well-being, satisfaction with diet and self-care. They found positive effects of dietary changes on the overall perception of HRQOL and on life perceptions.

Until recently, very few studies existed that established the association between dietary changes and psychosocial factors like HRQOL with separate dimensions like physical functioning. Ortega et al. (1996) were the first to establish an association between diet and physical functioning, indicating that a low fat diet and a high consumption of fruits and vegetables were associated with higher levels of physical functioning among a Spanish sample at risk for cardiovascular disease.

Functional decline may cause a serious reduction to older cancer patients’ HRQOL. When functioning decreases, cancer patients face various consequences related to their psychological well-being (loss of independence, loss of control) which result in reduced HRQOL. Interventions may aim at improving physical functioning in order to prevent the decline of their HRQOL. In the meantime, by changing their lifestyle prostate cancer patients may regain their sense of personal control (Patterson et al., 2003), prevent
declines in physical functioning (Demark-Wahnefried et al., 2006) and thus enhance (or at least prevent the decline) of their HRQOL.

The association between lifestyle factors and physical functioning is suggested by the fact that functioning is better when older patients exercise more and eat more healthily (Demark-Wahnefried et al., 2004). In addition, Morey et al. (2009) suggest that some intervention studies target overweight or obese cancer patients due to the possibility that obesity could compromise functional status. This study in particular found that when overweight and long-term cancer patients change their lifestyle behaviour, their functional decline improves.

3.3.1.5 Measuring HRQOL in Cancer Research

HRQOL is generally measured through self-administered questionnaires (Mosvás, 2003, Osoba, 1994). There are two types of HRQOL psychometrically validated multidimensional questionnaires: generic (i.e. MOS SF-36, WHOQOL) and disease-specific (i.e. EORTC QLQ-C30). Galalae et al. (2004) point out the advantages and disadvantages of each type of questionnaire: generic are more appropriate when comparing different conditions and interventions and when the generalizability of findings is important for the research but may not focus on specific aspects of a condition. On the other hand, disease-specific psychometrics may detect more adequate behaviour change. A combined use of both generic and disease-specific instruments is sometimes observed in cancer research.

Two issues that concern the psychometrics of tools measuring HRQOL are validity and reliability. Validity refers to the extent that an instrument measures what it supposed to measure and reliability refers to how consistent an effect is when replicated (Breakwell et al., 1995). That happens when measurement error is minimal. Due to the fact that HRQOL measures have multiple items, which relate to quality of life dimensions, internal consistency of these measures is very important (Galalae et al., 2004). Internal
consistency is assessed using the Cronbach’s coefficient $\alpha$ (alpha) and a value higher than 0.70 is preferred (Nunnally, 1978).

Marin Caro et al. (2007) in their review outline the most frequently used HRQOL tools in psycho-oncology research. The European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 (Aaronson et al., 1993) and MOS SF-36 (Ware and Sherbourne, 1992) are two of the most widely used and validated tools that measure HRQOL in cancer research and they have been extensively used in studies investigating the association between lifestyle changes and HRQOL. EORTC QLQ-C30 is a cancer-specific questionnaire while MOS SF-36 is a generic questionnaire.

The Medical Outcomes Study Short Form 36 (MOS SF-36) is a 36-item, well-validated tool and one of the most widely used generic HRQOL measurements. It includes two scales (Physical and Mental component) each of which contains eight subscales: physical functioning; role functioning-physical; bodily pain; general health (Physical), vitality; social functioning; role functioning-emotional and mental health (Mental).

EORTC QLQ C-30, on the other hand, is a 30-item, cancer-specific questionnaire with a longstanding tradition of being a reliable and robust tool for measuring HRQOL, as indicated by studies with cancer patients, and its main characteristic is that it has been internationally validated and translated into many languages, and it is found to have a good psychometric functioning when it comes to specific sites and stages of cancer (Urdaniz et al., 2008). EORTC QLQ C-30 includes five functional scales (physical functioning; role emotional; emotional functioning; cognitive functioning; social functioning), three symptom scales (fatigue, pain, nausea/vomiting) and a global health status. Also it has six single questions, which measure the symptoms and the financial aspect of cancer.

The WHOQOL (World Health Organization, 1997) is a generic and validated tool to measure HRQOL and is used in a wide variety of countries because it is available in over 20 languages. It includes 5 components (physical health, psychological health, level
of independence, social relationships, environment and spirituality/religion/personal beliefs).

The Functional Assessment of Cancer Therapy (FACT) is a valid and reliable questionnaire, sensitive to functional changes especially among colorectal cancer patients (Ward et al., 1999). It contains four subscales: physical well-being, social (family) well-being, emotional well-being and functional well-being.

### 3.4 A Theoretical Context: Stress, Appraisal and Coping Model

When an event is threatening, individuals can develop stressful reactions, which can in turn initiate action (or change). Cancer patients’ general health and quality of life can be improved if an understanding is developed of the factors that contribute to stress and coping. Lazarus and Folkman (1984) provided a useful framework when seeking to understand the coping reactions of cancer patients to their diagnosis (Figure 3.2).

![Lazarus and Folkman Stress Appraisal and Coping Model (1984)](image)

*Figure 3.2 Lazarus and Folkman Stress Appraisal and Coping Model (1984)*
At first, a patient appraises the stressful situation. Factors like danger, level of pain and discomfort are taken into consideration. If a threat is perceived, patients pass through a second appraisal stage in which a patient uses self-efficacy and past experience to re-evaluate the stressor and decide on coping mechanisms. Therefore physiological (increases heart rates, hyperventilation, nausea, loss of appetite, headaches etc.) and psychological (loss of control, guilt, depression, loss of interest etc.) responses are developed towards the stressor and for the purpose of coping with it. As outlined above losing control over their lives is common among cancer patients and can be explained in the context of the Stress, Appraisal and Coping Model.

3.5 Conclusions and Gaps in Knowledge

3.5.1 Gender Issues

Based on the literature, in order for cancer patients to change their lifestyle they need information, social support and appropriate healthcare guidance while several psychological constructs are related to changes in lifestyle (HRQOL, control, perceived causes of disease). Furthermore, even though men are more likely to adhere to risky behaviours (Courtenay, 2000; Oksuzyan et al., 2008), no studies have investigated the determinants of post-diagnosis health behaviour changes in men only. The challenge to identify what makes men change their health behaviours after diagnosis is evident in studies that have shown that men are less likely to change or maintain their health behaviour (Patterson et al., 2003; Demark-Whanefried et al., 2005; Mosher et al., 2009).

On the other hand, studies of women with breast cancer (Patterson et al., 2003; Salminen et al., 2004; Salminen et al., 2000; Maunsell et al., 2002) found that 30%-48% of women change their diet after diagnosis. The proportion of these changes for prostate cancer patients, what dictates them and how they make sense of them is still unknown.
Similarly, evidence by Pinto, Eakin and Maruyama (2000), who conducted a systematic review on dietary intake interventions after cancer diagnosis, found that until 2000 there were four studies involving dietary interventions for cancer patients (Nordevang et al., 1992; Chlebowski et al., 1993; Pierce et al., 1997; Kristal et al., 1997). These studies recruited only breast cancer patients and looked at whether members of this population modified their dietary behaviour after diagnosis, during and after treatment. They also looked at the effect these changes have on survival and recurrence but none looked at the effect of these changes on bio-behavioural outcomes, HRQOL, physical functioning, etc.

3.5.2 Dietary Change

Thus there is a big gap in the literature for two reasons. Firstly, until 2000 no study existed that investigated the effect that dietary behaviour change has on psychological and bio-behavioural outcomes, such as aspects of HRQOL, physical functioning, etc., or which psychosocial constructs have an effect on prostate cancer patients’ dietary changes post-diagnosis. Also, no similar systematic review has been carried out since then. At the same time, even though a systematic review had identified studies that focused on the psychosocial outcomes of exercise change among breast cancer patients (McNeely et al., 2006), after 2000 the studies that elaborated on dietary changes after cancer diagnosis suffered from limited evidence on causal relationships (Blanchard et al., 2003; Demark-Wahnefried et al., 2004; Mosher et al., 2009). Secondly, the majority of these studies investigated breast cancer patients while only a few studies focused on the effect of dietary changes on prostate cancer patients’ HRQOL (Mosher et al., 2009; Daubenmeier et al., 2006; Demark-Wahnefried et al., 2006; Morey et al., 2009; Blanchard et al., 2008; Demark-Wahnefried et al., 2004; Blanchard et al., 2004).

McGinnis et al. (2002) indicate that approximately half of annual deaths in the USA can be explained by unhealthy behaviours. Even though similar reports are not available for Europe and the UK it can be postulated that similar trends exist in the UK. A review previously (Andersen, 1994) suggests that interventions will be more effective if
psychosocial interventions include health behaviour components. The review suggests that HRQOL along with health-protective and health-promoting behaviours may affect survivorship as well.

Evidence from a systematic review regarding the role of lifestyle changes in managing diabetes is compelling (Gillies et al., 2007). It found lifestyle changes to be equally important to managing Type 2 diabetes as drug treatment. Even more so, maintaining changed lifestyle behaviour is even harder, with another systematic review (Curioni and Lurenc, 2005) indicating that 50% of people on a diet regain their lost weight after a year.

3.5.3 Information Needs

The time during which patients develop their information needs after diagnosis has yet to be clarified. There is inconclusive evidence indicating that patients develop their needs closer to diagnosis (Noh et al., 2009) while others argue that the needs develop in time as the diagnosis develops (Salminen et al., 2004; Friis et al., 2003). At the same time, the role of health care providers and significant others in patients’ adaptation is significant but underexplored. For example, there are no studies in the literature comparing significant others’ information needs with those of patients even though they constitute a population at risk of developing depressive symptoms after their significant others’ diagnosis (Couper et al., 2006; Street et al., 2010). Health care providers’ perceptions of patients’ needs are also important in optimizing patients’ health care provision and meeting patients’ needs.

The Centre for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation (LAF) have urged public health agencies to focus on providing access to resources available and to focus on the importance of health education in strategies aiming to improve health through multiple stages of cancer survivorship (Hawkins et al., 2010). This Thesis builds on the understanding of the psychosocial processes, which
occur in prostate cancer patients after diagnosis and which are related to lifestyle changes focusing on diet.

The clinical importance of focusing on the processes that can have an impact on prostate cancer patients’ dietary changes post-diagnosis is to provide evidence for future interventions focusing on this cancer population. Blanchard et al. (2008) highlight the importance of designing intervention programmes that aim at healthier lifestyles among cancer survivors by indicating that these groups may benefit because of reports of suboptimal dietary behaviours. Findings on these processes can answer the question of what makes prostate cancer patients change their diets and inform future interventions aiming at promoting healthier lifestyles among this particular cancer population.

3.5.4 Social and Medical Support

In addition, the existing literature on health behaviours after cancer diagnosis including diet is not without its limitations. Intervention studies often use multi-faceted interventions, making it difficult to identify the effect of dietary changes while intervention studies, which aim at changing diet, lack theoretical integration. The role of healthcare providers in delivering the interventions is underutilized (Pinto and Trunzo, 2005). There is also minimal evidence in the literature on cancer patients’ readiness to adhere to changes in their health behaviour especially bearing in mind evidence that prostate cancer diagnosis interrupts couple’s relationships and their HRQOL (Galbraith et al., 2011).
3.5.5 A Model of the Psychosocial Processes Post-Cancer Diagnosis

The evidence of loss of personal control due to cancer diagnosis (Eyre et al., 2001; Patterson et al., 2003) and the coping mechanisms that are used to regain control, provide the need to establish a model to understand the psychosocial processes taking place on prostate cancer patients post-diagnosis (Figure 3.3). It has been established (see section 3.2) that patients make efforts to understand their condition by acquiring information, seeking support and comfort from their significant others and health care professionals and by changing their health behaviours.

Figure 3.3: A Model of Psychosocial Processes after Cancer Diagnosis
There are also gender issues that are common for prostate cancer patients and which can influence patients’ coping process whereas the physical and psychological health of patients may also moderate the coping process. This Thesis will use this Model of Psychosocial Processes after Prostate Cancer Diagnosis, evidence from the literature and health behaviour theories and findings from the empirical Chapters to reach its objective. Based on this Model, the aims of the Thesis are to:

- Investigate the information needs of patients and their significant others as a result of prostate cancer diagnosis, their predictors and the time these needs are developed (Chapter 4)
- Compare the time of patients and significant others’ information needs development with GPs’ perceptions, exploring their predictors (Chapter 5)
- Systematically review the literature for evidence of an association between health (physical-psychological) and dietary behaviour change (Chapter 6)
- Investigate the predictors of dietary behaviour change after diagnosis and after therapy (Chapter 7)
- Explore patients’ underlying mechanisms of dietary behaviour changes after diagnosis (Chapter 8)

The previous three Chapters have established the Theoretical (Chapter 2) and Methodological (Chapter 1) context of the Thesis while previous research and gaps in knowledge have now been examined (Chapter 3). The following Chapters will attempt to answer the Research aims of the Thesis.
4.1 Introduction

This Chapter looks at the role of two prerequisites of change: having information and perceiving behaviour as a cause of the disease. Information giving is a frequent component of interventions aiming to change individuals’ health behaviours (see Sebregts et al., 2000; Rees et al. 2004). However, in order for information giving to be meaningful, we have to understand the information needs and information-seeking behaviour of patients.

Attempts to “take control” succeed a period of “blocking response” (McCaughan and McKenna, 2007) and most probably this is the period when patients develop an information-seeking behaviour. On the other hand, it is common that the information needs of patients are not satisfied (McPherson et al., 2001; Sinfield et al., 2008). Needs related to support, knowledge of recurrence and side effects of the illness were found to be the most unmet (Boberg et al., 2003). Moreover, Lee, Francis and Walker (2004) note the three main interests that cancer patients have after being diagnosed are related to treatment, their body’s response and possible side-effects.

Information-seeking behaviour is thought to be beneficial for cancer patients. It provides increased certainty and assists them in finding meaning with regard to their experiences (Rees et al., 2003). On the other hand, seeking information may enhance patients’ stress by focusing on the negative aspects of their stressors (Miller, 1983).

Information needs lead patients and significant others in search of available information and the way they process information is crucial in order to make decisions. Noh et al (2009) explored the way cervical cancer patients search for information, indicating that the closer the time is to the diagnosis the more the need for acquiring information. At the same time, there is also evidence that at the time of diagnosis patients are not receptive
to information (Friis et al, 2003) due to anxiety, stress and their inability to think clearly (Parry, 1990).

Gray et al. (1999) reported findings from their 1-year longitudinal study with 34 prostate cancer patients undergoing surgery and their partners. They support that the need for information can be associated with coping with prostate cancer diagnosis after elevated stress because of the diagnosis. Cliff and Macdonagh (2000) found the partners of prostate cancer patients to be more concerned with treatment-related worry (pain and physical symptoms) whereas patients were more concerned about sexual functioning. Previously Kornbith et al (1994) found that partners revealed higher levels of psychological distress than patients. However, another study (Baider et al., 2003) found patients reporting higher levels of psychological distress than their partners.

The time of information needs development is critical. The theoretical framework proposed by McCaughan and McKenna (2007) attempts to explain the stages people with cancer go through when attempting to regain control over their lives by engaging in information-seeking behaviour. In particular, they pass through several stages on their journey to make sense of their condition: from “taking in” and experiencing the stressful event of the diagnosis, through “taking hold” of the experience and engaging in information-seeking behaviour, to “taking on” where cancer is considered as a life-changing experience (Wallace and Storms, 2007). There is a challenge to identify the timeline of information needs development of cancer patients as well as their significant others, in order to inform health care providers on the important times after diagnosis when patients need support and information.

Salminen et al. (2004) suggest that interest in diet and dietary modifications has been found to increase with the time since diagnosis and educational level increases. They propose that more educated people can better evaluate the benefits of modifying their behaviour in order to return to a “normal” life.

Significant others share similar concerns and interest in health behaviours to those of patients (Lemon et al., 2004). The importance of assessing significant others’ needs is
evident from studies that have shown cancer patients’ first-degree relatives to carry similar health risks to patients if they have similar behavioural risk factors as well (Offit and Brown, 2004; Slattery et al., 2003; Tung et al., 2004). Significant others were also found to carry on unhealthy behaviours after their significant others’ diagnosis (Audrain et al., 2001; Lemon et al., 2004) and they also play an important role in the patients’ coping process (Karademas and Giannousi, 2013).

Health behaviours are associated with health perceptions. For example, an unhealthy diet has been described as a risk factor for cancer (Steinmeitz and Potter, 1991). The perception that health behaviours such as having an unhealthy diet are associated with cancer is more likely to lead to a change to the specific behaviour. One study supported this assessing three health behaviours (diet, exercise, and alcohol consumption) but found no association with smoking (Lemon et al., 2004). The same study found that control was associated with improvements in fruit and vegetable consumption.

Beagan and Chapman (2004) found that breast cancer patients who believed that diet is related to their breast cancer diagnosis were more prone to change their diet after diagnosis. Even those who did not change their dietary behaviour after diagnosis but still believed in a cancer-diet relationship had their reasons: either they believed it was too late or that it was what they had been eating before diagnosis that mattered. Similarly, Rabin and Pinto (2006) found that breast cancer patients were more likely to change the health behaviour they perceived as having contributed to their cancer. Leventhal’s Self-Regulation Model of Health Behaviour (Leventhal et al., 1998) provides a theoretical context for these findings (see Chapter 2, section 2.2.6).

Diet is an unmet information need for cancer patients (Pullar et al., 2012). There is evidence from early studies (Reardon and Aydin, 1993; Taylor et al., 1984; Lee et al., 2000; Burstein et al., 1999) that post-diagnosis and post-treatment women with breast cancer report the need to initiate the following changes: dietary changes, physical activity, seeking information and managing stress. The need for information and the information-seeking behaviour of these women has been associated with the initiation of healthier behaviours (physical activity and diet). There is currently minimalresearch
exploring these relationships among men with prostate cancer. A study (Pullar et al., 2012) conducted with colorectal cancer patients in New Zealand suggests that even though patients were prepared to make changes to their diet post-diagnosis and post-treatment, they reported insufficient information, which was a barrier for change. Another study (Karlsen et al., 2012) indicated that, in general, men with cancer change their dietary behaviour more frequently compared to cancer-free men. There is also evidence (Franks et al., 2010; Hickman and Douglas, 2010) that the post-diagnosis coping process and adherence to health behaviour changes is a dynamic process which involves the needs of significant others along with those of patients. Conversely a recent study (Bidstrup et al., 2013) conducted in Denmark found that women with breast cancer did not reduce their BMI and their alcohol consumption compared to cancer-free women highlighting the need for guidelines and interventions to alter lifestyle behaviours post-diagnosis. This chapter investigates the information seeking and needs of men with prostate cancer post-diagnosis because they form an important indicator of whether patients will adhere to a healthier lifestyle based on previous findings. It will attempt to answer the question of what the trajectory is regarding information needs in the 6-month period after diagnosis for patients and significant others.

This Chapter’s objective is to investigate two prerequisites of behaviour change: information and the perceived cause of cancer. The way to reach the objective is therefore twofold: firstly, to assess patients’ and significant others’ information needs by type and time of information needs’ development and then to investigate whether perceived causes of cancer can predict lifestyle changes and information needs. The aims of the Chapter are:

- To investigate the relationship between lifestyle changes after diagnosis and cancer-related information-seeking behaviour, cancer-related information needs, perceived behavioural control, and a healthy lifestyle prior to diagnosis.

- To investigate the role of educational level on participants’ need for information and the time of their information needs’ development from diagnosis and beyond.
• To compare prostate cancer patients’ and significant others’ need for information and the time of their information needs’ development from diagnosis and beyond.

• To investigate whether perceived prostate cancer risk factors can predict lifestyle changes and dietary information needs after diagnosis.

4.2 Methods

4.2.1 Research Design

A cross-sectional research design using an online questionnaire was used. A mixed design was used, with a between-subjects design to compare patients and significant others, and within-subjects design to compare patients’ needs and the predicting utility of perceived cause of cancer on patients’ information needs and lifestyle change. Participants were asked to state to which group they belonged prior to completing the questionnaire. In particular, they were asked: “Have you been diagnosed with prostate cancer?” and if not they were asked, “Has anyone you are significantly linked with been diagnosed with prostate cancer?” Those that did not meet the above criteria (i.e. were at risk of developing prostate cancer) were excluded. The study received a favourable ethical opinion from the University of Surrey Ethics Committee (Appendix I).

4.2.2 Recruitment

Participants were recruited and were able to access the questionnaire(Appendix II) by two means: 1) Buyers of the Prostate Care Cook Book (Rayman, Dilley and Gibbons, 2009) through an advert which was published in the book (Appendix III) and 2) through the Prostate Cancer Charity which put link to the questionnaire on its website and in its monthly bulletin “Voices” (Appendix IV). Before accessing the questionnaire, participants were able to read a screen with information about the survey and provide
their consent to participate (Appendix V). Those who gave their consent were automatically diverted to the online questionnaire.

In order to take part in the study participants should: a) have been diagnosed with prostate cancer or have been significantly linked (friends and relatives) with a person diagnosed with prostate cancer and b) been able to complete the online questionnaire.

4.2.3 Measures

Patients completed measures about lifestyle changes after diagnosis (diet, exercise, smoking, alcohol consumption), and both groups responded on their information needs and the time when each need was developed, information-seeking behaviour (satisfaction, need, intention), control and perceived causes of cancer. Demographic information (i.e. education, gender) was also assessed as well as their involvement in food shopping and food preparation. Patients provided their medical information (Gleason Score, age of diagnosis, medical treatment and treatment phase) as well. Each measure is outlined below (Table 4.1).
Table 4.1: Measures included in the study

<table>
<thead>
<tr>
<th>Measures used</th>
<th>Number of items</th>
<th>Reference</th>
<th>Group that completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic information</td>
<td>5</td>
<td>New</td>
<td>Patients, Significant others</td>
</tr>
<tr>
<td>Medical Information</td>
<td>4</td>
<td>New</td>
<td>Patients</td>
</tr>
<tr>
<td>Involvement in food shopping</td>
<td>1</td>
<td>New (based in some previous studies i.e. Grunert et al., 2007; Dean et al., 2008)</td>
<td>Patients</td>
</tr>
<tr>
<td>Involvement in food preparation</td>
<td>1</td>
<td>New (based in some previous studies i.e. Grunert et al., 2007; Dean et al., 2008)</td>
<td>Patients</td>
</tr>
<tr>
<td>Lifestyle change after diagnosis</td>
<td>4</td>
<td>Rabin and Pinto (2006)</td>
<td>Patients</td>
</tr>
<tr>
<td>Information needs</td>
<td>11</td>
<td>Rutten et al. (2005)</td>
<td>Patients, Significant others</td>
</tr>
<tr>
<td>Time of information need development</td>
<td>11</td>
<td>New, based on Rutten et al. (2005)</td>
<td>Patients, Significant others</td>
</tr>
<tr>
<td>Information-seeking behaviour (satisfaction, need, intention)</td>
<td>3</td>
<td>Noh et al. (2009)</td>
<td>Patients</td>
</tr>
<tr>
<td>Control</td>
<td>1</td>
<td>New</td>
<td>Patients</td>
</tr>
<tr>
<td>Perceived cause of cancer</td>
<td>12</td>
<td>Sanderson et al. (2008)</td>
<td>Patients</td>
</tr>
</tbody>
</table>

“Demographic and medical information”

All participants were asked to provide details on their age, gender, and marital status (married/living as married, living with another adult(s), single/living alone), level of education (6 choices ranging from “no formal schooling” to “postgraduate degree completed”) and their employment status (full time, part time, retired/not working). Those participants who were diagnosed with prostate cancer were also asked to provide medical information on their Gleason Score, their treatment status (under treatment, in complete remission and recurrent), the age at which they were diagnosed with prostate cancer and the treatments they had undergone (surgery, radiation therapy, chemotherapy or other).
“Involvement in food shopping and food preparation”

Participants’ involvement in food preparation (“What is your involvement in food preparation in your household”) was assessed with participants asked to tick a box to the following statements: “no involvement”, “prepare snacks/drinks occasionally”, “prepare snacks/drinks daily”, “prepare or help prepare meals occasionally”, “prepare or help prepare meals daily”, and “prepare or help prepare all snacks/drinks and meals”. Participants’ involvement in food shopping was assessed (“What is your involvement in food shopping”) with participants asked to tick a box to the following statements: “no involvement”, “discuss with spouse/companion what to buy”, “accompany spouse/companion when food shopping”, do food shopping by self”.

“Lifestyle changes after diagnosis”

The questions related to lifestyle changes after diagnosis in this study were previously used by Rabin and Pinto (2006). In that study, they investigated the relationship between modifiable risk factors and cancer-related beliefs. The lifestyle changes after diagnoses used in the current study were: diet (eating a healthier diet), exercise (increased my level of exercise), alcohol consumption (drink less alcohol) and smoking (have cut down/quit smoking). Participants were asked to rate their response retrospectively (“Since diagnosis I…”) in a 5-point Likert Scale ranging from “strongly agree” to “strongly disagree” on the four lifestyle changes.

“Information needs”

The responses to the question on participants’ information needs are based on a systematic review (Rutten et al., 2005), which identified a typology of cancer patients’ information needs based on the relevant literature. They created a set of categories for information needs. One information need from each category has been included (the one with the highest rating - % found in the literature) while also adding an extra item (“diet
and nutrition”). The 11 categories were: “available treatments/treatment options”, “more information about prostate cancer”, “likely progress of disease”, “self-care issues or home care during delivery”, “effects on family, friends and caregivers”, “emotional reactions, emotional support, coping with cancer”, “interaction issues with health care providers”, “sexuality”, “cost of treatment, insurance coverage or other financial issues”, “diet and nutrition” and “maintaining psychological health” with the added “diet and nutrition”. For each of the 11 needs, participants who were diagnosed with prostate cancer were asked “To what extent were you interested in getting information in relation to the following after being diagnosed” and the question was modified for significant others to “…after the person you are significantly linked with was diagnosed”. Participants were asked to respond on a 5-point Liker Scale ranging from “not at all interested” to “extremely interested”.

The items were also computed into new variables based on a systematic review (Rutten et al., 2005) along with the researcher’s understanding of the items. Specifically, the new variables were: treatment-specific (“available treatments-treatment options”, “self-care issues or home care during recovery”, “cost of treatment, insurance coverage and other financial issues”), disease-specific (“likely progress of disease” and “more information about prostate cancer”), interaction-specific (“effect on family, friends or caregivers” and “interaction issues with health care providers”), emotional health-specific (“emotional reactions, emotional support, coping with cancer” and “maintaining psychological health”) and lifestyle-specific or physical health-specific (“sexuality” and “diet and nutrition”).

“Time of information need development”

Participants were asked to give information on how soon after diagnosis they developed an interest in each of the 11 items. Responses were “immediately”, “less than 1 month”, “1-3 months”, “4-6 months” and “more than 6 months”. Significant others were asked how soon after the person they were significantly linked with was diagnosed with, they developed an interest on each of the 11 items.
“Information-seeking behaviour”

For this study some items were used from Noh et al.’s (2009) study in order to investigate participants’ satisfaction (“I am satisfied with the information received about prostate cancer”), need at the time of diagnosis (“I had a need for information about prostate cancer”) and intention to seek information (“I had the intention of seeking cancer information”). Participants were asked to rate these three items on a 5-point Liker Scale ranging from “strongly agree” to “strongly disagree”.

“Perceived cause of cancer “

For this variable, 12 of the 29 pre-defined categories about cancer that were used in another study (Sanderson et al., 2008) were included in this study. These items were associated with lifestyle changes compared with the rest of the 29 categories in the study, and included “having a weakened or impaired immune system”, “diet in general”, “smoking” and “genetics” etc. Patients were asked to rate how much they considered each item to be associated with their diagnosis on a 5-point Liker scale ranging from “not at all” to “extremely”.

“Control”

An item was used measuring the level of control of participants. They were asked to rate how much they agreed with the statement “By living healthily I can influence the course of my cancer” on a 5-point Liker scale ranging from “strongly agree” to “strongly disagree”.


4.2.4 Analytic Plan

a) Between-subjects: After checking for the assumption of the collected data’s normality of distribution, a series of independent t-tests and chi squares was used to investigate differences in demographic information between participants recruited through the Prostate Care Cook Book and those who were recruited through the Prostate Cancer Charity. Bivariate and multivariate analyses were used to examine differences between groups. Spearman’s correlations were used to investigate the relationship between the study’s included variables. A series of Kruskall Wallis tests and Mann-Whitney post-hoc tests were used to investigate the effect of educational level on i) the need for information after diagnosis and ii) the time of information need development after diagnosis. A Mann-Whitney test was used to investigate differences between the groups (patients/significant others) on their need for information and the time of their information need development after diagnosis.

b) Within-subjects: A Friedman’s ANOVA and a series of Wilcoxon signed-rank post-hoc tests were used to determine participants’ interest in included information needs. A series of linear regressions were used with two sets of variables: i) diet as a perceived cause of cancer and healthier diet as a lifestyle change, ii) a lack of exercise as a perceived cause of cancer and more exercise as a lifestyle change and iii) alcohol consumption as a perceived cause of cancer and less alcohol consumption as a lifestyle change. It was decided not to assess smoking because participants were not asked whether they smoked or not on the onset of the study. The hypothesis is that if prostate cancer patients believe certain health behaviours to be a cause of their illness they will change that behaviour after diagnosis. Similarly, linear regression analysis was implemented to investigate whether diet as perceived cause of cancer predicts diet as an information need after diagnosis (Figure 4.1).
4.3. Results

4.3.1 Data Screening

Data was analysed using SPSS for Windows, Version 19.0 (SPSS, Chicago, IL). There was less than 5% missing data (Tabachnik and Fidell, 2007) and no significant differences were found between missing values so no data was excluded. Data was screened for outliers (univariate and multivariate) and for assumptions of normality. A Kolmogorov Smirnov (KS) test was implemented for checking normality of data distribution. The KS test was significant for all variables except lifestyle changes and a set of information needs (including diet) and thus the assumption of normality of distribution for these variables could not be confirmed. Demographics (age, level of education etc.) were normally distributed.
4.3.2 Participants

In total 98 participated in the study (N=98), 73 of whom were diagnosed with prostate cancer and 25 were significantly linked with a person who was diagnosed with prostate cancer. The participants’ age ranged from 23 to 81 for those diagnosed with prostate cancer, 22 to 80 and 23 to 70 for those significantly linked with a person diagnosed with prostate cancer.

The majority of the respondents were married or living as married (n= 87) while fewer were single/living alone (n= 11). Regarding the participants’ educational level, most had received education from secondary school or gained a job-related qualification and higher (n = 59) and fewer had only a primary education or no schooling (n = 39). The majority of the participants were involved in food shopping (n = 69) and food preparation (n = 71). Of the 25 respondents who were significantly linked with a person diagnosed with prostate cancer, 9 were male and 16 female. More details on the participants’ demographics, medical information and involvement in food shopping and food preparation can be found in Table 4.2.
Table 4.2. Characteristics of respondents (N = 98)

<table>
<thead>
<tr>
<th></th>
<th>Prostate cancer patients</th>
<th>Significant others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>73</td>
<td>50.9</td>
</tr>
<tr>
<td>Age of diagnosis</td>
<td>73</td>
<td>58.3</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>73</td>
<td>100</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Gleason Score</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>73</td>
<td>7.1</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living as married</td>
<td>54</td>
<td>74</td>
</tr>
<tr>
<td>Living with another adult(s)</td>
<td>10</td>
<td>13.7</td>
</tr>
<tr>
<td>Single/living alone</td>
<td>9</td>
<td>12.3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No formal education</td>
<td>14</td>
<td>19.2</td>
</tr>
<tr>
<td>Less than primary school</td>
<td>3</td>
<td>4.1</td>
</tr>
<tr>
<td>Primary school completed</td>
<td>3</td>
<td>4.1</td>
</tr>
<tr>
<td>Secondary school or job-related qualifications</td>
<td>14</td>
<td>19.2</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>26</td>
<td>35.6</td>
</tr>
<tr>
<td>Postgraduate degree</td>
<td>13</td>
<td>17.8</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time paid work</td>
<td>45</td>
<td>61.6</td>
</tr>
<tr>
<td>Part-time paid work</td>
<td>7</td>
<td>9.5</td>
</tr>
<tr>
<td>Retired/Not working</td>
<td>21</td>
<td>18.9</td>
</tr>
<tr>
<td><strong>Treatment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under treatment</td>
<td>21</td>
<td>60</td>
</tr>
<tr>
<td>In complete remission</td>
<td>3</td>
<td>8.6</td>
</tr>
<tr>
<td>Recurrent</td>
<td>6</td>
<td>17.1</td>
</tr>
<tr>
<td>Not reported</td>
<td>5</td>
<td>14.3</td>
</tr>
<tr>
<td><strong>Treatment type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>14</td>
<td>19.2</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>16</td>
<td>21.9</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Other/Unspecified</td>
<td>42</td>
<td>57.5</td>
</tr>
</tbody>
</table>
## Involvement in food shopping

<table>
<thead>
<tr>
<th></th>
<th>Prostate cancer patients</th>
<th>Significant others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>No involvement</td>
<td>18</td>
<td>24.7</td>
</tr>
<tr>
<td>Discuss with spouse/companions what to buy</td>
<td>14</td>
<td>19.2</td>
</tr>
<tr>
<td>Accompany spouse/companion with food shopping</td>
<td>27</td>
<td>37</td>
</tr>
<tr>
<td>Do food shopping by self</td>
<td>14</td>
<td>19.2</td>
</tr>
</tbody>
</table>

## Involvement in food preparation

<table>
<thead>
<tr>
<th></th>
<th>Prostate cancer patients</th>
<th>Significant others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>No involvement</td>
<td>18</td>
<td>24.7</td>
</tr>
<tr>
<td>Prepare snacks/drinks occasionally</td>
<td>5</td>
<td>6.8</td>
</tr>
<tr>
<td>Prepare snacks/drinks daily</td>
<td>2</td>
<td>2.7</td>
</tr>
<tr>
<td>Prepare or help to prepare meals occasionally</td>
<td>21</td>
<td>28.8</td>
</tr>
<tr>
<td>Prepare or help to prepare meals daily</td>
<td>18</td>
<td>24.7</td>
</tr>
<tr>
<td>Prepare or help to prepare all snacks/drinks and meals</td>
<td>9</td>
<td>12.3</td>
</tr>
</tbody>
</table>

A series of independent sample t-tests were performed in order to identify any differences in the sample between participants who had accessed the online questionnaire through the Prostate Care Cook Book and participants who had accessed the online questionnaire through the Prostate Cancer Charity. Significant differences were found only regarding the level of education with participants accessing the online questionnaire through the Prostate Cancer Charity (M = 4.2, SE = 0.2) more educated than participants accessing the online questionnaire through the Prostate Care Cook Book (M = 3.3, SE = 0.3), t(98) = -2.45, p < .05 representing a small effect size r = .24 (Table 4.3). Furthermore, a chi square test showed no significant differences between the two recruitment sources and marital status, $\chi^2(1, N = 98) = 1.19$, p > .05.
Table 4.3: Comparing means between different sources of recruitment

<table>
<thead>
<tr>
<th></th>
<th>Prostate Care Cook Book (N=44)</th>
<th>Prostate Cancer Charity website (N=54)</th>
<th>t</th>
<th>df</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SE</td>
<td>M</td>
<td>SE</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>46.4</td>
<td>2.6</td>
<td>52.9</td>
<td>2.2</td>
<td>-1.93</td>
</tr>
<tr>
<td>Education</td>
<td>3.3</td>
<td>0.3</td>
<td>4.2</td>
<td>0.2</td>
<td>-2.45*</td>
</tr>
<tr>
<td>Involvement in food shopping</td>
<td>2.3</td>
<td>0.2</td>
<td>2.5</td>
<td>0.1</td>
<td>-0.69</td>
</tr>
<tr>
<td>Involvement in food preparation</td>
<td>3.3</td>
<td>0.3</td>
<td>3.6</td>
<td>0.2</td>
<td>-0.72</td>
</tr>
</tbody>
</table>

* p < .05

4.3.3 Correlation Analysis

Before conducting any further analyses, Spearman’s correlation coefficients were used to investigate the associations between study variables for prostate cancer patients (Table 4.4). Perceived lifestyle prior to diagnosis was not correlated with two types of lifestyle changes (diet and smoking) and two types of information-seeking behaviour (intention and need). Another important finding is that information-seeking behaviour (intention, satisfaction and need) were all positively correlated with changes after diagnosis (diet, smoking, alcohol consumption and exercise) and also with perceived behavioural control.
### Table 4.4: Spearman’s Correlations coefficients between study variables for patients (N=73)

<table>
<thead>
<tr>
<th></th>
<th>Lifestyle change (diet)</th>
<th>Lifestyle change (exercise)</th>
<th>Lifestyle change (smoking)</th>
<th>Lifestyle change (alcohol consumption)</th>
<th>Information-seeking behaviour (satisfaction)</th>
<th>Information-seeking behaviour (need)</th>
<th>Information-seeking behaviour (intention)</th>
<th>Perceived healthy lifestyle</th>
<th>Perceived behavioural control</th>
<th>Perceived lifestyle prior to diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle change (diet)</td>
<td>_</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle change (exercise)</td>
<td>682**</td>
<td>_</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle change (smoking)</td>
<td>.482**</td>
<td>.622**</td>
<td>_</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifestyle change (alcohol consumption)</td>
<td>.600**</td>
<td>.738**</td>
<td>.890**</td>
<td>_</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Information-seeking behaviour (satisfaction)</td>
<td>.508**</td>
<td>.617**</td>
<td>.571**</td>
<td>.667**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking behaviour (need)</td>
<td>.343*</td>
<td>.521**</td>
<td>.365*</td>
<td>.433**</td>
<td>.231</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information-seeking behaviour (intention)</td>
<td>.396*</td>
<td>.626**</td>
<td>.514**</td>
<td>.643**</td>
<td>.423**</td>
<td>.630**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived healthy lifestyle</td>
<td>.632**</td>
<td>.570**</td>
<td>.378*</td>
<td>.585**</td>
<td>.720**</td>
<td>.379*</td>
<td>.512**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived behavioural control</td>
<td>.508**</td>
<td>.540**</td>
<td>.324*</td>
<td>.506**</td>
<td>.439**</td>
<td>.578**</td>
<td>.735**</td>
<td>.711**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived lifestyle prior to diagnosis</td>
<td>.333</td>
<td>.416**</td>
<td>.280</td>
<td>.391*</td>
<td>.586**</td>
<td>.163</td>
<td>.206</td>
<td>.698**</td>
<td>.436**</td>
<td></td>
</tr>
</tbody>
</table>

* p < .05 (1-tailed) ** p < .01 (1-tailed)
Specifically for the relationship between information-seeking behaviour and lifestyle changes after diagnosis, the $R^2$ used for interpreting the amount of variability in one variable explained by the other reveal that a need for more information accounts for a higher variability (41%) in drinking less alcohol after diagnosis ($R^2 = .41$). Intending to look for more cancer-related information accounts for a higher variability (39% and 34% respectively) in exercising more ($R^2 = .39$) and drinking less alcohol after diagnosis ($R^2 = .34$). Finally being satisfied with information received accounts for a higher variability (38% and 32% respectively) in exercising more ($R^2 = .38$) and smoking less after diagnosis ($R^2 = .32$). However, satisfaction ($R^2 = .25$), need ($R^2 = .11$) and intention ($R^2 = .15$) do not explain a great variance in having a healthier diet after diagnosis even though the correlation is significant.

4.3.4 The role of educational level on information needs and their development

An independent samples t-test was performed to investigate differences between patients and significant others regarding their age and level of education. No significant differences were found regarding their age, $t (98) = 0.95, p = .34$ or their level of education, $t (98) = 1.99, p = .07$. To investigate the role of educational level on information needs and the time of information needs development, a series of Kruskall Wallis tests were used: a) one for comparing the need for information between participants with different levels of education (Table 4.5) and b) one for comparing the time of information needs development between participants with different levels of education (Table 4.7). Because of the small number of participants who had no formal education, participants with less than primary and primary education completed were grouped together. Consequently four groups were compared: No education-primary school completed, secondary education, tertiary education and postgraduate education.
4.3.4.1 Comparing the need for information between groups of educational level

Results revealed that the educational level of participants significantly affected the participants’ need for information of all types. In general, less educated participants were less in need of all the types of information after their diagnosis or the diagnosis of their significant other. All effects are reported at $p < .001$. Jonckheere’s tests for all types of information needs revealed a similar significant trend in the data: the more educated participants were, the more they were in need of information (Table 4.5).

Mann-Whitney tests were used to follow up these findings (Table 4.6). A Bonferroni correction was applied so all effects are reported at a .016 level of significance. Mann-Whitney tests confirmed the findings from Kruskall Wallis with participants with education ranging from “no education” to “primary school” being less in need of information than the other 3 groups (secondary, tertiary, postgraduate). The effect size was large for all information needs.
Table 4.5: Differences between level of education and information needs (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>No education/primary (n=32)</th>
<th>Secondary (n=17)</th>
<th>Tertiary (n=32)</th>
<th>Postgraduate (n=17)</th>
<th>H</th>
<th>p</th>
<th>J</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>22.1</td>
<td>58.2</td>
<td>65.7</td>
<td>61.8</td>
<td>50.48*</td>
<td>.000</td>
<td>6.11</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>20.8</td>
<td>62.1</td>
<td>65.9</td>
<td>60</td>
<td>54.18*</td>
<td>.000</td>
<td>5.88</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>20.9</td>
<td>60.9</td>
<td>63.4</td>
<td>65.8</td>
<td>53.52*</td>
<td>.000</td>
<td>6.42</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>20.7</td>
<td>61.7</td>
<td>64.6</td>
<td>63.2</td>
<td>52.99*</td>
<td>.000</td>
<td>6.13</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>22.7</td>
<td>64.2</td>
<td>64.2</td>
<td>57.5</td>
<td>46.45*</td>
<td>.000</td>
<td>5.1</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>24.2</td>
<td>60.9</td>
<td>62.6</td>
<td>61</td>
<td>40.98*</td>
<td>.000</td>
<td>5.29</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>21.6</td>
<td>62.9</td>
<td>62.1</td>
<td>64.9</td>
<td>49.15*</td>
<td>.000</td>
<td>5.95</td>
</tr>
<tr>
<td>Sexuality</td>
<td>24.8</td>
<td>62.9</td>
<td>57.2</td>
<td>68.2</td>
<td>40.67*</td>
<td>.000</td>
<td>5.64</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>28.7</td>
<td>62.2</td>
<td>55.7</td>
<td>64.4</td>
<td>29.19*</td>
<td>.000</td>
<td>4.6</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>20.7</td>
<td>59.2</td>
<td>62.2</td>
<td>76.2</td>
<td>56.43*</td>
<td>.000</td>
<td>7.02</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>15.5</td>
<td>50.7</td>
<td>66.2</td>
<td>55.9</td>
<td>54.52*</td>
<td>.000</td>
<td>6.29</td>
</tr>
</tbody>
</table>

*p < .001
Table 4.6: Mann-Whitney post-hoc tests between different levels of education and information needs (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>No education/primary (n=32)</th>
<th>Secondary (n=17)</th>
<th>U</th>
<th>r</th>
<th>No education/primary (n=32)</th>
<th>Tertiary (n=32)</th>
<th>U</th>
<th>r</th>
<th>No education/primary (n=32)</th>
<th>Post-graduate (n=17)</th>
<th>U</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/options</td>
<td>18.5</td>
<td>32.2</td>
<td>64.5*</td>
<td>.71</td>
<td>19.1</td>
<td>45.9</td>
<td>81.5*</td>
<td>.78</td>
<td>17.6</td>
<td>39</td>
<td>34*</td>
<td>.79</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>18.2</td>
<td>37.9</td>
<td>53.5*</td>
<td>.76</td>
<td>18.2</td>
<td>46.8</td>
<td>55.5*</td>
<td>.82</td>
<td>17.4</td>
<td>39.4</td>
<td>28*</td>
<td>.82</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>18.1</td>
<td>38.1</td>
<td>49.5*</td>
<td>.77</td>
<td>18.9</td>
<td>46.1</td>
<td>77.5*</td>
<td>.79</td>
<td>17</td>
<td>40.1</td>
<td>15.5*</td>
<td>.87</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>18.1</td>
<td>38.1</td>
<td>50*</td>
<td>.76</td>
<td>18.6</td>
<td>46.5</td>
<td>65.5*</td>
<td>.8</td>
<td>17.1</td>
<td>39.9</td>
<td>19*</td>
<td>.84</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>18.2</td>
<td>37.7</td>
<td>55.5*</td>
<td>.76</td>
<td>19.5</td>
<td>45.6</td>
<td>94.5*</td>
<td>.76</td>
<td>18.1</td>
<td>38.1</td>
<td>49.5*</td>
<td>.76</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>18.5</td>
<td>37.3</td>
<td>63*</td>
<td>.72</td>
<td>21.1</td>
<td>43.9</td>
<td>147*</td>
<td>.67</td>
<td>17.6</td>
<td>38.9</td>
<td>36.5*</td>
<td>.79</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>18.1</td>
<td>37.9</td>
<td>52*</td>
<td>.75</td>
<td>19.3</td>
<td>45.7</td>
<td>89*</td>
<td>.76</td>
<td>17.2</td>
<td>39.8</td>
<td>21*</td>
<td>.84</td>
</tr>
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<td>Sexuality</td>
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<td>37.3</td>
<td>63.5*</td>
<td>.71</td>
<td>21.4</td>
<td>43.6</td>
<td>158*</td>
<td>.65</td>
<td>17.8</td>
<td>38.5</td>
<td>43*</td>
<td>.77</td>
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<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>19.1</td>
<td>36.1</td>
<td>83*</td>
<td>.65</td>
<td>23.8</td>
<td>41.2</td>
<td>234*</td>
<td>.52</td>
<td>18.8</td>
<td>36.8</td>
<td>72*</td>
<td>.68</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>18.1</td>
<td>37.9</td>
<td>52*</td>
<td>.76</td>
<td>18.6</td>
<td>46.4</td>
<td>67.5*</td>
<td>.8</td>
<td>16.9</td>
<td>40.2</td>
<td>14.5*</td>
<td>.87</td>
</tr>
<tr>
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<td>14.5</td>
<td>32.9</td>
<td>26*</td>
<td>.8</td>
<td>14.5</td>
<td>40.6</td>
<td>26*</td>
<td>.82</td>
<td>13.5</td>
<td>34.5</td>
<td>0*</td>
<td>.89</td>
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</tbody>
</table>

* p < .001
Table 4.7: Differences between level of education and time of information need development (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>No education-primary (n=32)</th>
<th>Secondary (n=17)</th>
<th>Tertiary (n=32)</th>
<th>Postgraduate (n=17)</th>
<th>H</th>
<th>p</th>
<th>J</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>42.6</td>
<td>45.4</td>
<td>49.9</td>
<td>60.3</td>
<td>8.51*</td>
<td>.03</td>
<td>2.76</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>43.7</td>
<td>46.1</td>
<td>47.1</td>
<td>62.4</td>
<td>8.85*</td>
<td>.03</td>
<td>2.4</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>42.1</td>
<td>44.7</td>
<td>50.6</td>
<td>60.5</td>
<td>7.94*</td>
<td>.04</td>
<td>2.72</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>33.3</td>
<td>44.6</td>
<td>55.3</td>
<td>68.9</td>
<td>24.62**</td>
<td>.000</td>
<td>5.07</td>
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<tr>
<td>Effect on family, friends or caregivers</td>
<td>36.1</td>
<td>43.2</td>
<td>54.4</td>
<td>66.8</td>
<td>19.53**</td>
<td>.000</td>
<td>4.49</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>35.5</td>
<td>46.2</td>
<td>51.5</td>
<td>70.1</td>
<td>22.21**</td>
<td>.000</td>
<td>4.65</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>34.4</td>
<td>45.9</td>
<td>53</td>
<td>69.7</td>
<td>22.83**</td>
<td>.000</td>
<td>4.75</td>
</tr>
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<td>35.2</td>
<td>42.1</td>
<td>59.6</td>
<td>60.4</td>
<td>19.92**</td>
<td>.000</td>
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<td>47.9</td>
<td>57</td>
<td>69.4</td>
<td>31.85**</td>
<td>.000</td>
<td>5.6</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>35.5</td>
<td>49.6</td>
<td>49.6</td>
<td>70</td>
<td>22.24**</td>
<td>.000</td>
<td>4.44</td>
</tr>
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<td>36.7</td>
<td>45.6</td>
<td>51.6</td>
<td>68.1</td>
<td>18.78**</td>
<td>.000</td>
<td>4.3</td>
</tr>
</tbody>
</table>

* p < .05 ** p < .001
**Table 4.8: Mann-Whitney post-hoc tests between different levels of education and time of information needs development (N = 98)**

<table>
<thead>
<tr>
<th>Information Need</th>
<th>No education-primary (n=32)</th>
<th>Secondary (n=17)</th>
<th>U</th>
<th>r</th>
<th>No education-primary (n=32)</th>
<th>Tertiary (n=32)</th>
<th>U</th>
<th>r</th>
<th>No education-primary (n=32)</th>
<th>Post-graduate (n=17)</th>
<th>U</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/ options</td>
<td>24.5</td>
<td>25.9</td>
<td>256</td>
<td>.07</td>
<td>29.2</td>
<td>33.8</td>
<td>407</td>
<td>.18</td>
<td>21.9</td>
<td>30.9</td>
<td>171*</td>
<td>-.4</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>24.6</td>
<td>25.8</td>
<td>259</td>
<td>.05</td>
<td>30.5</td>
<td>32.5</td>
<td>449</td>
<td>.07</td>
<td>21.6</td>
<td>31.5</td>
<td>162*</td>
<td>-.4</td>
</tr>
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<td>Likely progress of disease</td>
<td>24.6</td>
<td>25.9</td>
<td>257.5</td>
<td>.06</td>
<td>28.8</td>
<td>34.4</td>
<td>394</td>
<td>.19</td>
<td>21.8</td>
<td>31.1</td>
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<td>Self-care issues or home care during recovery</td>
<td>23</td>
<td>28.8</td>
<td>207</td>
<td>.25</td>
<td>24.4</td>
<td>39.1</td>
<td>253**</td>
<td>.45</td>
<td>18.9</td>
<td>36.4</td>
<td>78**</td>
<td>-.66</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>23.5</td>
<td>27.8</td>
<td>224</td>
<td>.19</td>
<td>25.6</td>
<td>37.7</td>
<td>293*</td>
<td>.39</td>
<td>19.9</td>
<td>34.6</td>
<td>109**</td>
<td>-.56</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>22.9</td>
<td>28.9</td>
<td>205.5</td>
<td>.26</td>
<td>26.3</td>
<td>37</td>
<td>314**</td>
<td>.35</td>
<td>19.3</td>
<td>35.8</td>
<td>88**</td>
<td>-.64</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>22.9</td>
<td>28.9</td>
<td>206</td>
<td>.25</td>
<td>25.5</td>
<td>37.9</td>
<td>288*</td>
<td>.39</td>
<td>18.9</td>
<td>36.4</td>
<td>78**</td>
<td>-.66</td>
</tr>
<tr>
<td>Sexuality</td>
<td>23.9</td>
<td>27.1</td>
<td>236</td>
<td>.15</td>
<td>23.9</td>
<td>39.6</td>
<td>236**</td>
<td>.49</td>
<td>20.4</td>
<td>33.6</td>
<td>126**</td>
<td>-.52</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
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<td>31.2</td>
<td>166*</td>
<td>.42</td>
<td>23.1</td>
<td>40.5</td>
<td>210**</td>
<td>.55</td>
<td>17.9</td>
<td>38.3</td>
<td>46**</td>
<td>-.78</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>22.6</td>
<td>29.6</td>
<td>194</td>
<td>.31</td>
<td>26.9</td>
<td>36.5</td>
<td>331*</td>
<td>.33</td>
<td>19.1</td>
<td>36.2</td>
<td>81**</td>
<td>-.66</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>23.4</td>
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<td>221</td>
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<td>36.8</td>
<td>36.8</td>
<td>322*</td>
<td>.33</td>
<td>19.8</td>
<td>34.9</td>
<td>104**</td>
<td>-.58</td>
</tr>
</tbody>
</table>

* p < .01 ** p < .001
4.3.4.2 Comparing the time of information need development between groups of different educational levels

Results revealed that the educational level of the participants significantly affected the time of information need development regarding all types of information needs. In general, the less educated participants were in need of all the types of information closer to the time of diagnosis rather than the more educated participants. However, the significance level was less for “available treatments/treatment options”, \( H (3) = 8.51, p < .05 \), “more information about prostate cancer”, \( H (3) = 8.85, p < .05 \) and “likely progress of disease”, \( H (3) = 7.94, p < .05 \). All the other effects are reported at \( p < .001 \). Jonckheere’s tests for all types of information needs revealed a similar significant trend in the data: the less educated the participants were, the more they were in need of information closer to diagnosis.

A series of post-hoc Mann-Whitney tests were used to follow up these findings (Table 4.8). A Bonferroni correction was applied so all effects were reported at a .016 level of significance. Mann-Whitney tests showed that the participants with education ranging from “no education” to “primary school” significantly differed from participants with a “secondary education” only as regards “Cost of treatment, insurance coverage and other financial issues” (\( U = 166, r = -.42 \)) with less educated participants in need of this type of information closer to diagnosis.

Participants with “no formal” to “primary education” were significantly more in need of all types of information closer do diagnosis compared to participants with tertiary education except for “Available treatments/treatment options” (\( U = 407, r = -.18 \)), “More information about prostate cancer” (\( U = 449, r = -.07 \)) and “Likely progress of disease” (\( U = 394, r = -.19 \)). Also, between these two groups, three types of information had a higher effect size and significance level than the others: “Self-care issues or home care during recovery” (\( U = 253, r = .45 \)), “Sexuality” (\( U = 236, r = .49 \)) and “Cost of treatment, insurance coverage and other financial issues” (\( U = 210, r = .55 \)).

On the other hand, participants with “no formal” to “primary education” were significantly more in need of all types of information closer to diagnosis than patients with postgraduate education. The effect size was large for all information
needs except for three, which had medium effect sizes: “Available treatments/treatment option” (U = 171, r = .4), “More information about prostate cancer” (U = 162, r = .4) and “Likely progress of disease” (U = 168, r = .38). Thus, the more “distance” between educational levels existed, the more significant differences were observed.

4.3.5 Compare information needs and their time of development between patients and significant others

To compare the two groups on their information needs and their time of development, a series of between-subjects analyses was performed. Initially the means of both groups’ responses on the time of information need development post-diagnosis are shown in Table 4.9. The period 6 months post-diagnosis reveals the trajectory of patients’ and significant others’ information needs development (Figure 4.2). While most of the participants from both groups indicated that they developed their information needs closer to diagnosis, data from patients reported a rise in responses after 3 months of diagnosis while significant others showed a decline of responses after the 1st month post-diagnosis.

Table 4.9: Frequencies of participants’ responses on time of information needs development

<table>
<thead>
<tr>
<th></th>
<th>Immediately</th>
<th>Less than 1 month</th>
<th>1-3 months</th>
<th>4-6 months</th>
<th>More than 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>40.55 (6.06)</td>
<td>11.73 (3.26)</td>
<td>3.18 (1.54)</td>
<td>5.18 (1.54)</td>
<td>10.36 (2.73)</td>
</tr>
<tr>
<td>Significant others</td>
<td>17.82 (2.4)</td>
<td>3.91 (1.14)</td>
<td>1.91 (0.7)</td>
<td>0.36 (0.5)</td>
<td>1 (1)</td>
</tr>
</tbody>
</table>

Note: Standard Deviations are reported in parentheses.
A Mann-Whitney test was implemented to investigate the differences in information needs between patients and significant others (Table 4.10). The two groups did not significantly differ on the type of their information needs.

A Mann-Whitney test was then implemented to test differences between the two groups on the time of information needs development (Table 4.11). Significant others were found to develop the need for information earlier than patients on a number of items. There were significant differences between patients and significant others on the development of the “available treatments/treatment options” need (U = 729, r = -.15), the “more information about prostate cancer” need (U = 734.5, r = -.18), the “self-care issues or home care during recovery” need (U = 681.5, r = -.12), the “interaction issues with health care providers” need (U = 571.5, r = -.09) and the “maintaining psychological health” need (U = 709, r = -.15). All of the effect sizes were small. For all of these information needs, significant others were found to develop the need for information significantly closer to diagnosis than patients did.
Table 4.10: Mann-Whitney test for differences between patients and significant others on type of information needs (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Patients (n=73)</th>
<th>Significant others (n=25)</th>
<th>U</th>
<th>R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/ options</td>
<td>51.2</td>
<td>44.5</td>
<td>788</td>
<td>-.11</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>51.2</td>
<td>44.5</td>
<td>787</td>
<td>-.11</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>51.4</td>
<td>43.9</td>
<td>772</td>
<td>-.12</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>51.4</td>
<td>43.9</td>
<td>772.5</td>
<td>-.12</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>50.8</td>
<td>45.7</td>
<td>812</td>
<td>-.08</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>50.7</td>
<td>45.9</td>
<td>822</td>
<td>-.07</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>50.4</td>
<td>46.9</td>
<td>847</td>
<td>-.05</td>
</tr>
<tr>
<td>Sexuality</td>
<td>52</td>
<td>42.3</td>
<td>731.5</td>
<td>-.09</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>51</td>
<td>45.1</td>
<td>801.5</td>
<td>-.15</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>51</td>
<td>45.1</td>
<td>802</td>
<td>-.1</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>45.8</td>
<td>41</td>
<td>685</td>
<td>-.08</td>
</tr>
</tbody>
</table>

Therefore, even though there were no significant differences between the groups regarding their information needs there were significant differences in the time of some of the needs’ development after diagnosis between patients and significant others.
Table 4.11: Mann-Whitney test for differences between patients and significant others on time of information needs development (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Patients (n=73)</th>
<th>Significant others (n=25)</th>
<th>U</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/ options</td>
<td>50.7</td>
<td>42.1</td>
<td>729</td>
<td>-.15*</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>50.7</td>
<td>42.4</td>
<td>734.5</td>
<td>-.18*</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>50.2</td>
<td>43.6</td>
<td>764.5</td>
<td>-.16</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>51.4</td>
<td>40.3</td>
<td>681.5</td>
<td>-.12*</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>50.7</td>
<td>42.3</td>
<td>731.5</td>
<td>-.19</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>49.9</td>
<td>44.4</td>
<td>785.5</td>
<td>-.14</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>53</td>
<td>35.9</td>
<td>571.5</td>
<td>-.09**</td>
</tr>
<tr>
<td>Sexuality</td>
<td>49.3</td>
<td>46.3</td>
<td>833</td>
<td>-.29</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>50</td>
<td>44.3</td>
<td>782.5</td>
<td>-.05</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>50.7</td>
<td>42.3</td>
<td>731.5</td>
<td>-.09</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>51</td>
<td>41.4</td>
<td>709</td>
<td>-.15*</td>
</tr>
</tbody>
</table>

* p < .05 ** p < .01

In order to further investigate the nature and differences between the two groups with regard to their information needs development after diagnosis, the needs were then conceptualized according to their content (see section 4.2.3).

A reliability analysis was conducted in order to establish the grouping variables’ interrelated reliability and unidimensionality (Table 4.12). All new variables had a Cronbach’s α higher than the generally accepted value of .7 which is considered appropriate for measuring psychological constructs (Kline, 1999).
Table 4.12: Reliability Analyses for tested scales (N=98)

<table>
<thead>
<tr>
<th>Scales</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment-specific information needs</td>
<td>.94</td>
</tr>
<tr>
<td>Disease-specific information needs</td>
<td>.98</td>
</tr>
<tr>
<td>Interaction-specific information needs</td>
<td>.90</td>
</tr>
<tr>
<td>Emotional health-specific information needs</td>
<td>.91</td>
</tr>
<tr>
<td>Lifestyle-specific information needs</td>
<td>.87</td>
</tr>
</tbody>
</table>

Since all scales were consistent, the Mann-Whitney test for differences between patients and significant others regarding the time of information needs development were repeated to investigate any differences in the nature of information needs (Table 4.13). The computed variables were used in the analysis.

Table 4.13: Mann-Whitney test for differences between patients and significant others on time of information needs development (N = 98)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Patients (n= 73)</th>
<th>Significant others (n= 25)</th>
<th>U</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment-specific</td>
<td>51.7</td>
<td>39.4</td>
<td>660.5</td>
<td>-.20*</td>
</tr>
<tr>
<td>Emotional health-specific</td>
<td>50.6</td>
<td>42.5</td>
<td>736.5</td>
<td>-.12</td>
</tr>
<tr>
<td>Lifestyle-specific</td>
<td>50.4</td>
<td>43.2</td>
<td>755.5</td>
<td>-.11</td>
</tr>
<tr>
<td>Disease-specific</td>
<td>50.3</td>
<td>43.4</td>
<td>760.5</td>
<td>-.13</td>
</tr>
<tr>
<td>Interaction-specific</td>
<td>52.1</td>
<td>38.3</td>
<td>632.5</td>
<td>-.23*</td>
</tr>
</tbody>
</table>

* p < .05

Results from the analysis indicate that significant differences were found between patients (Mdn = 51.7) and significant others (Mdn = 39.4) on treatment-specific information needs, U = 660.5, p < .05 and between patients (Mdn = 52.1) and significant others (Mdn = 38.3) on interaction-specific information needs, U = 632.5, p < .05. On both scales, significant others reported developing the need for relevant information closer to diagnosis than patients did. No significant differences were
found between the two groups on disease-specific, emotional health-specific and lifestyle-specific information needs.

To sum up, patients and significant others both reported developing their need for information closer to diagnosis. However, patients reported an increased interest in information after the third month post-diagnosis while significant others reported a gradual decline in their interest in information after the diagnosis of their significant other.

Also, patients and significant others did not significantly differ on their information needs. However they significantly differed on the time when they developed a need for information regarding available treatments and treatment options, more information on prostate cancer, self-care issues-home care during recovery, interaction issues with health care providers and maintaining psychological health with significant others reporting that they developed a need for relevant information closer to diagnosis rather than the patients did. Overall, significant others developed a need for treatment-specific and interaction-specific information closer to diagnosis than patients.

4.3.6 Differences between different types of information needs

Results from Friedman’s ANOVA between the five types of information needs indicated that after diagnosis, patients’ interest in the different types of information differed on how interested they were in obtaining different types of information, \( \chi^2 (4) = 23.27, p < .001 \). This was not the case for significant others, \( \chi^2 (4) = 4, p = .42 \).

A series of Wilcoxon signed-rank post-hoc tests (Table 5.14) were used to determine differences between the information needs for patients. A Bonferroni correction was applied and so all effects are reported at \( p = .005 \) level of significance. Patients reported higher interest in treatment-specific (Mdn = 6.65) and disease-specific (Mdn = 6.78) information when compared to interaction-specific (Mdn = 6.62) and emotional-specific (Mdn = 5.98) information.
Table 4.14: Wilcoxon signed-rank post-hoc test between information needs for patients (n=73).

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Treatment-specific</td>
<td>z=-1.41 *</td>
<td>z=-3.56 *</td>
<td>z=-3.14 *</td>
<td>z=-1.54 *</td>
</tr>
<tr>
<td></td>
<td>(Mdn = 6.65)</td>
<td>r = -.16</td>
<td>r = -.42</td>
<td>r = -.37</td>
<td>r = -.18</td>
</tr>
<tr>
<td>2</td>
<td>Disease-specific</td>
<td>z=-3.92 *</td>
<td>z=-3.54 *</td>
<td>z=-2.33 *</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Mdn = 6.78)</td>
<td>r = -.46</td>
<td>r = -.41</td>
<td>r = -.27</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Interaction-specific</td>
<td>z=-0.06</td>
<td>z=-1.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Mdn = 6.62)</td>
<td>r = -.01</td>
<td>r = -.16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Emotional-specific</td>
<td></td>
<td>z=-1.32</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Mdn = 5.98)</td>
<td>r = -.15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Lifestyle-specific</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
|   | (Mdn = 6.32)   |  * p < .05 *

4.3.7 Perceived causes of cancer and lifestyle changes

Results from regression analyses (Table 4.15) on three perceived causes of cancer (diet, alcohol consumption and exercise) only partly support the hypothesis that after diagnosis patients change the lifestyle factor they consider as a cause of cancer. Only lack of exercise as a perceived cause of cancer was a significant predictor of exercising more after diagnosis (β = .384, p = .028). However diet (β = .283, p = .111) and alcohol consumption (β = .124, p = .492) were not significant predictors of participants’ lifestyle changes after being diagnosed with prostate cancer. Thus, only lack of exercise as a perceived cause of cancer can explain the similar lifestyle changes in prostate cancer patients (R² = .147) explaining 14.7% of variations in the outcome variable.
Table 4.15: Perceived causes of cancer as predictors of lifestyle changes after diagnosis (n = 73)

<table>
<thead>
<tr>
<th>Lifestyle change after diagnosis</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>0.169</td>
<td>.103</td>
<td>.283</td>
</tr>
<tr>
<td>Exercise</td>
<td>0.309</td>
<td>.133</td>
<td>.384*</td>
</tr>
<tr>
<td>Alcohol consumption</td>
<td>0.125</td>
<td>.180</td>
<td>.124</td>
</tr>
</tbody>
</table>

* p < .05

Patients who believed that lack of exercise may have been a cause of their cancer report that they exercise more after diagnosis. No significant results were found in having a healthier diet and drinking less alcohol post-diagnosis.

4.3.8 Diet as a perceived cause of cancer and as an information need

Diet as a perceived cause of cancer was found to be a significant predictor of diet as an information need after diagnosis in prostate cancer patients (Table 4.16). In particular, in this study diet as a perceived cause of cancer can account for 56.2 % of variation of those in need for dietary-related information after diagnosis (R² = .562). The ANOVA was also significant at F (35) = 83.32, p< .001. Table 4.15 outlines the linear regression model’s parameters.
Table 4.16: Diet as a perceived cause of cancer as a predictor of diet as an information need (n = 73)

<table>
<thead>
<tr>
<th></th>
<th>( B )</th>
<th>( SE ) ( B )</th>
<th>( \beta )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prostate Cancer Patients</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>0.765</td>
<td>0.313</td>
<td>0.75*</td>
</tr>
<tr>
<td>Diet as a perceived cause of cancer</td>
<td>0.858</td>
<td>0.094</td>
<td></td>
</tr>
</tbody>
</table>

* \( p < .001 \)

4.4 Discussion

The main aim of this study was to investigate two prerequisites of dietary behaviour change: information and the perceived cause of cancer. The findings indicate that a perceived lifestyle prior to diagnosis is not correlated with dietary changes after diagnosis whereas information-seeking behaviour is correlated with the three types of lifestyle change (diet, exercise and alcohol consumption). Results from correlation analysis indicate presumably that it was the prostate cancer diagnosis that resulted in interest in behavioural change. After diagnosis participants were more interested in health behaviour change. In general, less educated patients and significant others were less in need of information after diagnosis but developed their needs closer to diagnosis compared to higher educated patients and significant others. In the period 6 months after diagnosis, the findings indicate that some patients are more interested in information after the 3rd month compared to significant others who, even though they develop their needs earlier, reported a reduced interest in their needs in the same period. The types of information needs that significant others develop earlier than patients are treatment- and interaction-specific. Regarding the interest of the participants in the various types of information needs, it was found that patients differ on the level at which they are interested in the various type of information needs, showing greater interest in treatment and disease-specific information whereas significant others did differ on the different types of information needs. Finally, diet as a perceived cause of cancer does not predict a healthier diet after diagnosis. It does
though predicts diet as an information need after diagnosis. On the other hand exercise as a perceived cause of cancer predicts exercising more after diagnosis.

The current findings support findings from a previous study (Noh et al., 2009), which found that the closer the time was to the diagnosis, the greater the need for acquiring information. However they are also contrary to other studies (Salminen et al., 2004; Friis et al., 2003; McCaughan and McKenna, 2007), which supported that interest in diet increases as the time from diagnosis increases. In particular, Friis et al (2003) consider that when patients are closer to diagnosis they cannot easily accept information. However, like Noh et al (2009) the study assessed a series of different and specific information needs rather than more general ones and thus provides more conclusive results.

Patients are often given information about how to maintain their quality of life and sustain their health while managing their diet (Glanz, 1994; Winter, 1998) and this can be perceived as the norm by patients when it comes to health care provision. Recent findings (Bidstrup et al., 2013) suggest that diagnosis itself is not a strong enough indicator to trigger lifestyle change and guidelines and interventions are used which will help patients to overcome obstacles to change their lifestyle. Therefore, this is what the patient expects during health care. This study also shows that patients need information regarding their disease and treatment rather than information on lifestyle, emotional and interaction issues. They seem to rank the medical information and the Biomedical model (Annandale, 1998) as opposed to other information, which are more related to the bio-psychosocial model of health care.

Previous findings provide indications on the development of information needs in the trajectory of cancer. Before treatment and after diagnosis, patients were found to need treatment-related information (Hathaway, 1986; Suls and Wan, 1989). While on and immediately after treatment, they report a need for information related to side effects (Sanso-Fisher et al., 2000; Hervouet et al, 2005), emotional health-related and interaction-related information focusing on coping with new roles (Steginga et al., 2001). After treatment they need recurrence-related information (Lee-Jones et al., 1997). This study suggests that patients are more in need of treatment and disease-specific information compared to other information needs.
Previous studies have shown that cancer patients have a range of unmet needs post-diagnosis, which can explain the great need for information in the immediate period post-diagnosis (Sanson-Fisher et al., 2000; Steginga et al., 2001; McPherson et al., 2001; Sinfield et al., 2008; Boberg et al., 2003). Also the coping process of prostate cancer patients may bear similarities to the coping process found in women with abnormal Papanicolaou smears who seek information immediately after the initial anxiety at disclosure (Bertram and Magnussen, 2008). It can also be associated with reassurance seeking, which has been found to cause health anxiety (Stark et al., 2004) and is developed gradually after diagnosis where the patient seeks medical consultations, asks friends and family about symptoms and reads about the illness (Lucock and Morley, 1996).

Based on the participants’ self-reports in this study, it is not clear why patients’ responses on their need for information after the 3rd month after diagnosis is higher than in the period 1-3 months after diagnosis. However, these results provide evidence of the trajectory of interest in information after diagnosis. It may be that once the “blocking response” period is over after the 3rd month post-diagnosis and patients are more susceptible to information. It may also be that stress levels are lower after the 3rd month so patients report an increase in information needs. Stead et al (2012) note that there is a point after cancer diagnosis where the “teachable moment” is lost and Dowswell et al (2012) discuss how a possible explanation can be systemic where the health care system is responsible for patients’ information needs development. Other studies have explained a period of blocking information suggesting that fear of cancer can be associated with information avoidance (McCaffery et al., 2001; Miles et al., 2008). This study indicates that there is an increase of responses in information needs’ development after the 3rd month only for patients. Patients are possibly unable to make lifestyle changes at times of stress and might be in the contemplative stage (Prochaska and Di Clemente, 1982). Moreover patients may at that time have experienced and evaluated the symptoms and consequences of cancer diagnosis in their daily lives and will then seek information for coping purposes.

The decrease in information needs of significant others over time can be explained by the patients’ quest for self-reliance which leads significant others to hesitate
offering the same levels of support as previously (Gray et al., 2000) and thus less in need for information during that period. Significant others’ levels of involvement in decision-making and problem-solving activities related to the cancer is higher than that of patients (Lavery and Clarke, 1999) and so are more in need for information immediately after diagnosis compared to the later.

Findings support that less educated patients and significant others develop their needs closer to diagnosis than those who are more educated confirming previous studies that also found need for information to increase as the participants’ educational level increased (Salminen et al., 2004; Noh et al., 2009). Also, treatment-related information about prostate cancer, the likely progress of the disease and available treatments and options was not as significantly different as others. This information is seen as vital for all patients and significant others because they may be conceptualized as “life and death” issues which are crucial for their coping with cancer. On the other hand practical information like cost of treatment and self-care issues are considered more important and are developed much earlier for less educated patients and significant others. Overall, more educated patients and significant others were in need of additional information after prostate cancer diagnosis. Higher educated patients were more in need of information on sexuality while higher educated significant others were more in need of information on the cost of treatment, insurance coverage and other financial issues.

Less educated individuals usually come from a lower social class so for them, issues that affect their financial state seem crucial. The time when patients and significant others develop the need for information regarding the cost of treatment is found to differ significantly even between those with secondary education and those with less education. An alternative explanation of the differences found between less and more educated participants may be that more educated people, who may come from the upper class, have the financial ability to seek information from various sources and to gain second opinions from health-care professionals. However, the findings regarding educational level must be interpreted with caution, bearing in mind that the participants were recruited by two means and were found to differ in their educational level between these means.
Although significant others did not differ on the level to which they were interested in the various pieces of information, they were found to be more in need of information about treatment and interaction issues than the patients. The differences between patients and significant others can be seen in the context of the significant other’s role. While a patient can be in denial or experience the shock of diagnosis, the significant other can strive for information in order to support the patient. The quality of health care delivery can also affect the patient, prompting the significant other to obtain more information and to understand the disease so as to they can be part of the coping process. Regarding the information needs which were not found to significantly differ between patients and significant others, the question remains whether patients are less or more interested in those needs.

Furthermore, the differences between patients and significant others on specific needs can be seen in the context of the significant others’ needs. In general significant others experience high levels of stress (Persson and Sundin, 2008; Murray et al., 2010) and lower levels of HRQOL (Sarna et al., 2006) compared to patients. Significant others are found to develop a need earlier for information that will provide them with reassurance and practical information (treatment-related) and the information to help them deal with the changes to their lives (interaction issues).

In their study, Rabin and Pinto (2006) found cancer patients’ beliefs of what had caused their illness an important predictor of making a lifestyle change after diagnosis. Specifically, Leventhal’s Model of self-regulation (Leventhal et al., 1997) proposed that a belief might affect the strategy patients adopt to cope with their illness after developing an illness representation of their condition. Similarly, Stewart et al (2001) found the cause of the illness representation to be a significant predictor of behavioural change.

The findings of this study only partly support the idea that patients who perceive behaviour as a risk for their condition will make efforts to change that behaviour after diagnosis. Previous findings (Beagan and Chapman, 2004; Lemon et al., 2004; Rabin and Pinto, 2006) did not confirm that perceived causes of cancer predict healthy behaviours. In this study, not all perceived causes of cancer could predict engagement in a healthier lifestyle after diagnosis. Only lack of exercise was found
to significantly predict lifestyle health behaviour change post-diagnosis. This finding can be associated with the fact that lifestyle behaviours are related to increasingly widespread public health messages that highlight the importance of a healthy lifestyle in reducing cancer recurrence and risk (Glanz, 1994; Holmes and Willett, 1995), making the perceived causes of cancer less important when it comes to lifestyle changes.

Thus, even though diet as a perceived cause of cancer predicted seeking information on diet after diagnosis it did not predict changing dietary behaviour after diagnosis. This suggests that receiving or looking or needing information related to health behaviours does not in and of itself lead to health behaviour adherence. Therefore other social and psychological factors need to be examined that may determine whether patients adhere to a health behaviour after diagnosis or not.

4.4.1 Limitations

There are other issues to consider. The study’s research design limits the accuracy of its findings because a retrospective self-report is used and the period after diagnosis is not examined in a longitudinal design. Perceptions, behaviours and needs when assessed using self-report measures are prone to self-report bias. It is difficult to generalize the results, given the fact that response rates to the online questionnaire were low. A small sample means low clinical significance. Also, the small number of participants in the significant others group gives any attempt to draw conclusions about this population only limited validity.

Thus the cross sectional design of the study limits findings coming from retrospective self-reporting on the time of information needs development or lifestyle changes after diagnosis. The participants’ age at diagnosis and the time since diagnosis differed so the stage they had reached at the time of recruitment was not homogeneous. Also, the participants’ varying cultural backgrounds may have affected the study’s results.

A number of the participants were recruited through the Prostate Care Cook Book and were invited to complete an online questionnaire. It may be assumed that these
participants were already interested in diet related to prostate cancer and their responses to diet-related questions are not representative of the general cancer population. However, findings still provide an indication.

Results are interpreted with caution as no directional relationship or causality can be inferred by correlation analysis and the variance explained can be the other way round. However, the results describe the relationship between the variables and provide useful information regarding the processes patients go through after diagnosis of prostate cancer.

Finally, the study did not assess the relationship status with the patient of significant others with the patients so it is not possible to draw stronger conclusions about this population (i.e. for partners).

4.4.2 Clinical Implications

In spite of their limitations, the findings are important in identifying the stage at which a patient develops information needs. It is similar to the importance of establishing the patients’ stage of change (Palmeira et al., 2007; Prochaska and Velicer, 1997) to enable healthcare professionals to implement stage-specific interventions. Pinto and Trunzo (2005) state that identifying the most opportune time to intervene after cancer diagnosis is essential. Findings from this study can add to the understanding of the stages through which patients pass after diagnosis. Also, identifying patients’ information needs can benefit treatment-related choices (Roos, 2003) while identifying significant others’ information needs can benefit their health, as highlighted by findings that significant others carry on unhealthy behaviours after the patients’ cancer diagnosis (Audrain et al., 2001; Lemon et al., 2004).

“Health Behaviour Change: a guide for practitioners” (Rollnick, Mason and Butler, 1999) discussed whether healthcare provision on changing health behaviour is a continuum or a stage process. It seems that when it comes to patients’ needs development, the first month after diagnosis constitute a crucial period where patients and their significant others are in need of information in general. So that might be a stage where healthcare communication and interaction is very sensitive.
Thus significant others and patients may be in need of more intense healthcare provision and a more scrutinized explanation of issues regarding treatment, interaction issues, costs, the disease, diet and coping.

Prostate cancer diagnosis may enhance the need for acquiring information and interventions may focus on the first period after diagnosis for giving adequate information so that the population’s needs are met. This is a very important aspect of healthcare delivery, given that there is controversy over whether patients should be given information the first month after their diagnosis due to high anxiety and stress levels (Parry, 1990).

Findings from this study, indicate the relevance of the need for tailoring information brochures to the needs of both patients and their significant others. Moreover, health professionals can tailor health care provision to prostate cancer patients’ needs, taking into account the needs of significant others who are found to be more in need of information related to interactions and treatments.

The growing number of patients living with prostate cancer (Cancer Research UK, 2010) and its consequences creates a psychological, physical and social impact on their significant others. A recent review (Couper et al., 2006) suggests that the partners of prostate cancer patients are more distressed than the patients themselves. Findings from the current study suggest that significant others (including partners) may develop their need for information closer to diagnosis. Thus family interventions can benefit both patients and their significant others whereas significant others constitute a well-defined population for healthcare providers to focus on delivering appropriate intervention and information.

For example, Manne et al. (2011) use a longitudinal study design to investigate the efficacy of a five-dimensional Intimacy-Enhancing Therapy (IET) on the psychological and relationship functioning of prostate cancer patients and their partners. They found IET to significantly lower concerns and improve general well-being. Similar family and systemic therapies as well as psycho-education can benefit patients and their families.
4.4.3 Future Recommendations

Future research can prospectively tackle the journey of patients and their significant others after diagnosis and develop a theoretical framework, taking into account the different stages of coping with prostate cancer diagnosis and the psychological processes which diagnosis triggers. Educational interventions may be effective if they take into account the point after which a patient is discharged from cancer follow-up back to the GP.

Patients might have made the lifestyle changes they were previously contemplating but have not achieved. Thus, research can differentiate and investigate associations between intentions and actual behaviour. Longitudinal research designs may test these hypotheses. The perception of healthcare providers can also be compared with patients’ actual information needs. Future studies should also investigate the predictors of patients’ greater interest in diet after the third month post-diagnosis or their decline in their interest in the first three months post-diagnosis.

4.5 Conclusion

In conclusion, the results of this study provide evidence on the role of two prerequisites of dietary change: information needs and perceived cause of cancer. Patients and significant others develop their needs closer to diagnosis. Significant others constitute a population of clinical importance based on the time they take to develop their needs. Patients show a “stage” approach where the first three months after diagnosis show a fall in their information needs and then an increase after the third month. This study could support the hypothesis that diet as a perceived cause of cancer predicts diet as an information need but not as a lifestyle change. Expanding upon previous work, we can argue that the closer the time to diagnosis or the realisation of a risk of developing prostate cancer, the greater the need for prostate cancer-related information. Post-diagnosis health care provision for prostate cancer patients and significant others should take into consideration the “stage process” of their needs development, which may interact with the stage’s nature of assessing health behaviour change.
The findings of this Chapter are important because they provide evidence that can inform health care delivery. However, it is equally important for health professionals to meet patients’ and significant others’ needs in order to facilitate the process of adhering to health behaviours. The next Chapter will focus on GPs’ perceptions of the time when patients develop their information needs and what socio-demographic factors predict these perceptions. GPs’ awareness on prostate cancer-related diet will also be examined. Studies using longitudinal research design differentiating between intentions and actual behaviour, and investigating health professionals’ perceptions as well as the predictors of patients’ needs are needed. They will provide stronger evidence on the trajectory of patients’ needs after diagnosis while health professionals’ perceptions can inform on a “patient-provider” gap when it comes to patients’ needs.
Chapter 5: Study 2: GP’s awareness of diet and perception of patients’ information needs compared with that of patients and significant others

5.1 Introduction

The findings of the previous Chapter indicate that patients and significant others following diagnosis immediately develop a need for information including lifestyle information such as diet. GPs’ perceptions of when patients develop their information needs are also important so this Chapter will investigate the predictors of GPs’ perceptions of the time of development of patients’ information needs following diagnosis and will compare their perceptions with the patients’ and significant others’ actual time of information needs development. It will also investigate GPs’ awareness of food items that are considered beneficial to prostate cancer patients based on a Prostate Care Cook Book (Rayman et al., 2008). Information needs are an important aspect of healthcare provision and the targeting of patients’ unmet needs may reduce the burden of the cancer experience (Brazil et al., 2004).

British patients in primary care do not comply with nutritional advice even if when it is provided to them. This is based in a large countrywide survey (Schoen et al., 2004) found a lower percentage among British patients when it comes to prevention experiences relevant to nutritional advice in the UK (28%) compared to the USA (52%), Canada (45%), New Zealand (33%) and Australia (38%). The problem, though, can be that GPs themselves may lack the knowledge, time and evidence to provide adequate nutritional advice.

Healthcare and information provision can be affected by GPs’ beliefs and subsequently can affect patients’ satisfaction as well. In a qualitative study (Rozmovits et al., 2004) colorectal cancer patients report having been given little or no advice about diet after surgery. As a result, they had difficulties in readjusting their eating habits and were confused by contradictory, inappropriate and sometimes no advice about what to eat.
However, there is limited evidence in the UK on GPs’ and cancer patients’ perceptions in terms of dietary advice and generally lifestyle. Generally, cancer patients view their doctor as the person primarily responsible for emotional and informational support (Bulsara et al., 2005; Gray et al., 2002), but they sometimes report little involvement of their GPs in providing cancer-related information and support (Norman et al., 2001) even though their relationship with their GP may affect their quality of life (Matthieson et al., 1996).

A systematic review (Gathirwa, 2013) found that there are inconclusive results in the literature regarding food items considered beneficial for men with prostate cancer. The strongest association of an increased risk of prostate cancer is with meat and dairy consumption. On the other hand, there is an inconsistent association on the beneficial role of fruit and vegetables (from cohort studies) and fish (from epidemiological studies). On the other hand, in the UK, a Prostate Care Cook Book has been published based on a systematic review (Rayman et al., 2008) outlining food items and recipes, which are beneficial for prostate cancer patients.

Several interventions have also been developed targeting health professionals’ nutritional knowledge and perceptions. Ockene et al. (1995) designed a training programme in the USA to improve physicians’ nutritional knowledge, attitudes and skills and found it to be effective. Moreover, Klein et al (2006) found that during consultation, doctors were willing to discuss healthy eating concerns with healthy adolescents. In the USA intensive behavioural interventions, which promote dietary behaviour changes are recommend by the US Preventive Services Task Force (2003). Consequently, nutritional interventions are important “patches” to health-care provision.

Ockene et al (1995) discuss several reasons which may lead to a lack of interest by Medical Schools to enhance young health-care providers’ nutritional skills: reimbursement, a focus on cure rather than health promotion/prevention and a “specialization philosophy” which leaves little space for obtaining other skills. A pan-European network of experts (EUROPREV) has indicated that most national colleges of GPs in Europe lack their own nutritional and dietary tools (Pineiro et al., 2005). In the UK, health professionals’ nutrition knowledge seems to be low (Moore
and Adamson, 2002) which may affect lifestyle modification practices and information provision and focus attention on changing the British Medical Schools’ curriculum (Buttriss, 1997). Therefore, recent recommendations highlight the need for an undergraduate medicine curriculum to include training in lifestyle modification, especially as regards diet, physical activity and smoking (Parker et al., 2010).

So do health-care providers – and especially those in primary care – currently offer nutritional counselling? The results from the literature are not very optimistic. In the USA and Canada, very few oncologists offer healthy lifestyle change guidance (Demark-Wahnefried et al., 2000; Jones et al., 2005). In the UK, more than half of GPs are reported as finding it difficult to incorporate health promotion and prevention discussions and activities into consultations (Brotons et al., 2005) and only 9% of GP’s always assess information on diet and nutrition during consultation (McAvoy et al., 1999). Barriers to the provision of healthy promotion messages and strategies and specifically nutritional counselling, as reported in the literature, include competing treatments, health concerns and uncertainty about the health message (Ahuja et al., 2003; Kuhn et al., 2005; Yarnall et al., 2003), a lack of training and knowledge (Schucker et al., 1987; Shea et al., 1990; Langner et al., 1989; McClinchy et al., 2011) a lack of time (Schucker et al., 1987; Shea et al., 1990; Langner et al., 1989; Ahuja et al., 2003; Kuhn et al., 2005; Yarnall et al., 2003; Lopez-de-Munain et al., 2001; Parker et al., 2010; McClinchy et al., 2011), a lack of confidence to alter patients’ lifestyles and eating patterns and give dietary recommendations, combined with a lack of interest in diet (Lyznicki, 2001) and a lack of perceived patient adherence (Parker et al., 2010; McClinchy et al., 2011; Bocquier et al., 2005). GPs also may focus on the therapeutic aspect of care rather than prevention, health promotion or well-being management.

Recent randomized-control trials have shown that health-care providers’ recommendations can positively affect the adoption of healthy lifestyle practices such as smoking cessation (Ahuja et al., 2003) and physical activity (Jones et al., 2005). Using the Theory of Planned Behaviour (Ajzen, 1985), a study (Jones et al., 2005) found a direct relationship between oncologists’ recommendations on lifestyle and their perceived behavioural control. Many studies conclude that lifestyle changes
– specifically dietary changes – can benefit from counselling provided by health professionals (Stead et al., 2008; Egede, 2003; Kreuter et al., 2000; Truswell, 2000).

Studies with GPs which use qualitative methods propose that health promotion and prevention activities are not a priority for GPs and are greatly overlooked (Williams and Calnan, 1994; Lawlor et al., 2000) while GPs’ and patients’ perceptions of these activities at the primary health care level are different in content and priority (Calderon et al., 2011). There are contrary results regarding health professionals’ attitudes towards similar activities. For example, one study found a positive attitude from health professionals towards lifestyle modification among chronic patients (Parker, 2008) while another study found family physicians not considering themselves responsible for providing supportive cancer care (Brazil et al., 2010). However, patients and practitioners tend to agree on the practitioners’ lack of knowledge and time to provide adequate dietary advice (McClinchy et al., 2011). It is important to discuss these different perspectives to improve consultations’ health outcomes and make behavioural change strategies more effective.

The rationale for this study is that health professionals’ views on patients’ information needs are important in helping them inform their patients about current recommendations regarding lifestyle behaviours and motivate them to adhere to a healthier lifestyle. A systematic review (Demark-Wahnefried et al., 2005) found that only 20% of health professionals provide guidance to cancer patients on how to make positive lifestyle changes after diagnosis. This suggests that health professionals are either unaware of the benefits of lifestyle changes or their perceptions of patients’ needs are different than those of the patients. Furthermore, patients’ misinterpretation of healthy eating messages (Wood et al., 2010) along with the discrepancies between health professionals in providing relevant information and lifestyle risk factor management (Ampt et al., 2009; Foster et al., 2003; Brown et al., 2007) have created a need to identify how GPs think about patients’ information needs and how aware they are about the role of diet in cancer.

Anderson et al. (2010), evaluating personalized lifestyle intervention for overweight colorectal patients, suggested that the timing of the intervention should be further explored. At the same time, the same study identified serious gaps in patients’ and
health professionals’ knowledge related to diet. Recently, Dowswell et al (2012) found that colorectal cancer patients lacked understanding of the means to achieve dietary change. GPs’ perceptions were important because currently dietary counselling in primary care in the UK lacks consistent and clear suggestions related to dietary behaviour change (Phillips et al., 2012). GPs’ perceptions may shed some light in this respect.

Therefore this Chapter’s objectives are a) to investigate GPs’ awareness of prostate cancer dietary recommendations and its determinants as well as the determinants of their perception of patients’ information needs development and b) to compare GPs’ perceptions of patients’ information needs development with responses from patients and significant others. The specific aims of this Chapter are:

- To assess the determinants (age, years in practice) of a) GPs’ perception of the time of information needs development.

- To compare prostate cancer patients’ actual and GPs’ perception of patients’ time of information need development and that of significant others.

- To investigate GPs’ awareness regarding food items which are considered beneficial to patients with prostate cancer.

5.2 Methods

5.2.1 Research Design

This is a cross-sectional study using an online questionnaire. The study has two parts. To reach the first objective a within-subjects research design was used, analysing GPs’ responses to the online questionnaire. In the second part a between-subjects research design was used, comparing GPs’ responses with retrospective data from patients and significant others completed in the survey from the previous Chapter (see section 4.2.3).
5.2.2 Recruitment

For this study GPs were recruited because they are the healthcare professionals who have the initial contact with cancer patients. The Royal College of GPs agreed to facilitate the online questionnaire and the South West Thames Faculty of the College was specifically involved in the process by uploading the survey to its website. Letters providing information about the study’s aims and procedure were sent to the members of the South West Thames Faculty asking them to take part and complete the online survey after providing informed ethical consent. For their time, all participants were rewarded with a copy of the Prostate Care Cook Book after agreement with the principal writer (Prof Margaret Rayman). The participants completed the questionnaire online and their responses were transferred to SPSS for analysis.

Full details of the recruitment process of prostate cancer patients and significant others whose data are retrospectively used in this study are described in Chapter 4 (see section 4.2.2).

5.2.3 Measures

Because of GPs’ time constraints and in order to maximize the likelihood of them completing the questionnaire (Appendix VI) the number of questions was kept to a minimum. The only demographic information collected by GPs was age, gender and years in practice. The questionnaire consisted of three closed-ended questions and one open-ended question which asked for GPs’ comments. The measures used are described below (Table 5.1).
“Awareness of the role of diet in reducing the risk of prostate cancer” was assessed for the following 11 items: Vitamin D, selenium foods, pomegranate, green tea, oily fish, soya products, cruciferous vegetables, garlic and onion, tomato as positive items (they help reduce the risk of prostate cancer by consuming) and cooked meat and dairy products as negative items (they help reduce the risk of prostate cancer by avoiding). The items were selected based on the Prostate Care Cook Book (Rayman et al., 2009) and after consulting a GP with specific expertise in dietary research that was working at the University of Surrey at the time. Each item was assessed with a dichotomous response of “yes” or “no” asking GP’s awareness of whether it helped reduce the risk of prostate cancer or not.

“Timing of information need development” was assessed in the same way as the one used in Chapter 4, to enable comparisons between the three groups (Chapter 4, section 4.2.3).

**Table 5.1: Measures included in the study**

<table>
<thead>
<tr>
<th>Measures used</th>
<th>Number of items</th>
<th>Reference</th>
<th>Group that completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic information</td>
<td>3</td>
<td>New</td>
<td>GPs</td>
</tr>
<tr>
<td>Awareness of food items in the prevention of prostate cancer</td>
<td>11</td>
<td>New, based on Rayman et al. (2009)</td>
<td>GPs</td>
</tr>
<tr>
<td>Time of information need development</td>
<td>11</td>
<td>New, based on Rutten et al. (2005)</td>
<td>GPs, patients, significant others</td>
</tr>
</tbody>
</table>

**5.2.4 Analytic Plan**

Means and standard deviations were used for the participants’ demographic characteristics. Bivariate and multivariate analyses were used to examine differences between groups. To examine whether years in practice and gender were associated with GPs’ perceptions of the 11 variables related to “time of information need development”, a series of Kruskall Wallis tests was used. Mann-Whitney post-hoc tests were followed to identify inter-correlations between years in practice and
gender. A Bonferroni Correction was applied in post-hoc tests in order not to overestimate significance levels. Only data from GPs was used in these analyses.

To compare GPs’ perceptions of patients’ information needs development with patients’ and significant others’ responses, a Kruskall Wallis test was conducted. Mann-Whitney post-hoc tests were followed to identify inter-correlations between the three groups of participants. A Bonferroni Correction was applied in post-hoc tests in order not to overestimate significance levels.

To identify GPs’ awareness of food items, which are considered beneficial for prostate cancer, a Cochran’s Q test was applied. A chi-square test followed to investigate significant differences between two age groups of GPs: a) GP’s aged 20-40 (n = 69) and b) GPs aged 40+ (n= 56) on their awareness of the 11 food items which are considered beneficial for prostate cancer.

### 5.3. Results

#### 5.3.1 Data Screening

Data was analysed using SPSS for Windows, Version 19.0 (SPSS, Chicago, IL). The first step in the data analysis was to screen data for missing values, outliers (univariate and multivariate) and for assumptions of parametric tests (normal distribution and homogeneity of variance).

There was less than 5% missing data (Tabachnik and Fidell, 2007) and no significant differences were found between missing values so no data was deleted. To test for the normality of distributions of included variables, a Kolmogorov-Smirnov test was conducted. The distribution of all included variables was found to be significantly non-normal. Levene’s test also showed violations of the homogeneity of variance assumption. Thus non-parametric tests were used to look for between-subjects analyses.
5.3.2 Participants

The sample of this study consisted of English-speaking GPs working in England as well as prostate cancer patients and significant others who had participated in a previous study (Chapter 4, section 4.2.2).

Some 224 participants (N = 224) were included in this study: 126 GPs, 73 prostate cancer patients and 25 significant others of prostate cancer patients (Table 5.2). Patients’ and significant others’ (n = 98) demographics are outlined in Chapter 4 (section 4.3.2). The majority of the GPs were female (64.5%) and the mean number of years in practice was 12.5 (SE = 1). Their mean age was 40.4 (SE = 2.6). The GPs were working in the area of London.

Table 5.2: Characteristics of respondents (N=224)

<table>
<thead>
<tr>
<th></th>
<th>GPs</th>
<th>Prostate cancer patients</th>
<th>Significant others</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
<td>SE</td>
</tr>
<tr>
<td>Age</td>
<td>126</td>
<td>40.4</td>
<td>2.6</td>
</tr>
<tr>
<td>Age of diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46</td>
<td>36.5</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>80</td>
<td>64.5</td>
<td></td>
</tr>
<tr>
<td>Years of practice</td>
<td>12.5</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

5.3.3 GPs’ perceptions of the time of patients’ information needs development

Significant differences were found from a Mann-Whitney test between male and female GPs in their perceptions of the time of patients’ information needs development (Table 5.3). Specifically, their perception on 4 information needs differed for “available treatments/treatment options”, $U = 1693.5$, $r = -.1$ “more information about prostate cancer”, $U = 1527.5$, $r = -.15$, “interaction issues with health care providers”, $U = 1510.5$, $r = -.16$ and “maintaining psychological health”, $U = 1358.5$, $r = -.23$. For these four information needs, male GPs perceived that patients developed a need for information sooner than female GPs did.
Further analyses were conducted to assess the effects of age and gender combined on GPs’ perceptions of patients’ time of information needs development. A dummy variable was created containing both variables (years in practice and gender) which resulted in four groups: males with 0-15 years of practice, females with 0-15 years of practice, males with 16+ years of practice and females with 16+ years of practice. A Kruskall Wallis test revealed significant differences between the four GP groups (males with 0-15 years of experience, females with 0-15 years of experience, males with 16+ years of experience and females with 16+ years of experience). These were found regarding “sexuality” (H (3) = 8.01, p< .05) and “maintaining psychological health” (H (3) = 8.39, p< .05). No significant differences were observed between the four groups regarding their perception of the rest of patients’ information needs (Table 5.4).

Table 5.3: Mann Whitney test for differences on perception of patients’ information need development between male and female GPs (n = 126)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Male GPs (n= 46)</th>
<th>Female GPs (n= 80)</th>
<th>U</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/ options</td>
<td>60.3</td>
<td>65.3</td>
<td>1693.5*</td>
<td>.132</td>
<td>-.10</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>56.7</td>
<td>67.4</td>
<td>1527.5*</td>
<td>.042</td>
<td>-.15</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>59.1</td>
<td>66</td>
<td>1639</td>
<td>.117</td>
<td>-.10</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>58.2</td>
<td>66.5</td>
<td>1597</td>
<td>.096</td>
<td>-.11</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>61</td>
<td>65</td>
<td>1723</td>
<td>.265</td>
<td>-.06</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>57.9</td>
<td>66.7</td>
<td>1581.5</td>
<td>.074</td>
<td>-.13</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>56.3</td>
<td>67.6</td>
<td>1510.5*</td>
<td>.039</td>
<td>-.16</td>
</tr>
<tr>
<td>Sexuality</td>
<td>60</td>
<td>65.5</td>
<td>1680</td>
<td>.199</td>
<td>-.07</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>63.7</td>
<td>63.4</td>
<td>1833</td>
<td>.487</td>
<td>-.003</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>63.2</td>
<td>63.7</td>
<td>1828</td>
<td>.473</td>
<td>-.01</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>53</td>
<td>69.5</td>
<td>1358.5*</td>
<td>.005</td>
<td>-.23</td>
</tr>
</tbody>
</table>

* p < .05
For post-hoc Mann-Whitney tests, a Bonferroni Correction was applied so that all effects were reported at $p = .012$ level of significance. Significant differences were observed between female GPs with 0-15 years of experience (Mdn = 71.8) and female GPs with 16+ years of experience (Mdn = 48.8) about “sexuality” ($U = 414$, $r = -.28$) and between female GPs with 16+ years of experience (78.3) and male GPs with 16+ years of experience (Mdn = 54.2) about “maintaining psychological health” ($U = 179$, $r = -.33$) (Table 5.5).
**Table 5.4: Kruskall Wallis test for the effect of gender and years of practice on GPs’ perceptions of patients’ information needs development (n=126)**

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Male GPs with 0-15 years of experience (n=20)</th>
<th>Female GPs with 0-15 years of experience (n=59)</th>
<th>Male GPs with 16+ years of experience (n=26)</th>
<th>Female GPs with 16+ years of experience (n=22)</th>
<th>H</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>60</td>
<td>65.2</td>
<td>60.5</td>
<td>65.6</td>
<td>1.28</td>
<td>.747</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>50</td>
<td>66.2</td>
<td>66.8</td>
<td>71.6</td>
<td>4.66</td>
<td>.205</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>53.2</td>
<td>64.5</td>
<td>63.7</td>
<td>70.1</td>
<td>3.15</td>
<td>.371</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>53.8</td>
<td>70.2</td>
<td>62.4</td>
<td>56.8</td>
<td>4.99</td>
<td>.181</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>53.7</td>
<td>63.5</td>
<td>66.5</td>
<td>68.8</td>
<td>2.33</td>
<td>.508</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>59</td>
<td>64.5</td>
<td>57</td>
<td>72.5</td>
<td>3.03</td>
<td>.396</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>59.2</td>
<td>69.8</td>
<td>54.1</td>
<td>61.8</td>
<td>4.21</td>
<td>.244</td>
</tr>
<tr>
<td>Sexuality</td>
<td>63.8</td>
<td>71.8</td>
<td>57.1</td>
<td>48.8</td>
<td>8.01*</td>
<td>.044</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>67.4</td>
<td>66.5</td>
<td>60.8</td>
<td>55.2</td>
<td>2.06</td>
<td>.570</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>66.3</td>
<td>62</td>
<td>60.9</td>
<td>67.9</td>
<td>.72</td>
<td>.872</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>51.6</td>
<td>66.2</td>
<td>54.2</td>
<td>78.3</td>
<td>8.39*</td>
<td>.040</td>
</tr>
</tbody>
</table>

*p < .05
Table 5.5: Mann Whitney post-hoc tests for the effect of gender and years of practice on GPs’ perceptions of patients’ information needs development (n = 126)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>Groups 1-2 (n = 78)</th>
<th>Groups 1-3 (n = 46)</th>
<th>Groups 2-4 (n = 80)</th>
<th>Groups 3-4 (n = 48)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males 0-15 years</td>
<td>Females 0-15 years</td>
<td>U</td>
<td>r</td>
</tr>
<tr>
<td>Available treatments/treatment options</td>
<td>37.1</td>
<td>40.3</td>
<td>532</td>
<td>-0.09</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>31.9</td>
<td>42.1</td>
<td>428</td>
<td>* -0.22</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>34.2</td>
<td>41.3</td>
<td>474</td>
<td>-0.16</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>31.9</td>
<td>42.1</td>
<td>428</td>
<td>* -0.21</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>34.9</td>
<td>41.1</td>
<td>487</td>
<td>-0.13</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>36.9</td>
<td>40.4</td>
<td>529</td>
<td>-0.07</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>34.7</td>
<td>41.2</td>
<td>483</td>
<td>-0.13</td>
</tr>
<tr>
<td>Sexuality</td>
<td>36.2</td>
<td>40.7</td>
<td>513</td>
<td>-0.09</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>40.3</td>
<td>39.2</td>
<td>564</td>
<td>-0.02</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>41.5</td>
<td>38.9</td>
<td>539</td>
<td>-0.05</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>32.6</td>
<td>41.9</td>
<td>441</td>
<td>-0.19</td>
</tr>
</tbody>
</table>

* p < .05
To sum up, male GPs are found to believe that patients develop an interest in “more information about prostate cancer”, “interaction issues with health care providers”, and “maintaining psychological health” earlier after diagnosis than female GPs. Female GPs with less experience are found to believe that patients are in need of information regarding sexuality earlier after diagnosis than experienced female GPs. Also, experienced male GPs believe that patients are more in need of information regarding maintaining psychological health earlier after their diagnosis than experienced female GPs so. No significant differences were found regarding the time GPs believe patients develop a need for all other information including diet.

5.3.4 GPs’ perceptions of patients’ information needs compared to patients’ and significant others’ actual needs

Significant differences were found from Kruskall Wallis analyses between GPs’ perceptions of patients’ information needs development and the actual time of information needs development of patients and their significant others. Specifically, significant differences were found for “available treatments/treatment options” (H (2) = 6.47, p<.05), “more information about prostate cancer” (H (2) = 11.5, p <.01), “self-care issues or home care during recovery” (H (2) = 34.28, p <.001), “interaction issues with healthcare providers” (H (2) = 18.83, p <.001), “sexuality” (H (2) = 20.34, p <.001), “cost of treatment, insurance coverage, or other financial issues” (H (2) = 13.69, p <.01), “diet and nutrition” (H (2) = 55.66, p <.001) and “maintaining psychological health” (H (2) = 41.45, p <.001). “Available treatments/treatment options” is the only need, which GPs (Mdn = 106.8) perceive that patients (Mdn = 122.5) develop the need for information earlier than they actually do. For all the other information needs where significant differences were found, GPs were underestimating the time of patients’ information need development. No significant differences were observed in the rest of the information needs (Table 5.6).
Table 5.6: Kruskall Wallis test for differences in perceptions of the time of information needs development between GPs, patients and significant others (N = 224)

<table>
<thead>
<tr>
<th>Information Need</th>
<th>GP's (N=126)</th>
<th>Patients (N=72)</th>
<th>Significant Others (N=24)</th>
<th>H</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>106.8</td>
<td>122.5</td>
<td>103.4</td>
<td>6.47*</td>
<td>.037</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>120.7</td>
<td>105.9</td>
<td>79.9</td>
<td>11.50**</td>
<td>.003</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>112.4</td>
<td>115.6</td>
<td>94.3</td>
<td>2.84</td>
<td>.240</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>131.2</td>
<td>94.2</td>
<td>60.2</td>
<td>34.28***</td>
<td>.000</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>115.8</td>
<td>112.8</td>
<td>84.9</td>
<td>5.46</td>
<td>.066</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>110.6</td>
<td>117.9</td>
<td>97</td>
<td>2.38</td>
<td>.306</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>119.5</td>
<td>112.9</td>
<td>60.7</td>
<td>18.83***</td>
<td>.000</td>
</tr>
<tr>
<td>Sexuality</td>
<td>127.5</td>
<td>94.5</td>
<td>78.7</td>
<td>20.34***</td>
<td>.000</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>124.6</td>
<td>97.3</td>
<td>85.2</td>
<td>13.69**</td>
<td>.001</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>138.4</td>
<td>80.4</td>
<td>63.2</td>
<td>55.66***</td>
<td>.000</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>133.4</td>
<td>91.4</td>
<td>56.8</td>
<td>41.45***</td>
<td>.000</td>
</tr>
</tbody>
</table>

*p < .05 ** p < .01 *** p < .001

For Mann-Whitney post-hoc tests, a Bonferroni Correction was applied so that all effects were reported at p = .016 level of significance. Significant differences were observed on “more information about prostate cancer” between GPs and significant others (U = 933.5, r = -.26), on “self-care issues or home care during recovery” between GPs and patients (U = 3054.5, r = -.27), GPs and significant others, (U = 516.5, r = -.43) and patients and significant others, (U = 627, r = -.22) on “effects on family, friends or caregivers” between GPs and significant others (U = 1069.5, r = -.19), on “interaction issues with health care providers” between GPs and significant others, (U = 649, r = -.38), on “sexuality” between GPs and patients (U = 3214, r = -
.025) and GPs and significant others (U = 823, r = -.29), on “cost of treatment, insurance coverage, or other financial issues” between GPs and patients (U = 3451, r = -.02) and GPs and significant others (U = 946, r = -.24), on “diet and nutrition” between GPs and patients (U = 2165, r = -.44) and GPs and significant others (U = 488, r = -.44), on “maintaining psychological health” between GPs and patients (U = 2854.5, r = -.31), GPs and significant others (U = 431.5, r = -.46) and patients and significant others (U = 631, r = -.22) (Table 5.7).

To sum up, the three groups of participants (GPs, patients and significant others) differed significantly regarding their perceptions on the time patients develop an interest in seven out of eleven information needs: available treatments/treatment options, more information about prostate cancer, self-care issues, sexuality, cost of treatment, diet and nutrition and maintaining psychological health (Figure 6.1). Post-hoc tests revealed that GPs’ perceptions differed significantly with significant others on eight information needs (more information on prostate cancer, self-care issues, effects on family, friends and caregivers, interactions with health care providers, sexuality, costs of treatment and other financial issues, diet and nutrition and maintaining psychological health) and on five with patients (self-care issues, sexuality, costs of treatment and other financial issues, diet and nutrition and maintaining psychological health). Finally, patients and significant others significantly differed on two information needs (self-care issues and maintaining psychological health), partly confirming findings from the previous Chapter. However, differences between GPs and patients on cost of treatment and sexuality had a minimum effect while diet and nutrition and maintaining psychological health had the largest effect size between GPs and patients and between GPs and significant others.
<table>
<thead>
<tr>
<th>Information Need</th>
<th>Groups 1-2 (n = 198)</th>
<th></th>
<th></th>
<th>Groups 1-3 (n = 150)</th>
<th></th>
<th></th>
<th>Groups 2-3 (n = 98)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>GPs</td>
<td>Patients</td>
<td>U</td>
<td>r</td>
<td>GPs</td>
<td>Significant others</td>
<td>U</td>
<td>r</td>
<td></td>
</tr>
<tr>
<td>Available treatments/ treatment options</td>
<td>94.4</td>
<td>108.5</td>
<td>3891</td>
<td>-.17</td>
<td>75.9</td>
<td>73.5</td>
<td>1465</td>
<td>-.03</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.5</td>
<td>42.4</td>
<td>717</td>
<td>-.17</td>
<td></td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>104.1</td>
<td>91.4</td>
<td>3951.5</td>
<td>-.11</td>
<td>80.1</td>
<td>51.4</td>
<td>933.5**</td>
<td>-.23</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>51</td>
<td>41</td>
<td>683</td>
<td>-.2</td>
<td></td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>98.4</td>
<td>101.4</td>
<td>4396</td>
<td>-.01</td>
<td>77.5</td>
<td>64.8</td>
<td>1256</td>
<td>-.13</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>50.7</td>
<td>42</td>
<td>708</td>
<td>-.17</td>
<td></td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>111.3</td>
<td>78.9</td>
<td>3054.5**</td>
<td>-.28</td>
<td>83.4</td>
<td>34</td>
<td>516.5**</td>
<td>-.43</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>51.8</td>
<td>38.6</td>
<td>627**</td>
<td>-.22</td>
<td></td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>100.3</td>
<td>98.1</td>
<td>4434</td>
<td>-.02</td>
<td>79</td>
<td>57.1</td>
<td>1069.5*</td>
<td>-.2</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>51.2</td>
<td>40.3</td>
<td>667</td>
<td>-.19</td>
<td></td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>97</td>
<td>103.9</td>
<td>4221.5</td>
<td>-.06</td>
<td>77.1</td>
<td>67.2</td>
<td>1311.5</td>
<td>-.1</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.5</td>
<td>42.4</td>
<td>717.5</td>
<td>-.14</td>
<td></td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>100.7</td>
<td>96</td>
<td>4262.6</td>
<td>-.04</td>
<td>82.4</td>
<td>39.5</td>
<td>649**</td>
<td>-.38</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>52.8</td>
<td>33.7</td>
<td>508.5**</td>
<td>-.33</td>
<td></td>
</tr>
<tr>
<td>Sexuality</td>
<td>110</td>
<td>81.1</td>
<td>3214**</td>
<td>-.25</td>
<td>81</td>
<td>46.8</td>
<td>823**</td>
<td>-.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.9</td>
<td>44.4</td>
<td>766</td>
<td>-.09</td>
<td></td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>108.1</td>
<td>84.4</td>
<td>3451**</td>
<td>-.21</td>
<td>80</td>
<td>51.9</td>
<td>946*</td>
<td>-.24</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>49.4</td>
<td>45.7</td>
<td>798.5</td>
<td>-.06</td>
<td></td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>118.3</td>
<td>66.6</td>
<td>2165**</td>
<td>-.45</td>
<td>83.6</td>
<td>32.8</td>
<td>488**</td>
<td>-.44</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50.4</td>
<td>42.9</td>
<td>729</td>
<td>-.14</td>
<td></td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>112.9</td>
<td>76.2</td>
<td>2854**</td>
<td>-.32</td>
<td>84.1</td>
<td>30.5</td>
<td>431.5*</td>
<td>-.46</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>51.7</td>
<td>38.8</td>
<td>631**</td>
<td>-.23</td>
<td></td>
</tr>
</tbody>
</table>

*  p < .01 ** p < .001
Figure 5.1: Proportion of respondents’ time of information need development.
The Figure 5.1 demonstrates schematically GPs’ underestimation of patients’ development of information needs regarding self-care issues or home care during recovery, sexuality, diet and nutrition, cost of treatment/insurance coverage and other financial issues and maintaining psychological health. For all of these information needs, GPs consider the period 1-3 months post-diagnosis as the period when patients develop their needs whereas patients tend to develop their needs immediately after, and closer to, diagnosis.

5.3.5 GPs’ awareness of food items that reduce the risk of prostate cancer

Cochran’s Q analysis was used to identify any discrepancies between GPs (n=126) in their awareness of food items that benefit prostate cancer patients. Their awareness of the eleven items was found to significantly differ between GPs, Q (10) =108.224, p<. 001.

In order to identify the years in practice and gender influence on GPs’ awareness of food items that are beneficial to prostate cancer patients, a series of chi square analyses was conducted between GPs’ responses to the eleven food items and the four groups used in previous analyses (male GPs with 0-15 years of practice, female GPs with 0-15 years of practice, male GP with 16+ years of practice and female GPs with 16+ years of practice).

5.3.5.1 Checking for assumptions of chi square analysis

Chi-square tests assumptions were tested. All cells of the contingency table included in the analysis were independent and expected frequencies were large enough for a reliable analysis. The criterion of expected frequencies < 5 (Field, 2000) was tested using a crosstabulation. The assumption of expected frequencies was violated for 4 food items (onions and garlic, soya, vitamin D and dairy), so they were excluded from further analyses. There were no more than 20% of cells with an expected frequency of more than five in the rest of the crosstabulation.
5.3.5.2 The main analysis

After conducting chi square analyses between the four GP groups and their responses to whether they were aware of food items that are beneficial for prostate cancer, it was found that the four groups significantly differed in their awareness for four out of seven food items: tomatoes $\chi^2 (1, N = 126) = 5.605, p < .05$, broccoli, $\chi^2 (1, N = 126) = 8.145, p < .01$ oily fish $\chi^2 (1, N = 126) = 6.887, p < .01$ and pomegranates $\chi^2 (1, N = 126) = 6.211, p < .05$. No significant differences were found for green tea, brazil nuts and meat among the four groups of GPS. The findings confirm the discrepancies between GPs’ awareness found in the previous analysis but also reveal the effect of gender and years in practice for some of the food items. The frequencies were crosstabulated (Table 5.8).

Table 5.8: Crosstabulation between GPs years in practice and gender and food items

<table>
<thead>
<tr>
<th>Food item</th>
<th>GPs’ gender and years in practice</th>
<th>$\chi^2$</th>
<th>V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male 0-15 years (n = 20)</td>
<td>Female 0-15 years (n = 59)</td>
<td>Male 16+ years (n = 26)</td>
</tr>
<tr>
<td>Tomatoes</td>
<td>10(50)</td>
<td>25(43.1)</td>
<td>17(68)</td>
</tr>
<tr>
<td>Broccoli</td>
<td>5(26.3)</td>
<td>20(34.5)</td>
<td>8(30.8)</td>
</tr>
<tr>
<td>Oily fish</td>
<td>9(45)</td>
<td>11(19.3)</td>
<td>7(26.9)</td>
</tr>
<tr>
<td>Green tea</td>
<td>8(40)</td>
<td>12(21.4)</td>
<td>8(30.8)</td>
</tr>
<tr>
<td>Pomegranates</td>
<td>6(30)</td>
<td>15(25.9)</td>
<td>10(38.5)</td>
</tr>
<tr>
<td>Brazil nuts</td>
<td>7(36.8)</td>
<td>15(26.3)</td>
<td>6(23.1)</td>
</tr>
<tr>
<td>Meat</td>
<td>12(66)</td>
<td>25(43.1)</td>
<td>12(40)</td>
</tr>
</tbody>
</table>

* p < .05 ** p < .01

Female GPs with more than 16 years of experience were more likely to be aware of the benefits of tomatoes, broccoli, oily fish and pomegranates compared with male GPs and female GPs with less years of experience.
5.4 Discussion

The general aim of this study was to investigate GPs’ perceptions of the time when prostate cancer patients develop information needs and their awareness regarding food items that are considered beneficial to prostate cancer patients. Male GPs considered that patients develop a need for more information about prostate cancer, interaction issues and maintaining psychological health sooner than female GPs did. Female GPs with more experience considered that patients develop a need for information about sexuality sooner than younger female GPs did. GPs perceive patients as developing their information needs earlier than they actually do except regarding available treatments and treatment options. More specifically, GPs underestimated the development of patients’ needs for more information about prostate cancer, self-care issues, sexuality, cost of treatment, diet and maintaining psychological health and their perceptions also differed from significant others’ needs for more information about prostate cancer, self-care issues, effects on family and friends, interaction issues with health care providers, cost of treatment, diet and maintaining psychological health. GPs seem to consider the 1st-3rd months post-diagnosis as the period during which patients develop their needs whereas that is the period when patients’ interest actually show a decline. GPs show a discrepancy in their knowledge of food items that are considered beneficial to prostate cancer patients whereas female GPs in general show the greatest awareness.

No previous study identified in the literature has investigated the socio-demographic factors that determine GPs’ perceptions of the time when prostate cancer patients develop their information needs. For female GPs, years of practice play a significant role in beliefs about sexuality and gender may play a significant role in beliefs about psychological health, interaction issues and more information about prostate cancer with male GPs believing that patients will develop earlier needs regarding their psychological health. Male GPs may also have an increased sensitivity to prostate cancer, which is a male-only cancer.

A previous study (Eisinger et al., 2011) found that female GPs were more likely than men to refer for breast cancer screening than men but men were not more likely to refer for prostate cancer screening than women. This study adds to this knowledge by
indicating an increased sensitivity on the part of male GPs towards the information needs of prostate cancer patients compared to female GPs. This is contrary, though, to the findings on female GPs’ tendency to provide more counselling than male GPs (Henderson and Weisman, 2001; Flocke and Gilchrist, 2005).

It has been previously suggested that GPs fail to provide patients with the information they need (McPherson et al., 2001; Sinfield et al., 2008; Schinkel et al., 2013) and fail to address patients’ unmet needs (da Silva et al., 1996) while they often underestimate their patients’ needs (Fallowfield et al., 1995; Zemencuk et al., 1998). At the same time, in a recent study, cancer patients reported that they did not see a role for the GP in their therapy and believed they did not need active follow-up (Khan et al., 2011). In addition, there is little involvement of GPs themselves in the provision of information to patients (Norman et al., 2001; Demark-Wahnefried et al., 2005).

GPs are found to underestimate the time during which patients develop a need for information on self-care issues, sexuality, cost of treatment, diet and nutrition and maintaining psychological health while they overestimate the time that patients develop a need for information on available treatments and treatment options. The difference seems to be related to the perception of cancer care: GPs focus on a “treatment-related” cancer care provision and patients in need of a “coping-related” cancer care provision. However, the findings in a previous Chapter (see Chapter 4, section 4.4) indicate that patients also rank treatment and disease-related information higher than coping-related treatment even though, as shown in this study they are developed at a later stage. Thus, patients seem to need information more related to the bio-psychosocial model of healthcare earlier but are more in need of treatment- and disease-specific information.

The information needs in which all three groups differed were one that dealt with physical health (self-care issues) and one that dealt with mental health (maintaining psychological health). GPs seemed to have very different perceptions compared with both patients and significant others. Boberg et al. (2003) found that the most unmet needs of patients were support, knowledge of recurrence and side effects. Recently Khan et al (2011) found that, even though patients had physical and emotional
needs, they were reluctant to talk about these issues with their GPs. This study adds to this by proposing that GPs also underestimate the time after diagnosis when patients may develop an interest in physical and emotional health issues.

Discrepancies in the provision of dietary information can lead to patients’ lack of understanding of the strategies needed in order to change their dietary behaviour (Dowswell et al., 2012). GPs showed discrepancies in their awareness of food items that are considered beneficial to prostate cancer patients and they underestimated patients’ development of a need for diet-related information. The discrepancies in GPs’ awareness of prostate cancer diet that were found in the study support previous findings (i.e. Anderson et al., 2010). They also add to the previous literature, which found discrepancies in the provision of lifestyle information (Ampt et al., 2009; Foster et al., 2003; Brown et al., 2007). They also provide an understanding of the reasons why patients are in need of more information about diet (Salminen et al., 2000; Boberg et al., 2003; McPherson et al., 2001; Sinfield et al., 2008).

The lack of consistency in UK dietary counselling (Philips et al., 2012) may explain discrepancies found in this study regarding GPs’ awareness. It may also be that conflicting evidence in the literature regarding the role of diet in prostate cancer can create scepticism and confusion among health professionals. Recently Gathirwa-Mwangi and Zhang (2013) conducted a systematic review and found that inconsistent evidence exists on the role of diet in prostate cancer. GPs also may believe that patients acquire information from other sources, either secondary care or the media (Pineiro et al., 2005).

Female GPs with more than 16 years’ experience are more likely to be aware of tomatoes, broccoli, oily fish and pomegranates compared with male GPs and female GPs with fewer years of experience. The interest of women in diet and nutrition is not only evident in general but among health professionals specifically. The experience of being a GP is also important for awareness but it is evident only in female GPs rather than in males where experience is not so effective. This indicates that gender is a stronger indicator of awareness than experience.
5.4.1 Limitations

There are issues that need to be considered when interpreting the results of this study. It has limitations regarding research design and the recruitment of patients and significant others, as identified in Chapter 4 (see section 4.4.1). Moreover, GPs were recruited only from one area of the UK (London) and minimal socio-demographic information was collected which may have had an impact on the study’s findings. The cultural background of GPs is not addressed in this study. The educational background of GPs might have influenced their responses because medical education differs in various countries. Furthermore, education may also vary across the UK and no information was collected on the participants’ place of study.

5.4.2 Clinical Implications

The importance of targeting patients’ needs and GPs’ understanding is evident from the fact that patients need to perceive behaviours as medically relevant in order to change it (Greiner et al., 2008). At the same time, patients and GPs have a very different understanding about whether diet is discussed during consultations (Scott et al., 2004; Anis et al., 2004; Simkin-Silverman et al., 2005).

Rozmovits (2004) found non-contradictory dietary information to be one of the primary described needs after the treatment of colorectal cancer. Wood et al. (2010) found patients misinterpreting healthy eating messages. This study adds to the literature in order to understand the different perceptions of GPs on patients’ information needs compared to those of the patients themselves. This can help with meeting patients’ unmet needs which can reduce the burden of disease (Brazil et al., 2004). Benefiting doctor-patient communication and understanding can also enhance cancer patients’ health outcomes (Mainous et al., 2004).

This study suggests that beyond the type and amount of information that patients may need after diagnosis, the time when patients receive information is important as well. Consequently, patients’ and GPs’ perceptions of when patients need specific information may influence healthcare provision, patient satisfaction etc.
GPs may be the healthcare providers with whom patients may spend significant time after diagnosis for various health-related issues and if patients need information on mental and physical health issues and do not receive them, it may affect their well-being.

5.4.3 Future Recommendations

Providing information does not necessarily lead to behaviour change (Coulter and Ellins, 2006). However, it does help in structuring a treatment plan (Falvo, 2004) and may implement self-help behaviours, provided that they are tailored to meet patients’ needs. Perhaps GPs could devote a specific appointment with prostate cancer patients post-treatment to a discussion of their needs and cover lifestyle modification, dietary advice, sources of information and health promotion issues, as well as adding nutritional counselling during regular consultations.

Addressing patients’ awareness of lifestyle and dietary issues is also important. Nutritional training can be induced as UK GPs’ knowledge on diet is low (Moore and Adamson, 2002) and European Colleges of GPs lack their own dietary tools with which to train health professionals (Pineiro et al., 2005).

Finally, future studies can assess GPs’ perceptions in a longitudinal study in the six-month trajectory after cancer diagnosis to identify the linear development of GPs’ perceptions along with the needs of the patients. Moreover, the association between GPs’ perceptions and their intention to provide information on each of the different types of information needs will provide information on the process and predictors of information giving behaviour. This will complement the information-seeking behaviour assessed in this Thesis.

5.5 Conclusion

There is only limited research surrounding the long-term needs of cancer patients, with previous studies focusing mostly on the period during therapy and diagnosis. Quality care provision is dependent on an understanding of when patients develop an
interest in information. Rutten et al (2005) in their review found that the most frequent information needs were treatment-related. They also indicated that the least-frequently cited information source was healthcare professionals. This highlights the importance on identifying whether healthcare professionals’ beliefs about when patients develop a need for information is in line with the patients’ actual needs.

Similarly to the previous Chapter, future studies should employ a longitudinal research design to examine the development of GPs’ perceptions on patients’ needs over a 6-month period post-diagnosis. This will provide safer conclusions on both patients’ and providers’ trajectory of needs after the patients’ diagnosis and how the GPs’ can meet these needs by providing information when the patient needs them.

Information provision and seeking is found to be associated with coping with cancer diagnosis and the implications of diagnosis on patients’ quality of life (Arora et al., 2002). The novelty of this study is that it emphasizes the time when information needs are developed among patients in the post-diagnosis continuum. Previous studies focused on understanding patients’ needs during diagnosis and treatment. Cancer care interventions may benefit from identifying the journey patients undertake after diagnosis.

Health professionals should encourage patients to adhere to healthier lifestyles closer to diagnosis, which, as suggested by the needs of patients in this and previous studies, has the potential to improve quality of life and survival (Bidstrup et al., 2013). Up to this point the following have been examined: the perceived causes of cancer as predictors of lifestyle change and information needs, patients’ and significant others’ information needs and the time of their development as well as the GPs’ perceptions together with GPs’ awareness of prostate cancer diet. Subsequently it is important to assess how patients who change their diet differ from those who do not.
Chapter 6: Study 3: Quality of Life and Dietary Changes among Cancer Patients: a Systematic Review

6.1. Introduction

In general, health is considered “a state of complex physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO, 1946). Ferrell, Dow and Grant (1996) note that “quality of life is a subjective multidimensional construct representing functional status, psychosocial well-being, health perceptions and disease/treatment-related symptoms” while it can be a very broad term which includes psychological, spiritual, physical, economic and social health (Galalae et al., 2004). Therefore, in clinical research, Health Related Quality of Life (HRQOL) is used and constitutes “patients’ appraisals of their current level of functioning and satisfaction compared to what they perceive to be ideal” (Kuchler and Schreiber, 1989). In general, HRQOL quantifies the psychological, social and physical aspects of therapy and the illness itself (Marin Caro et al., 2007).

Cancer patients are likely to pursue lifestyle changes and represent a group that could benefit from dietary interventions (Patterson et al., 2003). Demark-Wahnefried et al. (2000) found a strong interest among cancer patients in health promotion programmes that encouraged healthier diets. In particular, Marin Caro et al. (2007) highlight in their review the importance of nutritional interventions in oncology and the critical importance of the relationship between HRQOL and changes in diet.

When assessing the relationship between dietary change and HRQOL it is not clear whether diet affects HRQOL or whether it reflects it. Therefore, systematically investigating the relationship between changes in diet and HRQOL are prone to showing a potential association. Currently the question remains: is dietary change the factor which affects HRQOL or is HRQOL the factor that predicts whether people with cancer will change their diet or not? Also, some studies are limited by using a cross-sectional research design, which does not allow assessment of causal
relationships between HRQOL and changes to cancer patients’ diet (Blanchard et al., 2004; Demark-Wahnefried et al., 2004; Mosher et al., 2009).

Until now, behaviour change strategies are reported to have failed to have an impact on patients’ HRQOL because of research design, poor reported information in reports and the multifaceted interventions that make it difficult to evaluate the effect of different components (Michie and Abraham, 2004). This review aims to fill the gap in knowledge regarding the association between HRQOL and dietary changes among cancer patients. The importance of targeting HRQOL is evident from the radical increase of HRQOL-related citations in Pub Med the past two decades (Armstrong et al., 2007).

The aims of this Chapter are twofold:

a) To evaluate the relationship between change to diet after cancer and change to HRQOL among cancer patients and

b) To evaluate the quality of available evidence to inform on gaps in our understanding and propose directions for future research.

6.2 Methods

6.2.1 Search Criteria

The Phases of papers’ extraction are presented in Figure 6.1. Abstracts were initially reviewed using combinations of the following keywords: “cancer” “survivors”, “quality of life”, “health-related quality of life”, “functioning”, “diet”, “nutrition intervention”, “well-being”. Limits were set on the search in terms of “English” and “adults”. The rationale behind these limits was that a) there was no opportunity for translating foreign-language papers into English, and b) potential papers with children diagnosed with cancer have the potential to skew the homogeneity of participants because of specifics of child cancer. The MEDLINE, PSYCINFO and IOS WEB OF KNOWLEDGE databases were searched for published research
No duplicates were identified. During the 1st Phase, studies were excluded for the following reasons: they did not report a change in diet, they did not use standardized tools to measure HRQOL, they used qualitative methods, they were not reported in English, and they did not include adult patients.

Following Phase 2, studies were included based on the following criteria:

- Studies with participants on active treatment or active surveillance as well as survivors a wide length of time after diagnosis.
- Studies using a randomized control (RCT) or clinical trials. Studies with cross-sectional and prospective research design were excluded. The rationale for using this criterion in Phase 2 was that trials – as opposed to cross-sectional or prospective designs – are more likely to detect the direction of the relationship between dietary change and HRQOL
- Studies with a single or multiple facet intervention trial that assessed at least dietary change with HRQOL as one of the outcomes (primary or secondary).
- Studies with HRQOL as the research outcome measured by standardized tools.

Therefore, in Phase 3, the focus of reviewing papers was on information regarding the sample (cancer patients), study design (randomized-control or clinical trials with at least a nutritional aspect on the intervention), outcome measures (HRQOL), measurement tools (standardized HRQOL tools) and the testing association (between dietary changes and HRQOL). Abstracts were assessed against the above criteria and studies that failed to meet the criteria were excluded. Details on the exclusion process are shown in Figure 6.1.
Figure 6.1: Study selection for inclusion in this review

6.2.2 Search Results

Initially, 448 studies were identified using the keywords, while at Phase 1 631 studies were excluded based on the exclusion criteria of Phase 1. In Phase 2, 17 studies published between 2000 and 2009, featuring 13,695 individuals diagnosed with cancer, exploring the association between dietary change and HRQOL were identified. Eleven studies were RCTs, of which two focus on diet only (Carmody et al., 2008; Ravasco et al., 2003), seven on diet and exercise (Demark-Wahnefried et al., 2006; Demark-Wahnefried et al., 2007; Demark-Wahnefried et al., 2008; Morey et al., 2009; Mosher et al., 2009; von Gruenigen et al., 2009; Haseen et al., 2010), one on diet, exercise and stress management (Daubenmeier et al., 2006) and one on diet, exercise, sedentary behaviour, alcohol consumption and smoking (Hawkes et al., 2009). Furthermore, two studies were prospective studies that aim at determining the relationship between diet quality and HRQOL (Wayne et al., 2006; Roberge et al., 2000) and four were cross-sectional studies. In Phase 3, prospective and cross-sectional studies were excluded (6 studies) and only RCTs were included. That was because RCTs offer robust evidence clearly designating their clinical implications.
(Cockle-Hearne and Faithful, 2010) while they also provide evidence on the direction of relationships and associations. Finally, the Haseen et al. (2010) study was excluded because it has not produced any data yet.

Therefore after Phase 3, ten studies published between 2000 and 2009, including a total of 3,519 individuals diagnosed with cancer, which explored the relationship between dietary change and HRQOL, were included in the review.

6.2.3 Data synthesis

A narrative approach (Petticrew and Roberts, 2008) was used to critically and qualitatively reflect on the association between changes to diet and HRQOL. Analysis focused on study characteristics (publication date; design; country of origin; participants’ characteristics – both clinical and non-clinical; tool assessment), key findings, and the conclusions of each study as well as their common findings.

6.2.4 Quality Assessment

The NHS has proposed a set of quality criteria (NHS CRD, 2001) that a systematic review should investigate:

- Adequate methodology for random allocation and concealment in order to avoid bias due to confounding variables and selection bias due to systematic differences between groups’ response to the intervention.

- Participants’ unawareness of the group to which they have been assigned, which minimizes performance and detection bias.

- Overcoming the attrition of bias caused by unexpected withdrawals from the study and the resulting systematic differences between participants withdrawing or excluded and those included in the comparison groups.

Therefore a standardized Quality Checklist (Kmet et al., 2004) was used to assess the quality of the included studies. This checklist draws upon a scoring system based on
existing tools and aims at evaluating the quality of quantitative research papers. It includes 14 assessment criteria (Table 6.1).

Table 6.1: Criteria used in Quality Checklist (Kmet et al., 2004)

<table>
<thead>
<tr>
<th></th>
<th>Question / objective sufficiently described?</th>
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<tbody>
<tr>
<td>2</td>
<td>Study design evident and appropriate?</td>
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<tr>
<td>3</td>
<td>Method of subject/comparison group selection or source of information/input variables described and appropriate?</td>
</tr>
<tr>
<td>4</td>
<td>Subject (and comparison group, if applicable) characteristics sufficiently described?</td>
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<tr>
<td>5</td>
<td>If interventional and random allocation was possible, was it described?</td>
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<tr>
<td>6</td>
<td>If interventional and blinding of investigators was possible, was it reported?</td>
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<tr>
<td>7</td>
<td>If interventional and blinding of subjects was possible, was it reported?</td>
</tr>
<tr>
<td>8</td>
<td>Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?</td>
</tr>
<tr>
<td>9</td>
<td>Sample size appropriate?</td>
</tr>
<tr>
<td>10</td>
<td>Analytic methods described/justified and appropriate?</td>
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<tr>
<td>11</td>
<td>Some estimate of variance is reported for the main results?</td>
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<tr>
<td>12</td>
<td>Controlled for confounding?</td>
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<tr>
<td>13</td>
<td>Results reported in sufficient detail?</td>
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<tr>
<td>14</td>
<td>Conclusions</td>
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</tbody>
</table>

Each study was scored using a 3-point scale (2= Yes, 1= Partially, 0= No). Where appropriate, a “non-applicable” score was given to studies where the specific criteria were not relevant. Then adding the scores and dividing them by the total number of items (excluding those non-applicable), a summary score was calculated. The score was then converted into a percentage of the maximum possible score.

6.3. Results

6.3.1 Study descriptions

Seven studies were from the USA, one was from Australia, one from Portugal, and one study included participants from the USA, Canada and the UK. Some studies
included post-diagnosis cancer patients with a range of 6 months-10 years after diagnosis (Mosher et al., 2009; Demark-Wahnefried et al., 2006; Demark-Wahnefried et al., 2007; Morey et al., 2009; Hawkes et al., 2009; von Gruenigen et al., 2009; Carmody et al., 2008) while other studies included cancer patients on therapy (Ravasco et al., 2003; Demark-Wahnefried et al., 2008) or on active surveillance (Daubenmeier et al., 2006). All of the studies included prostate, breast and colorectal cancer patients except one that included endometrial cancer patients only (von Gruenigen et al., 2009). One study included other cancer patient groups (head-neck/gastrointestinal tract, prostate, breast, lung, brain, gallbladder and uterus) as well (Ravasco et al., 2003).

All the studies used standardized tools to assess HRQOL. Four studies used the Medical Outcomes Study Short Form-36 (MOS SF-36) - RAND-36 Health Status Inventory; one study used the Physical Functioning subscale of MOS SF-36; two studies used the European Organization for Research and Treatment of Cancer (EORTC) QLQ C-30 and its modules; and three studies used the Functional Assessment of Cancer Therapy (FACT) tool. The studies also used the colorectal (Hawkes et al., 2009), breast (Demark-Wahnefried et al., 2007; Demark-Wahnefried et al., 2008) and prostate (Carmody et al., 2008) subscale of Functional Assessment of Cancer Therapy (FACT) while von Gruenigen et al. (2009) also used SF-36 to measure functional status and fatigue and endometrial symptoms subscales. This information is outlined and the studies are presented according to whether they had a diet-only intervention (Table 6.2), a diet and exercise intervention (Table 6.3) or a multifaceted intervention (Table 6.4).
Table 6.2: Included studies with an intervention focused on diet only

<table>
<thead>
<tr>
<th>Study</th>
<th>Aims</th>
<th>Sample and data collection</th>
<th>Main and subsidiary outcomes</th>
<th>Intervention</th>
<th>HRQOL measurement</th>
<th>Key findings about the association of HRQOL with dietary changes</th>
<th>Other results</th>
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<tbody>
<tr>
<td>Carmody et al. (2008)</td>
<td>To investigate whether men with prostate cancer are able to make changes to a diet that is strong in plant-based foods and fish and examine the effect on HRQOL and prostate-specific antigen velocity.</td>
<td>36 prostate cancer patients and their partners Received primary treatment but not in the last 6 months.</td>
<td>1) HRQOL. 2) Prostate-specific antigen (PSA) velocity.</td>
<td>Dietary intervention (11 weeks and 3 months from baseline)</td>
<td>Functional Assessment of Chronic Illness Therapy – Prostate Cancer Scale (FACT-P).</td>
<td>The intervention group had a significant increase in HRQOL (p = .02) compared to controls.</td>
<td>Significant reduction in the consumption of saturated fat and increased consumption of vegetable proteins with accompanying reductions in animal proteins among those in the intervention group. The mean PSA doubling time for the intervention group was substantially longer at the 3-month follow-up visit than that of the controls.</td>
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<td>Ravasco, Monteiro-Grillo and Camillo (2003)</td>
<td>To investigate cancer patients’ QoL at the beginning and at the end of radiotherapy (RT); to investigate whether nutrient intake after nutritional</td>
<td>125 cancer patients (head-neck/gastrointestinal tract, prostate, breast, lung, brain, gallbladder, uterus cancer) aged 33-86 Participants were divided into high-risk (head-neck/gastrointestinal tract) and low-risk groups (all others).</td>
<td>1) QoL. 2) Nutritional status and nutritional intake.</td>
<td>Diet focused trial assessing nutritional status Theory: unspecified Intervention strategies and delivery: nutritional counselling. Nutritional Status (Ottery’s Subjective Global Assessment, Ottery, 1996) Nutritional Intake (24hr recall food questionnaire)</td>
<td>EUROQOL and EORTC (QLQ) – C30</td>
<td>Individualized nutritional counselling improves HRQOL. Lower risk patients always had better HRQOL than high-risk patients (p = .01). QoL improvement in HRQOL.</td>
<td>Individualized nutritional counselling improves nutritional intake. Prevalent baseline malnutrition in HR vs. LR (p=.02). Nutritional intake associated with nutritional status (p=.007) and status did not improve.</td>
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<tr>
<td>Study</td>
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<td>counselling influences QoL and to see which symptoms affect poor QoL and reduced nutritional intake.</td>
<td>neck/gastrointestinal tract, low-risk (prostate, breast, lung, brain, gallbladder, uterus) patients.</td>
<td>In therapy (radiotherapy)</td>
<td>high-risk patients was correlated with nutritional intake (p = .001) and both remained stable in low-risk patients.</td>
<td>change significantly during radiotherapy.</td>
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Table 6.3: Included studies with an intervention focused on diet and exercise

<table>
<thead>
<tr>
<th>Study</th>
<th>Aims</th>
<th>Sample and data collection</th>
<th>Main and subsidiary outcomes</th>
<th>Intervention</th>
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<th>Key findings about the association of HRQOL with dietary changes</th>
<th>Other results</th>
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<tr>
<td>Demark-Wahnefried et al. (2007) USA</td>
<td>To test the efficacy of a Fresh Start trial and compare sequentially tailored versus standardized mail materials on improving cancer survivors' diet and exercise behaviour*</td>
<td>543 breast and prostate cancer patients (57 ±10.8 years), 519 completed the follow-up Early staged patients with in situ, localized or regional cancer within 9 months of diagnosis</td>
<td>1) Diet 2) Exercise Behaviours 3) QoL 4) Risk of depression 5) Social support 6) Comorbidity 7) Perceived health 8) Self-efficacy 9) Stage of readiness for undertaking dietary and exercise change 10) Tobacco use 11) Weight Status</td>
<td><strong>Diet and exercise</strong> focused trial called FRESH START aiming at improving fruit and vegetable consumption, reducing fat intake and increasing exercise – baseline and 10 months follow-up <strong>Theory</strong>: Social Cognitive Theory and Transtheoretical Theory <strong>Intervention strategies</strong>: 10-month programme of tailored mailed print materials or 10-month programme of non-tailored mailed materials. <strong>Intervention delivery</strong>: 1 telephone survey at baseline and 1 year afterwards assessing BMI, dietary consumption, physical activity and psychosocial/behavioural variables. <strong>Dietary intake</strong> (Diet History Questionnaire, eating 5 or more servings of fruits and vegetables and eating a low-fat diet only at baseline, weight status)</td>
<td>Functional Assessment of Cancer Therapy FACT- B</td>
<td>No improvements were observed in HRQOL by either positive dietary or exercise changes on follow-up.</td>
<td>Both arms of the intervention improved their lifestyle behaviours (p &lt;.05). Significantly greater gains occurred in the Fresh Start intervention versus the control arm (on practice of two or more goal behaviours, exercise minutes per week, F&amp;V per day, total fat, saturated fat and BMI).</td>
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*there are indications of these behaviours’ effect on HRQOL
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<tr>
<th>Study</th>
<th>Aims</th>
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</table>
| Demark-Wahnefried et al. (2008) | To test the feasibility and variability of a home-based intervention trial to prevent weight gain and concurrent losses in muscle mass. | 90 pre-menopausal breast cancer patients 25-53 years old Newly diagnosed stage I-IIIA and on adjuvant chemotherapy | 1) Physical Activity  
2) Diet  
3) Body Composition  
4) Body Density  
5) Serologic Biomarkers  
6) Quality of Life, Anxiety and Depression.  
7) Feasibility | Diet focused trial called Survivor Training for Enhancing Total Health (STRENGTH) – baseline and 6 months follow-up  
Theory: Social Cognitive Theory (verbal and written instructions)  
Intervention strategies: 3 intervention trials: one attention control group with a calcium-rich diet (CA) intervention and two experimental arms: one with CA and exercise (EX) and one with CA, EX and high fruit and vegetable and low-fat diet (FVLF) arm.  
Intervention delivery: telephone counselling with 14 contacts of 10-30 minutes – weekly during the first month and bi-weekly for the remaining 5 months  
Dietary intake (Diet History Questionnaire and maintenance of high fruit and vegetable and low-fat diet during the intervention) | Functional Assessment of Cancer Therapy FACT-B  
Also the Hospital Anxiety and Depression Scale (HADS) | Significant improvements to HRQOL on all groups of the intervention including the FVLF group.  
No significant differences on anxiety and depression scales. | Modest attrition observed (8.8%).  
Increased calcium intake in all arms and higher F&V intake and lower fat intake in the CA+EX+FVLF arm.  
No differences in physical activity.  
Significant difference in the percentage of body fat.  
No differences observed in other end points. |
| Mosher et al. (2009)          | To investigate the association between healthy behaviours and quality of life outcomes. | 753 older (≥65 years) long-term breast, prostate and colorectal cancer survivors Long-term survivors (≥ 5) | 1) QoL | Diet and exercise focused trial called Reach Out to Enhance Wellness (RENEW)  
Theory: unspecified  
Intervention strategies: home-based diet and exercise  
Intervention delivery: 2 | MOS SF-36 – 8 domains. | Diet quality significantly associated with physical functionality and vitality.  
There is high prevalence of suboptimal health behaviours among older long-term survivors. | Indications of a |
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<th>Other results</th>
</tr>
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<tbody>
<tr>
<td>Demark-Wahnefried et al. (2006) USA</td>
<td>To investigate whether adherence to a healthy lifestyle behaviour intervention may prevent functional decline.</td>
<td>420 older prostate and breast cancer patients (≥65 years) Within 18 months of diagnosis (therapy stage: unknown)</td>
<td>1) Declines in physical functioning (PF) 2) Physical Activity 3) Diet quality</td>
<td>Diet and exercise focused trial (6 and 12 months from baseline) called Leading the Way in Exercise and Diet (LEAD) Theory: unspecified Intervention strategies: aimed to increase exercise and improve diet (increasing fruits and vegetables and whole grains consumption, decrease total fat; cholesterol and saturated fat and adequate calcium and iron) Diet Quality (Diet Quality Index from 3-day dietary recalls – Nutrition Data System Software – NDS, Minneapolis)</td>
<td>MOS SF-36 Physical Functioning Subscale with four items from Satariano et al., 1990</td>
<td>Differences between intervention group and controls were clinically but not statistically significant. Intervention improved both HRQOL and depression.</td>
<td>The intervention after 6 months is associated with statistically significant improvements in diet quality (p &lt;.003) but non-significant changes in other domains. Recidivism was not significant (all p&lt;.05) from 6 to 12 months. Significant improvements in self-efficacy for exercise but no changes were observed in readiness to exercise measures. Emotional well-being and self-efficacy are improved with weight-loss.</td>
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<tr>
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<tr>
<td>Von Gruenigen et al., (2009)</td>
<td>To assess the effects of a lifestyle intervention in overweight and obese endometrial cancer survivors’ QoL, depression, self-efficacy and eating behaviour changes.</td>
<td>45 early stage endometrial cancer survivors of unknown age.</td>
<td>1) QoL</td>
<td><strong>Diet and exercise</strong> focused intervention (6 months from baseline)</td>
<td>Functional Assessment of Cancer Therapy-General FACT-G with fatigue and endometrial symptoms subscales and MOS SF-36 for functional status.</td>
<td>Intervention did not have effects on global QoL outcomes but significant differences observed for emotional wellbeing QoL (p=.02).</td>
<td>Significant improvements for self-efficacy related to social pressure (p =.03) and restraint (p =.02) and significant differences for self-efficacy related to negative emotions (p &lt;.01), food availability (p =.03) and physical discomfort (p =.01).</td>
</tr>
<tr>
<td>USA</td>
<td></td>
<td>Unknown if in treatment but with stage I-II endometrial cancer.</td>
<td>2) Depression</td>
<td><strong>Theory</strong>: Social Cognitive Theory (Bandura, 1986)</td>
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<td></td>
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<td></td>
<td>3) Self-efficacy</td>
<td><strong>Interventions strategies</strong>: aiming at nutrition and exercise</td>
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<td></td>
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<td>4) Eating behaviour changes.</td>
<td><strong>Intervention delivery</strong>: conducted by a registered dietician (contracting participants), the primary investigator (met with participants at 3, 6 and 12 months) and a psychologist (conducted cognitive and behavioural self-management strategies for stress management and weight-loss).</td>
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<td></td>
<td><strong>Eating Behaviour</strong> (Three-Factor Eating Questionnaire TFEQ)</td>
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<td></td>
<td>**Patient anthropometric data (i.e. weight, BMI, measured manually by a clinician).</td>
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<tr>
<td>Morey et al. (2009)</td>
<td>To investigate the effect of a diet and exercise intervention in older overweight cancer survivors’ functional decline</td>
<td>641 overweight (BMI ≥25 and &lt;40) – 319 intervention participants and 322 controls (aged 65-91) prostate, breast and colorectal cancer patients</td>
<td>1) Physical Functioning (primary)</td>
<td><strong>Diet and exercise</strong> focused trial called Reach Out to Enhance Wellness (RENEW) (12 months from baseline)</td>
<td><strong>MOS SF-36 Physical functioning Subscale</strong></td>
<td>Overall HRQOL decreased after the intervention but were of lower magnitude compared to the control group and were sustained for overall and mental health. (-2.15; 95%CI, -0.36 to -3.93 vs. -1.89 (95% CI, -0.70 to -3.09) with p=0.005.</td>
<td>The mean baseline lower extremity function were 78.2 and changes were 0.34 (95% CI, -0.84 to 1.52) in intervention group compared with control -1.89 (95% CI, -0.70 to -3.09) with p=0.005.</td>
</tr>
<tr>
<td>USA</td>
<td></td>
<td></td>
<td>2) Changes in function on basic and advanced lower extremity function subscales of</td>
<td><strong>Theory</strong>: Social Cognitive Theory (Bandura, 1986) and Trans-theoretical models (Marcus et al., 1996)</td>
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<td></td>
<td><strong>Intervention strategies</strong>: home-based intervention aiming at promoting exercise, improving</td>
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<tr>
<td>Study</td>
<td>Aims</td>
<td>Sample and data collection</td>
<td>Main and subsidiary outcomes</td>
<td>Intervention</td>
<td>HRQOL measurement</td>
<td>Key findings about the association of HRQOL with dietary changes</td>
<td>Other results</td>
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<td>Long-term cancer survivors (≥ 5 years after diagnosis)</td>
<td>Life Function and Disability Index</td>
<td>diet quality and modest weight-loss</td>
<td>95% CI, -3.04 to -6.63) and with p = .03.</td>
<td>Physical functioning declined post-intervention (p=0.03).</td>
<td>dietary behaviours increased significantly in the intervention group compared with the control while weight loss was greater (2.06 kg – 95% CI, 1.69 to 2.43 kg) vs. 95% CI, 0.51 to 1.33 kg respectively with p &lt;.001.</td>
</tr>
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<td></td>
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<td>3) Physical Activity</td>
<td>Intervention delivery: a program of telephone counselling and automated prompts (15 sessions and 8 prompts), a personally tailored workbook and a series of newsletters.</td>
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<td>4) BMI</td>
<td>Changes in function (basic and advanced lower extremity function subscales of the Late Life Function and Disability Index)</td>
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<td></td>
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<td>5) Overall QoL</td>
<td>Dietary intake (2 24-hour recalls - Nutrition Data System Software)</td>
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</table>

Dietary intake increased significantly in the intervention group compared with the control while weight loss was greater (2.06 kg – 95% CI, 1.69 to 2.43 kg) vs. 95% CI, 0.51 to 1.33 kg respectively with p <.001.
<table>
<thead>
<tr>
<th>Study</th>
<th>Aims</th>
<th>Sample and data collection</th>
<th>Main and subsidiary outcomes</th>
<th>Intervention</th>
<th>HRQOL measurement</th>
<th>Key findings about the association of HRQOL with dietary changes</th>
<th>Other results</th>
</tr>
</thead>
</table>
| Hawkes et al., (2009) | To test the short-term effectiveness and feasibility of a lifestyle intervention targeting colorectal cancer survivors. | 20 colorectal cancer survivors, 6 months after diagnosis, aged 20-80 years old.Had undergone surgery or chemotherapy. | 1) Programme feasibility (programme retention, satisfaction)                                | General lifestyle intervention (6 weeks from baseline) called “CanChange”:  
  **Theory:** Social Cognitive Theory (Bandura, 1986) including psychosocial and lifestyle support aiming at positive lifestyle behaviour changes.  
  **Interventions strategies:** included healthy eating and dietary goals and were based on national guidelines for the prevention of colorectal cancer.  
  **Intervention delivery:** by telephone sessions while participants received a handbook for goal setting and personal assessment | Functional Assessment of Cancer Therapy-Colorectal-FACT-C V4.  
  [M (SD): 109.1 (17.8) vs. 111.9 (17.3)] | Post-intervention non-significant improvements in CRC-specific symptoms from baseline to post-intervention, significant decrease in processed meat intake, non-significant improvements in sedentary behaviour, and to meeting the national guidelines for fruits and vegetables intake, no changes in smoking status, and variable results for alcohol intake, physical activity and BMI. | Non-significant improvements in all CRC-specific symptoms from baseline to post-intervention, significant decrease in processed meat intake, non-significant improvements in sedentary behaviour, and to meeting the national guidelines for fruits and vegetables intake, no changes in smoking status, and variable results for alcohol intake, physical activity and BMI. |
| Daubenmienier et al. (2006) | To investigate the effects of lifestyle changes on prostate cancer patients’ HRQOL, perceived stress and self-reported | 93 prostate cancer patients (44 intervention, 49 usual-care controls)Participating in active | 1) Health-related Quality of Life  
  2) Perceived Stress  
  3) Self-reported | Diet, exercise and stress management focused trial (12 months from baseline)  
  **Theory:** unspecified  
  **Intervention strategies:** a low-fat, vegan diet, enhanced exercise and stress management  
  **Intervention delivery:** MOS SF-36 | Significant correlations between lifestyle changes and specific areas of HRQOL – the physical health summary score (role limitations due to physical symptoms, physical function, general health perceptions, vitality) were significantly associated with dietary changes.  
  Healthier lifestyle at entry associated with greater | Significant correlations between lifestyle changes and specific areas of HRQOL – the physical health summary score (role limitations due to physical symptoms, physical function, general health perceptions, vitality) were significantly associated with dietary changes.  
  Healthier lifestyle at entry associated with greater | Significant correlations between lifestyle changes and specific areas of HRQOL – the physical health summary score (role limitations due to physical symptoms, physical function, general health perceptions, vitality) were significantly associated with dietary changes.  
  Healthier lifestyle at entry associated with greater |
<table>
<thead>
<tr>
<th>Study</th>
<th>Aims</th>
<th>Sample and data collection</th>
<th>Main and subsidiary outcomes</th>
<th>Intervention</th>
<th>HRQOL measurement</th>
<th>Key findings about the association of HRQOL with dietary changes</th>
<th>Other results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>sexual function. surveillance sexual function</td>
<td>delivery of a diet, 3-hours per-week moderate exercise, and 1 hour of daily stress management practice. Also weekly support group meetings were held throughout.</td>
<td>Lifestyle behaviors (lifestyle index)</td>
<td>vitality, social functioning, role limitations due to emotional symptoms, mental health and bodily pain $r = .21$ (p &lt; .05) to $r = .32$ (p &lt; .01).</td>
<td>Changes in lifestyle index not related to changes in the individual SF-36 subscales among intervention participants and across experimental groups but changes over time showed enhanced physical HRQOL.</td>
<td>physical and mental health and sexual functioning</td>
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<td>Changes in lifestyle index not related to changes in sexual function.</td>
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<td>Participants whose lifestyle improved over time showed decreased perceived stress.</td>
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</table>
6.3.2 Themes identified

6.3.2.1 Association between HRQOL and dietary change

Only two studies (Ravasco et al., 2003; Carmody et al., 2008) used an intervention focusing on diet only. Five studies (Demark-Wahnefried et al., 2006; 2007; Morey et al., 2009; Mosher et al., 2009; von Gruenigen et al., 2009) used a combined intervention focusing on diet and exercise, one study (Daubenmier et al., 2006) used a combination of diet, exercise and stress management and another study (Hawkes et al., 2009) used a general lifestyle intervention which included healthy eating.

Four studies (Hawkes et al., 2009; Carmody et al., 2008; von Gruenigen et al., 2009; Demark-Wahnefried et al., 2007) showed a non-significant relationship between dietary changes and HRQOL while five studies (Mosher et al., 2009; Daubenmeier et al., 2005; Demark-Wahnefried et al., 2006; Demark-Wahnefried et al., 2008; Morey et al., 2009; Ravasco et al., 2003) found significant results either for the relationship between dietary changes and HRQOL or with some aspects of HRQOL (physical functioning) and dietary changes. Even though Demark-Wahnefried et al. (2006) found clinically significant effects of a home-based diet (aiming at healthier diet) on HRQOL they were unable to demonstrate that this association was statistically significant. The relationship between dietary change and change in HRQOL is found to be in the following direction: dietary change (factor) – HRQOL (outcome). Carmody et al. (2008) found a significant increase on prostate cancer patients’ HRQOL (p= .02) after having healthier diets with an improvement in diet quality showing a positive association with increased HRQOL.

Some researchers found that interventions to improve diet quality did indeed improve psychosocial well-being/depression and HRQOL (Demark-Wahnefried et al., 2006) and overall HRQOL (Morey et al., 2009; Blanchard et al., 2008; Ravasco et al., 2003; Daubenmeier et al., 2006). Other studies using the 5-A-Day fruit and vegetable recommendation found that the interventions did not significantly affect or lead to a change in HRQOL (Blanchard et al., 2003; von Gruenigen et al., 2009). However von Gruenigen et al. (2009) found weight loss (which possibly indicates a change in eating habits) to improve emotional well-being and self-efficacy.
All of the standardized HRQOL tools comprise measures of mental and physical health. Not all studies have reported significant changes in both domains. For example, Mosher et al. (2009) found diet quality to have a positive effect on physical HRQOL outcomes only. On the other hand, Daubenmeier et al (2006) found significant improvements to six HRQOL subscales (role limitations due to the physical symptoms, vitality, social functioning, and role limitations due to emotional symptoms, mental health and bodily pain) but not on physical functioning and general health. Furthermore different subscales of HRQOL are differently associated with dietary changes. Three studies found significant differences in physical functioning for all patients (Mosher et al., 2009; Demark-Wahnefried et al., 2006; Morey et al., 2009;) and one only for head and neck cancer patients (Ravasco et al., 2003). Two studies found significant differences in social functioning (Daubenmeier et al., 2006; Morey et al., 2009), two in vitality (Mosher et al., 2009; Daubnmeier et al., 2009), one in general health (Morey et al., 2009) and one in bodily pain, role-emotional, role functioning and mental health (Mosher et al., 2009).

6.3.2.2 Cancer Type

One study (Demark-Wahnefried et al., 2007) including breast cancer patients found significant improvements to HRQOL in all groups of the intervention. Specifically, components with a) a selenium-rich diet with exercise and b) a selenium-rich diet with exercise and a diet high in fruit and vegetables and lower in fat led to improved HRQOL, but no significant improvements were found with regard to anxiety and depression. At the same time, dietary changes were found to be associated with changes on 3 out of 4 mental health subscales: social functioning (p = .05), role limitations-emotional (p = .02), mental health (p = .01) and 2 out of 4 physical health subscales: physical functioning (p = .02) and bodily pain (p = .03). Two studies, which included prostate cancer patients, found an association between HRQOL and changes in diet. The one found a significant increase of HRQOL (p =.002) after adhering to a healthier diet and an association between a healthier lifestyle and physical, mental health and sexual functioning (Carmody et al., 2008)while the other found improvements to lifestyle associated with improvements to physical health and perceived stress (Daubenmeier et al., 2006).
Two studies (Demark-Wahnefried et al., 2006; 2007), which included both prostate and breast cancer patients, found that changes to physical functioning were clinically significant but not statistically significant. One found that HRQOL and depression scales were improved (Demark-Wahnefried et al., 2006). On the other hand, Demark-Wahnefried et al (2007) found no significant improvement to HRQOL (p=.16).

A study that included colorectal cancer patients found no significant improvements to HRQOL (Hawkes et al., 2009). Two studies that included prostate, breast and colorectal cancer patients found a decrease in physical functioning (p = .03), an increase in overall HRQOL (p < .001) and changes to social functioning and general health (p = .02) (Morey et al., 2009). A healthier diet was found to be associated with increased physical health (vitality and physical functioning) (p < .05) and lower a BMI associated with reduced physical health (p < .001). One study with endometrial cancer patients found a significant increase in overall HRQOL (p = .02) (von Gruenigen et al., 2009).

Finally, one study (Ravasco et al., 2003) included patients with head-neck and gastrointestinal tract (high-risk group) and prostate, breast, lung, brain, bladder and uterus cancer (low-risk group) and found an improvement to HRQOL after nutritional counselling in both groups but higher in high-risk patients than low-risk patients (p = .001). Also, at the end of radiotherapy, HRQOL was found to improve through dietary change in high-risk patients (p = .001). This study is the only one that indicates the differences in how dietary changes affect HRQOL according to cancer type with high-risk patients having higher improvement onto their HRQOL than the low-risk group.

6.3.2.3 Stage of treatment

It appears that results from studies using interventions focused on cancer patients at an early stage after diagnosis and while undergoing treatment (Demark-Wahnefried et al., 2007; Demark-Wahnefried et al., 2008; Wayne et al., 2006; von Gruenigen et al., 2009; Ravasco et al., 2003; Demark-Wahnefried et al., 2006) have mixed results.
On the other hand, studies with participants who were cancer survivors and with most of them already having undergone treatment (surgery, radiotherapy, chemotherapy) more than two years before or who were on active surveillance found a significant association between dietary change and HRQOL (Carmody et al., 2008; Morey et al., 2009; Daubenmeier et al., 2006; Mosher et al., 2009) with the exception of one (Hawkes et al., 2009).

6.3.3 Quality appraisal

The overall quality of studies can be rated as very high. Nine out of ten studies scored higher than 90% with only one scoring less. Ratings ranged from 87.5% to 95.8% (Mean = 91.9, SD = 2.4). All of the studies succeeded well in having a question or objective sufficiently described an evident and appropriate study design, a recruitment method and source appropriate and described, sufficiently described subject characteristics, appropriate and described analytic methods, variance estimations, detailed reported results, and a conclusion supported by results. Studies were less successful in having well-defined outcome and exposure measures that were robust to measurement bias, and having clearly described randomization procedures. There was limited information on sample size calculations and this is discussed in detail later in the limitations of the included studies (see section 6.3.4). All studies were only partly successful at controlling for confounding variables (Table 6.5).
Table 6.5: Quality appraisal of included studies in the systematic review

<table>
<thead>
<tr>
<th>Study</th>
<th>Question or objective sufficiently described</th>
<th>Study design evident and appropriate</th>
<th>Method of subject/comparison group selection or source of information/input variables described and appropriate?</th>
<th>Subject (and comparison group, if applicable) characteristics sufficiently described?</th>
<th>If interventional and random allocation was possible, was it described?</th>
<th>If interventional and blinding of investigators was possible, was it reported?</th>
<th>If interventional and blinding of subjects was possible, was it reported?</th>
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</thead>
<tbody>
<tr>
<td>Carmody et al (2008)</td>
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Table 6.5: Quality appraisal for included studies in the systematic review (continued)

<table>
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<tr>
<th>Study</th>
<th>Outcome and exposure measures well defined and robust to measurement bias? Means of assessment reported?</th>
<th>Was a sample size calculation reported?</th>
<th>Analytic methods described/justified and appropriate? (e.g., testing of parametric assumptions)</th>
<th>Some estimate of variance is reported for the main results?</th>
<th>Controlled for confounding?</th>
<th>Results reported in sufficient detail?</th>
<th>Conclusion supported by results?</th>
<th>Overall % of available score for all item checklists</th>
</tr>
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<tr>
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</table>
6.3.4 Limitations of included studies

The included studies have several limitations that influence their internal and external validity and limit the generalizability of their findings. The use of self-report tools to measure HRQOL is not really a limitation even though it is reported as such by some of the authors of the included studies. In cancer research, most of the information used to measure HRQOL is collected using self-report questionnaires. Moreover, Osoba et al. (1994) indicate that quality of life measures are more appropriately assessed using questionnaires even though self-report assessment has minimum objectivity. However, four authors state this as a study limitation (Demark-Wahnefried et al., 2008; Hawkes et al., 2009; Morey et al., 2009; Mosher et al., 2009). Self-report methods for measuring HRQOL continue to be widely used and are regarded as an accepted means of measurement so it is not a major barrier for measuring HRQOL.

A low response rate leading to response bias is another limitation common to most of the included studies. Three studies explicitly state this as a limitation of their study with a response rate of 32.7% (Blanchard et al., 2008), 34% (Demark-Wahnefried et al., 2006) and 6% (Mosher et al., 2009) while Demark-Wahnefried et al. (2007) indicate differential dropout between the study arms as a limitation (6.6% - intervention arm and 2.2% - attention control arm). In particular Mosher et al. (2009) found significant differences between respondents and non-respondents with respect to sex, age, race and time since diagnosis. The rest of the studies fail to report response rates or outline the differences between respondents and non-respondents, nor do they control for these differences (von Gruenigen et al., 2009; Daubenmeier et al., 2006; Carmody et al., 2008; Hawkes et al., 2009; Ravasco et al., 2003; Wayne et al., 2006) while Morey et al. (2009) provide the exclusion criteria and the numbers of participants before their exclusion without indicating whether they controlled for the non-respondents’ characteristics.

Also, not all the studies reported sample size calculations and some even had a small number of participants. This has affected the quality of reporting of relationships given the limited variance in diet and HRQOL seen with such a small sample, especially since patients with higher HRQOL are more likely to enrol in intervention trials compared to those with low HRQOL.
Finally it was not possible to determine whether the source of change in HRQOL is the healthier diet or the behavioural change itself. The mechanisms of behavioural change are important for an understanding of why some patients change their behaviour while others do not. An association is evident in some studies rather than a causal explanation.

### 6.4 Discussion

The aim of this review was to evaluate the relationship between change in diet after cancer and change in HRQOL and to evaluate the quality of available evidence. The findings have been mixed. Ten studies were identified with a range of cancer type patients, using standardized tools to measure HRQOL and interventions that targeted dietary change. Six of the included studies found significant differences between changes in diet and changes in HRQOL while four did not. Results have been mixed for the domains of HRQOL affected by dietary changes. Findings per cancer type and stage of treatment varied but overall studies that included prostate, breast and colorectal cancer patients found significant results as opposed to patients with early stage cancer or in treatment. The quality appraisal of included studies revealed highly rated quality.

The mixed findings from this systematic review reflect contrary findings found previously on two prospective studies. One (Roberge et al., 2000) included head and neck (group a) or oesophageal cancer patients (group b) that were evaluated one and three weeks after hospital discharge and used as their own controls and found a non-significant relationship between dietary changes and HRQOL. On the contrary, Wayne et al., (2006) included breast cancer patients evaluated 2 years after study entry and found a significant relationship between diet and HRQOL, which was stronger for mental rather than physical functioning. This strengthens the argument in this review that survivors rather than patients can more adequately enhance their HRQOL through dietary changes.

A meta-analysis of physical activity interventions (Conn et al., 2002) and a review of physical activity primary care interventions (Eakin et al., 2000) point out that single-
factor intervention are more effective in achieving lifestyle change-related outcomes rather than multiple-factor interventions. Unlike these findings, this systematic review could not support this. There was no consistent evidence that included studies that pertained to a diet-only intervention found significant results compared to multifaceted interventions.

Only one study (Daubenmeier et al., 2009) found dietary change to affect mental health, contrary to Wayne et al. (2000) who, in their prospective study, had previously found better diet quality to be associated with three of the four mental health subcategories (social functioning, role-emotional, mental health but not vitality) and two out of four physical health subcategories (physical functioning, bodily pain but not role-physical and general health) and diet quality to be associated with mental and physical functioning.

Cancer patient groups in the included studies were affected differently by changes to their diet. This is in line with Blanchard et al., (2008) who found that healthy eating recommendations significantly affected the HRQOL of breast, prostate and colorectal and skin melanoma patients but not of bladder and uterine cancer patients. This also adds to the findings of a cross-sectional study (Ashing-Giwa et al., 2010) that demonstrated a significant relationship between physical well-being and diet among cervical cancer patients while breast cancer patients had a significant improvement to their physical well-being and exercise but not to their diet. A greater tendency towards significant results among studies that included prostate, breast and/or colorectal cancer patients was observed. This may indicate the importance, when assessing cancer survivors rather than cancer patients who are in treatment, of noting that it can have adverse side effects, which can interfere with their HRQOL.

Overall cancer populations with a high percentage of survivors (breast, prostate and colorectal) seem to be most responsive to interventions, judging by the indications of dietary modification effects on their HRQOL. This may be due to the fact that they are the most researched population but it can also reflect gender issues with female patients more interested in changing their diets or even media coverage of dietary effects. There are also concerns with external validity that make generalizing the
findings of these studies problematic, namely that the majority of them deal with the most frequently researched cancer populations.

Prostate cancer patients’ HRQOL can be also improved through changes to some aspects of their lifestyle that are associated with their condition, especially if they undergo active surveillance treatment (Daubenmeier et al., 2006). Active surveillance consists of very widespread treatment that involves actively intervening in the aspects of the disease, which show progression. Research in this area has come up with diverse findings, with some suggesting that men undergoing active surveillance have a similar HRQOL to patients undergoing active treatment (Litwin et al., 1995; Lubeck et al., 1999; Siston et al., 2003) while others argue that they have a worse HRQOL (Bacon et al., 2001).

Differences between cancer types were also found in a study looking at changes to head and neck cancer patients’ relationship with food (McQuestion et al., 2011). This is similar to what Ravasco et al. (2003) found with the high-risk group of cancer patients (head and neck) having less improvement in their HRQOL after the intervention rather than low-risk group. It is expected that head and neck cancer patients would report differently as the cancer has a direct influence on their capacity to eat. However, if patients’ perspectives and attitudes towards food differ among cancer groups, this may explain the wide variance in results when it comes to eating behaviour, especially among cancer groups receiving different and diverse therapies.

Methodological issues can also explain the variability of findings such as the fact that three of the four included studies (Carmody et al., 2008; Hawkes et al., 2009; von Gruenigen et al., 2009) that found that non-significant associations between HRQOL and dietary change suffer from small sample size. There is also a chance of ceiling effects because scores on HRQOL were already high at baseline.

Until recently, very few studies existed that investigated the association between dietary behaviour and psychosocial factors such HRQOL and physical functioning. Ortega et al. (1996) were among the first to establish an association between diet and physical functioning, indicating that a low-fat diet and high consumption of fruit and vegetables were associated with higher levels of physical functioning among a Spanish sample at risk of cardiovascular disease. Demark-Wahnefried et al. (2004)
extended this by adding that cancer patients’ physical functioning can be improved with dietary change. This review is useful in identifying and summarizing this relationship and the direction of the relationship in a specific clinical population. It can be concluded that a relationship seems to exist but needs further establishment.

Identifying any associations between any form of lifestyle change and HRQOL is vital as it can help health practitioners and policy makers decide whether modifications to a cancer patients’ lifestyle will be beneficial or not. The literature provides useful indications that an association may be present but suggests that more research is needed to identify how different forms of HRQOL are affected by lifestyle changes and, moreover, to focus on dietary change in particular. More work in this area is clearly needed as previous research (Blanchard et al., 2003) indicates that physicians’ recommendations can lead to significant positive dietary change among patients.

6.4.1 Limitations

The review has a number of limitations. A major problem derives from the fact that very few studies include diet as the single target of the intervention. Most of them include other changes as well, like exercise, smoking cessation, etc. The issue of multi-behavioural interventions creates a difficulty in isolating the effects of dietary change from those of other lifestyle changes. Other lifestyle changes need to be controlled in order to identify the effect of dietary change in HRQOL.

Another problem with the review is that the included patients were at different treatment stages. Intervening with a group of cancer patients who are undergoing active treatment is different from intervening with cancer survivors while the time since diagnosis also plays an important role in the type and efficacy of the intervention. Side-effects on patients in active treatment can substantially influence their HRQOL through effects on their eating capacity (swallow, appetite), bowel function, treatment-related anxiety, etc. Interventions targeting patients in active treatment must overcome the effects of the therapy. For example, two randomized control trials (Courneya et al., 2006; Moadel et al., 2006) share a lot of similarities
but differ significantly due to the fact that one had patients on active treatment and the other did not. On the other hand, the impact of interventions on dietary behaviour can be clearer at the time of treatment except HRQOL, which may not necessarily constitute an outcome, which is responsive at this point in time (Demark-Wahnefried, 2007). Schmitz et al. (2005) in their meta-analysis of exercise interventions and their impact upon HRQOL found that during treatment the impact was weak while after treatment the impact was strong. Demark-Wahnefried (2007) suggests that the timing of lifestyle intervention is important when HRQOL is the primary outcome. However, most of the included studies did not have HRQOL as the primary outcome.

### 6.4.2 Future Recommendations

This variance in results on HRQOL domains confirms the need for robustly designed RCTs that aim to investigate the effects of lifestyle changes on HRQOL and the necessity to re-visit the properties of HRQOL psychometric testing. It could be that relating HRQOL with other mental and physical health variables such as self-efficacy and control or depression, sleep quality and anxiety levels may highlight the overlap of HRQOL with other psychological constructs and explain mixed results. Nonetheless, the variability in results can be moderated by the inclusion of a perceived behavioural control measure in future studies. The importance of control is one that might interlink with other constructs like HRQOL. Future studies should aim to identify whether there is an underlying dimension linking HRQOL and an internal sense of control and investigate whether changes to lifestyle or behaviour affect either or both of these constructs. Future systematic reviews can consider including patients in active treatment or active surveillance only.

### 6.5 Conclusions

Even though an association between HRQOL and dietary change is evident, the exact nature of that relationship remains unclear. More research is clearly needed to identify the mechanisms responsible and the specific domains of HRQOL affected
by dietary change. Future interventions could possibly target singlebehaviours to isolate the effects of dietary change and control for changes in other lifestyle behaviours while including constructs such as perceived behavioural control to moderate the effect of dietary change to HRQOL.

The above conclusion raises a number of interesting questions on the different domains of HRQOL that are affected by dietary change that will be explored in Chapter 7.
Chapter 7: Study 4: Differences in psychosocial outcomes between those who change their diet and those who do not after prostate cancer diagnosis

7.1 Introduction

Chapters 4 and 5 have investigated two prerequisites of dietary change (the perceived cause of cancer and information needs) as well as the needs of significant others and the perceptions and awareness of health professionals. Chapter 6 also partly identified an association between dietary changes and HRQOL among cancer patients and this will be further explored for prostate cancer patients. This Chapter will assess the psychosocial factors that may be related to whether prostate cancer patients change their dietary behaviour after prostate cancer diagnosis and after therapy has started. A need has been identified for studies at an international level that will inform on the associations between diet and dietary changes with HRQOL and overall well-being (Brown et al., 2003). Also, psychosocial factors are known to play an important role in promoting HRQOL (Ogden, 2012).

Research suggests a trend towards making positive rather than negative dietary changes after diagnosis (Hawkins et al., 2010), while 40%-72% of cancer patients report dietary improvements such as reduced fat intake and increased fruit and vegetable consumption (Humpel et al., 2007; Patterson et al., 2003; Satia et al, 2004; Maskarinec et al., 2001; Maunsell et al., 2002).

The association between changes to exercise and physical functioning, though considered strong (Brown et al., 2003), has not yet been fully established yet. One RCT (Kolt et al., 2007) found non-significant differences in physical functioning decline using an exercise-related intervention while another study (Morey et al., 2009) found significant results when assessing physical functioning after a 12-month diet and exercise-related intervention. Results on the effect of dietary changes to HRQOL and the functioning subscales have already been investigated in Chapter 6. This Chapter further investigates the differences to HRQOL and the functioning subscales between changers and non-changers.
Perceived behavioural control is also used to examine patients’ adherence to health behaviours and can explain the level of confidence that individuals require in order to perform new health behaviours (Ajzen, 1991). Patients with high levels of internal locus of control were found to be more likely to adhere to medication (Ono et al., 2008) while patients who perceive health as a matter of chance less likely to adhere to healthy behaviours (Grotz et al., 2011). A higher sense of control was also found to be associated with health outcomes (Roddenberry and Renk, 2010; Sengul, Kara and Arda, 2010). Previous findings suggest that perceived behavioural control is also associated with a greater likelihood of making difficult behaviour changes (Thompson and Spacaman, 1991; Thompson and Schlehofer, 2008).

Perceived behavioural control is closely linked with the construct of self-efficacy, which was introduced to the Theory of Planned Behaviour (see Chapter 2, section 2.2.2). Williams and French (2011), in a meta-analysis of intervention techniques that aim at changing physical activity, self-efficacy and physical activity behaviours showed that the techniques associated with changes to self-efficacy effect sizes were also associated with the self-efficacy behaviour. From a theoretical point of view, Du et al (2011) propose that enhancing self-efficacy benefits physical activity interventions. However, the findings from dietary behaviour interventions have been mixed. Kelly (2010) found a commitment to health and beliefs about the importance of changing dietary behaviours to significantly predict dietary behaviour change but not confidence in the ability to change dietary behaviours. Moreover, there are no strong indications of what the predictors are for changing or maintaining dietary behaviour or what theories may best explain dietary behaviour change (Kristal et al., 2000; Ory et al., 2002; Di Noia and Prochaska, 2010. Hagger and Orbell (2003), in a meta-analysis of studies investigating illness representations, found that control had a weak correlation with behavioural change whereas illness representations and HRQOL were strongly correlated. Also, Raats et al. (1993) partly supported the view that perceived behavioural control predicts greater milk consumption.

Finally, previous studies show that socio-demographic factors such as marital status, age and education may affect adherence to health behaviours (Demark-Wahnefried et al., 2000; Umberson et al., 2010). The findings from a systematic review (Demark-Wahnefried et al., 2005) suggest that male, older and less educated cancer patients
are less likely to make positive lifestyle changes after diagnosis. Marriage and spousal support has been associated with a reduction in health risk behaviours among men (Waite and Gallagher, 2000).

The rationale for this study is based on previous investigations that have linked psychosocial outcomes with dietary behaviour changes. One study (Maunsell et al., 2002) supported that those women with breast cancer who changed their diet during the 12 months after diagnosis experienced a reduction in their psychological distress. Furthermore, they found that women who changed their diet after diagnosis reported a need to regain a sense of control over their cancer. A series of early studies (Spencer et al., 1998; Reardon and Aydin, 1993; Taylor et al., 1984) provided clinical and research evidence that women are prone to initiate lifestyle and dietary changes post-diagnosis and post-treatment. Also, dietary changes have been found to relate to a general quality of life (Blanchard et al, 2008) or aspects of HRQOL. However, patterns of behaviour have not been established among prostate cancer patients post-diagnosis and post-treatment.

The objective of this Chapter is to gain some insight into the psychological processes and socio-demographic factors that can predict whether a prostate cancer patient will change his diet after diagnosis and after therapy. The time after therapy has been also identified as important for prostate cancer patients’ adherence to lifestyle change (Sanson-Fisher et al., 2000). More specifically, the aims of the Chapter are to investigate:

- The differences in medical and demographic information between dietary changers and non-changers post-diagnosis and post-therapy.

- The differences in HRQOL, perceived behavioural control and self-efficacy between dietary changers and non-changers post-diagnosis. The hypothesis is that participants who have changed their diet will have a higher sense of control, self-efficacy and HRQOL.
7.2 Methods

7.2.1 Research Design

A cross-sectional within-participants research design using an online or paper questionnaire was used. The study received favourable ethics approval from the University of Surrey Ethics Committee (Appendix VII).

7.2.2 Recruitment

A number of prostate cancer self-help groups and patient support charities based in the UK were identified through the Prostate Cancer Charity website and they were approached to help with recruiting participants or advertise the link to the online questionnaire. Subsequently, the following Charities were asked and agreed to advertise the study: Forum “Men’s Health”, Prostate Cancer UK (bulletin “Voices”) and the Prostate Cancer Support Federation. Also, the researcher visited Maggie’s Cancer Centre in London where participants were recruited during a workshop. Finally, the Friends of Prostate Sufferers (FOPS) charity based in Chorleywood (UK) invited the researcher to attend a Prostate Road Show where participants were given the questionnaire to complete.

All of the charities and self-help groups were based in England. Participants provided ethical consent before completing the questionnaire and after reading the information sheet (Appendix VIII). When completing the online questionnaire, the participants’ responses were stored and downloaded by the researcher whereas when a paper questionnaire was used, the researcher added their responses to SPSS.

7.2.3 Measures

The participants were invited to complete a questionnaire (Appendix IX) on their demographic and medical information, dietary changes after diagnosis and therapy, their quality of diet after diagnosis and therapy, their cancer locus of control, general
self-efficacy and cancer-specific health-related quality of life – both general and prostate-specific (Table 7.1).

Table 7.1: Measures included in the study

<table>
<thead>
<tr>
<th>Measures used</th>
<th>Number of items</th>
<th>Number of items</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic information</td>
<td>4</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>Medical information</td>
<td>4</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>Dietary change post-diagnosis</td>
<td>1</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>Dietary change post-therapy</td>
<td>1</td>
<td>New</td>
<td></td>
</tr>
<tr>
<td>Diet quality post-diagnosis</td>
<td>6</td>
<td>Maunsell et al. (2002)</td>
<td></td>
</tr>
<tr>
<td>Diet quality post-therapy</td>
<td>6</td>
<td>Maunsell et al. (2002)</td>
<td></td>
</tr>
<tr>
<td>General Self-Efficacy Scale</td>
<td>10</td>
<td>Schwarzer and Jerusalem (1995)</td>
<td></td>
</tr>
<tr>
<td>Perceived Behavioural Control</td>
<td>18</td>
<td>Watson et al. (1990)</td>
<td></td>
</tr>
<tr>
<td>EORTC QLQ C-40 (HRQOL)</td>
<td>30</td>
<td>Aaronson et al. (1993)</td>
<td></td>
</tr>
<tr>
<td>EORTC QLQ PR25 (HRQOL prostate specific)</td>
<td>25</td>
<td>Van Andel et al. (2008)</td>
<td></td>
</tr>
</tbody>
</table>

A reliability analysis was conducted for scales having more than one item (Table 7.2). The “sexual functioning” subscale was excluded from further analyses because it had a very low reliability ($\alpha = .33$).

"Demographic and Medical Information"

All participants were asked to provide demographic information on their age, marital status (married/living as married, living with another adult(s), single/living alone), level of education (six choices ranging from “no formal schooling” to “postgraduate degree completed”) and their employment status (employee, unemployed, self-employed, still at school, in full time education). Also participants were asked to provide medical information on their Gleason Score, their treatment status (under treatment, in complete remission or recurrent), the age at which they were diagnosed with prostate cancer and the treatments they had undergone (surgery, radiation therapy, chemotherapy or other).
Table 7.2: Reliability analyses for included scales

<table>
<thead>
<tr>
<th>Scales</th>
<th>α</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Self-Efficacy</td>
<td>.91</td>
</tr>
<tr>
<td>Internal Locus of Control</td>
<td>.82</td>
</tr>
<tr>
<td>Control-Chance</td>
<td>.82</td>
</tr>
<tr>
<td>Control-Doctors</td>
<td>.64</td>
</tr>
<tr>
<td>Control-Other People</td>
<td>.68</td>
</tr>
<tr>
<td>Physical Functioning</td>
<td>.8</td>
</tr>
<tr>
<td>Role Functioning</td>
<td>.92</td>
</tr>
<tr>
<td>Emotional Functioning</td>
<td>.91</td>
</tr>
<tr>
<td>Cognitive Functioning</td>
<td>.62</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>.79</td>
</tr>
<tr>
<td>Global Health</td>
<td>.85</td>
</tr>
<tr>
<td>Fatigue</td>
<td>.87</td>
</tr>
<tr>
<td>Nausea</td>
<td>.65</td>
</tr>
<tr>
<td>Pain</td>
<td>.88</td>
</tr>
<tr>
<td>Sexual Activity</td>
<td>.87</td>
</tr>
<tr>
<td>Sexual Functioning</td>
<td>.33</td>
</tr>
<tr>
<td>Urinary Symptoms</td>
<td>.83</td>
</tr>
<tr>
<td>Bowel Symptoms</td>
<td>.6</td>
</tr>
<tr>
<td>Hormonal Treatment</td>
<td>.63</td>
</tr>
</tbody>
</table>

“Dietary Changes”

Two questions were used to inform dietary changes after diagnosis (question 1) and after therapy has started (question 2). Responses were given on a 4-point Likert scale ranging from “not at all” to “extremely”. For the purposes of grouping, the participants were divided into changers (if they responded “quite a bit”, “a lot” and “extremely”) and non-changers (if they responded “not at all”) for two occasions: after diagnosis and after therapy. This type of simple and direct self-reporting of health behaviour change has been found to have good correspondence in behaviours such as diet and exercise (Mullens et al., 2004; Wayne et al., 2004).

“Diet Quality”

The quality of diet (after diagnosis and after therapy) was used for the purpose of describing the participants in terms of their current diet. Diet quality was assessed
implementing a method previously used by Maunsell et al. (2002) where each change was qualified as positive or negative in the following order: positive changes if the intake of fish and fruit and vegetables is increased (or introduced) and if the intake of meat, sweets, dairy products and alcohol is reduced (or eliminated), negative changes if the intake of fish and fruit and vegetables is reduced (or eliminated) and if the intake of meat, sweets, dairy products and alcohol is increased (or introduced). No changers where those participants who reported that they made no changes in consumption of these food items. Participants were asked to rate the consumption of each food item on a 7-point Likert scale ranging from “very much less” to “very much more” with the middle option being “the same” to assess no change. Responses about diet quality were used to confirm responses about dietary change.

“General Self-Efficacy”

The 10-item General Self-Efficacy Scale (Schwarzer and Jerusalem, 1992) was used to assess the participants’ level of self-efficacy by assessing positive beliefs to cope with a difficult situation such as cancer diagnosis. Since its development, the scale has been used in various studies (Hsu et al., 2011; Kelly, 2011) in cancer research related to lifestyle changes and has good validity and reliability. Responses are assessed on a 4-point Likert Scale ranging from “not at all true” to “very much true”. Data from the self-efficacy scale was summed up to get one score for each participant.

“Perceived behavioural control”

The participants completed the 18-item Cancer Locus of Control Scale (Watson et al., 1990) to assess their perceived behavioural control, which consists of four subscales: internal locus of control, chance, doctors and other people. This is the only cancer-specific tool for measuring perceived behavioural control. Cancer Locus of Control is widely used and is considered to have high validity and reliability (Henderson and Donatelle, 2003). The locus of control refers to beliefs about
whether or not people can obtain good outcomes and avoid bad through their own actions. When this happens then they have a high internal locus of control. When external factors control these aspects, they have a high external locus of control.

Responses ranged from “strongly disagree” to “strongly agree”. In order to keep the overall questionnaire as brief as possible, only the disease-specific part (Form C) of the questionnaire was used and no general health locus of control beliefs was measured. Where participants responded to at least two thirds of the items, a score for each sub-scale was calculated. Otherwise the scale was treated as missing.

“Health-Related Quality of Life (HRQOL)”

Participants completed the 30-item EORTC QLQ C30 (Aaronson et al., 1993) and the prostate cancer-specific questionnaire EORTC QLQ PR25 (Van Andel et al., 2008) assessing their HRQOL. EORTC QLQ C-30 is a cancer-specific questionnaire with a longstanding tradition of being a reliable and robust tool for measuring HRQOL. Its main advantages are that it has been internationally validated, translated into many languages and found to have a good psychometric functioning when it comes to specific sites and stages of cancer (Urdaniz et al., 2008). Furthermore, as opposed to generic HRQOL instruments, it can be included in a conceptual framework because it measures HRQOL during the underlying disease process (Armstrong et al., 2007).

EORTC QLQ C-30 includes five functional scales (physical functioning; role emotional; emotional functioning; cognitive functioning; social functioning), eight symptom scales (fatigue, pain, nausea/vomiting, dyspnoea, insomnia, appetite loss, constipation, diarrhoea) and a global health status. EORTC PR25 is a prostate-specific questionnaire, which includes two functional scales (sexual activity and sexual functioning) and four symptom scales (urinary, bowel, hormonal treatment-related symptoms and inconsistency aid). EORTC PR25 is administered together with EORTC QLQ C-30.

Data from EORTC QLQ C-30 measures (5 functional scales, a global health status/QoL scale and 9 symptom scales) were transformed in a score ranging from 0-
100 with a high score representing a higher response level. The calculations were as follows:

Function scales: \[ S = \left\{ 1 - \frac{(RS-1)}{range} \right\} \times 100 \]

Symptom scales: \[ S = \{(RS-1)/range\} \times 100 \]

Global health status/QoL: \[ S = \{(RS-1)/range\} \times 100 \]

To deal with missing items from multi-item scales, the following criteria were followed: if at least half of the items from the scale had been answered, the items that were answered were completed using the following equation:

\[ \text{Score} = \left\{ 1-(\text{RawScore}-1)/\text{items not missing} \right\} \times 100 \]

If the criterion of having at least half of the items completed was not met, the scale score was set as missing. The same applied to when single item scales were missing.

7.2.4 Analytic Plan

Demographic and medical information were described by calculating means, range and standard deviations. Frequencies were used to describe the participants’ diet quality.

Two logistic regression analyses were used based on the model described in Figure 7.1, one for dietary changes post-diagnosis (diagnosis model) and one for dietary changes post-treatment (treatment model).
Figure 7.1: Models for logistic regression analyses.

A series of Chi Square tests were used to compare the two demographic information (marital, and educational status) and the two dietary change groups created based on the participants’ responses about whether they had changed their diet after diagnosis and after therapy (“Change” and “No change”).

An independent samples t-test was used to compare the two groups in terms of their fatigue, insomnia and sexual activity. A Mann-Whitney test was used to measure the differences between the two groups on their nausea/vomiting, pain, dyspnoea, appetite loss, constipation, diarrhoea, financial problems, urinary symptoms, bowel symptoms and hormonal symptoms.

7.3 Results

7.3.1 Data Screening

Data was analysed using SPSS for Windows, Version 19.0 (SPSS, Chicago, IL). There was less than 5% missing data (Tabachnik and Fidell, 2007) and no significant
differences were found between missing values so no data was deleted. Data was screened for outliers (univariate and multivariate) and for assumptions of normality. A Kolmogorov Smirnov (KS) test was implemented for checking the normality of data distribution. Non-parametric tests were used for variables where the KS test was significant. Demographics (age, level of education etc.) were normally distributed.

7.3.2 Participants

Ninety-five (N = 95) participants responded to the study (Table 7.3). They had been diagnosed with prostate cancer 1 to 21 years before (M = 4.5, SE = 0.4) with their age range from 55-93 (M = 68.6, SE = 0.7). The majority of participants were married or living as married (n = 73), retired or not seeking a job (n = 79) Participants were welleducated with no participants reporting “no formal education” and the majority having a secondary school or job-related qualification and tertiary education (n = 79).
Table 7.3: Characteristics of Respondents (N = 95)

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
<th>M</th>
<th>SE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>95</td>
<td>68.6</td>
<td>0.67</td>
<td></td>
</tr>
<tr>
<td>Years since diagnosis</td>
<td>95</td>
<td>4.49</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living as married</td>
<td>73</td>
<td>76.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with another adult(s)</td>
<td>3</td>
<td>3.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/living alone</td>
<td>19</td>
<td>20.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
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<td></td>
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<tr>
<td>Primary school completed</td>
<td>3</td>
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<tr>
<td>Secondary school or job-related qualifications</td>
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<tr>
<td>Tertiary education</td>
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<td>Postgraduate degree</td>
<td>13</td>
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<tr>
<td>Employment status</td>
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<td></td>
</tr>
<tr>
<td>Full-time paid work</td>
<td>8</td>
<td>8.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Part-time paid work</td>
<td>7</td>
<td>7.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>62</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
<td>1.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not working (not seeking job)</td>
<td>17</td>
<td>17.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment status</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Under treatment</td>
<td>50</td>
<td>52.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>In complete remission</td>
<td>35</td>
<td>36.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recurrent</td>
<td>8</td>
<td>8.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>27</td>
<td>28.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>31</td>
<td>32.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>5</td>
<td>5.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>6</td>
<td>6.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
<td>26.3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentages were used to describe the participants’ diet quality for each food item (fruit, vegetables, red meat, dairy, alcohol, sweets and fish) and to estimate whether they had a positive, negative or no change after diagnosis and after therapy (Table 7.4). The results show only minor percentages of the participants having negative changes post-diagnosis or post-therapy from a range of food items from 0% - 6.4%.
The results were similar to those of a previous study (Maunsell et al., 2002), which reported a range of negative changes after breast cancer diagnosis 0%-8.8%. Diagnosis and therapy do not seem to trigger negative changes to diet among respondents.

Table 7.4: Frequency of reported dietary changes among respondents after starting therapy and after diagnosis (N = 95)

<table>
<thead>
<tr>
<th></th>
<th>Positive change</th>
<th>Negative Change</th>
<th>No Change</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Diagnosis</td>
<td>Therapy</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>Fruit</td>
<td>47.3</td>
<td>46.8</td>
<td>3.2</td>
</tr>
<tr>
<td>Vegetables</td>
<td>51.5</td>
<td>48.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Red meat</td>
<td>56.8</td>
<td>59.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Dairy</td>
<td>54.7</td>
<td>57.4</td>
<td>3.2</td>
</tr>
<tr>
<td>Alcohol</td>
<td>46.3</td>
<td>51.1</td>
<td>4.2</td>
</tr>
<tr>
<td>Sweets</td>
<td>50.5</td>
<td>50.0</td>
<td>3.2</td>
</tr>
<tr>
<td>Fish</td>
<td>43.2</td>
<td>44.5</td>
<td>5.3</td>
</tr>
</tbody>
</table>

Thus the highest percentages of participants were either positive changers or non-changers regarding changes to their diet (eating more fruit, vegetables, fish and less red meat, dairy, alcohol and sweets) after diagnosis and after starting their therapy. This is an indication that, within the sample, patients did not tend to adhere to a negative dietary change after diagnosis or after starting therapy.

7.3.3 Predicting prostate cancer patients’ dietary change post-diagnosis

7.3.3.1 Checking for Logistic Regression assumptions

Logistic regression can handle different kinds of relationship so no assumption of linearity is necessary. The outcome variable is binary. The responses to whether participants changed their diet after diagnosis were used to create two groups of responders: non-changers were those who responded “not at all” and changers were those who responded “quite a bit”, “a lot” and “extremely”. The same procedure was
used for changes to diet after therapy. The entry method was used for predictors. An adequate sample size calculation was used based on Miles and Shevlin’s (2001) estimations where, in order to detect a large effect, a sample < 80 is sufficient.

Finally, the most important assumption of logistic regression is a lack of multicollinearity. In order to assess multicollinearity, Spearman’s correlation coefficients (Table 7.5) were used to check for correlations between the predictor variables in the model: Global Health Status/QoL, physical functioning, role functioning, emotional functioning, cognitive functioning, social functioning, self-efficacy, internal locus of control, control (chance), control (other people) and control (doctors). No variable was very highly correlated with another using Field’s (2000) cut-off point of < .8.
Table 7.5: Spearman’s correlation coefficients between predictors\(^1\) (n=84).

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. SE</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. Chance (control)</td>
<td>.03</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Other people (control)</td>
<td>.14</td>
<td>.24*</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Doctors (control)</td>
<td>.17</td>
<td>.25*</td>
<td>.54**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. HRQOL</td>
<td>.38**</td>
<td>.01</td>
<td>.31</td>
<td>.05</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. PF</td>
<td>.17</td>
<td>-.11</td>
<td>-.06</td>
<td>-.14</td>
<td>.58**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. RF</td>
<td>.13</td>
<td>-.05</td>
<td>-.06</td>
<td>-.09</td>
<td>.53**</td>
<td>.48**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. EF</td>
<td>.28**</td>
<td>-.20</td>
<td>-.30**</td>
<td>-.06</td>
<td>-.47**</td>
<td>-.36**</td>
<td>-.30**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. SF</td>
<td>-.03</td>
<td>-.14</td>
<td>-.25*</td>
<td>-.16</td>
<td>.44**</td>
<td>.30**</td>
<td>.52**</td>
<td>.39**</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. CF</td>
<td>.16</td>
<td>.01</td>
<td>-.14</td>
<td>.05</td>
<td>.26*</td>
<td>.37**</td>
<td>.24*</td>
<td>.48**</td>
<td>.11</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>11. Internal (control)</td>
<td>.33**</td>
<td>-.06</td>
<td>.01</td>
<td>-.07</td>
<td>.01</td>
<td>.21*</td>
<td>.00</td>
<td>-.07</td>
<td>-.19</td>
<td>.03</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p <.05 (2-tailed) ** p < .001 (2-tailed)

\(^1\) Abbreviations: SE – Self-efficacy, HRQOL – Health-Related Quality of Life, PF – Physical Functioning, RF – Role-Functioning, EF – Emotional Functioning, SF – Social Functioning, CF – Cognitive Functioning.
7.3.3.2 Checking for residuals

Two logistic regression models were created: one for changes to diet after diagnosis (diagnosis model) and one for changes to diet after therapy (therapy model). Eighty four (n = 84) participants were included in the analysis because eleven (n = 11) participants had missing values. The predicted probabilities and residuals of the two models were used to examine the good fitness of the models. Standardized residuals were used to check that no more than 5% of cases had absolute value above 2, no more than 1% had absolute value above 1 and that no case was above 3 (outlier). No cases were further excluded. Cook’s distance values above 1 were checked. Two cases in the diagnosis model were excluded from the analysis. The average leverage of the two models was calculated using the equation $\frac{\text{predictors}+1}{N} = .14$ and leverage values greater than three times this average value (.42) were checked. Two cases in the diagnosis model and one in the therapy model were above this value so since one of them was the same for the two models, two cases were excluded from the analysis. Finally, DFBeta values greater than 1 were checked and no value was found. After checking residuals, four participants were excluded from further analysis, with the remaining participants numbering 80 (N = 80).

7.3.3.3 Main analysis

Two models of logistic regression were used using 11 predictor variables and change to diet after diagnosis – diagnosis model (Table 7.6) – and change to diet after therapy – therapy model (Table 7.7) – as binary outcomes.

The addition of HRQOL-related functioning subscales, self-efficacy and locus of control variables was significant for the diagnosis model, $x (11) = 27.69, p = .004$ but not for the therapy model, $x (11) = 16.16, p = .135$. Thus, predictor variables were able to explain whether the participants changed their dietary behaviour after diagnosis but not after therapy.
Table 7.6: Logistic Regressions for predicting changes in diet after diagnosis (n = 80)

<table>
<thead>
<tr>
<th>Included</th>
<th>95% CI for exp b</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (SE)</td>
</tr>
<tr>
<td>Constant</td>
<td>4.43 (4.46)</td>
</tr>
<tr>
<td>Global health status/QoL</td>
<td>-0.03 (0.03)</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>0.06 (0.04)</td>
</tr>
<tr>
<td>Role functioning</td>
<td>-0.01 (0.02)</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>-0.03 (0.02)</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>-0.07* (0.03)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>0.03 (0.02)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>0.05 (0.09)</td>
</tr>
<tr>
<td>Internal locus of control</td>
<td>0.13 (0.11)</td>
</tr>
<tr>
<td>Control-chance</td>
<td>0.04 (0.09)</td>
</tr>
<tr>
<td>Control-doctors</td>
<td>-0.50* (0.24)</td>
</tr>
<tr>
<td>Control-other people</td>
<td>0.06 (0.2)</td>
</tr>
</tbody>
</table>

Note $R^2 = 9.99$ (Hosmer & Lemeshow), .29 (Cox & Snell), .42 (Nagelkerke). Model $\chi^2 (11) = 27.69$, * $p < .05$
Table 7.7: Logistic Regressions for predicting changes in diet after therapy (n = 80)

<table>
<thead>
<tr>
<th>Included</th>
<th></th>
<th>95% CI for exp b</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (SE)</td>
<td>Lower</td>
</tr>
<tr>
<td>Constant</td>
<td>7.24 (4.01)</td>
<td>0.95</td>
</tr>
<tr>
<td>Global health status/QoL</td>
<td>-0.01 (0.03)</td>
<td>0.95</td>
</tr>
<tr>
<td>Physical functioning</td>
<td>0.01 (0.03)</td>
<td>0.95</td>
</tr>
<tr>
<td>Role functioning</td>
<td>0.00 (0.02)</td>
<td>0.96</td>
</tr>
<tr>
<td>Emotional functioning</td>
<td>-0.01 (0.02)</td>
<td>0.96</td>
</tr>
<tr>
<td>Cognitive functioning</td>
<td>-0.06* (0.03)</td>
<td>0.90</td>
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<tr>
<td>Social functioning</td>
<td>0.00 (0.02)</td>
<td>0.97</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>-0.04 (0.07)</td>
<td>0.83</td>
</tr>
<tr>
<td>Internal locus of control</td>
<td>0.01 (0.08)</td>
<td>0.86</td>
</tr>
<tr>
<td>Control (chance)</td>
<td>0.10 (0.08)</td>
<td>0.95</td>
</tr>
<tr>
<td>Control (doctors)</td>
<td>-0.17 (0.17)</td>
<td>0.59</td>
</tr>
<tr>
<td>Control (other people)</td>
<td>0.09 (0.17)</td>
<td>0.66</td>
</tr>
</tbody>
</table>

Note $R^2 = 4.50$ (Hosmer & Lemeshow), .18 (Cox & Snell), .25 (Nagelkerke). Model $\chi^2(11) = 16.16, *p < .05$

The estimates for the coefficients of predictors included in the diagnosis model show that for the diagnosis model, the coefficients for cognitive functioning and control (doctors) are significant with Confidence Intervals (CI) for exp. (B) for cognitive functioning 0.88 to 0.99 and for control (doctors) 0.38 to 0.98. The estimates for the coefficients of predictors included in the therapy model show that the coefficients for
cognitive functioning are significant with CI for exp. (B) 0.90 to 0.99. This indicates that non-changers are more likely to have higher cognitive functioning and control from doctors rather than changers after diagnosis and higher cognitive functioning than changers after therapy.

The Hosmer and Lemeshow test of goodness-fit of the diagnosis model, $\chi^2 (8) = 9.99$, $p = .266$ and the therapy model $\chi^2 (8) = 4.49$, $p = .81$ show that the models predict values which are not significantly different from those observed and thus indicate a good-fit of both models. The diagnosis model is 80% accurate compared to 72.5% of the null model table and for the therapy model is 72.5% accurate compared to 60% of the null model table. Finally, five cases in the diagnosis model and one case in the therapy model were incorrectly classified by the models.

7.3.4 Socio-demographic factors and the level of dietary behaviour change after diagnosis and therapy.

7.3.4.1 Checking for chi-square assumptions

Chi-square tests assumptions were examined. All cells of the contingency table included in the analysis were independent and expected frequencies were large enough for a reliable analysis. The criterion of expected frequencies < 5% (Field, 2000) was tested using crosstabulation. Between educational status and dietary change after diagnosis there was one cell (primary education) having an expected count lower than 5 and between marital status and dietary change after therapy there was one cell (living with another adult) with an expected count lower than 5. To overcome this violation of assumption, it was decided to combine (collapse) levels of variables that it made sense to combine. Thus for further analyses, “primary education” was combined with “secondary education” and “living with another adult” was combined with “married/living as married”. The reason behind the first combination was that the interest was in examining differences in education hierarchically and for the second combination that the interest was in examining peer support and its effect on dietary change. Living as married or
living with another adult did not make a big difference. A crosstabulation was then created after collapsing these levels of variables. There were no expected count less than 5 in the 2x2 tables and only one expected count less than 5 in the 2x3 tables. There were no more than 20% of cells with an expected frequency more than 5.

### 7.3.4.2 Main Analysis

After conducting chi square analyses between marital status and changes in diet, it was found that the relationship between these variables was not significant for changes after diagnosis, $\chi^2(1, N = 95) = 2.23, p = .11$ nor after therapy, $\chi^2(1, N = 95) = 1.45, p = .18$. The frequencies were crosstabulated (Table 7.8).

**Table 7.8: Crosstabulation of change in diet after diagnosis and therapy and marital status (N = 95)**

<table>
<thead>
<tr>
<th>Change in diet</th>
<th>Marital status</th>
<th>$\chi^2$</th>
<th>$\Phi$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Single (N=19)</td>
<td>Married/living with another adult (N = 75)</td>
<td></td>
</tr>
<tr>
<td>Change (post-therapy)</td>
<td>14 (73.7)</td>
<td>44 (58.7)</td>
<td>1.45</td>
</tr>
<tr>
<td>No Change (post-therapy)</td>
<td>5 (26.3)</td>
<td>31 (41.3)</td>
<td></td>
</tr>
<tr>
<td>Change (post-diagnosis)</td>
<td>16 (84.2)</td>
<td>50 (66.7)</td>
<td>2.23</td>
</tr>
<tr>
<td>No change (post-diagnosis)</td>
<td>3 (15.8)</td>
<td>25 (33.3)</td>
<td></td>
</tr>
</tbody>
</table>

Chi square analyses revealed a significant relationship between educational status and changes to diet after diagnosis, $\chi^2 (1, N = 94) = 8.65, p < .01$ but not after therapy, $\chi^2 (1, N = 94) = 1.2, p = .11$. The frequencies were crosstabulated (Table 7.9).
Table 7.9: Crosstabulation of change to diet after diagnosis and therapy and educational level (N = 95)

<table>
<thead>
<tr>
<th>Change in diet</th>
<th>Educational status</th>
<th>$\chi^2$</th>
<th>V</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Primary/secondary (N= 33)</td>
<td>Tertiary (N= 48)</td>
<td>Postgraduate (N = 13)</td>
</tr>
<tr>
<td>Change (post-therapy)</td>
<td>18 (54.5)</td>
<td>31 (64.6)</td>
<td>9 (69.2)</td>
</tr>
<tr>
<td>No change (post-therapy)</td>
<td>15 (45.5)</td>
<td>17 (35.4)</td>
<td>4 (30.8)</td>
</tr>
<tr>
<td>Change (post-diagnosis)</td>
<td>17 (48.5)</td>
<td>38 (79.2)</td>
<td>11 (84.6)</td>
</tr>
<tr>
<td>No change (post-diagnosis)</td>
<td>16 (51.5)</td>
<td>10 (20.8)</td>
<td>2 (15.4)</td>
</tr>
</tbody>
</table>

* $p < .01$

7.3.5 Comparing changers and non-changers

Based on their response on whether they changed their diet after diagnosis participants were divided into two groups: changers (n = 66) and non-changers (n = 29). The demographic and medical information for both groups are reported (Table 7.10). A series of independent t-tests was conducted to establish whether the two groups significantly differed on their demographic and medical information. No significant differences were found between the two groups except for educational status, t (95) = -2.78, p < .05. Changers (M = 4.88, SE = 0.71) had a higher educational level than non-changers (M = 4.45, SE = 0.69).
### Table 7.10: Characteristics of changers and non-changers (N = 95)

<table>
<thead>
<tr>
<th></th>
<th>Changers</th>
<th></th>
<th></th>
<th>Non changers</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>M</td>
<td>SE</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>66</td>
<td>68.9</td>
<td>0.8</td>
<td></td>
<td>29</td>
<td>67.9</td>
</tr>
<tr>
<td><strong>Years since diagnosis</strong></td>
<td>66</td>
<td>4.9</td>
<td>0.5</td>
<td></td>
<td>29</td>
<td>3.4</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living as married</td>
<td>49</td>
<td>74.2</td>
<td></td>
<td></td>
<td>24</td>
<td>82.8</td>
</tr>
<tr>
<td>Living with another adult(s)</td>
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<td>1.5</td>
<td></td>
<td></td>
<td>2</td>
<td>6.9</td>
</tr>
<tr>
<td>Single/living alone</td>
<td>16</td>
<td>24.2</td>
<td></td>
<td></td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
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<td></td>
</tr>
<tr>
<td>Primary school completed</td>
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<td>3</td>
<td></td>
<td></td>
<td>1</td>
<td>3.2</td>
</tr>
<tr>
<td>Secondary school or job-related qualifications</td>
<td>15</td>
<td>22.7</td>
<td></td>
<td></td>
<td>16</td>
<td>55.2</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>38</td>
<td>57.6</td>
<td></td>
<td></td>
<td>10</td>
<td>34.5</td>
</tr>
<tr>
<td>Postgraduate degree</td>
<td>11</td>
<td>16.7</td>
<td></td>
<td></td>
<td>2</td>
<td>6.9</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time paid work</td>
<td>4</td>
<td>6.1</td>
<td></td>
<td></td>
<td>4</td>
<td>13.8</td>
</tr>
<tr>
<td>Part-time paid work</td>
<td>4</td>
<td>6.1</td>
<td></td>
<td></td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td>Retired/Not working</td>
<td>58</td>
<td>87.8</td>
<td></td>
<td></td>
<td>22</td>
<td>75.8</td>
</tr>
<tr>
<td><strong>Treatment status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under treatment</td>
<td>37</td>
<td>56.1</td>
<td></td>
<td></td>
<td>13</td>
<td>46.4</td>
</tr>
<tr>
<td>In complete remission</td>
<td>20</td>
<td>30.3</td>
<td></td>
<td></td>
<td>16</td>
<td>53.6</td>
</tr>
<tr>
<td>Recurrent</td>
<td>9</td>
<td>12.1</td>
<td></td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Treatment type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>17</td>
<td>26.2</td>
<td></td>
<td></td>
<td>10</td>
<td>34.5</td>
</tr>
<tr>
<td>Radiation therapy</td>
<td>22</td>
<td>33.8</td>
<td></td>
<td></td>
<td>9</td>
<td>31</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>3</td>
<td>4.5</td>
<td></td>
<td></td>
<td>3</td>
<td>10.3</td>
</tr>
<tr>
<td>Hormone Therapy</td>
<td>23</td>
<td>35.4</td>
<td></td>
<td></td>
<td>7</td>
<td>24.1</td>
</tr>
</tbody>
</table>

Data was screened for outliers and for normality distribution. Changers and non-changers were compared on prostate cancer-specific HRQOL and symptoms. For variables (fatigue, insomnia, sexual activity) which had a skewness and kurtosis value of < 1.96, a parametric test was used while when the normality of distribution assumption was violated (nausea/vomiting, pain, dyspnoea, appetite loss, constipation, diarrhoea,
financial problems, urinary symptoms, bowel symptoms, hormonal symptoms) a non-parametric test was used.

Results from independent t-tests (Table 7.11) showed no significant differences between the two groups on three symptoms (fatigue, insomnia and sexual activity).

Table 7.11: Comparing means of HRQOL subscales between changers and non-changers

<table>
<thead>
<tr>
<th></th>
<th>Changers (n = 66)</th>
<th>Non-changers (n = 29)</th>
<th>t</th>
<th>df</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>28.41 23.88</td>
<td>28 23.65</td>
<td>-0.08</td>
<td>85</td>
<td>0.01</td>
</tr>
<tr>
<td>Insomnia</td>
<td>27.69 28.6</td>
<td>26.19 33.16</td>
<td>-0.22</td>
<td>91</td>
<td>0.01</td>
</tr>
<tr>
<td>Sexual activity</td>
<td>4.03 1.94</td>
<td>3.77 1.8</td>
<td>-0.58</td>
<td>90</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Results from Mann-Whitney tests (Table 7.12) showed that the two groups differed only on one symptom. Specifically changers (Mdn = 44.16) scored lower on dyspnoea symptom than non-changers (Mdn = 53.59), U = 725.5, r = .21. All other differences were insignificant.
Table 7.12: Comparing medians of HRQOL subscales between changers and non-changers

<table>
<thead>
<tr>
<th></th>
<th>Changers (n = 66) Mdn</th>
<th>Non-changers (n = 29) Mdn</th>
<th>U</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nausea/vomiting</td>
<td>48.85</td>
<td>42.7</td>
<td>789.5</td>
<td>-.16</td>
</tr>
<tr>
<td>Pain</td>
<td>46.01</td>
<td>49.3</td>
<td>845.5</td>
<td>-.06</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>44.16</td>
<td>53.59</td>
<td>725.5*</td>
<td>.21</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>46.01</td>
<td>49.3</td>
<td>845.5</td>
<td>-.09</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>46.01</td>
<td>49.3</td>
<td>845.5</td>
<td>-.09</td>
</tr>
<tr>
<td>Constipation</td>
<td>48.18</td>
<td>44.27</td>
<td>833.5</td>
<td>-.08</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>45.28</td>
<td>49.43</td>
<td>798.5</td>
<td>-.1</td>
</tr>
<tr>
<td>Financial problems</td>
<td>45.14</td>
<td>48.04</td>
<td>809</td>
<td>-.08</td>
</tr>
<tr>
<td>Urinary symptoms</td>
<td>44.06</td>
<td>50.59</td>
<td>740</td>
<td>-.11</td>
</tr>
<tr>
<td>Bowel symptoms</td>
<td>46.54</td>
<td>43.07</td>
<td>785</td>
<td>-.07</td>
</tr>
<tr>
<td>Hormonal symptoms</td>
<td>45.63</td>
<td>43.56</td>
<td>798</td>
<td>-.03</td>
</tr>
</tbody>
</table>

*p < .05

7.4 Discussion

The aim of this Chapter was to gain some insight in the psychological processes and socio-demographic factors that can predict whether a prostate cancer patient will change his diet after diagnosis and after therapy. The addition of HRQOL scales, self-efficacy and perceived behavioural control significantly predicted changing dietary behaviour after diagnosis but not after starting therapy. Cognitive functioning was found to be a significant predictor of change to dietary behaviour, both after diagnosis and after starting therapy. The scale “control-doctors” was found to be a significant predictor of change to dietary behaviour after diagnosis only. No significant relationships were found between marital status and changes to diet after diagnosis or after therapy started. On the other hand, a significant relationship was found between educational level and changes to diet after diagnosis with more educated patients more likely to change their diet. No similar relationship was found between educational level and changes in diet after therapy have started. Finally, changers and non-changers after diagnosis differed
significantly on one prostate cancer-specific symptom (dyspnoea) with non-changers experiencing more severe symptoms of dyspnoea.

Previously, Maunsell et al. (2002) and Salminen et al. (2002) had found one third to half of cancer patients reporting positive dietary changes after diagnosis. Contrary other findings indicated that negative health behaviours following cancer diagnosis were also common (Blachard et al., 2003; Ganz et al., 2002; Stull et al., 2007). Park et al. (2008) clustered the positive and negative changes across behaviours and addressed the factors that were related to positive (social support, sense of control, life meaning and approach coping) and negative health behaviours (lack of life meaning and avoidance coping). The findings of this study are consistent with those, which indicate that cancer patients make positive, rather than negative dietary changes after diagnosis (Hawkins et al., 2010; Humpel et al., 2007; Patterson et al., 2003; Satia et al, 2004; Maskarinec et al., 2001; Maunsell et al., 2002). Therefore, prostate cancer diagnosis triggers positive changes to diet rather than negative. The same happens after therapy has started.

This study found that marital status does not predict dietary changers. Being married or living with another adult does not affect whether patients will change their dietary behaviour after diagnosis or after therapy has started. Conversely, previous studies (Waite and Gallagher, 2010; Demark-Wahnefried et al., 2000) found that marriage and spousal support influence dietary changes after cancer diagnosis. However, in this study it is not possible to know the level of spousal support so no conclusive results can be reached. It is possible that a lack of spousal support and not marriage itself can predict dietary behaviour change.

On the other hand, educational level was found to predict dietary changes after prostate cancer diagnosis. This adds to previous findings (Demark-Wahnefried et al., 2005; Demark-Wahnefried et al., 2000) that found that less educated patients were less likely to change their diet positively after diagnosis. This is evident in other chronic conditions as well. For example, Murray et al (2013) in their systematic review also identified education as an important influence on lifestyle change among people with high cardiovascular risk. More educated patients can be more exposed to educational
materials, information, the Internet etc. Also, less educated people can often be less financially established and therefore have easier access to, and a preference for, junk food rather than healthier options due to the fact that junk food is generally the cheaper option.

Side effects during therapy seem to have an impact on dietary changes. For example, even though educational level was found to predict dietary changes after diagnosis, the same did not happen after therapy has started with changes not explained by educational level. Similarly, external locus of control was found to predict non-dietary change after diagnosis but not after therapy has started. The period during therapy can be a qualitatively distinct phase where socio-demographic and psychosocial factors do not have an impact on patients’ choices.

The findings indicate that changers are more likely to have lower cognitive functioning and control from doctors rather than non-changers after diagnosis and lower cognitive functioning after therapy. There is limited evidence in the literature on the impact of changes to diet during the coping process and especially from the patients’ perspective. This study adds to this gap in knowledge by proposing that HRQOL, and especially cognitive functioning, differs between changers and non-changers. No differences were found for other functioning subscales as opposed to the literature on exercise (Brown et al., 2003), which supports that physical functioning predicts changes to physical activity. On the other hand, there is evidence in the literature that physical functioning has been found to change after diet is changed (see Chapter 6, section 6.4).

The differences found between changers and non-changers on their cognitive functioning are innovative but in agreement with the previous literature on dietary assessment. The findings add to the literature on cognitions and health behaviours. McNeill et al. (2009) supported that cognitive decline influences dietary assessment. At the same time, cognitive functioning, including memory, executive functioning and spatial orientation, has been found to become impaired with age and, as a result, can significantly affect dietary assessment (Dubois and Boirin, 1990; Correa Leite et al., 2001; Biro et al., 2002; Small, 2002). Wood, Quinn and Kashy (2002) argue that two of
the benefits of acquiring a new habit are cognitive economy and a greater feeling of control. Changing an established habit requires effort. Therefore, patients who use cognitive loading for their changed habit may have lower cognitive functioning than those who do not. Stage theories and self-regulation theories have discussed cognitive mobility (using cognitive resources) during behaviour change. Exercise is proposed as a way of overcoming ego depletion (Muraven et al., 1999) and rest can help the restoration of resources (Baumeister, Heatherton and Tice, 1994).

Research on the regulation of behaviour has shown that the cognitive inhibition process is important in protecting intentions to change health behaviour against distractions (Marsh et al., 1998; Veling and van Knippenberg, 2006). More specifically, when an individual develops an intention to change health behaviours, the information that is semantically associated with the intention’s content is inhibited to protect against distraction from the initiation of the goal of behaviour change (Veling and van Knippenberg, 2006). Danner et al. (2011) confirmed this by showing that, when focusing on a change in behaviour intentions, individuals create inhibition processes to protect against interference by existing habits. Therefore, as shown by the findings of this study, patients who change their dietary behaviour require the initiation of cognitive inhibition processes and therefore have enhanced cognitive functioning.

However, alternative explanations may exist. Assuming than no other differences exist between changers and non-changers before the initiation of change, then dietary changes can impose a cognitive load, which requires cognitive resources, making it harder to concentrate and remember things and explain the lower levels of cognitive functioning among changers. Also, cognitive functioning can be a result of dietary change. Therefore, adhering to a healthier diet may have a biological impact on patients’ cognitive functioning. A study with rats (Winocur et al., 2013) found that a high-risk environment (high fat diet, highly stressed, low activity, isolated) results in cognitive deficits in rats with cerebral ischemia. A review (Nyaradi et al., 2013) supports that malnutrition, a lack of breastfeeding and not eating breakfast result in cognitive decline whereas the association between cognition and obesity is inconclusive.
Non-changers were found to have a higher external locus of control compared to changers, specifically regarding control from doctors. A recent qualitative study (Dowswell et al., 2012) concluded that colorectal cancer patients who changed their diet linked their behavioural change to their doctor’s advice, with some participants indicating that they were more likely to change behaviour if recommendations came from trusted sources, including health professionals. Moreover, Greiner et al. (2008) found that in order for patients to change health behaviours, they have to perceive it as medically relevant. On the other hand, Salminen et al., (2000) found that only 11.8% of those who changed their diet after diagnosis did it because they had received advice from a healthcare professional. The results of this study challenge this finding, indicating the importance of the health professional’s role to those who have not changed their diet. Internal locus of control was found to predict adherence to medication (Ono et al., 2008) while those with a higher external locus of control are less likely to adhere (Grotz et al., 2011). Therefore, the role of health professionals in changing health behaviours is confirmed from the patients’ perspective and external locus of control predicts non-change after prostate cancer diagnosis, as opposed to the findings of Kelly (2010) who suggested that perceived behavioural control could not predict dietary behaviour.

Participants in the study who had changed their dietary behaviour differed from those who had not in one cancer symptom, dyspnea. Rise (2006) has associated dyspnea with lower levels of quality of life. Cognitive Behavioural Therapy identifies dyspnea as a symptom of anxiety and seeks ways to modify patients’ response to the symptom by using techniques such as relaxation and distraction. In addition, it moderates and reduces anxiety related to biological changes due to medical conditions (Schmidt et al., 1997). This finding suggests that anxiety can be a barrier to changing dietary behaviour. Anxious patients are not acting on their situation (see Chapter 8, section 8.3.1.2.4). An alternative explanation is that dyspnea is a consequence of not changing dietary behaviour after diagnosis and as a consequence of not acting on the illness. Modifying cancer patients’ dietary behaviour by through nutritional interventions has been investigated in a recent systematic review and meta-analysis (Baldwin et al., 2012).
assessing thirteen studies and using 1414 participants, finding that dietary modifications have a significant impact on HRQOL and especially the symptom of dyspnea. Therefore dietary behaviour change can influence well-being.

7.4.1 Limitations

In this study no differences were found on internal locus of control between changers and non-changers. Thus, interpretations of the role of perceived behavioural control (internal and external) must be cautious. Also the use of self-efficacy in a cross-sectional study, which does not assess initiation of an intended behavioural change, is not very informative as it deals with behavioural intentions. Finally, a problem with locus of control is the conceptualization of the construct (i.e. how internal locus of control differentiated from external in real life) (Ogden, 2012).

A confounding variable is possible if patients who have undergone chemotherapy have suffered losses to their cognitive functioning. For example, Collins et al (2013) compared neuropsychological data between 28 breast cancer patients before and after chemotherapy with healthy controls and found that the chemotherapy group had a more than 21% significant cognitive decline than the control group, the pre-chemotherapy group and published norms.

Findings regarding differences between the two groups on their external locus of control must be interpreted with caution because of the medium reliability of the “control-doctors” scale ($\alpha = .64$) in this study.

7.4.2 Clinical Implications

In spite of their limitations, these findings have clinical importance. Future interventions aiming to change prostate cancer patients’ diet can consider assessing the predictor variables found in the study to significantly predict whether patients will change their diet or not: HRQOL, self-efficacy and perceived behavioural control. However, in
particular the finding that patients who do not change their diets post-diagnosis are more dependent on health professionals and have a higher sense of external locus of control, can shape healthcare professionals’ attitudes towards patient’s diets. In particular, these findings indicate the need to target health professionals’ attitudes towards patients’ diets in order to improve patients’ adherence to healthier practices.

The finding that participants who change their diet after diagnosis and also during therapy have lower cognitive functioning than those who do not is new. It proposes that behavioural change requires cognitive loading and that replacing a habitual behaviour with a new one requires a higher sense of cognition. Finally, the findings also confirm the need for psychological support during the prostate cancer coping process and when initiating behavioural change, since dyspnoea is higher for patients who do not change their dietary habits. Cognitive Behavioural Therapy can help reduce elevated levels of stress (Falsetti and Resnick, 2000). It uses a technique called stress-inoculation training and changes an individual’s thoughts when challenging an anticipated threat.

### 7.4.3 Future Recommendations

Future studies can benefit from evidence of pre/post-diagnosis dietary changes among prostate cancer patients. Evidence from this study cannot support post-diagnostic or therapy changes in prostate cancer patients but, given the relationship that these changes may have with aspects of HRQOL, it will be useful to further investigate them. Currently there is only two studies published using pre/post-diagnosis design and they were conducted with women with breast cancer (Velentzis et al., 2011; Wayne et al., 2011). A study like this can also identify the impact of dietary change on HRQOL for prostate cancer patients.

Previously, Satia et al. (2001) had conducted a randomized-controlled trial which found that 72% of participants reported that dietary change was important for making them feel better and 57% said it helped them control their health. Larsson et al. (2005) found that dietary change can affect weight loss and recovery and can significantly affect patients’
HRQOL. This study provides evidence of differences between changers and non-changers regarding their HRQOL. Future studies can use a randomized control trial to establish whether HRQOL is a predictor of change or a result.

Future studies should also measure intentions to perform a health behaviour, which can be used as a proxy for behavioural change. Furthermore, future studies can distinguish between habitual and voluntary behavioural change when assessing differences in cognitive functioning in order to address how the new behaviour affects the habitual. Cognitive functioning can also be measured by cognitive tasks to assess differences between patients who change their health behaviour and those who do not.

Future studies should use more sophisticated ways to measure health behaviour change such as objective indices and calculations of health behaviour in order to overcome self-report bias. They should also aim to investigate both groups of patients and survivors in order to draw firmer conclusions on the processes and perceptions of each population. Finally, they should investigate the predicting utility of psychological constructs, which are considered as similar (i.e. self-efficacy and perceived behavioural control).

7.5 Conclusions

This Chapter demonstrates that prostate cancer patients who change their dietary behaviour after diagnosis differ from those who don’t. Patients who changed their diet have higher cognitive functioning and higher external locus of control over health professionals. Moreover, more educated patients are more likely to change their dietary behaviour after diagnosis but not after therapy where the two groups do not differ. Also, from a theoretical point of view, it is important to establish the mechanisms that establish the differences between those who change their behaviours and those who do not.
Recommendations for future research are also discussed. Intervention studies using a pre/post-diagnosis time design can identify the direction of the relationship between dietary behaviour change and HRQOL. At the same time, more intellectual ways to measure cognitive functioning can be employed to confirm the relationship between dietary behaviour changes and cognitive functioning.

Quantitative data from the previous Chapters have provided an insight into significant associations and differences. However, these associations can be meaningless to the patients themselves. In order to add to the previous conclusions, more in-depth data is needed. The next Chapter will use qualitative research methods to gain in-depth knowledge of how prostate cancer patients make sense of the changes in their diet.
Chapter 8: Study 5: An underlying mechanism of change: How prostate cancer patients make sense of dietary changes

8.1 Introduction

After cancer diagnosis, patients are involved in a process of making sense of their condition and the new circumstances of their lives. A study supports evidence that even though cancer patients tend to change their dietary behaviour post-diagnosis, this is more common in women rather than men (Patterson et al., 2003). Also, there is little information on what determines the changes or what the results of these changes are. Using qualitative methods, this Chapter will try to gain in-depth explorations of the sense-making implemented by prostate cancer patients to explain and understand changes to their diet after diagnosis.

Epidemiological studies have shown that men are more prone to most illnesses (Courtenay, 2004; Huggins, 1998), their diet is poorer and different from that of women (Wardle et al., 2004) and they are sceptical towards health promotion programmes (Lee and Owens, 2002). More importantly, a report (“Excess cancer burden in men”, 2013)suggests that men are 35% more likely to die from cancer, with advances in breast cancer treatment, late diagnosis and drinking and eating habits cited as the reasons for the differences. These trends may be associated with men’s health behaviours (Oliffe and Mroz, 2005) so there is a challenge to identify patterns of behaviour among men diagnosed with prostate cancer. The impact of gender on dietary changes is evident in a review of how masculinity shapes dietary behaviour (Mroz et al., 2011).

Chapman and Ogden (2009) explored which factors are involved in the process of how people change their diet and they concluded that dietary change may be achieved with or without the involvement of the individual. More specifically, they named these as the active path and the passive path and by investigating the mechanisms of behavioural change, they found four themes: accumulation of evidence and trigger to action in line
with the active path and imposed change and seamless change in line with the passive path. Participants seemed to follow an active involvement in their diet when they observed evidence of factors that affected their well-being and self-perception (accumulation of evidence) and subsequently experienced internal and external triggers to proceed to action (trigger to action). In contrast, the majority of participants experienced behavioural change without their active involvement by seamless or imposed changes, brought about by general changes in their lives.

Another qualitative study with breast cancer patients showed that dietary behaviour and actions are influenced by both social and personal factors, with family support, employment, financial resources and cultural food patterns as important predictors of dietary behavioural change (Beagan and Chapman, 2004). In Australia and Finland, only 11.8% changed their dietary behaviour because of healthcare provider advice and for most of them (52.9%) the reason was their desire to be cured (Salminen et al., 2000). However, the decision to change their dietary behaviour was also influenced by relatives or friends – a finding supporting that of Helarkopi et al. (1999) who found that patients are influenced by non-professionals about whether they change their dietary behaviour or not.

Cancer diagnosis and treatment also have a severe impact on patients’ perspective on eating and, more specifically, on the meaning of food. The use of combined treatment (i.e. chemotherapy with radiotherapy and their side-effects) severely reduces patients’ quality of life and changes their meaning of food. McQuestion et al. (2011) investigated these changes among head and neck cancer patients, using an in-depth qualitative research design, and concluded that there are physical, emotional and social losses associated with the meaning of food among patients. The literature around the meaning of food has been investigating healthy populations (Hetherington, 2002; Ulijaszek, 2002), health and palliative populations (Crogan et al., 2004; Evans et al., 2005), women with breast cancer (Adams and Glanville, 2005) and patients with heart problems (Jacobsson et al., 2004). The first study looking at patients’ altered meaning of food was by Adams and Glanville (2005) who investigated women with breast
cancer, while McQuestion et al., (2011) investigated a mixed male and female head and neck cancer patients. However, head and neck cancer patients’ relationship with diet is more complex because of the side effects of the cancer which affect eating. Thus, there are only a few studies (Mroz et al., 2010; 2011) focusing on a non-healthy, men-only population in relation to the changed meaning of food as a result of cancer diagnosis.

Adams and Glanville (2005) suggest that the way breast cancer patients make sense of their relationship with food consists of two phases. In the first phase (active treatment), food is used to control, cope, comfort and hope; whilst in the second phase (post-treatment), the meaning of food is shaped by perceptions of food’s role in breast cancer cessation according to whether they believe a relationship exists between diet and their diagnosis. No qualitative studies on men have been identified researching their relationship with food. Given the significance of food in our lives, and especially to cancer patients during their recovery period, it is important to understand further these processes of change in relation to the meaning of food post-diagnosis. In terms of food choice, Maskarinec et al. (2001) propose that many patients (both men and women) use non-scientific reasons when making sense of their dietary changes after diagnosis.

From a social constructionist perspective, gender issues are related to daily practices and men’s health studies indicate the emergence of hegemonic masculinity and a plurality of masculinities. The gender theory proposes that men’s health and dietary practices are affected by the ideals of masculinity. Also, Mroz et al. (2011) suggest that after prostate cancer diagnosis, men are more interested in their diet in the context of a “feminisation” process. In terms of dietary behaviour change, Mroz et al. (2010) identify four main domains that inform dietary behaviour changes: perception of pre-diagnosis diet, diet and health understandings, orientation towards prostate cancer and finally the need to “do something”. The need to act is also evident in studies using quantitative methods and identifies a need among cancer patients to regain control after diagnosis (Maskarinec et al., 2001; Eyre, 2001; Salminen et al., 2004). This may also be associated with a (perceived) diminution of possibilities for exerting agency and control at the time of diagnosis and during any subsequent treatment.
Finally, adherence to change may be determined by the external physical and social environment (Shepherd, 1999). Thus, determinants may be divided into interpersonal and intrapersonal factors. Contenko (2011) identifies perceptions, beliefs, attitudes and motivations as intrapersonal determinants of food choice. Moreover, she suggests that cancer patients’ decisions are shaped by the expected consequences of the change, the desired consequences and personal meanings and values. On the other hand, relationships with significant others, food shopping and economic and environmental issues can be viewed as interpersonal determinants of food choice. What is missing from the literature is how patients view these interpersonal, intrapersonal and social influences on their decision-making. This study aims to fill this gap in knowledge.

Murray et al. (2013) conducted a systematic review of qualitative observational studies and found that social support along with beliefs and psychological factors were the most commonly reported factors that influence lifestyle change in individuals with a high cardiovascular risk. This study tries to investigate whether similar inter-relationships exist among prostate cancer patients when they reflect on their dietary changes post-diagnosis. The participants’ explorations can form an underlying mechanism of dietary change after prostate cancer diagnosis. Identifying underlying mechanisms has been the main aim of sociological research, according to the model of social relationships and health behaviour across life course proposed by Umberson et al. (2010).

Taking this further, it would be useful to understand how prostate cancer patients experience the change to their diet. How do cancer patients account for changes to their dietary behaviour? How can the way they make sense of these changes shape their behaviour and well-being and inform on the factors they take into account for adhering to healthier behaviours?

The aim of this Chapter is to explore how prostate cancer patients do account for any changes that they make to their diet after diagnosis. To achieve this, the study makes use of qualitative methods in order to understand how they themselves explain any changes to their diet. The objective is to identify what underlying mechanisms exist that can explain patients’ understanding of dietary behaviour changes after prostate cancer.
The study explores these mechanisms among people with prostate cancer and expands upon the idea of whether changing eating behaviour has an underlying mechanism as viewed by patients themselves (Willig, 2008).

8.2 Methods

8.2.1 Research Design

This is a qualitative study using semi-structured interviews and analysed using thematic analysis (Braun and Clarke, 2006). A qualitative research methodology was preferred because of the aim to explore the participants’ in-depth accounts of their dietary change after diagnosis. The decision to use a qualitative methodology in this Chapter was also based on Denzin and Lincoln’s (2000) definition criteria of qualitative research: in cases aiming for a) rich data concerning description rather than the restricted and structured information from quantitative methods b) capturing the participants’ perspective, bearing in mind their individuality c) using a post-positivist view that captures the participants’ multiple realities, d) postmodern sensibility by using in-depth interviews and e) examining the constraints of everyday life such as social influences.

8.2.1.1 Rationale for the Method

Thematic analysis is a widely used qualitative method, which identifies, analyses and reports patterns within data (Braun and Clarke, 2006). There is an argument in the literature as to whether thematic analysis can be used as a method on its own or as a “multi-method tool” (Boyatzis, 1998). In this study, thematic analysis was used as a method on its own. Also thematic analysis is theoretically free and can be in line with constructionist perceptions as well as essentialist theories within behavioural research. Howitt (2010) describes thematic analysis as a simple descriptive rather than theory-building method of analysing the major themes found in an interview or other qualitative
data. The decision for choosing thematic analysis was firstly based on the need to observe what the participants had to say.

Debates exist on whether researchers give voice to their participants or not (Fine, 2002) and whether there is a single appropriate theoretical framework in which to interpret and analyse data. Therefore, it is important before collecting qualitative data to make a statement of the decisions and the methods that match with what this study explores: the aim is for analytic flexibility and the data set is approached in a contextualized way by exploring the interrelationship between personal meanings and social contexts and how participants construct their reality through personal and social processes. The participants are seen through analysis as patients, partners and family men and, generally, as individuals in different contexts (family, society etc.). Thus the purpose is to identify how they make sense of their experiences and not whether these experiences form a “reality” for them.

8.2.1.2 Thematic over other qualitative methods

Thematic analysis was chosen rather than other qualitative methods because of the flexibility and latitude it affords to researchers in terms of theoretical and epistemological assumptions, as well as in the analytic process. The decision was also based on the aim of the study, which is to identify and describe patterns across data rather than building a theory.

Narrative analysis (Riessman, 1994) might have been used. Narrative analysis is epistemologically similar to social constructionism. Thematic analysis was used, however, as it is more relevant to the aims of this study of identifying an underlying mechanism of prostate cancer patients’ behavioural change related to diet after diagnosis with minimum theoretical assumptions. For the same reason, discourse analysis (Potter and Wetherell, 1987) was not used. Another reason is that discourse analysis does not recognize the possibility that verbal accounts are mapping with underlying cognitions. Finally, grounded theory (Glaser and Strauss, 1968) can form the basis of a “stage 2”
analysis of the data to develop a theoretical account of the process of dietary behaviour change after diagnosis. Thematic analysis is the starting point for hearing patients’ voices and experiences and this phenomenology of their accounts can form the starting point of further analysis in the future.

8.2.1.3 Analytic process

The process of analysis used in this study was also informed by the recommendations and processes proposed by Braun and Clarke (2006). The analytic process was based on Howitt and Cramer’s (2011) central process of analysis, which requires transcribing textual material, analytic effort (generating themes) and identifying themes and sub-themes. Even though analysis was not conducted in a linear way, it was conducted in roughly 5 steps:

1. **“Meeting” with the data:** First by reading the text and creating unfocused notes on associations, statements, language use, repeated words, etc. These notes were recorded in the left margin of the transcripts. The notes were divided into a) descriptive and conceptual comments on what participants say in relation to the study’s aims and what they say they do and b) linguistic comments on words and language use.

2. **Initial coding:** Identify and label codes that constitute the contents of small quantities of data describing the perceived essence of what the participants say from the researcher’s point of view. These codes were recorded on the right margin of the text. The first two steps allowed the analysis to move forward from the participants’ words to an area of interpretation. Codes were data-driven and not theory-driven. Coding is also a way for the researcher to step away from data.

3. **Structuring themes:** After generating the codes, themes were then considered. A structure was introduced into analysis by listing the codes in a
table. This process created a cluster of themes and the participants’ own words reflected the associations between the codes. The rationale for associating codes was based on identifying common themes on the processes of how they accounted for changes to their diet and also on differentiating each theme from the other.

4. **Reviewing and summary tables:** A summary table of all the structured themes was produced using the participants’ quotations next to each theme.

5. **Write-up:** The findings were then written-up and discussed. During write-up, the table of themes was further developed as the ideas developed as well in an on-going process.

The analysis was conducted at the latent level, aiming for underlying ideas, assumptions and patterns within the data.

### 8.2.1.4 Quality checks (“Confirmability”)

One limitation of any qualitative method and especially one that contains interpretation is the level of the researcher’s own perspective and approach. To ensure the validity of a qualitative study, the researcher’s perspective has to be clearly understood by others. This study used two steps to ensure that analysis was as accurate as possible in terms of interpretation of the participants’ meaning-making:

1. After finishing the first reading of each transcript and during the development of the table of themes, a second opinion was requested from a colleague.

2. Once the first draft of analysis was ready, two supervisors were consulted to obtain a robust set of findings. Dallos and Vetere (2005) propose this triangulation of ideas in order to ensure that analysis is not biased by the researcher’s own predispositions.
Guba (1981) proposed the idea that qualitative researchers should ensure that their findings have “confirmability”. The idea of “confirmability” is to tackle the qualitative researcher’s concerns about objectivity. How much qualitative research can be objective is debatable but steps can be taken to ensure that the findings are the result of the participants’ ideas and experiences rather than the researcher’s preferences and characteristics (Shenton, 2004). One way to achieve this is the triangulation described above to control for the researcher’s assumptions and beliefs. A second step is an in-depth methodological description, which was described earlier (see section 8.1.2.3). A third step is the realization of the researcher’s beliefs and assumptions, which is described, in the next section (section 8.2.1.5).

One of the criteria for distinguishing between “good” and “bad” qualitative work is the ability to distinguish between participants’ responses and the researcher’s interpretation (Smith, Jarman and Osborn, 1999). From an epistemological point of view, Coyle (2007) notes that qualitative research in psychology deals with “possible explanations of people’s meaning making – how they make sense of the world and how they experience particular events”.

8.2.1.5 Reflections before interviewing

In order to reflect on the interviews and to take my personal assumptions and beliefs into account I created a list of concerns and thoughts prior to conducting the interviews. I tried to highlight the boundaries between my experiences and assumptions and those of the participants. My concerns can be summarised as concerns with personal experiences and age. My personal experience of seeing my father being diagnosed with oesophagus cancer and eventually losing him a few years before could be evident. I tried to distance myself from the participants’ experiences and their relationship with their significant others. Their experiences could also perhaps sensitise me so I had to remain focused on what I was trying to find. Finally, the distance between my age (28) at the time of interviews and the participants’ (55-76) could elicit different perspectives while interpreting the data. On the other hand, the difference in age could be a way of
motivating me to “enter” into their world during the interview in order to understand their perspective and understanding.

In terms of interviewing, Herod (1993) questioned whether the sex of the researcher and the participant can affect the dynamic of the interview and work as a barrier to the interview itself, given the sensitivity of the information shared on issues that many men feel uncomfortable to discuss with other men. This issue was critical in getting the most out of the interviews. Thus, without falling in the trap of “self-fulfilling prophecies”, the interview schedule was reviewed under the recommendations of Oliffe and Mroz (2005) who proposed recognizing and overcoming preconceived notions such as “men do not talk”. Also, because men often respond within a gendered context, the interviewer may try to present a non-competitive and organised masculine self and also use techniques to overcome silence. More importantly, to project the participants’ interpretations, thoughts, feelings and ideas, lessons learned from studies with prostate cancer patients (Reinharz and Davidman, 1992; Oliffe, 2005), that suggest using semi-structured interviews with some general questions related to diagnosis, were used.

Apart from obtaining an interesting data set, this study gave me the opportunity to engage with the reality of cancer diagnosis and of coping with the condition. It offered me an opportunity to explore patients’ experiences and analyse how these experiences had a significant impact upon their identity, behaviour and whether their experiences and attitudes had an impact on behavioural change.

8.2.2 Recruitment
8.2.2.1 Participant Characteristics

Prospective participants were either buyers of the Prostate Care Cook Book (Rayman et al., 2008) or readers of “Voices”, the Prostate Cancer Charity’s monthly bulletin. They participated in the study described in Chapter 4 (see section 4.2.2). The participants indicated in their responses to a previous online questionnaire that they were interested in volunteering for a subsequent interview study, by providing their e-mail address. They
were invited to participate by e-mail, and they were sent a cover letter including an information sheet and consent form to sign (Appendix X). The consent form was later returned, either scanned by e-mail or by post, to the researcher who then arranged a convenient time to conduct the telephone interview. Subject to the agreement of the participant, interviews were recorded, and the text transcribed for analysis. Information was available about the socio-demographic and cancer history of volunteers from the previous study (Chapter 4).

8.2.2.2 Interview Schedule

The interview schedule (Appendix XI) is loosely based on one used in a previous study with post-menopausal women previously treated for breast cancer (Parry et al., 2009). The study mirrors that earlier study, using a similar interview where no dropout or distress was experienced. The questions asked participants what they eat, how they decide what to eat, any changes in their dietary habits since diagnosis with cancer and how they view their diet, diet in general and their relationship with food. The interview schedule was amended in order for the questions to be non-directive and rather open-ended to allow for discussion considering that this study was investigating men with prostate cancer rather than women with breast cancer.

8.2.2.3 Interview process

Eight individual telephone interviews were conducted using a room at the University of Surrey. A telephone was used as well as digital recording equipment to record the telephone interviews for transcription purposes. This ensured that the researcher had the necessary privacy during the interview. Each participant was aware of the day/time when the interview would take place so that they, too, could ensure no distraction would occur during the interview. Generally, the interviews took 20-30 minutes each.
After reading the information sheet, participants were asked to sign and return a written consent prior to the interview. They were asked both at the time of arranging the interview, and at the beginning of the interview, whether they were willing for the interview to be recorded. After each recorded interview, the text was transcribed and the data (recordings and transcripts) securely stored in locked filing cabinets or on password-protected computers. The participants were given unique study numbers so that only a record number could identify their data and complete confidentiality was assured.

8.2.3 Ethics

The ethical principles of this study aimed to respect the participants and the information they provided and also to resolve any potential problems that might arise from the interview due to sensitive questions dealing with their diagnosis. A formal ethical opinion was obtained from the University of Surrey Ethics Committee for the study (Appendix XII). The application included a detailed information sheet and a risk assessment outlining potential risks to participants; the procedure for dealing with possible distressed participants; the procedure for ensuring anonymity and confidentiality and indicating their right to withdraw from the study at any time without giving a reason for doing so. Participants were told in the information sheet that they had the option of allowing their interview to be recorded, or stating that they did not wish this to happen.

8.3 Results

8.3.1 Participants

Eight men (N = 8) living in the UK with a diagnosis of prostate cancer were interviewed by telephone. Potential participants were respondents to a previous online
questionnaire (see Chapter 4, section 4.3.2). The inclusion criterion for participating in the qualitative study was:

- Having been diagnosed with prostate cancer and with no mental health disorders in order to be able to reflect on post-diagnosis changes to their diet.

Participants were aged 55-76 and they had all been diagnosed with prostate cancer for 0-5 years. They resided in the UK. Three were under treatment; two recurrent, one in complete remission while two patients did not report their treatment status (Table 8.1).
Table 8.1 Participant demographics and medical information (N = 8)

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Years since diagnosis</th>
<th>Treatment status</th>
<th>Treatment</th>
<th>Occupation</th>
<th>Highest level of education</th>
<th>Relationship Status</th>
<th>Involvement in food preparation</th>
<th>Involvement in food shopping</th>
<th>Source of recruitment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 1</td>
<td>59</td>
<td>5</td>
<td>Recurrent</td>
<td>Radiotherapy</td>
<td>Social Worker</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals daily</td>
<td>Discuss with spouse what to buy</td>
<td>Prostate Cancer Charity monthly bulletin</td>
</tr>
<tr>
<td>Participant 2</td>
<td>66</td>
<td>2</td>
<td>Recurrent</td>
<td>Surgery</td>
<td>Elected Councillor</td>
<td>Postgraduate Degree</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals/ snacks/ drinks</td>
<td>Accompany spouse when food shopping</td>
<td>Google website</td>
</tr>
<tr>
<td>Participant 3</td>
<td>76</td>
<td>1</td>
<td>Under treatment</td>
<td>Radiotherapy</td>
<td>Civil Engineer</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals occasionally</td>
<td>Accompany spouse when food shopping</td>
<td>Prostate Cancer Charity monthly bulletin</td>
</tr>
<tr>
<td>Participant 4</td>
<td>55</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Postgraduate Degree</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals/ snacks/ drinks</td>
<td>Do shopping by self</td>
<td>Not reported</td>
<td></td>
</tr>
<tr>
<td>Participant 5</td>
<td>75</td>
<td>0</td>
<td>Under treatment</td>
<td>Radiotherapy</td>
<td>Army Officer</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare snacks/ drinks occasionally</td>
<td>Discuss with spouse what to buy</td>
<td>Amazon website</td>
</tr>
<tr>
<td>Participant 6</td>
<td>62</td>
<td>Not reported</td>
<td>Not reported</td>
<td>Architect</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals/ snacks/ drinks</td>
<td>Discuss with spouse what to buy</td>
<td>Prostate Care Cook Book advert (Rayman et al., 2008)</td>
<td></td>
</tr>
<tr>
<td>Participant 7</td>
<td>58</td>
<td>1</td>
<td>In complete remission</td>
<td>Surgery</td>
<td>Company Director</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals occasionally</td>
<td>Discuss with spouse what to buy</td>
<td>Prostate Cancer Charity monthly bulletin</td>
</tr>
<tr>
<td>Participant 8</td>
<td>68</td>
<td>3</td>
<td>Under treatment</td>
<td>Radiotherapy</td>
<td>Contracts Manager</td>
<td>Tertiary Education</td>
<td>Married/Living as married</td>
<td>Prepare or help to prepare meals occasionally</td>
<td>Accompany spouse when food shopping</td>
<td>Prostate Cancer Charity monthly bulletin</td>
</tr>
</tbody>
</table>
8.3.2 The analysis

The aim of the study is to identify how prostate cancer patients make sense, if any, of changes to their diet after diagnosis. Coding and analyses of data revealed two superordinate themes related to “perceived determinants of dietary change” and “perceived results of dietary change”. The reason for having these two superordinate themes was that the data showed that these two types of perception referred to different timelines (before and after dietary change) and were thus referred to separately. Several codes were identified related to doctor-patient communication, family influences, the meaning of food and information evaluation. Subsequently, these codes were summarized into seven themes. These themes were: “the perceived role of relationships with health professionals in influencing action on diet”, “attitudes towards dietary information in influencing action on diet”, “family influences towards action on diet” and “psychological processes as influencing action on diet” which explained determinants of change and “the perceptual aspects of change towards influencing the relationship with food” and “strategies for maintaining behaviour” which explained the results of change. The themes are schematically presented in Figure 8.1.

The rationale for looking at dietary change in the period after diagnosis is evident in the words of one participant where he interestingly stressed the importance of diet as the obvious starting point to act and contribute towards his therapy:

“In a major way but not immediately – only when it came back a year after surgery – did I begin to think about what I could do to help myself. And diet was the obvious area to start. (Participant 2)

The superordinate themes explain participants’ meaning making experience along two axes: time (before – determinants and after – results) and dynamic (internal – attitudes - behaviours and external – relationships).
8.3.2.1 Determinants of dietary change

The first superordinate theme concerns both internal (attitudes) and external (relationships) processes and relates to the participants’ perceived determinants of dietary change. Four themes were identified that designate what participants believe to be the factors that may affect their engagement in dietary change: a) the perceived role of relationships with health professionals in influencing action on diet, b) the attitudes towards diet in influencing action on diet, c) family influences towards action on diet and d) psychological processes as influencing action on diet.

The term “action on diet” is used for themes instead of “behavioural change” or “dietary changes” as the focus here is on the participants as active agents – “action” implies a more active role by the participants in their dietary change and thus it is
preferred. A determinant is a broad superordinate theme that captures the “function” of the themes: the participants’ rationale for changes in their diet after diagnosis.

8.3.2.1.1 Theme 1: The perceived role of relationships with health professionals in influencing action on diet

The first theme deals with the participants’ meaning making as patients, seen through their relationship with healthcare providers. All prostate cancer patients indicated in one way or another that their negative or positive relationship with health professionals had a central role in their therapeutic “journey” after diagnosis and in how they understood dietary changes. Most of the participants focused on health professionals’ lack of knowledge while, at the same time, they mentioned that a lack of information leads in one way or another to individual differences when it comes to changing lifestyle behaviours.

“One thing that I would add is that all my contacts with the medical profession, physician or whatever, none of them told me that diet has any relevance at all...” (Participant 3)

It is evident that Participant 3 had developed a certain attitude towards health professionals’ lack of knowledge. And he spoke about “all” his contacts with the medical profession, meaning all the health care professionals he met during his therapeutic journey. He seemed to believe that health professionals did not consider diet important. Participant 4 took this one step further, indicating that a health professional’s lack of knowledge had led to him taking the wrong message and possibly taking different action from what he would have done if the health professional’s attitude had been different. He seemed to believe that there was a link between health professionals’ attitude towards diet and preventative behaviour, revealing a feeling of surprise towards the medical profession’s attitudes in relation to diet. The way his GP’s attitude affected his perception (“I took the wrong message”) can be also seen as a reflection of their relationship in a therapeutic context (doctor and patient) where the patient expects from his health provider – whom he may perceive as an expert – advice on how to deal with difficult situations.
“Well, I went to the doctor and he said, ‘Well, ignore it, don’t worry and don’t bother at all.’ And I said to the doctor, ‘What about diet?’ and he said, ‘Nothing. Diet is useless. It doesn’t make a difference at all what you like.’ And I took the wrong message. So what I thought the doctor did was what I wanted to do, which was because I felt that this would make me healthier... It [the GP’s reaction] didn’t seem to be a healthy living message given, and it surprised me that maybe just the attitude of doctors who look for people who are ill and make them better rather than preventative...it didn’t seem to be a priority.” (Participant 4)

At the same time, Participant 6 highlighted a change in a health professional’s attitude towards diet which, in the end, affected his actions, saying that “He [the GP] was a bit sceptical about it [diet] but he has now come around and says, ‘Well there are some slight indications that it may help.’” It seems as though patients’ expectations of health professionals’ knowledge of diet is high and at times this expectation is not met. The health professionals’ opinion is important to patients and Participant 7 confirmed the importance of his health professional’s beliefs. There are studies (Eyre, 2001; Maskarinec et al., 2001) proposing that after diagnosis, cancer patients lose control and consequently they depend on health professionals.

“He [the GP] said, ‘It would be helpful if you lost some weight,’ so I immediately changed my diet at that point from having being diagnosed to knowing I would have surgery in ten weeks’ time.” (Participant 7)

Providing dietary advice seems not to be a perceived priority for their GPs. On the other hand, the participants generally felt skeptical about their health professionals’ knowledge of diet or how important the professionals perceived diet to be.

8.3.2.1.2 Theme 2: Attitudes towards dietary information in influencing action on diet

The second theme deals with the participants as active agents through their individuality (perceptions and beliefs) but also as passive agents of information from various sources. From the participants’ perspective, information availability considering diet is an important aspect of how they cope with the necessity to make
changes to their dietary lifestyle. In his account, Participant 3 highlighted a lack of specific information, even though diagnosed patients are bombarded with information. Similarly Dowswell et al. (2012) found conflicting and confusing evidence for patients.

“Yes, dietary advice is available but not specifically for prostate cancer... There are a lot of different sources aren’t there? I mean, there’s a lot...published sources are often a lot nowadays.” (Participant 3)

Participants 7 and 8 further discussed the issue of over-information: patients are in need of dietary information and dietary guidance after diagnosis and they read almost anything that is available. Participant 8 mentioned that, “Once you get involved in something you pick up anything you see on the paper or on the television and that is one point I picked up from.”

The availability of information is higher today due to the Internet and this fact highlights the importance of accurate and evidence-based information based on scientific facts and interventions. In the context of societal influences, the participants mentioned the media and the Internet as what they viewed as the first step in their search for dietary-related information. Given the fact that they had also previously indicated that they recognized their GP’s lack of interest in, or knowledge of, diet then this would seem to be the logical next step.

“Well, I have done a lot of research on prostate cancer. After I was diagnosed and before I decided what to eat and to have for my diagnosis, I spent many days on the Internet, reading everything I could about all those treatments and what the success ratios were, about impotence and all the other stuff and also a lot of the research on diet.” (Participant 7)

Participant 7 here talked about an issue relevant to many contemporary and cultural aspects of television and advertising. Sometimes using common sense about the available information rather than evidence-based research may lead to misinterpretation. Thus, Participant 7, like other participants, highlighted a preference for evidence-based information rather than common sense, which may provide a scientific aspect on information and a feeling of confidence with that specific information. There is also vocabulary evidence from Participants 6, 3 and 4 of their
preference for evidence-based information as they often used words like ‘facts’, ‘evidence’, ‘theories’, ‘study’, ‘researched’, etc. Their talk appears to be located within a discourse of evidence-based decision-making with a very rationalist focus. They seem to base their knowledge not on their experiences and senses but on concepts gained independently. They seem exposed to this mode of talk through external information providers such as the Internet, leaflets, books, etc.

“Well what I would feel confident about is whether there would be some evidence-based advice because I think there is probably a lot of…if you look at television and magazines, newspapers, etc. there are facts that come and go and I would be more impressed if I could say that there are some researched evidence-based [facts]…” (Participant 4)

Apart from a preference for evidence-based evidence, Participant 1 focused on well-written argument as opposed to faith as a vital aspect of making sense of evidence-based information: information has to really “talk” to the patient and his/her needs – it has to be tailor-made. Of course, the background of Participant 1 in science may also be a reason for his preference for well-written arguments.

“Well there is advice everywhere isn’t there? It depends on what you listen to… I don’t listen to advertisements… I tend to… the thing… I… I am scientist… my background is in science… things you have faith in don’t really move me that much but a well-written well-argued book like the one from Prof Jane Plant where she puts all the evidence and scientific papers to back-up what she is saying… well, that influences me a lot.” (Participant 1)

Also, information is considered important not only in managing their condition but also in disease prevention as well. Dietary information can be associated with preventive behaviours and Participants 7 and 1 focus on the perceived non-relevance of dietary advice. They also talk about seeking explanations for their diagnosis in past behaviour. This is part of a consistent endeavour among people with health conditions – to develop a satisfactory explanation for their condition.

“But it’s a bit late for me… if someone had told me when I was 25, ‘You have to cut out red meat because your chances of getting prostate cancer are 40% more’ I would have chopped out red meat then… But I would be intrigued to
know whether at some point in my life I have been “poisoned”...or something has triggered...because something I don’t understand is why the incidence of prostate cancer seems to be rocketing in the UK.” (Participant 7)

“If I am to believe what I now believe, that dairy products are a really bad idea as far as breast and prostate cancer goes, that may have been a bad thing because ever since I was at the age of 18 I have eaten lots of cheese and drunk lots of milk, a pint of milk a day.” (Participant 1)

8.3.2.1.3 Theme 3: Family influences on action on diet

The fourth theme deals with the participants as members of a social context – their family environment – and their different roles within this environment: as parent and partner. Most of the participants described the influence of their family either by answering a question on decision-making (“how did you decide to...”) during the survey study (see Chapter 4) or on their involvement in food preparation or food choice (Table 4.2). Moreover, there are indications of family involvement in the interview data.

Specifically, regarding food choice and preparation, for some of the participants their wives seem to play an important role with most of them indicating their wife’s involvement in food shopping, food choice and food preparation. There seems to be a dependence on partners rather than shared decision-making when it comes to dietary change.

“I tend to...my wife tends to take that decision for me. Well she just says, ‘I think we will have some pork chops tonight’ and I say, “Sounds great” and that’s the end of it. And I don’t know what I will get... It’s [His own minor involvement in food preparation] probably because my wife is a nurse practitioner.” (Participant 7)

Apart from the participants’ responses, there is evidence of an interruption by Participant 5’s wife during the interview, providing more evidence to support the current argument. The background of partners also seems to influence their decisions.
in some way. Some participants mention that their wife’s specialization is important when it comes to influencing their decisions or their dietary lifestyle.

“My wife was trained in domestic science and she has, broadly speaking, kept me on a healthy diet with a good variety and plenty of fruit and vegetables.” (Participant 3)

“The selenium was on the advice of my consultant and the garlic is on the advice of my wife because she is South African and she believes in the antibiotic properties of garlic and because she said it would be a good idea. I have read a lot on it and it does seem that it has good properties…” (Participant 1)

Other family members, such as children, are also central to two aspects of dietary behaviour: control of diet and food choice. The participants were mostly older so the multi-membered type of family they used to have is now a dyadic relationship between them and their partner due to the fact that their children are no longer living with them. Participant 4 highlighted this issue and clarified that this makes food choice and a change to a healthier lifestyle easier. At the same time, controlling their diet is also easier.

“Also, our children grew up and left home and they all wanted meat and dairy and all sort of things which I didn’t want to eat... but because of that it was much easier for me or for us to choose what we want to. Now when they come and stay with us I don’t go and cook the things they want and probably join me eating as well... Circumstances made it easier for me to control my diet and so I chose to go a certain way... Also I was worried because my father died about the same age as I am now and he had heart problems that I don’t have but he did have prostate cancer and that’s what finished him off really. So I was worried because I am susceptible to this (cancer) and I should do something about it.” (Participant 4)

Whether a patient will alter his behaviour after diagnosis may also depend upon his own family history. Previous incidents of serious illness motivate some patients to adhere to a healthier lifestyle both after and before diagnosis. Participant 4 used words
like ‘worried’ and ‘do something about it’ showing both worry and motivation to act on his diet.

**8.3.2.1.4 Theme 4: Psychological processes on influencing action on diet**

The fourth theme deals with the participants as agents of their health care within the social context of health care provision and their role as patients. This is the main difference with the second theme: even though it deals with the participants as agents of healthcare, it also deals with a broader social context and the influence on the participants’ meaning making of Western capital characteristics (i.e., the Internet, the media, etc.). Most of the participants described internal psychological processes, which could influence whether they changed their dietary habits. These processes can be described as similar to self-efficacy and agency. There are two characteristics among the participants regarding psychological processes: the active patient and the passive patient.

**i) Active patient**

Moving towards greater agency in relation to dietary behaviour seems to be important for most of the participants. They seem in need of feeling that what they choose and what they eat is the result of their own choice rather than “being told to”. The word “control” was used and described by most of the participants as the rationale for changing their diets. Participant 4, for example used “control” to explain that now he could eat “what he wants to” and not what he was “pushed to eat”.

“I am quite happy with what I am eating now. It is quite easy for me to control what I eat now. So I don’t feel pushed to eat something unless I want to. That’s quite what I am eating now... So I was worried because I am susceptible to this [prostate cancer] [unclear] and I should do something about it...”(Participant 4)

Participant 4 felt worried and diet and exercise were perceived as behaviours that might help him start feeling healthier. Also, he formulated and explained a state of
worry ("I was worried because I am susceptible to this") and presented a health behaviour response arising from personal agency ("I should do something about it…and I started doing more exercise") that is said to have enhanced well-being("and I started feeling much more healthy").

ii) Passive patient

The concern with control, personal agency and efficacy is present in the words/phrases used by Participant 2 ("what I could do to help myself") and Participant 4 ("easy for me to control what I eat now", "I should do something about it"). On the other hand, Participant 3 challenged himself, citing the fact that diet is impossible to control and therefore he relied on others. He accepts his role in health care provision ("as a patient") and is a good example of a patient who has lost control over his life due to prostate cancer diagnosis ("there is nothing you can do about it"). Also, he noted two interesting facts: that his diet prior to diagnosis was considered as "normal" and that, on the other hand, he was now starting to consider changes to his diet as a return to normality.

"You cannot really as a patient…there is nothing you can do about it. You can’t control your diet. I felt that I might as well do this and at least I can feel I am doing something towards a cure. Will it be good or not…? I don’t know… I think it was one and a half or two years but over the past year I have progressively relaxed that [dairy avoidance], returning more or less to a normal diet. I am tending to do so now [to consider his current diet as ‘normal’]…with certain revelations you are aware of the things she [the health professional] suggested are best avoided.” (Participant 3)

8.3.2.2 Perceived results of change

The second superordinate theme deals with post-diagnosis perceived results of dietary change. It is evident from the participants’ reflections that the perceived results of change are double-dimensioned: they may determine the maintenance of dietary behaviour change and they may be used as an evaluation “tool” regarding the
behaviour change’s benefits. Consequently, two themes emerged that determine this dynamic: perceptual aspects of change towards the relationship with food, and the maintenance of behaviour change focusing on the change’s evidence. The participants explored their role in coping with these two aspects (relationship with food and behavioural maintenance).

8.3.2.2.1 Theme 5: Perceptual aspects of change on influencing the relationship with food

The participants’ responses revealed a tendency to change how food is used in everyday life after prostate cancer diagnosis. Almost all the participants expressed certain arguments about the meaning of food either before or after diagnosis. There seems to be a phase of “re-approaching” food with the participants re-evaluating the use of food, its role and also its meaning after diagnosis.

“I often make tuna fish salads and things like that whereas I never had them in a hotel because I thought of them not be particularly filling. My job was particularly stressful. So I ate for comfort... Since I was diagnosed I have been more conscious of my weight...and although I am still overweight I am very fit...so I eat very well now...a balanced diet.” (Participant 7)

It seems that prostate cancer diagnosis is considered by Participant 7 as a life-changing event, not only in terms of dietary behaviour but also in terms of how he perceives food. Also, most of the participants reported having experienced increased post-diagnosis vigilance in relation to (health-enhancing and health-threatening) foods and to health and well-being in general.

“It [the diagnosis] made me more aware of certain things I should be definitely be avoiding...reduction in red meat... reduction of dairy products and reduction in sugar.” (Participant 5)

Participant 5 thinks that, as a result of diagnosis, there is also a change in the perceived affective value of food and the motivation for food consumption. Participants are active recipients of various influences and information when it comes to diet but the disease itself seems to be a perceptive trigger of awareness and
avoidance. On the other hand, Participant 7 argues that life before diagnosis was more stressful due to other life events (i.e. his job, travelling, etc.) and stress thus led to eating for comfort. His prostate cancer diagnosis triggered his perceived awareness of diet and, as a result, he has a more balanced diet now. Of course, there are other life events that may have changed his interest in, awareness and consciousness of diet but diagnosis seems to be viewed by some participants as an important event in relation to how they make sense of all the changes that happen in their diet.

This perceived positive relationship with food after diagnosis is also evident in Participant 1’s report on how the diagnosis of prostate cancer positively changed his perceived meaning of food. A biological schema (eating for survival) may now be perceived as a positive schema (eating is a pleasure so I will enjoy it) or, as Participant 7 mentioned earlier, “eating for comfort”.

“It [diet] is more important. Although I am stricter in my diet, I think actually that I enjoy food more now. It just used to be something you did three times a day, you ‘put the fuel in’. Nowadays because I choose and I watch what I eat, I think it is true to say that I enjoy food more now. We can take more care over the preparation of food. I think I appreciate it! I think I took it for granted before and I appreciate it more now… We don’t really look at the prices any more, we try and buy...you know...the better fruit. It’s not a problem at home… We are very used to looking at the ingredients and see if they contain milk or dairy products and when I go out to a restaurant it’s not usually a problem if you tell the waiter that you don’t eat dairy food; there’s always something that you can have.”(Participant 1)

How Participant 1 re-evaluates the role of food can also be seen in its social context when his diet is not dependent on himself – when going out. He seems to have developed an awareness that food is not only a matter of survival but is also used socially (i.e. going out to a restaurant) and, thus, any changes to his diet can be adapted to the social context as well.

The fact that not all unhealthy habits change after diagnosis creates emotional distress, even though patients would like to adhere to a healthier diet.
Consequently, negative feelings of guilt are evident in some of their responses, using words and phrases like “frustrated”, “weakness”, “indulgence”, and “naughty”.

“I should say of my weakness for chocolate…dark, fruit and nut chocolate…eight squares…that’s very naughty, that’s my indulgence.” (Participant 5)

8.3.2.2 Theme 6: Strategies for maintaining behaviour

Maintaining dietary behaviour might be just as effortful as changing behaviour. Most of the participants focus on behavioural maintenance. What seems to make them evaluate whether to maintain the dietary behaviour change or not is how they evaluate the benefits of change. Participant 8 made this very clear: “It [a healthier diet and exercise] is helping me because I feel good”. So what is important for him is feeling good and that is how he decides whether to keep the effort of change or not.

However, apart from subjective benefits (“I feel good”), some participants also use medically objective benefits (PSA levels, illness symptoms) to evaluate the effectiveness of dietary behaviour change. Participant 4 talks about the medically objective types of benefits: the PSA level which is “something, anyway” and the physical symptoms of therapy of the disease. Within the context of his health care provision, he seems to take a step towards being an active patient who decides on and evaluates his symptoms and PSA levels in relation to changes to his diet. So if the benefits were perceived as positive it could be that he would maintain his dietary behaviour change.

“It seemed to be in the right direction and I know PSA is not very accurate measure but it is something anyway… And in fact the symptoms which I was having and had a link with prostate cancer like going to the toilet more often, seemed to disappear when I had a healthier diet.” (Participant 4)

Participant 3 takes these thoughts a step further, proposing that even when not knowing for sure what the exact contribution of diet is, it provides a hopeful contribution when observing PSA levels. He also goes on to refer to dietary changes
as “dietary discipline” referring to something that needs a lot of effort but can be evaluated through its benefits (PSA levels).

“I have no idea whether this dietary discipline is good or not. In fact, I am advised that the cancer has probably been cured but it might return. So to that extent, the treatment and the dietary discipline seem to be effective. But what contribution diet has had, I have no idea. Whether there would have been any difference if I had not taken any notice of my diet, I don’t know…now I am relaxing as the only monitoring that I have is a PSA test every three months.”(Participant 3)

Participant 1 reveals feelings of shame and embarrassment that have to do with the change of diet as a response to prostate cancer experience.

“I still feel after seven years…no, six years…I still feel embarrassed when I visit people and I insist but I have too much to lose if I…I mean if I…dairy products may not be poison but they maybe and I am not prepared to do the experiment.”(Participant 1)

Whilst Participant 1 is not sure of the benefits of dietary behaviour change and even though he feels embarrassed in social situations where he has to stick to this change, he has decided that he “has too much to lose” if he does not adhere to the healthier diet. Perhaps this signifies the process of evaluation and how the disadvantages of not adhering to a healthier diet overcome the effort and the “discipline”.

**8.4 Discussion**

The aim of this study was to identify how prostate cancer patients make sense of any changes to their diet after diagnosis. A pattern of the determinants and results of dietary change after prostate cancer diagnosis was discerned from the interviews. The idea of this study is that the themes identified can form an underlying mechanism used by the participants to determine and explain dietary changes post-diagnosis. The identified themes follow closely those identified by Murray et al. (2013) in their qualitative synthesis of the influence of lifestyle factors among cardiovascular
patients: social support (formally – health professionals and informally – significant others), beliefs and psychological factors (coping styles, attitudes, etc.).

When diagnosed prostate cancer patients face the challenge of making changes to their diet, dealing with the significant role (positive or negative) of their health professionals and, as a result, they develop emotions and attitudes towards diet. The participants stated that they have a preference for evidence-based information in contrast with a previous study (Maskarinec et al., 2001), which found that cancer patients used non-scientific reasons to make sense of changes to their diet. Also, they have a way of explaining and compromising over dietary changes by highlighting prevention when reflecting on their experiences to develop a satisfactory explanation of their illness.

Society has been rapidly changing in recent years and developments in the media, the Internet and elsewhere can affect people in vulnerable situations, including cancer patients. As one participant put it, patients are bombarded with information and there is no way for them to acknowledge which health messages are useful and true or not. The findings of this study propose that patients along the trajectory of their cancer journey may develop mechanisms to recognize and filter information. This may explain why they prefer evidence-based information and why, on the process of maintaining their dietary behaviour change, they use scientific factors (like PSA levels) to evaluate the benefits of adhering to a healthier diet.

Family relationships, especially those with partners and children, seem to play an important role in decision-making related to food shopping, food choice and food preparation. This study has shown that men with prostate cancer, even though they face psychosocial processes which can be compared with the feminisation process, when dealing with dietary changes (Mroz et al., 2011) they still rely on their partner to make important decisions regarding their diet. They also tend to focus on the role of their partner in coping with the changes to their diet, proposing that a dyadic regulation approach exists (Karademas and Giannousi, 2013). The participants in this study were older patients whose multi-member families have been transformed into mainly dyadic (patient-partner) ones. Thus, it is unknown what the influence is of this dyadic relationship in younger prostate cancer patients with younger children even though Umberson et al. (2010) consider the transformation of social relationships, like
that of an individual transferring from one stage to another, as being influential on health behaviours. More data is needed for safer conclusions.

Previous studies have also identified partners as having a significant role when men with cancer cope with their disease and make changes in their lifestyle (Badr et al., 2010; Dagan et al., 2011). A qualitative study (Dowswell et al., 2012) of colorectal cancer patients and their partners concluded that dietary changes were not dependent on the patient alone. Partners who cook have a central role in patients’ dietary change and they should be provided with information in order to facilitate patients’ change.

The themes identified can be also understood as interpersonal (i.e. the role of health professionals) and intrapersonal (perceptions and attitudes). When facing a terminal illness, patients’ need to control the illness is parallel with the need to control their lifestyle. It is also interesting to consider the cultural value that the desire for control represents. In capitalistic Western society, people are losing more and more independence and control and are becoming increasingly depending on external factors (the Internet, professional advice) for making decisions about their diet. The participants in this study showed evidence of having to deal with two paths when facing decisions about their diet post-diagnosis – the active and the passive path. The findings of this study were also explored in Chapman and Ogden (2009). The passive path is concerned with control, personal agency and efficacy, and is present in the words or phrases used by participants such as “what I could do to help myself”, “easy for me to control what I eat now”, “I should do something about it”, etc. This was similarly proposed previously in another study (Adams and Glanville, 2005).

The first overarching theme is dynamic in nature in that it proposes that factors that determine action on diet have an interpersonal (relationships) and intrapersonal (attitudes and beliefs) structure. Also, the findings add to a previous study (Chapman and Ogden, 2009) where the participants seemed to follow an active involvement in their diet when they observed evidence of factors that affected their well-being and self-perception (accumulation of evidence) and subsequently experienced internal and external triggers to proceed to action (trigger to action). However, in this study, active involvement was not only imposed by seamless life events but there seems to be a schema of determinants of change throughout their cancer journey after diagnosis.
which also encompass their relationships with others (health professionals and family).

The second overarching theme is also double dimensional: it suggests that the participants’ perceived results of their behavioural change determine the maintenance of the behaviour, using evidence to evaluate the change. Thus, evidence is used as an evaluation tool of the change’s benefits. This finding is a novel one and is not evident in previous studies or, at least, studies using qualitative methods. It is important for health providers to acknowledge how patients take the decision to maintain their adherence to healthier lifestyles. And this study gives an indication of how patients evaluate change in the process of making sense of their dietary changes.

Change has also a dynamic role on patients’ lives. On the perceptual level, it changes the meaning of food and its everyday use by re-evaluating food’s role and its social role, focusing more on the aspect of pleasure. On the emotional level, change triggers feelings and the participants seem to react to change; this may be an indication that change in any situation is a lot to bear. Finally, patients seem to use the evidence from change to determine whether or not to maintain a behaviour. A recent study (Dowswell et al., 2012) also found that colorectal cancer patients use immediate benefits to reinforce behavioural change maintenance.

This is the first study that has focused on men’s changed meaning of food after cancer diagnosis. Previously, studies of breast cancer patients found a shift towards change in how patients perceive food after diagnosis (McQuestion, 2011; Adams and Glanville, 2005). They also found that, post-treatment, the meaning of food is shaped by the perception of food’s role in breast cancer cessation and in improving health. The present study also suggests that, when men with prostate cancer talk about the meaning of food, they are elaborating more on the social role of food rather than food as a biological need. Socializing with others while eating is also seen by patients as a way to receive comfort (McQuestion et al., 2011). However, there is no way of knowing whether this meaning was previously different but “change to the meaning of food” can only be explored through their own words and perceptions.

The findings of the study are also consistent in a theoretical context with Leventhal’s (1998) model of illness and behaviour on conceptualizing the attitudes, beliefs and
social relationships of prostate cancer patients around the behavioural change of diet. They are also useful when examining the importance of social relationships and ties and how they can affect health behaviours. The importance of these relationships to health has been the core of Healthy People 2010 (US Dep. Health Human Serv., 2009). They also add to the existing literature on cancer patients and habitual and behavioural changes after diagnosis. They add to previous studies (Helakoppi et al., 1999; Salminen et al., 2000) supporting that significant others affect patients’ decision-making regarding diet and that patients tend to seek advice outside healthcare. Also, a study with breast cancer patients (Beagan and Chapman, 2004), suggested that breast cancer patients perceived family influence as significant in food decision-making. Thus, from a gender theoretical aspect, it seems that when men explore their relationship with food, they have similar patterns of beliefs when it comes to their families’ role in their dietary behaviour change. Therefore this study makes different assumptions on the role and construction of masculinity, on how men make more sense of changes to their diet than in previous studies (Oliffe and Mroz, 2005; Mroz et al., 2011) and on theories of gender and health (Courtenay et al., 2000).

Some participants, who referred to the influence of their family, explored the positive effect that the departure of their children had on maintaining their dietary changes. Previously, Umberson et al. (2010) in their review suggested that the social relationships of an individual and their impact on health behaviour change as individuals’ transition from one stage of their life to another. The participants in this study were at a stage in their lives where their multi-member family (patient-partner-children) had been transformed into a dual family (patient-partner) and this had a positive impact on their efforts to maintain change.

Patients seemed in need of contributing to their treatment and, for some, diet was an obvious place to start. Previously, it had been found (Salminen et al., 2000; Maskarinec et al., 2001; Beagan and Chapman, 2004) that some changes to diet reflect a need to reduce the probability of cancer recurrence and thus the need to contribute to treatment.

These findings are similar of those of another study (Dowswell et al., 2012) who interviewed male and female colorectal cancer patients and their partners in a focus group to ascertain their views on dietary and physical activity interventions. The
participants in that study mentioned constraints associated with work and retirement as facilitators of change. The active-passive patient found in this study was also evident in Dowswell et al. (2012) with some participants indicating that they were in control of their health and ready to adhere to changes to their lifestyle as opposed to others in the group.

8.4.1 Limitations and Qualitative Quality Research Appraisal

This study has limitations. The sample is location-specific (UK patients) and cultural values can be present when talking about food. Also, all the participants were recruited through a previous online survey. One of the means of recruitment for that study was through an advertisement in the Prostate Care Cook Book. Thus, it can be assumed that the participants were already interested in exploring diet from before whereas explorations by other patients could be different. Another limitation of this study may be the variability between participants on how they express their experiences, based on the variations in the type of treatment, the stage of the disease and the time since diagnosis.

Using Yardley’s (2000) evaluative criteria for qualitative research, to consider the limitations of the current study, the criteria of reflexivity and comprehensiveness are of particular importance. Even though the researcher has provided reflections and perceptions, perspectives and personal experiences and motivations that shaped his involvement with the study and the research area it is inevitable that there might be some influence by all of these factors on interpretations and formulating the research questions. The sample is small and more participants would be needed to address the research’s question. Finally participants’ cultural background may have influenced their explorations regarding diet.

8.4.2 Clinical Implications

There is a clinical significance relevant to prostate cancer patients’ healthcare driven by the findings of this study. The study provides an insight into how patients understand changes to their diet. If clinicians have evidence of patients’ meaning
making, it is useful when attempting to explain to patients about the changes to their lifestyle that can happen post-diagnosis or even to understand which mechanisms of understanding patients use when reflecting on these changes. Also, understanding the communication between health care providers and patients may have the potential to increase adherence to a healthy diet after diagnosis among cancer patients.

Interventions usually focus on voluntary behavioural change and less on the social influences that may affect behaviour (Michie, van Stralen and West, 2011). The findings of this study highlight the meaning patients give to social influences that may shape their health behaviour. The findings also explain the difficulty of implementing changes to behaviour by acquiring an active or passive path (Chapman and Ogden, 2009).

In order to tailor healthcare to the needs of the patient, health professionals have to view patients as “active participants” rather than “passive patients” (Rittenhouse and Shortell, 2009). Therefore how patients’ act on their health is also important for shaping health professionals’ attitudes towards them.

8.5 Conclusions

To conclude with the processes that determine and result from changes to diet after prostate cancer, diet has a social and individual nature as previously suggested by Beagan and Chapman (2004). The processes identified in the study are in line with a systematic review (Murray et al., 2013) that the factors, which influence health behaviour change, are also used for maintaining behaviour and that social support, beliefs and psychological factors are the most commonly reported influences on lifestyle change.

It is an important addition to the existing literature dealing with gender issues and masculinity (Courtenay, 2000) and also to the traditional self-regulation theories and the cognitive processes when acting on change. This issue is not elaborated in detail in the literature but there is one study (Furnham and Kirklady, 1997), which found men to have less control over their health than women. This study found men to be acting both as active and passive patients so there seems to be a phase in their
meaning making process regarding diet where they elaborate on the issue of controlling their health from a “male perspective”. Men-specific prostate cancer diet-related health interventions and health promotion programmes may have multiple health benefits and may form a more appropriate way of targeting dietary behaviour change if they understand the processes used by men when making sense of changes in their diet.

Chapter 9: General Discussion

The objective of this Thesis was to investigate the psychosocial processes around lifestyle changes after prostate cancer diagnosis focusing on diet. A mixed methods approach was used. A systematic review was conducted which aimed to identify evidence of an association between dietary changes and cancer patients’ HRQOL. Subsequently, three cross sectional studies using online surveys methods investigated the psychosocial processes of prostate cancer patients related to dietary behaviour change, compared patients’ information needs with those of their significant others as well as with GPs’ perceptions and then investigated GPs’ awareness on prostate cancer diet. Finally a qualitative study explored how patients make sense of changes in their diet after diagnosis.

The relationship between cancer diagnosis and eating is complex. One reason for this is because cancer patients experiences appetite loss (Poole and Froggatt, 2002), which can affect the decisions on diet. The findings in the Thesis further extend this by
proposing that psychosocial factors are also important for patients’ post-diagnosis lifestyle. Overall the findings suggest that adhering to a healthier diet for prostate cancer patients reflects several complexities, which can be psychological (cognitive functioning, perceptions, control, HRQOL), physical (dyspnoea), interpersonal (relationship with significant others and GPs) and educational. Patients explore these complexities when they make sense of changes in their diet.

Findings from the systematic review are inconclusive but indicative of the need to further investigate the association between dietary changes and HRQOL among cancer patients. Firstly, it is suggested that the interventions used to change patients’ dietary behaviour have mixed effects on patients’ HRQOL. Secondly, different constructs of HRQOL are differently affected by changes in diet with no clear indication of a strong effect on physical or emotional health. Therefore there is need to explore the areas of patients’ HRQOL that are associated with dietary behaviour change. Thirdly, patients diagnosed with a cancer with high survival rates (prostate, breast and colorectal cancer) or those categorized as lower risk (Ravasco et al., 2003) are more likely to experience changes in their HRQOL after changing their diet compared to other cancer types. Therefore, cancer survival rates create the need to understand the association between HRQOL and dietary behaviour change. This can trigger clinicians to focus on patients’ adherence to healthy eating recommendations.

Findings from Chapters 4 and 7-8 offer an insight on the patients’ psychological processes associated with dietary changes. In general patients are found to develop a need for information earlier than what their GPs perceive. They also adhere to positive changes when changing their diets after diagnosis with only a small percentage adhering to negative changes. More educated patients are more in need for information about prostate cancer but develop their needs later, compared to less educated patients. Consequently, more educated patients are also found to be more likely to change their diets after diagnosis but not while on therapy. Marital status on the other hand does not affect the dietary behaviour change. As discussed in the Thesis (Chapter 8, Section 8.4) spousal support would be more useful to examine rather than marital status in general.
Patients who change their diets after diagnosis are different from those who do not in three aspects of their HRQOL and sense of control. In particular, patients who change their diets have lower cognitive functioning, are less dependent on their doctors and experience less symptoms of dyspnea, which is also a symptom of anxiety. Therefore anxiety, external locus of control and lower cognitive functioning can be barriers of patients’ adherence to a healthier diet. Overall, HRQOL and perceived behavioural control are found to predict changes in diet among prostate cancer patients.

The fact that external locus of control and specifically control of doctors can be a barrier of changes in diet can further be explained with findings from Chapter 7. There are differences between GPs in terms of their awareness of the relationship between prostate-specific and diet. GPs also underestimate the extent of patients’ information needs after diagnosis including with regard to diet and nutrition. GPs’ socio-demographic characteristics in part explain these differences. A GPs’ gender explains perceptions of the development of need for information on prostate cancer, interaction issues and maintaining psychological health; with female GPs underestimating the development of patients’ needs on this information. Consequently, male GPs are more likely to have a greater understanding of patients’ information need rather than females. At the same time, experience as a GP is important with regard to not underestimating the development of the need for information on sexuality.

Overall GPs perceive patients’ information needs to be more treatment-focused. They overestimate the development of treatment-related information needs and underestimate the other needs. Patients have an opposite approach developing a need for disease-specific and interaction-specific needs earlier than GPs perceive them to. Thus GPs perceptions are more related to the Biomedical Model of Health (Annandale, 1998) whereas patients’ needs are more related to the Bio-psychosocial model of health. These different “worlds” can interact and have an impact on the health care delivery. Findings from the Thesis provide the ground for further investigating the different perspective of patients’ needs between patients and health care professionals.
Park et al (2008) found social support, sense of control, life meaning and approach coping to relate with positive health behaviour changes. Findings in this Thesis highlight the negative effect of external locus of control on adhering to a healthier diet. The relationship between cognitive functioning and information needs was explored previously. Jensen et al. (2012) found that even though awareness can increase the processing of information other cognitive factors can interfere. Findings from this Thesis highlight the importance of focusing on patients’ cognitive functioning as a barrier for adhering to a healthier diet after prostate cancer diagnosis.

Previous findings from qualitative studies have found that information provided by national screening programmes is confusing and inadequate for patients (Goldsmith et al., 2007; Austin et al., 2009; Prinjha et al., 2006). Furthermore Dowswell et al. (2012) suggest that health professionals’ current priority is patients’ reassurance rather than patients’ awareness. Findings from the Thesis strengthen the need for providing patient-centered information and health provision, which will enable adherence to a healthier diet and a healthier lifestyle in general.

Findings from Chapter 4 indicate that the development of significant others’ information needs are different than those of patients. These findings are important because they provide the ground for investigating issues of social and family support during patients’ coping and the process of adhering to a healthier lifestyle. More educated significant others are more in need of information about prostate cancer but develop their need later compared to less educated significant others. They also develop a need for information related to treatment and interaction issues earlier than patients. This is an important finding in that it suggests that significant others make efforts to gain information related to issues that can potentially help them to support the patient.

An alternative explanation can be that patients develop their need for information later than significant others because they experience a period of denial and “blocking response” (McCaughan and McKenna, 2007) which constitutes a barrier for receiving information. Findings from the Thesis support this with significant others report a decreased interest in receiving information on the 6-month period after diagnosis.
whereas patients report a “regained” interest after the 3rd month after diagnosis. Thus, patients have a different type of “journey” after prostate cancer diagnosis compared to significant others. The 3rd month after diagnosis seems to be a point that can be further investigated. More specifically, the question remains what triggers patients to report a decreased interest in information at that point and why they report an increased interest afterwards. Even though findings in the Thesis are from cross sectional studies, they still are a starting point for further research.

Diet as a perceived cause of cancer is found to predict the development of diet as an information need of patients, but not diet as a lifestyle change after diagnosis. Therefore there seems to be a mediating factor between the perceived cause of cancer and lifestyle change. Health Behaviour Theories have explained these factors as the intentions to change several behaviours. Findings from this Thesis also indicate that receiving related information can also be a mediating factor between perceived cause of cancer and behavioural change. Future research can use mediate regression analysis to investigate the mediating role of behavioural change intentions and information needs.

Exercise has been the only health behaviour found in the Thesis to be predicted by lack of exercise as a perceived cause of cancer. Therefore men who believe that lack of exercise is a possible cause of their cancer will exercise more after diagnosis whereas when men consider that diet is a possible cause of their cancer will not necessarily change their diet after diagnosis. This finding raises two issues: firstly, different health behaviours can have different predictors and secondly diet can be a complicated health behaviour. Eating is a health behaviour initiated by all people with no exceptions. Therefore, it constitutes a strong habitual behaviour which requires a cognitive load (see Chapter 8), is strongly associated with external locus of control and especially doctors’ recommendations (see Chapter 7,8), is affected by anxiety symptoms like dyspnoea (see Chapter 8); while the evidence from the effect of dietary changes on HRQOL are mixed (see Chapter 6) and its predictors are more complicated than other health behaviours like exercise (see Chapter 4). Nonetheless, more data are needed to draw safer conclusions on the predictors of dietary behaviour change. The complexity of diet as a health behaviour is also evident on previous findings indicating that patients diagnosed with lower risk cancer are more likely to
experience more adverse treatment effects or appetite loss (Poole and Froggatt, 2002),
which can influence both their HRQOL and their eating.

Also diet as a perceive cause of cancer did not predict diet as a lifestyle change after
diagnosis and the Leventhal’s Common Sense Model of Self-Regulation (Leventhal et
al., 1984) was not supported nor findings from Stewart et al (2001) who found causal
beliefs of stress to predict actions to reduce stress. Nonetheless, diet is a complicated
lifestyle factor and can be attributed to a series of confounding factors. This Thesis
explored this by indicating that diet as a perceived cause of cancer can predict seeking
for dietary information but not diet as a lifestyle change. There seems to be a gap
between receiving information and changing health behaviour. The association
between causal beliefs and behaviour change can be more complicated when it comes
to lifestyle changes. Moreover, Leventhal’s model and previous findings (i.e.
McCaughan and McKenna, 2007) indicate that cancer patients make efforts to return
to a self-perceived stage of normality. Future qualitative can further explore findings
from Chapter 8 where it is not clear whether changing dietary behaviour is a coping
process of a return to normality or whether changing dietary behaviour can be an
effort to control over their illness.

Findings from Chapter 8 provide some insight into how patients themselves make
sense and experience the changes in their diet after diagnosis. These findings propose
that the themes identified can form an underlying mechanism of dietary behaviour
changes after prostate cancer diagnosis. They offer an insight on how patients explain
changes and how these changes affect their everyday life. Previously Meilier et al.
(1997) found that predictors of lifestyle changes can be intrapersonal(knowledge,
attitudes, confidence, perceived possibilities of change and intrapersonal (social
influence, experiences).

Findings from Chapter 8 are complementary to findings from Chapters 4-5 and 7
indicating the two dimensions which are used by patients when making sense of
dietary behaviour changes: intrapersonal (attitudes towards receiving dietary
information, active or passive patient, perceived evidence for maintaining behaviour
change, changed meaning of food) and interpersonal (family and health professional
influences on acting on their diet). More specifically patients understand changes in their diet to be a result of the attitudes they develop when receiving information on diet with most of them discussing the availability and quality of available evidence. They seem to follow an active or passive path previously discussed by Chapman and Ogden (2009), which is affected by their attitude towards their diagnosis. They also explain that in order to maintain their health behaviour change they need evidence that the change has enhanced their well-being. Behavioural maintenance is one of the core elements of the Stage Theories which aim to identify the post-intentional phases of behavioural change (Schwarzer, 2008). Findings from the Thesis identify these behavioural maintenance processes and propose patients use that evidence-evaluation. Patients also explain how food, which is a strong habitual behaviour, has a different meaning for them after diagnosis.

The reason that this underlying mechanism is important is because it can offer information on processes, which are meaningful for patients and are perceived as affecting their everyday life and consequently their well-being. Therefore, findings related to patients are important for the following reasons: they provide information on the time which is best to intervene and the trajectory of patients’ information needs’ development post-diagnosis; they explain the prerequisites needed to help patients adhere to a healthier lifestyle and especially diet; they explain the interpersonal and intrapersonal results of dietary behaviour change; and generally how men who change their diets differ from those who donot. Clinicians and decision-makers need to understand the “profile” of men who change their diets in order to shape their health approach.

Findings from the Thesis can also be interpreted theoretically. The traditional Biomedical Model of Health (Annandale, 1998) has been challenged in previous years mainly by the bio-psychosocial Model (Engel, 1977), which introduced social factors as determinants of health and health behaviour change. There are three dimensions of evidence in in the Thesis pertaining to the usefulness and applicability of the bio-psychosocial Model for explaining differences between patients in their health behaviours: a) the role of educational level on changing diet after prostate cancer diagnosis, with more educated participants more likely to make changes in
their dietary behaviour (see Chapter 7, section 7.3.6), b) the fact that external locus of control and more specifically the level of control patients put on doctors can explain dietary behaviour changes after diagnosis (see Chapter 7, section 7.3.3.3) and c) patients’ sense-making of changes in their diet after diagnosis explained by interpersonal and intrapersonal factors (see Chapter 8, section 8.3.2). Therefore dietary behaviour change can be associated with social factors. The Health Belief Model (Rosenstock, 1966; Becker, 1974) also attributed health behaviour to internal and external factors.

Previously, Ogden (2012) discussing the evolution of health outcomes since the introduction of the bio-psychosocial Model of Health argued that not only social but also psychological factors can influence health. The Thesis provides evidence that two psychological constructs differentiate between prostate cancer patients who changed their diet after diagnosis and those who haven’t: a) higher levels of cognitive functioning (see Chapter 7, section 7.3.3.3) and b) more severe symptoms of dyspnoea (a symptom of anxiety) (see Chapter 7, section 7.3.6). These factors can indirectly affect health since they have an intermediate effect on diet as health behaviour. Therefore they constitute an indirect pathway of psychological factors affecting health. Moreover Chapter 6 has provided evidence from randomized control trials using an intervention with a diet component and which propose an association between dietary behaviour changes and HRQOL. This association was further explored in Chapter 7 (section 7.3.3.3) where HRQOL in general has been found as a predictor of dietary behaviour change after diagnosis. Therefore psychological factors can also indirectly affect health by affecting dietary health behaviour.

Being healthy or feeling healthy can trigger action. However it is difficult to ascertain a general HRQOL measure as the predictor of change and the HRQOL can more clearly explain the processes of health behaviour change. In this Thesis cognitive functioning was a strong predictor of change while the systematic review (Chapter 6) provided evidence of changes in physical functioning after cancer patients have changed their diet. It is interesting to further explore how the mental and physical components of HRQOL scales interact and whether there is a consistency that mental (cognitive) subscales can explain change whereas physical subscales constitute an outcome of change.
Health Psychology deals with the variability of people when it comes to health behaviours (Ogden, 2012). Cognitions such as perceived cause of illness and knowledge have been used to explain why some people change their health behaviours while others do not (see Chapter 2, section 2.2). The Thesis aimed to investigate information needs and perceived cause of cancer of prostate cancer patients. The time that patients develop their information needs forms a different reality from what their GPs perceive and the time that significant others develop their information needs. Leventhal’s Common Sense Model of Self-Regulation (Leventhal et al., 1984) proposed three stages of coping with an illness and suggested that in the first stage patients use cognitive representations like symptoms and social messages. It seems that symptom evaluation (like dyspnea which was found in the Thesis as a predictor of non-change) can significantly affect the initiation of dietary behavior change. In the second stage patients seek medical attention and discuss their condition with significant others. In the third stage (appraisal stage) they develop strategies for maintenance. These strategies for maintenance were explored in Chapter 8 where participants evaluated the results of changing their diet in order to maintain the change. It is suggested that evaluating the results of a behaviour change can be a mechanism used by patients when they are at the appraisal stage.

In the Thesis, patients were found to evaluate the results of the dietary behaviour change to decide whether they would maintain the change. This finding is associated with the Health Belief Model (Rosenstock, 1966; Becker, 1974) where individuals evaluate the benefits of adopting a new behaviour to adhere to change. Thus findings in the Thesis further expand this concept by proposing that patients use this evaluation procedure for behavioural maintenance after adopting a new behaviour. The aspect of mechanisms for behavioural maintenance were also explored by Stage Theories and the Transtheoretical Model (Prochaska and Di Clemente, 1982)

The Thesis also examines the social context of health and the social relationships that can affect health behaviours (Umberson et al., 2010). In the Thesis, the role of significant others and GPs is discussed. GPs are found to have different perceptions of the time that patients develop their information needs. Thus if information can be a form of social messages used by patients at the first stage of their illness trajectory it
is a matter of question whether at the second stage when they seek medical attention and talk to their significant others they can benefit because of the differences found on patients’ trajectory compared to that of their significant others and the different perceptions of their GPs. The indirect effect that social support can have on control and health behaviours discussed in Umberson et al’s (2010) conceptual model for mechanisms linking social relationships to health behaviours can be pertained to these findings.

Chapter 7 has investigated the role of two psychological constructs often used by the Theory of Planned Behaviour (Ajzen, 1991). They were used not as predictors of behavioural intentions but as possible factors that can explain the behaviour outcome. Self-efficacy and internal locus of control have not been found to predict behaviour directly (see Chapter 7, section 7.3.3.3). This finding partly confirms a previous meta-analysis (Armitage and Conner, 2001), which examined the efficacy of the TPB and concluded it is only weakly associated with behaviour outcomes whereas stronger associations exist with behavioural intentions. Future studies should include a construct of behavioural intentions to identify this potential intention-behaviour gap. Similarly to previous findings (Eyre, 2001; Maunsell et al., 2002; Salminen et al., 2004) who proposed that focusing on diet is a way of regaining the lost sense of control, findings in Chapter 8 support this with one participant indicating that “only when it came back a year after surgery did I begin to think about what I could do to help myself. And diet was an obvious area to start” (Participant 2, Chapter 8, section 8.3.2). On the other hand the cross sectional design of studies in Chapters 4-5 and 7 limit the interpretation of the role of perceived behavioural control and self-efficacy in dietary behaviour change. Thus higher sense of control can be an outcome of change or a predictor (Chapman and Ogden, 2009).

Overall dietary behaviour change is conceptualized in the Thesis as a dynamic process, which takes into consideration intrapersonal and interpersonal factors. The problems of individual variability within health behaviours (Molennar and Campbell, 2009) can be further explored using n-of-1 time series designs (Barlow et al., 2009) to investigate the predicting abilities of the constructs used in the Thesis.
The causal explanation provided by the patients in Chapter 4 and which are based on the Attribution Theory (Heider, 1958) and findings of which propose that cancer patients develop causal explanations for their cancer (Taylor, 1984). These causal explanations could not predict lifestyle changes after diagnosis for diet and alcohol consumption but they could for exercise. However, unhealthy diet could predict looking for dietary information after diagnosis.

The model proposed by the Thesis (Figure 3.3) is that prostate cancer patients pass through a very stressful situation when being diagnosed with prostate cancer which has major psychological consequences: loss of control and HRQOL which in turn motivate them to act on their situation. Lifestyle changes and particular dietary changes are seen as a starting and obvious point to regain the control over their lives which has been lost as a result of prostate cancer diagnosis.

The Thesis’ empirical Chapters have explored the different pathways proposed by the model. Patients, through their journey to cope with their illness, seek information related to their treatment and their disease. The interpersonal and intrapersonal mechanism identified in the qualitative study indicate that patients seek support from their significant others and rely on the support of their health care professionals. However the perceptions of health care professionals of their patients’ needs differ than patients’ real needs. Their significant others are in need of information related to treatment and interaction issues to provide adequate support to the patient. Finally, patients make effort to self-manage their condition by changing their health behavior. There are indications in the literature based on the systematic review that an association exists between dietary behavior change and physical and mental health and findings from the Thesis point out that cognitive functioning, internal locus of control and cancer symptoms (dyspnea) account for the health behavior change. On the other hand illness perceptions were not found to predict health behavior change. In general loss of control and coping processes after prostate cancer diagnosis create a new reality for the patient which may differ with how health professionals perceive it to be. However these processes trigger health behavior change and seeking support. Future research should seek to confirm the Model as it is proposed in the Thesis.
The “Stress, Appraisal and Coping Model” (Lazarus and Folkman, 1984) can also be used as a theoretical context of evidence. Patients coping processes related to their needs and HRQOL are evident. Prostate cancer diagnosis seems to be the trigger to action, which elevates stress and leads to action in order to re-capture whatever is lost by diagnosis itself. Therefore lifestyle changes can be the response to stress and control and should be further investigated as a coping process related to elevated levels of stress. Whether a teachable moment or not, prostate cancer diagnosis can trigger change.

9.1 Limitations

Some of the limitations of the Thesis make findings more suggestive rather than conclusive. Future research should overcome these limitations and to investigate more in-depth the psychosocial factors involved in dietary behaviour changes after prostate cancer diagnosis. Specific limitations of included studies were discussed earlier at each Chapter. Here some more general limitations are discussed.

In the Thesis participants were generally elderly people. Dietary data from older people can be less reliable than younger people (Samet, 1989; Taylor-Davis and Simiciklas-Wright, 1993). Older people have greater interest in diet and have more time available (McNeill, 2009). Thus it is difficult to generalize findings to the wider prostate cancer population.

The Thesis makes use of a number of non-parametrical statistical tests to answer the research questions. The decision to use non-parametric tests was based on the normality of distributions. However, interpretations should bear in mind the limitations of non-parametric tests. In particular non-parametric tests lack power as compared to parametric tests especially with small sample sizes (Siegel and Castellan, 1988). Therefore findings from significant others can have less power than if the sample was larger. Moreover the non-parametric tests test the distribution of scores and higher-ordered interactions are not dealt with.
Moreover, Chapters 4-5 and 7 are cross sectional studies and therefore are open to the criticism of this research design. The main limitation of cross sectional design is the inability to draw conclusions in causality and to test multiple models (Aldwin, 2007). Therefore longitudinal studies are needed to overcome the problems of cross sectional studies. A cohort study addressing patients over time and monitoring physiological and psychological changes using robust techniques (food diaries, PSA levels, physiological measures, interviews) will provide conclusive evidence on etiological associations. Elevated levels of stress will also be useful to identify in the context of appraisal and coping processes.

In order to obtain more robust findings and to overcome self-report bias future studies should consider double-checking patients’ self-reports with actual medical records or use of more accurate measures like food diaries as a way to validate patients’ questionnaire data. Moreover, as discussed earlier in Chapter 8 (section 8.4), marital support would be more useful to examine rather than marital status in general.

Sample size of included studies is adequate to draw suggestive evidence but more data are needed to draw conclusive evidence. Moreover a more straight-forward recruitment strategy enabling participants to take part that are not previously interested in diet will provide more generalizable findings. In the Thesis important findings are derived from a population with particular interest in diet and more general findings are needed. A small sample means low clinical significance. Also, the small number of participants in the significant others group gives any attempt to draw conclusions about this population only limited validity.

In general, measures of health behaviour change are crude. Furthermore there is evidence that cancer patients may overestimate their change (Wayne et al., 2004). Given the retrospective data collected on patients’ behaviour and cognitions during a certain period of time after diagnosis, even though findings which provide an indication of differences between changers and non-changers cannot be conclusive regarding whether these differences are the predictors or the results of change.

Finally, the Thesis makes use of men diagnosed with prostate cancer in multiple times since their diagnosis. The heterogeneity of “years since diagnosis” create problems
with the “identity” of participants with some recalling their changes as patients in active treatment and right after treatment and others recalling their changes after the period of transition from patient to survivor (Hewitt et al., 2005). Also Park et al. (2009) found differences between different identities of men diagnosed with cancer. The “survivor” identity was related with better psychological wellbeing and post-traumatic growth while they were more related with cancer-related activities (i.e. talking about prevention) rather than patients.

Chapter 10: Conclusions and Recommendations

It was previously supported that educational, behavioural and motivational strategies if combined can help changing dietary behaviour (Anderson et al., 1998). Anderson (2000) proposed that one of the steps needed to consider in designing a cost-effective lifestyle programme in order to achieve dietary behaviour change is the underlying behavioural theory of lifestyle change. This can help to inform decision-makers on patients’ level of readiness to change. This Thesis provides evidence of the psychosocial processes evident in prostate cancer patients’ process of dietary and general lifestyle change.
Findings from the Thesis are important for health care delivery because health professionals’ training regarding prostate cancer diet needs to be improved whereas at the same time more evidence are needed to convince health professionals on which food items are beneficial for patients. Health professionals’ views are important and can determine whether patients will change their diets. Therefore two needs are created: first to bridge the “gap” between patients’ real needs with health professionals’ perceptions of patients’ needs and second to implement a patient-centered health care which will enable patients to act on their coping process and enhance their wellbeing.

The systematic review of the literature suggests that dietary behaviour change is associated with higher HRQOL. What remains to be established is the direction of this association and the aspects of HRQOL that either contribute to dietary behaviour change or change when patients change their diet. To further investigate this, the predicting utility of HRQOL was examined comparing patients who change their diet after diagnosis and after therapy has started with those who did not. Findings are inconclusive. HRQOL can predict whether patients will change their diet after diagnosis but not after therapy has started. This indicates that the therapy-phase creates severe complexities for the patient and makes predicting their behaviour difficult. The finding that after diagnosis and up to the third month post-diagnosis patients report a decreased interest in their information needs whereas after the third month they report an increased interest also supported this. It was also controlled by findings from significant others who did not report an increase in their information needs after the third month post-diagnosis.

The results from the Thesis highlight a distinction of patients’ information needs following diagnosis. Whether this distinction equals distinct phases, in which patients are more susceptible to receive information or be more open to dietary behaviour change, remains to be further explored.

Family support, anxiety and cognitive functioning are important determinants of whether patients will change their diets after diagnosis and therefore specific psychotherapeutic interventions can help with dealing with barriers of dietary
behaviour change. Interventions like cognitive behavioural therapy or a more holistic and family therapeutic intervention can help. Findings indicate that significant others have strong needs and the trajectory of their information needs development is different from that of patients. Therefore health professionals should focus on intervening and approaching the patients’ significant others aiming to help with their coping process and also provide them the necessary information to enable them to support patients’ coping process.

The education of GPs is also important for patients, in order to change their diet after diagnosis and also to search for information related to their prostate cancer. Discrepancies observed between GPs’ awareness on prostate cancer diet could provide an explanation for the reason why patients with high external locus of control related to doctors do not adhere to changes in their diet after diagnosis. Nutritional counseling can be an important addition to GPs’ training. It was previously found to relate with the nutritional status of cancer patients (Dobrila-Dintinjana et al., 2011) and also enhance patients’ HRQOL (Prevost and Grach, 2012; Segura et al., 2005; Roila and Cortesi, 2001; Stull et al., 2007). Nonetheless, patients and practitioners agree on practitioners’ lack of dietary-related knowledge (McClishy et al., 2011).

Findings in the Thesis have also a more general and social implication that highlights how patients’ social background can interfere with their health care provision. Different social classes have different needs and it is evident that those from the lower social classes have enhanced needs and must constitute a priority for health care decision makers.

Generally patients re-evaluate their attitude towards their diet. During their coping process patients seem to use these intrapersonal processes to “think again” about what diet is, how to change or maintain a healthier diet and what are the effects of a healthier diet. Interpersonal factors like their relationship with their health professional and their family, which were explored in Chapters 4 and 7-8, are meaningful for patients. Health professionals’ lack of awareness can be a barrier for following a healthier diet.
In general, a more holistic approach to health that conceptualized the social context of health along with the role of psychological constructs in dietary health behaviour is needed. For example, receiving information about diet is not enough to convince patients to adhere to a healthier diet after diagnosis. GPs’ perceptions and their general knowledge on prostate cancer diet should be a priority of primary care research. The role of significant others and their own needs should be an additional priority of psychological and psychotherapeutic research. The social relationships that shape patients’ behaviour and how they make sense of changes in their diets after diagnosis are better understood in order to identify which mechanisms patients use to explain the changes in their diet. Finally, the psychological characteristics of patients who change their diet contrasted with those who do not offer a new “pool” of ideas for further research to understand the “profile” of men with prostate cancer who initiate change in their diet. All these issues were dealt with in the Thesis in order to understand the dietary behaviour changes of men with prostate cancer. To conclude, a more patient-centred and holistic approach to their health care delivery has the prospect of optimizing their HRQOL and their general well-being.

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http://www.who.int/mental_health/media/68.pdf


Appendices
Appendix I: Ethical Approval for Chapter 4
Appendix II: Questionnaire (Chapter 4)

There are 2 groups that might complete the questionnaire:

**Group 1:** Men with prostate cancer  
**Group 2:** Others with a link to men with prostate cancer

People with no link with prostate cancer will be excluded after question 4

Please answer all questions by ticking the appropriate box or by writing your answer in the space provided.

**ALL GROUPS You and prostate cancer**

1. Have you been diagnosed with prostate cancer?  
   - Yes  
   - No

2. Is a person you are significantly linked with a prostate cancer patient?  
   - Yes  
   - No  
   If yes is this person….
   - A member of your family  
   - A relative  
   - A friend  
   - Other (please specify)…………………

**ALL GROUPS About you**

3. How old are you?

4. Are you?  
   - male  
   - female

5. Are you currently?  
   - Married/ Living as married  
   - Living with another adult(s)  
   - Single/living alone
6. What is the highest level of education you have completed?
☐ No formal schooling
☐ Less than primary school
☐ Primary school completed
☐ Secondary school [OR job-related qualifications (e.g. apprenticeship) completed]
☐ Tertiary education such as college/university completed
☐ Post-graduate degree completed

7. How did you hear about this study?
☐ Prostate Care Cook Book
☐ A website, if so which
☐ Other, if so please specify how

ALL GROUPS You and food

8. What is your involvement in food shopping?
☐ No involvement
☐ Discuss with spouse/companion what to buy
☐ Accompany spouse/companion when food shopping
☐ Do food shopping by self

9. What is your involvement in food preparation for your household?
☐ No involvement
☐ Prepare snacks/drinks occasionally
☐ Prepare snacks/drinks daily
☐ Prepare or help to prepare meals occasionally
☐ Prepare or help to prepare meals daily
☐ Prepare or help to prepare all snacks/drinks and meals

10. Who is the chief income earner in your household?
☐ You
☐ Your partner
☐ Other adult in household

11. What is your employment status and (if you are not the chief income earner) what is the employment status of your household’s chief income earner? (Please tick ONE box only in each column)

<table>
<thead>
<tr>
<th>If working</th>
<th>You</th>
<th>Chief income earner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time paid work (30+ hours per week)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Part-time paid work (8-29 hours per week)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Part-time paid work (under 8 hours per week)</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Not working</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

If not working
Still at school □ □
In full time higher education □ □
Unemployed (seeking work) □ □
Not in paid employment (not seeking work) □ □

What is/was the occupation of your household’s chief income earner? (Please refer to their current main job or if they are not working now to their last main job)

12. What is/was your employment status?
☐ Self-employed
☐ Employee

13. How large is/was the organization?
☐ 1 employee
☐ 2 to 24 employees
☐ 25 or more employees

14. Does/did their role involve managing or supervising others on a day-to-day basis?
☐ Yes
☐ No

GROUP 1 You and your prostate cancer

15. What is your Gleason Score?

16. What is the current treatment status of your prostate cancer?
☐ Under Treatment
☐ In complete remission
☐ Recurrent

17. At what age were you diagnosed with prostate cancer?

18. Which of the following treatments have you had for your prostate cancer?
☐ Surgery
☐ Radiation therapy
☐ Chemotherapy
☐ Other

ALL GROUPS except where indicated Prostate Care Cook Book
19. How thoroughly did you read the introduction of the Prostate Care Cook Book

☐ not at all  ☐ Slightly  ☐ moderately  ☐ very  ☐ extremely
thoroughly  thoroughly  thoroughly  thoroughly  thoroughly

20. To what extent did you find the introduction…

Informative? ................................................... ☐ ☐ ☐
Useful? ......................................................... ☐ ☐ ☐
Difficult to understand? ............................... ☐ ☐ ☐
Credible? ....................................................... ☐ ☐ ☐
Personally relevant? ................................. ☐ ☐ ☐

21. Did you prepare a recipe from the book?
☐ Yes
☐ No

If yes, how many recipes have you prepared?

________________________________________

22. How interested are prostate cancer patients in acquiring information about diet after diagnosis (e.g. Prostate Care Cook Book)?

☐ not at all  ☐ slightly  ☐ moderately  ☐ very  ☐ extremely
interested  interested  interested  interested  interested
23. **GROUP 1** To what extent do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since diagnosis I eat a healthier diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since diagnosis I have increased my level of exercise</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since diagnosis I have decreased/quit smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since diagnosis I drink less alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with information received about prostate cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had need for information about prostate cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had intention of seeking cancer information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In general I would say I have a healthy lifestyle</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>By living healthily I can influence the course of the cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had a healthy lifestyle before diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

24. **A) GROUP 1** To what extent were you interested on getting information in relation to the following after being diagnosed?
B) GROUP 2 To what extent were you interested in getting information on the following points after realizing you were at risk of developing prostate cancer?

<table>
<thead>
<tr>
<th>Topic</th>
<th>not at all interested</th>
<th>slightly interested</th>
<th>moderately interested</th>
<th>very interested</th>
<th>extremely interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Effect on family, friends or caregivers</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Interaction issues with health care providers</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Sexuality</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Maintaining psychological health</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

25. A) GROUP 1 How soon after your diagnosis did you develop an interest in the following?

C) GROUP 2 How soon after you realized you were at risk of developing prostate cancer did you develop an interest in the following?

<table>
<thead>
<tr>
<th>Topic</th>
<th>immediately</th>
<th>less than 1 month</th>
<th>1-3 months</th>
<th>4-6 months</th>
<th>more than 6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Self-care issues or home care during recovery</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
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<td>Effect on family, friends or caregivers</td>
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<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
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<td>Interaction issues with health care providers</td>
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<tr>
<td>Sexuality</td>
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<tr>
<td>Cost of treatment, insurance coverage, or other financial issue</td>
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<tr>
<td>Diet and nutrition</td>
<td>□</td>
<td>□</td>
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<tr>
<td>Maintaining psychological health</td>
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<td>□</td>
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</tr>
</tbody>
</table>

26. GROUP 1 To what extent do you believe that the risk of a person developing cancer is affected by the following?
<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>not at all</th>
<th>slightly</th>
<th>moderately</th>
<th>very</th>
<th>extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having a weakened or impaired immune system</td>
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<tr>
<td>Fate/chance/bad luck</td>
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<tr>
<td>Pollution</td>
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<tr>
<td>Smoking</td>
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<tr>
<td>Diet in general</td>
<td></td>
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<tr>
<td>Drinking alcohol</td>
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<td></td>
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<tr>
<td>Old age</td>
<td></td>
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<td></td>
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<tr>
<td>Lack of exercise</td>
<td></td>
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<tr>
<td>Family history (a blood relative who has-had cancer)</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Not going for regular health checks</td>
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<tr>
<td>Genetics (&quot;it’s in the genes&quot;)</td>
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<tr>
<td>Stress</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

☐ I wish to get a summary of the results by providing my email below
☐ I wish to participate to another interview study and provide some contact details

Name:
Phone number:
Email:
Address:

Thank you for your participation!
If you have any queries please contact Angelos Kassianos at: a.kassianos@surrey.ac.uk
Appendix III: Advert in “The Prostate Care Cook Book”
Appendix IV: Advert in “Voices” Bulletin

Complete a survey for a study about the effect of prostate cancer on health related quality of life

The Department of Psychology at the University of Surrey would like men diagnosed with prostate cancer to complete a survey, contributing to a research study which is investigating whether changes in dietary behaviour affect the quality of life of men with prostate cancer, and whether control and self-efficacy can predict these changes after diagnosis and treatment.

If you would like to complete the survey online then please click here http://www.fahs.surrey.ac.uk/survey/dietary_changes/.

It will take approximately 20 minutes. If you have any questions or want more information about the study, please contact Angelos Kassianos Co-Investigator on a.kassianos@surrey.ac.uk, Department of Psychology, University of Surrey, Guildford, GU2 7XZ, UK.
Appendix V: Information Sheet for Participants (Chapter 4)

Dear Participant

The Prostate Care Cookbook Study

Information for Participants and Consent Process

Thank you for your interest in taking part in this study. Before you decide whether or not to participate, please read this information sheet carefully. When you understand what the study entails, and if you wish to participate, you will be directed electronically to the questionnaire. The questionnaire asks you for information about: you (your age, living arrangement, education and employment status; your association and experience with prostate cancer (as patients, carer or at risk); diet and lifestyle; and the Prostate Care Cook Book. Completing the survey will take about 10 minutes. Your completed questionnaire will be securely stored in both electronic media and paper forms and will be accessible only to members of the research group, members of the University of Surrey Web Office and the server administrator. All participants' data will be identified only by a unique identification number and kept confidential in accordance with the data protection act (1998). The study has been reviewed and been given a favourable ethical opinion by the University of Surrey Ethics Committee.

If you have any questions about this study please feel free to contact us at our study's email address: a.kassianos@surrey.ac.uk or by phone on 01483 686892 (Angelos Kassianos). The results of the study will be published and you will have the opportunity to request to see it if you complete the questionnaire.

☐ I have read and understood the information above and am willing to complete the online questionnaire. Ticking the box will activate the questionnaire.
Appendix VI: Questionnaire (Chapter 5)

**PROSTATE CANCER AND DIET**

If you are both a member of SW Thames Faculty and still in practice, we would be grateful if you could complete this short questionnaire which relates to recent research on the influence of diet on prostate cancer – both for prevention and treatment.

**About you**

1. Are you male or female? □ male □ female

2. How old are you (in years)?

3a. How many years have you been in general practice?

4. To what extent do you believe prostate cancer patients are interested in getting information in relation to the following after being diagnosed?

<table>
<thead>
<tr>
<th>Information</th>
<th>not at all interested</th>
<th>slightly interested</th>
<th>moderately interested</th>
<th>very interested</th>
<th>extremely interested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Available treatments/treatment options</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>More information about prostate cancer</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Likely progress of disease</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>Self-care issues or home care during recovery</td>
<td>□</td>
<td>□</td>
<td>□</td>
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<td>□</td>
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<tr>
<td>Effect on family, friends or caregivers</td>
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<tr>
<td>Emotional reactions, emotional support, coping with cancer</td>
<td>□</td>
<td>□</td>
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<td>□</td>
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<tr>
<td>Interaction issues with health care providers</td>
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<td>Sexuality</td>
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<tr>
<td>Cost of treatment, insurance coverage, or other financial issues</td>
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<tr>
<td>Diet and nutrition</td>
<td>□</td>
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<td>□</td>
<td>□</td>
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<tr>
<td>Maintaining psychological health</td>
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</tbody>
</table>

5. How soon after their diagnosis do you believe they develop an interest in the following?
6. Nutritional scientists researching prostate cancer risk have suggest that a diet that increases some food items and reduces others may reduce risk. Please tick yes/no to indicate whether you have heard any of the following foods mentioned in relation to prostate cancer risk:

- **Tomatoes**: Yes
- **Garlic and onions**: Yes
- **Broccoli, cabbage, or other cruciferous vegetables**: Yes
- **Soya products (soya milk etc.)**: Yes
- **Oily fish**: Yes
- **Green tea**: Yes
- **Pomegranates/pomegranate juice**: Yes
- **Brazil nuts and offal (for selenium)**: Yes
Vitamin D (usually from sunlight) Yes
No

Limit intake of milk and dairy products to 1 pt/d or equiv. Yes
No

Burnt and overcooked meat to be avoided Yes
No

Please add any further comments that you think are relevant to this case:

Answer (open ended):
Appendix VIII: Consent Form and Information Sheet for Participants
(Chapter 7)

Participant Information Sheet

**Dietary Changes after the diagnosis of Prostate Cancer: the Role of Control and the effect on Health-Related Quality of Life and Self-Efficacy**

**Introduction**

Dear Participant,

My name is Angelos Kassianos and I am doing my PhD at the University of Surrey (Department of Psychology). This Information Sheet will give you a rough idea of what the study entails.

I would like to invite you to take part in a research project. Before you decide you need to understand why the research is being done and what it will involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

**What is the purpose of the study?**

This study seeks to investigate whether changes in dietary behaviour affect people who are diagnosed with prostate cancer’ Quality of Life and whether Control and Self-efficacy can predict these changes after diagnosis and therapy.

**Why have I been invited to take part in the study?**

Because you have been at some time in the past diagnosed with prostate cancer and can contribute to the better understanding of the processes that people with prostate cancer face after diagnosis and after therapy.

**Do I have to take part?**

No, you do not have to participate. There will be no adverse consequences in terms of your: care or treatment if you decide not to participate ....You can withdraw at any time without giving a reason...

**What will happen to me if I take part?**

You will be asked to complete a questionnaire which will take up to 20 minutes just once.

**What will I have to do?**

If you would like to take part please complete the attached questionnaire.
What are the possible disadvantages or risks of taking part?

Some of the questions that you will be asked to respond to are sensitive. If you feel emotionally upset then you can withdraw without giving any reason for doing so. In this case you will be referred to your GP.

What are the possible benefits of taking part?

It is unlikely that you will not benefit directly but it is hoped that you will contribute in understanding what predicts dietary behaviour changes after prostate cancer diagnosis and therapy and also to investigate whether adhering to these changes affect Quality of Life.

What happens when the research study stops?

At the end of the questionnaire you will be able to request a copy of the study’s results by providing your email address. It is difficult to say but these should be ready in 6-8 months.

What if there is a problem?

Any complaint or concern about any aspect of the way you have been dealt with during the course of the study will be addressed; please contact Angelos Kassianos Co-Investigator on a.kassianos@surrey.ac.uk – 001483 686892

Will my taking part in the study be kept confidential?

Yes. All of the information you give will be anonymised so that those reading reports from the research will not know who has contributed to it.

Data will be stored securely in accordance with the Data Protection Act 1998.

Contact details of researcher and, where appropriate supervisor?

Angelos Kassianos – Department of Psychology, University of Surrey, Guildford, GU2 7XZ, UK

Who is organising and funding the research?

None

Who has reviewed the project?

The study has been reviewed and received a favourable opinion from the University of Surrey Ethics Committee.

Thank you for taking the time to read this Information Sheet.
<table>
<thead>
<tr>
<th>How can I complete the questionnaire?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The survey can be completed online using this link: <a href="http://www.fahs.surrey.ac.uk/survey/dietary_changes/">http://www.fahs.surrey.ac.uk/survey/dietary_changes/</a></td>
</tr>
</tbody>
</table>
Consent Form

**Dietary Changes after the diagnosis of Prostate Cancer: the Role of Control and the effect on Health-Related Quality of Life and Self-Efficacy.**

I the undersigned voluntarily agree to take part in the study on ………………..

- I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

- I agree to comply with any instruction given to me during the study and to co-operate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.

- I consent to my personal data, as outlined in the accompanying information sheet, being used for this study and other research. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of volunteer (BLOCK CAPITALS) ........................................................
Signed ........................................................................................................
Date ...........................................................................................................

Name of researcher/person taking consent (BLOCK CAPITALS) ........................................................
Signed ........................................................................................................
Date ...........................................................................................................
Appendix IX: Questionnaire (Chapter 7)

This study investigates whether changes in diet after prostate cancer diagnosis affect Health-Related Quality of Life and whether self-control is a predictor of these changes. Please complete the following questionnaire which will take approximately 15 minutes providing us with information on you, the diagnosis of prostate cancer and possible changes you made on your diet after being diagnosed.

Please answer ALL questions by ticking the appropriate box.

Date of completion:
27. How old are you?

28. Are you currently?
☐ Married/ Living as married
☐ Living with another adult(s)
☐ Single/living alone

29. What is the highest level of education you have completed?
☐ No formal schooling
☐ Less than primary school
☐ Primary school completed
☐ Secondary school [OR job-related qualifications (e.g. apprenticeship) completed]
☐ Tertiary education such as college/university completed
☐ Post-graduate degree completed

30. What is your employment status?

*If working*

Full-time paid work (30+ hours per week)
Part-time paid work (8-29 hours per week)
Part-time paid work (under 8 hours per week)
Not working

*If not working*
Still at school □
In full time higher education □
Unemployed (seeking work) □
Not in paid employment (not seeking work) □

31. What is the current treatment status of your prostate cancer?
□ Under Treatment
□ In complete remission
□ Recurrent

32. At what age were you diagnosed with prostate cancer?

33. Which of the following treatments have you had for your prostate cancer?
□ Surgery
□ Radiation therapy
□ Chemotherapy

8. To what extent has your diet changed after being diagnosed?
□ Not at all □ Quite a bit □ No change □ A lot □ Extremely

9. After diagnosis I have made the following changes in my weekly diet, the amount of the following I consume is:

fruits
very much less □ quite a bit less □ a little less □ the same □ a little more □ quite a bit more □ very much more □

vegetables
very much less □ quite a bit less □ a little less □ the same □ a little more □ quite a bit more □ very much more □

red meat
very much less □ quite a bit less □ a little less □ the same □ a little more □ quite a bit more □ very much more □

dairy products
very much less □ quite a bit less □ a little less □ the same □ a little more □ quite a bit more □ very much more □

alcohol
very much less □ quite a bit less □ a little less □ the same □ a little more □ quite a bit more □ very much more □
10. To what extent has your diet changed after therapy has started?

- Not at all
- Quite a bit
- No change
- A lot
- Extremely

11. After therapy has started I have made the following changes in my weekly diet, the amount of the following I consume is:

<table>
<thead>
<tr>
<th>Category</th>
<th>Very Much Less</th>
<th>Quite a Bit Less</th>
<th>A Little Less</th>
<th>The Same</th>
<th>A Little More</th>
<th>Quite a Bit More</th>
<th>Very Much More</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vegetables</td>
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<tr>
<td>Red Meat</td>
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<tr>
<td>Dairy Products</td>
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<tr>
<td>Alcohol</td>
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<td>Sweets</td>
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<td>Fish</td>
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</table>

Now you will then find a series of questions, the questions make use of rating scales with boxes: please select the box that best describes your opinion. Please tick only one box for each question. Please make sure that you answer every item and that you tick only one box per item. This is a measure of you personal beliefs and there are no right or wrong answers.

12. I can always manage to solve difficult problems if I try hard enough.

13. If someone opposes me, I can find the means and
ways to get what I want.

14 It is easy for me to stick to my aims and accomplish my goals.

15 I am confident that I could deal efficiently with unexpected events.

16 Thanks to my resourcefulness, I know how to handle unforeseen situations.

17 I can solve most problems if I invest the necessary effort.

18 I can remain calm when facing difficulties because I can rely on my coping abilities.

19 When I am confronted with a problem, I can usually find several solutions.

20 If I am in trouble, I can usually think of a solution.

21 I can usually handle whatever comes my way.

22 If my cancer worsens, it is my own behavior which determines how soon I will feel better again.

23 As to my cancer, what will be will be.

24 If I see my doctor regularly, I am less likely to have problems with my cancer.

25 Most things that affect my cancer happen to me by chance.

26 Whenever my cancer worsens, I should consult a medically trained professional.

27 I am directly responsible for my cancer getting better or worse.
28. Other people play a big role in whether my cancer improves, stays the same, or gets worse.

29. Whatever goes wrong with my cancer is my own fault.

30. Luck plays a big part in determining how my cancer improves.

31. In order for my cancer to improve, it is up to other people to see that the right things happen.

32. Whatever improvement occurs with my cancer is largely a matter of good fortune.

33. The main thing which affects my cancer is what I myself do.

34. I deserve the credit when my cancer improves and the blame when it gets worse.

35. Following doctor’s orders to the letter is the best way to keep my cancer from getting any worse.

36. If my cancer worsens, it’s a matter of fate.

37. If I am lucky, my cancer will get better.

38. If my cancer takes a turn for the worse, it is because I have not been taking proper care of myself.

39. The type of help I receive from other people determines how soon my cancer improves.

40. i. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?
ii. Do you have any trouble taking a long walk?

iii. Do you have any trouble taking a short walk outside of the house?

iv. Do you need to stay in bed or a chair during the day?

v. Do you need help with eating, dressing, washing yourself or using the toilet?

During the past week:

vi. Were you limited in doing either your work or other daily activities?

vii. Were you limited in pursuing your hobbies or other leisure time activities?

viii. Were you short of breath?

ix. Have you had pain?

x. Did you need to rest?

xi. Have you had trouble sleeping?

xii. Have you felt weak?

xiii. Have you lacked appetite?

xiv. Have you felt nauseated?

xv. Have you vomited?

xvi. Have you been constipated?

During the past week:

xvii. Have you had diarrhoea?
xviii. Were you tired?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xix. Did pain interfere with your daily activities?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xx. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxi. Did you feel tense?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxii. Did you worry?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxiii. Did you feel irritable?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxiv. Did you feel depressed?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxv. Have you had difficulty remembering things?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxvi. Has your physical condition or medical treatment interfered with your family life?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxvii. Has your physical condition or medical treatment interfered with your social activities?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

xxviii. Has your physical condition or medical treatment caused you financial difficulties?  
   • not at all  
   • a little  
   • quite a bit  
   • very much

41. How would you rate your overall health during the past week?  
   • Very poor  
   • Excellent

42. How would you rate your overall quality of life during the past week?  
   • Very poor  
   • Excellent

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

**During the past week**

43. i. Have you had to urinate frequently **during the day**?  
   • not at all  
   • a little  
   • quite a bit  
   • very much
ii. Have you had to urinate frequently **at night**?

iii. When you felt the urge to pass urine, did you have to hurry to get to the toilet?

iv. Was it difficult for you to get enough sleep, because you needed to get up frequently at night to urinate

v. Have you had difficulty going out of the house because you needed to be close to a toilet?

vi. Have you had any unintentional release (leakage) of urine?

vii. Did you have pain when you urinated?

viii. Answer this question only if you wear an incontinence aid. Has wearing an incontinence aid been a problem for you?

ix. Have your daily activities been limited by your urinary problems?

x. Have your daily activities been limited by your bowel problems?

xi. Have you had any unintentional release (leakage) of stools?

xii. Have you had blood in your stools?

xiii. Did you have a bloated feeling in your abdomen?

xiv. Did you have hot flushes?

xv. Have you had sore or enlarged nipples or breasts?

xvi. Have you had swelling in your legs or ankles?

**During the last 4 weeks...**

xvii. Has weight **loss** been a problem for you?

xviii. Has weight **gain** been a problem for you?
xix. Have you felt less masculine as a result of your illness or treatment?

xx. To what extent were you interested in sex?

xxi. To what extent were you sexually active (with or without intercourse)?

---

**PLEASE ANSWER THE NEXT FOUR QUESTIONS ONLY IF YOU HAVE BEEN SEXUALLY ACTIVE OVER THE LAST 4 WEEKS**

44. i. To what extent was sex enjoyable for you?

   | not at all | a little | quite a bit | very much |
---|-----------|---------|------------|----------|

   ii. Did you have difficulty getting or maintaining an erection?

   | not at all | a little | quite a bit | very much |
---|-----------|---------|------------|----------|

   iii. Did you have ejaculation problems (eg dry ejaculation)?

   | not at all | a little | quite a bit | very much |
---|-----------|---------|------------|----------|

   iv. Have you felt uncomfortable about being sexually intimate?

   | not at all | a little | quite a bit | very much |
---|-----------|---------|------------|----------|

I would like to receive a copy of the study’s results by email and thus I provide my email address:

If there were to be further related studies I would be interested in participating. My contact details are

Name:
Phone number:
Email:
Address:

Thank you for your participation! If you have any queries please contact Angelos Kassianos at: a.kassianos@surrey.ac.uk
Appendix X: Consent Form and Information Sheet for Participants
(Chapter 8)

INFORMATION SHEET

A qualitative study into mechanisms of dietary change among people with prostate cancer Information for Participants

Thank you for completing the on-line questionnaire and expressing an interest in taking part in a follow up interview.

We are now inviting you to take part in this interview study. The interview will take about 30 minutes, and will be conducted by telephone. You will be asked about what you eat, how you decide what to eat, any changes in your dietary habits since you were diagnosed with prostate cancer, and how you view your diet in general. Taking part in the study will give you the opportunity to think and talk about your dietary habits before and after cancer diagnosis. There is a small risk that discussing your cancer diagnosis could cause you distress, and if this happens the interview can be stopped. At the end of the interview we will send you a factsheet about diet and prostate cancer.

Before you decide whether or not to participate please read this information sheet carefully. When you understand the study, and if you wish to participate, please print and sign the consent form and send it back to the research team. A researcher will then contact you to arrange a convenient time to conduct the interview.

We would like to record the interview, and subsequently type up what is said, to ensure we have an accurate account. We will ask you if you are willing for the interview to be recorded when we arrange the interview appointment. Prior to the start of the interview you will be asked again to confirm you are willing for the conversation to be recorded. You are free to ask for your interview not to be recorded, and the interviewer will instead take notes of the
conversation. Any interview recordings will be transcribed. Tapes, transcriptions or notes will be securely stored in locked cabinets or password-protected computers for 10 years after the which the data will be deleted and shredded. Data will be accessible only to members of the research group. All participants' data will be identified only by a unique identification number and kept strictly confidential.

Please be aware that you do not have to take part in this study, and if you decide not to proceed, your care or treatment will not be affected in any way. If you do decide to take part, you can stop the interview and withdraw from this study at any time and you will not be asked to give a reason.

The study has been reviewed and given a favourable ethical opinion by the University of Surrey Ethics Committee. It is important to understand the study before you agree to take part, and so if you have any questions please feel free to contact us at our study's email address: a.kassianos@surrey.ac.uk, or by phone on 01483 686892 (Angelos Kassianos)

If you would like to receive a summary of the findings of this study, please let us know, and we will send you this when the analysis is complete.

Research group members:

Mr Angelos Kassianos: 01483 686892; a.kassianos@surrey.ac.uk

Dr. Monique Raats: 0118-9500281, m.raats@surrey.ac.uk

Food, Consumer Behaviour and Health Research Centre, Dept of Psychology, University of Surrey, Guildford. GU2 7XH
CONSENT FORM

A qualitative study into mechanisms of dietary change among people with prostate cancer

If you would like to take part in this research study, please print and sign this consent form and return it to the research team as a scanned document, or as hard copy, using the contact details below

Consent Form

I, the undersigned, voluntarily agree to take part in the study on mechanisms of dietary change among people with prostate cancer:

- I have read and understood the Information Sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort and possible ill-effects on my health and well-being which may result. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

- I agree to comply with any instruction given to me during the study and to cooperate fully with the investigators. I shall inform them immediately if I suffer any deterioration of any kind in my health or well-being, or experience any unexpected or unusual symptoms.

- I consent to my personal data, as outlined in the accompanying information sheet, being used for this study and other research. I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

- I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice.

- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

- I am providing my telephone number below for the purposes of this research study, and I understand that the research team will not give this number to any other parties for any other purpose.
Name of volunteer (BLOCK CAPITALS) ........................................................
Signed ........................................................................................................
Date .........................................................................................................

Telephone number at which I can be contacted for the purposes of this research study: ........................................................................................................

Name of researcher/person taking consent (BLOCK CAPITALS) ........................................................
Signed ........................................................................................................
Date .........................................................................................................

Research group members:
Mr Angelos Kassianos: 01483 686892; a.kassianos@surrey.ac.uk

Dr. Monique Raats: 0118-9500281, m.raats@surrey.ac.uk

Dr. Heather Gage: 01483 686948; h.gage@surrey.ac.uk

Food, Consumer Behaviour and Health Research Centre, 
Dept of Psychology, 
University of Surrey, 
Guildford. GU2 7XH
Appendix XI: Interview Schedule (Chapter 8)

Introduction: Thank you for agreeing to take part in this interview – I am going to ask you a number of questions about what you eat and how you choose what to eat. The whole interview will take about 30 minutes.

Before we start the interview, I want to confirm whether or not you are willing for our conversation to be tape recorded. If you agree to me recording the interview, I will be typing up what we say to help me to analyse your responses. If you would prefer that I did not record the interview, I will take notes instead. Either way, your name will not be reported.

Are you willing to have our conversation recorded?

<table>
<thead>
<tr>
<th>Question</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Would you describe yesterday as a typical day in terms of what you ate? If yes please could you tell me what you ate yesterday including snacks etc.</td>
<td>• Explore general eating pattern, • Types of foods e.g. milk…’would that be semi-skimmed, soya?</td>
</tr>
<tr>
<td>2 People decide what to eat in a variety of ways – how do you decide what foods to eat (not eat)?</td>
<td>• Explore reasons, vegetarian, religion, health, and influence of family members</td>
</tr>
<tr>
<td>3 Have you changed your eating habits since you were diagnosed with prostate cancer?</td>
<td>• Explore reasons • Explore changes</td>
</tr>
<tr>
<td>4 Are there any foods you feel you should eat more of?</td>
<td>• Prompt for which foods, • Explore reasons for choosing that particular food/foods • Whether any action to eat more has been taken, now or in the past</td>
</tr>
<tr>
<td>5 Are there any foods you feel you should eat less of?</td>
<td>• Prompt for which foods, • Explore reasons for choosing that particular food/foods • Whether any action to eat more has been taken, now or in the past</td>
</tr>
<tr>
<td>6 How would you define a healthy/unhealthy diet?</td>
<td></td>
</tr>
<tr>
<td>7 Would you say that your diet was healthy?</td>
<td>• Explore why diet is considered to be healthy/less healthy</td>
</tr>
<tr>
<td>8 Where do you get advice on healthy eating?</td>
<td>• Which sources of healthy eating advice would you feel confident about?</td>
</tr>
<tr>
<td>9 If needed: We’ve talked a lot about different sorts of food, I’d now like to ask you specifically about foods containing lycopene.</td>
<td>• Do you make an effort to eat more food containing lycopene (i.e. tomatoes)? • Why? Is it related to cancer diagnosis? What do they know about advantages/disadvantages of lycopene? Where did they get this information?]</td>
</tr>
<tr>
<td>10 Is there anything, which has come to mind during this conversation, which you’d like to add, or anything else you’d like to say?</td>
<td></td>
</tr>
</tbody>
</table>