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Portfolio of Doctorate in Health Psychology

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For the qualification of Professional Doctorate in Health Psychology

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TABLE OF CONTENTS

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Section C: PUBLICATIONS

ACKNOWLEDGEMENTS

DECLARATION

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EDITORIAL STYLE

The contents of this doctoral portfolio will use the editorial style of the American Psychological Association (APA) as outlined in the Publication Manual of the American Psychological Association (6th Edition).

ABBREVIATIONS

APA	American Psychological Society
BMI	Body Mass Index
CAM	Complementary Alternative Medicine
CBT	Cognitive Behavioural Therapy
CNMR	Centre for Nurse and Midwife led Research
CNS	Clinical Nurse Specialist
CPD	Continued Professional Development
DH	Department of Health
DHP	Division of Health Psychology
EHPS	European Health Psychology Society
GP	General Practitioner
HCPC	Health and Care Professions Council
HNA	Holistic Needs Assessment
IRAS	Integrated Research Application System
LTC	Long-Term Condition
MSIS	Macmillan Support and Information Service
NHS	National Health Service
MBSR	Mindfulness-based Stress Reduction
NICE	The National Institute for Health and Clinical Excellence
QOL	Quality of Life
SES	Socio Economic Status
TTM	Transtheoretical Model
UCH	University College Hospital
UCLH	University College London Hospitals
UK	United Kingdom
US	United States
WHO	World Health Organization

INDEX OF TABLES

INDEX OF FIGURES

PUBLICATIONS AND CONFERENCE CONTRIBUTIONS

Clarence-Smith, B., & Robson, E. (2017, February). An evaluation of yoga classes for cancer patients at UCH Macmillan Cancer Centre. Poster session presented at the meeting of the Centre for Nursing and Midwife Led Research annual conference, London.

Plant, H., Riley, V., Cowan-Dickie, S., Robson, E., & Carballo, L. (2016, November). *Evaluation of a service that integrates supportive cancer care into routine clinical practice.* Poster session presented at the meeting of the European Oncology Nursing Society, Dublin.

Robson, E. (2017, Spring Edition). Presenting research for the first time at the 2016 EHPS/DHP joint annual conference. *Health Psychology Update, 26*(1), 39-40.

Robson, E., & Corcoran, P. (2016, August). *An exploration into parental awareness of sugar consumption in children's diets.* Paper presented at the meeting of the joint European Health Psychology Society and Division of Health Psychology annual conference, Aberdeen.

Robson, E., & Turnbull, T. (2017, September). *The effectiveness of mindfulness-based interventions for adults with recurring chronic headaches and migraine: a systematic review.* Paper presented at the meeting of the Division of Health Psychology annual conference, Cardiff.

Robson, E., Plant, H., Carballo, L., & Riley, V. (2016, November). *Kindness: making an impact on patient experience.* Poster session presented at the meeting of University College London Hospitals cancer division 2016 educational event, London.

Robson, E., Riley, V., French, W., & Clarence-Smith, B. (2017, February). *An evaluation of the creative writing group for people affected by cancer.* Poster session presented at the meeting of the Centre for Nursing and Midwife Led Research annual conference, London.

Waters, R., Eedy, B., Wilson, B., Riley, V., & Robson, E. (2016, March). *Understanding cancer patients' perceptions and attitudes towards groups.* Poster session presented at the meeting of the Centre for Nursing and Midwife Led Research annual conference, London.

SECTION A: PREFACE

Applying Health Psychology to a clinical setting: Making an impact on patient experience

Introduction

This portfolio of work submitted for the Professional Doctorate in Health Psychology Training Programme was completed whilst undertaking two years' supervised practice as a trainee health psychologist at University College Hospital (UCH), Macmillan Support and Information Service (MSIS). The hospital is part of University College London Hospitals (UCLH) National Health Service (NHS) Foundation Trust. Professional competencies and research within this portfolio follow an overarching theme of psycho-oncology, with a specialised emphasis on supportive care for people living with and beyond a cancer diagnosis. However, sub-themes covering several other health psychology related topics are also evident throughout this portfolio of work. This ensures that the portfolio is multi-dimensional and reflective of the breadth of work covered during the previous two years of training. It also demonstrates an ability to practice as a well-rounded health psychologist and researcher. Sub-topics covered throughout this portfolio include:

- Self-management (research)
- Alternative therapies for managing pain (research)
- Holistic support (research)
- Neurological disorders (research)
- Children's health (publishable paper 1)
- Digital health (consultancy)
- Dietary and food-related behaviours (behaviour change intervention)
- Cancer screening and risk perception (teaching)
- Careers in health psychology (teaching)
- Communication skills in cancer care (training).

Throughout my patient-facing role at UCH MSIS I had to continually think of new ways to utilise and adapt my academic background into innovate ideas that had the potential to positively contribute towards excellent patient experience at UCH. It was also highly important to adhere to the British Psychological Society (BPS) and Health and Care Professions Council (HCPC) ethical codes of conduct, during my training

placement. Continually practicing as an ethical trainee health psychologist ensured that the research and professional competencies were properly and ethically conducted. It was also equally important to abide by the trust's core values during my training placement. Core values included *'kindness, safety, teamwork and improving'*.

Research Thesis

The main research element of this portfolio presents an original and unique qualitative study that focuses on holistic support for people living with and beyond a cancer diagnosis. The research specifically explores holistic support in the form of wellbeing groups, including yoga and creative writing for people affected by cancer. The focus of the study evolved as the trainee position at UCH MSIS was defined and established within a multidisciplinary team of healthcare professionals. The research reflects the valuable and specialised work that is carried out each day at the flagship supportive cancer care service at UCH. It also represents and amalgamates two years' worth of dedicated study, observations, and interactions and engagement with healthcare professionals and those affected by cancer.

As the research focus developed and ethical approval was sought, the data collection phase of the study commenced. Participants were recruited from UCH MSIS based on their regular attendance at a UCH MSIS facilitated wellbeing group. The study aimed to understand why people living with and beyond cancer continued to attend wellbeing groups within clinical settings, even after their cancer treatment had ended. It also set out to explore patients' attitudes, experiences and perceived impact of regularly attending a wellbeing group. In total, 20 participants took part in the study by taking part in a focus group, individual face-to-face interview or individual telephone interview. The researcher employed a semi-structured interview schedule and later inductively analysed the data using thematic analysis. As a result, three key themes and 9 sub-themes were identified. All emerging themes were presented alongside diagrammatic images and relevant participant quotations in order to support the researcher's interpretations and analysis of the data. Upon completion of the study, the research findings will be disseminated appropriately to relevant audiences via publication and presentation at academic and professional conferences.

Publications

Two publishable papers featured within this portfolio of work focus on two different aspects of health psychology. Firstly, publishable paper one titled *'A qualitative study exploring mothers' views on sugar and hidden sugar in their children's diets'*, explores children's health in relation to their sugar consumption. The paper aimed to add more knowledge and understanding to the topical and relevant research area. The research qualitatively analysed mothers' views and level of awareness regarding how much sugar their child regularly consumed. The research was prepared for publication to *Appetite* journal and if successful, will reach a vast audience. This will ensure that findings make an impact on members of the public, policy makers and researchers. Future research could perhaps build on the findings already identified, in order to produce a more in-depth understanding of the research question.

Secondly, publishable paper two titled *'The effectiveness of mindfulness techniques for adults with recurring chronic headaches and migraines: A systematic review'*, was amended from the original systematic review produced for the purposes of this doctoral portfolio. Upon completion of the original systematic review competency, the review was modified into a manuscript for publication. The review was tailored to author guidelines, as outlined by the *Mindfulness* journal. The review will contribute to already existing literature and help raise awareness of alternative therapies for the management of chronic pain and long-term conditions.

Finally, published paper three presents a short event review titled *'Presenting research for the first time at the 2016 EHPS/DHP joint annual conference'*. The aim of this article was to review and reflect upon the experience of attending and presenting at a large-scale conference. It was also intended to encourage and inspire readers, particularly students or early career researchers, to submit and showcase their work at future conferences. The peer-reviewed article was published in the 2017 spring edition of Health Psychology Update, which was available to all subscribed members of the Division of Health Psychology (DHP) and could be accessed online.

Professional Practice

Consultancy

The consultancy case study outlined a project that was completed in response to a request from the cancer division's high-level management team at University College London Hospitals NHS Foundation Trust. The proposed task consisted of a literature search and findings being subsequently presented at a hospital trust management meeting known as a *'service board meeting'*. The aim of the report was to support the funding application and development of a larger scale digital health project. The proposed project consisted of an online education programme for cancer patients to use at home, as a self-management tool to support routine care and on-going recovery. The aim of the requested literature review was to support the notion of self-management among people directly affected by cancer. The review also aimed to highlight the benefits of implementing digital technologies within healthcare services. In addition to this, the report identified other international healthcare providers that had similar online patient-centred programmes already in place. Once completed, the literature review was presented verbally to healthcare professionals, for their feedback and funding approval. In the final stage of the consultancy project, a six-month follow-up evaluation form was created and completed by the client, which identified the positive impact, which the work had made.

Behaviour Change Intervention

The health-related behaviour change intervention targeted cancer patients who had experienced some form of dietary or eating related side effects as a result of their cancer treatment. Three diet workshops were planned alongside a specialist dietitian and delivered within UCH MSIS. Workshops included: (1) Dietary information: facts and myths, (2) Managing your weight after treatment, and (3) Symptom management and building yourself up (with taster demonstration). Patients were encouraged to attend whichever workshop(s) they felt were most suitable to their individual needs. Promotional materials were created and workshop details were distributed accordingly throughout the hospital, including online platforms such as Twitter, the hospital website and across all visible patient screens. Patients that attended were asked to complete a pre- and post-evaluation form, which rated confidence and motivational levels. The workshops were generally well attended by both patients and

family members, and evaluation feedback forms identified positive improvements among both motivation and confidence measures.

Teaching and Training

The first two case studies present two separate teaching sessions, which were conducted with different population types; haematology patients and postgraduate students. The first teaching case study was delivered at a monthly support group for people affected by a red cell condition. I was invited as a guest speaker to the opening hour of the support group meeting where the talk primarily focused on how health psychology can be embedded into routine supportive cancer care. The teaching session was received well by support group members and prompted high level discussion that continued into the second hour.

The second case study highlights two interlinked sessions that were delivered to health psychology master's students; a three-hour lecture and a short careers teaching session. The lecture titled '*Impact of cancer screening*' was outlined at length for the purposes of the case study. The aim of the lecture was to highlight the psychosocial impact of cancer screening. The session was delivered using a combination of presentation slides, videos and group activities, in order to engage students. Both teaching sessions were delivered confidently and evaluated well.

Case study three highlights a training workshop, which was conducted to 27 allied health care professionals, at University College London Hospitals NHS Foundation Trust. The workshop was part of a two-day training course on communication skills. The aim of the training workshop was to build on healthcare professionals existing communication skills, particularly focusing on the importance of good communication in cancer care services. The workshop consisted of theoretical knowledge, practical tips, interactive group tasks, videos and open discussion of patient case studies. The training session was delivered successfully to those who attended. As a relatively inexperienced educator and trainee health psychologist, the experience also strengthened my presentation and communication skills, and increased my confidence to share and deliver information to qualified health professionals.

Systematic Review

The systematic review was conducted separately from the main research study, in an attempt to broaden the scope of this portfolio. Headache and migraine disorders are common and can cause debilitating pain if left untreated. Due to increasing financial pressures on health care services and the publics' growing awareness for alternative treatments, it was decided that both headache pain and alternative behavioural therapies would be interlinked and presented in the form of a systematic review research question. The aim of the review was to identify and assess the effectiveness of mindfulness techniques for adults managing recurring chronic headaches and migraines. Several electronic databases were searched and results were carefully reviewed based on an inclusion, exclusion and quality criteria. Results identified that mindfulness did tend to show positive outcomes in three key aspects of headache and migraine pain: (1) severity, (2) frequency, and (3) quality of life (QOL). Although all elements showed improvements when mindfulness techniques were applied, only frequency and QOL highlighted statistically significant change. The review concluded that more in-depth and rigorous randomised control trials were warranted, in order to explore the research question further. It also found that more work was needed to raise awareness about the efficacy and benefits of alternative therapies, amongst both members of the public and medical communities.

SECTION B: RESEARCH

Taking a holistic approach to supportive cancer care: A qualitative study exploring patients' experiences and perceived impact of attending a wellbeing group

Abstract

Introduction: Physical and psychosocial support is essential for people living with and beyond cancer. An increase in cancer survival rates has prompted a greater need for widely accessible patient-centred support services that integrate self-management techniques alongside routine care. Wellbeing groups, such as yoga therapy and creative writing, could improve QOL, enhance self-esteem and empower patients to make confident treatment decisions.

Aims: (1) To understand why people living with and beyond cancer attend groups, (2) explore patients' experiences and attitudes towards wellbeing groups, and (3) identify the perceived impact that attending a group may have.

Method: A qualitative design using semi-structured interviews was employed (n=20). Participants were recruited via an NHS Cancer Centre in Central London. All participants had received a cancer diagnosis and had participated in at least three group wellbeing sessions (yoga and/or creative writing). Transcripts were analysed using an inductive approach to thematic analysis.

Results: Upon completion of data analysis, 3 key themes and 9 sub-themes were established: (1) Identity, perception and reflection, (2) Feeling lost after cancer treatment ends, and (3) Always accepted, never judged.

Discussion: Generally, participants reported positively on their experiences of attending a wellbeing group with many suggesting that it had enhanced their patient experience. Groups fulfil the social needs of cancer patients who seek face-to-face interactions with others who have shared similar experiences. People also crave a sense of belonging and safety after cancer treatment ends, which may explain why many patients continue to attend groups based in clinical settings.

Conclusion: Further research should explore holistic cancer support further in order to raise awareness among health professionals and ensure that those living with and beyond cancer are being offered suitable psychosocial support that is right for them.

Chapter 1 – Introduction

1.1 Overview

Throughout this body of work an in-depth exploration into the importance and value of supportive care for people living with and beyond a cancer diagnosis will be sought. Prior to highlighting the present study's chosen methodology, results and detailed discussion, a thorough overview of literature to support the study's topic area will be identified and presented. This will provide the reader with a clear rationale for why a study in this area is needed. The second chapter will discuss the management of long-term conditions, which will offer the reader more insight into the notions of survivorship and living well beyond cancer. The third chapter will then move further into the idea of holistic care for cancer patients, focusing specifically on person-centred care and supported self-management. This chapter will provide the reader with a clear definition of the term *'holistic care'* and the significance of its meaning in relation to patient experience. Within Chapter four the concept of groups, specifically within clinical care settings will be explored in detail. Embedded within this chapter will also be published literature that focuses heavily on both yoga therapy and creative writing groups, respectively, for people who have been affected by cancer. Finally, the fifth chapter will provide a brief research overview, which will present study aims and the epistemological stance that was adopted throughout the research process.

1.2 Rationale for present study

Two key reasons provided a rationale for new and innovative research to be conducted in the field of psycho-oncology: (1) A gap within the literature, and (2) a rising number of people living beyond a cancer diagnosis with a consequently increased need for appropriate and accessible support services.

Firstly, existing research in this area has mostly focused on one individual form of group intervention, such as yoga therapy (Archer, Phillips, Montague, Bali, & Sowter, 2015; Cramer et al., 2016; McCall, Thorne, Ward, & Heneghan, 2015; Milbury et al.,

2015), walking (Chen, Tsai, Wu, Lin, & Lin, 2015; Fischer et al., 2015) or art (Bozcuk et al., 2017; Heiney, Darr-Hope, Meriwether, & Adams, 2017). Previous research has also typically focused on only one population type per study. For example, breast cancer patients (Fischer et al., 2015), lung cancer patients (Chen et al., 2015; Milbury et al., 2015) or colorectal cancer patients (Cramer et al., 2016). There is also very limited evidence, which highlights the impact of wellbeing groups, as most previous research in this area has focused heavily on support groups; the emphasis has usually been placed on the supportive element rather than the group construct itself (Giese-Davis et al., 2016; Grande, Arnott, Brundle, & Pilling, 2014). It is also perhaps worth noting that several papers published in this area have been conducted outside of the United Kingdom (UK); mostly in the United States (US) or Canada.

Secondly, as the number of newly diagnosed cancer cases continues to increase, whilst mortality rates in England steadily decrease (Office for National Statistics, 2017), patients diagnosed with cancer are now living longer than ever before. Many people living beyond a cancer diagnosis will have long-term side-effects from their cancer treatment and some may also be experiencing additional health problems unrelated to their cancer (Macmillan Cancer Support, 2016). This suggests that there is a growing need for integrated support services for people living with and beyond a cancer diagnosis.

Finally, research findings from the present study will assist readers in their understanding of holistic cancer support and the potential benefits that can emerge when people affected by cancer attend supportive wellbeing groups. Therefore, considering all of the above, it was assumed that a new and novel research study would add significant value to this important aspect of supportive cancer care.

Chapter 2 - Managing cancer as a long-term condition

2.1 Overview

Within this chapter an overview of long-term conditions, and the associated implications, will be documented. Current UK cancer statistics will also be presented and an overview of how these compare to international cancer incidence, mortality and survivorship rates will be outlined. The physical, psychological and social impact of cancer, and treatment for cancer, will also be detailed at length within this chapter. The chapter will then explore survivorship and how cancer patients can be supported to live well beyond cancer.

2.2 Defining long-term conditions

The term *'long-term condition'* (LTC) is defined as *"a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies"* (Department of Health (DH), 2012). Cancer is categorised under this term alongside a range of other health conditions such as diabetes, hypertension and asthma (DH, 2012). Reportedly around 15 million people in England have a LTC, with older aged people and those from deprived backgrounds being the most affected (DH, 2012). The UK population are continuing to live longer than ever before (Government Office for Science, 2016) which imposes a number of new and complex challenges for the twenty first century NHS to deal with (House of Commons Health Committee, 2014). As future research is conducted and new services are developed, it is vital to consider these current challenges and work towards finding an effective solution. This in turn will better support patients with LTCs and improve the overall standard of care and support that is delivered in the UK.

Currently, those with a LTC account for approximately 50% of general practitioner (GP) appointments (DH, 2012), and 70% of the health and social care costs are reportedly spent on treating and caring for those with a LTC (DH, 2010). Therefore, in order for LTCs to be successfully controlled and managed it is essential that health care systems are effectively adapted to meet such rapid changes in demand

(Government Office for Science, 2016). Developing interventions that prevent and manage chronic conditions, in addition to also providing individuals with the tools to take more responsibility for their own health (Government Office for Science, 2016), could potentially offer an effective solution for managing an ageing population and a consequently increased number of people with LTCs, such as cancer.

2.3 Cancer prevalence and mortality rates

A recent forecast for the UK predicted that one in two people are expected to receive a diagnosis of cancer at some point during their lifetime (Ahmad, Ormiston-Smith, & Sasieni, 2015). In 2016, there were 303,135 recorded cancer cases in the UK (Office for national Statistics, 2018). As Figure 1 shows, cancer incidence rates in England have significantly increased in both males and females since 1995 (Office for National Statistics, 2017). Although this figure is set to rise further, other research has positively found that survival rates have improved over the last 40 years, with 50% of people now diagnosed with cancer expected to survive their disease for at least ten years or more (Quaresma, Coleman, & Rachet, 2015). As figure 2 shows, mortality rates have visibly decreased, in males and females, since 1995 compared to 2015 (Office for National Statistics, 2017). This means that more people than ever before will be living with or beyond cancer in the UK.

Cancer in the UK currently affects a slightly higher proportion of men than women (Office for National Statistics, 2018), with those over the age of 65 years accounting for 65.2% of the total cancer cases recorded in 2015 (Office for National Statistics, 2017). There is also a notable correlation between old age and likelihood of death due to cancer. In contrast, recorded cancer incidences among children, teenagers and young adults (0-24 years) are much lower at 1.1% of all recorded cases (Office for National Statistics, 2017). The most common cancer types in 2015 and 2016 were breast, prostate, lung and colorectal, which together account for just over half of all recorded cancer incidences in England (Office for National Statistics, 2018). Breast cancer was the most common among women, whilst prostate cancer was recorded as the most common for men (Office for National Statistics, 2017).

In relation to European cancer incidence rates, the UK and Denmark are among the few European countries with the reportedly lowest cancer survival rates (Baili et al., 2015). Internationally, cancer has been named as the leading cause of disease worldwide with approximately 14.1 million new cancer cases reported in 2012 and around 8.2 million deaths associated with the disease in the same year (World Health Organization (WHO), 2012). It is also understood that the gap between the best performing countries (Australia, Canada and Sweden) and the worst performing countries (England, Northern Ireland, Wales and Denmark) remains significantly large with minimum sign of any notable improvements (Coleman et al., 2011). This raises significant concern and highlights a further need to improve cancer care services in the UK, both clinical and supportive, through investment in good quality research and education.

Cancer incidence rates 1995-2015
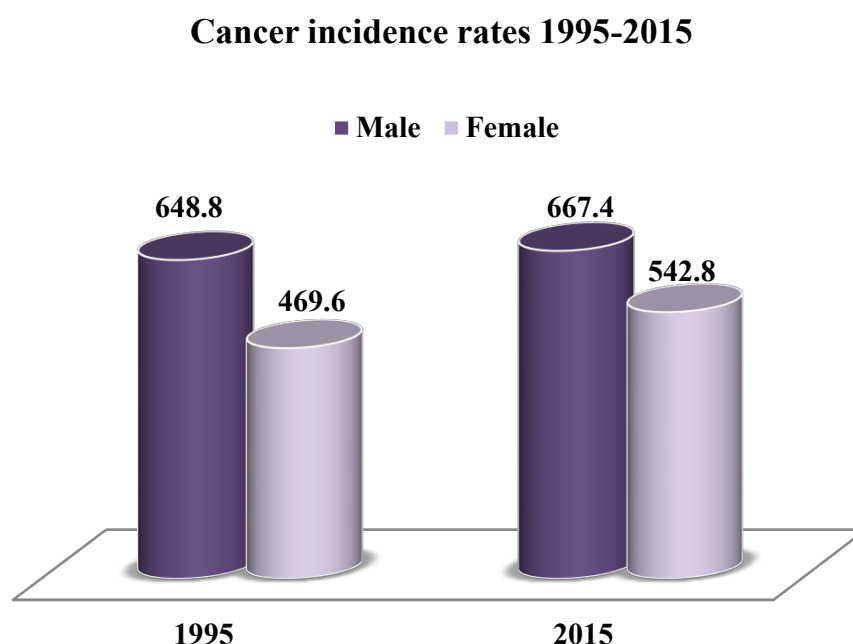
Figure 1. Cancer incidence rates (per 100,000 cases) in England for males and females from 1995 to 2015 (Office for National Statistics, 2017)

Cancer mortality rates 1995-2015

■ Male ■ Female

427.8

268.4

329.5

226.6
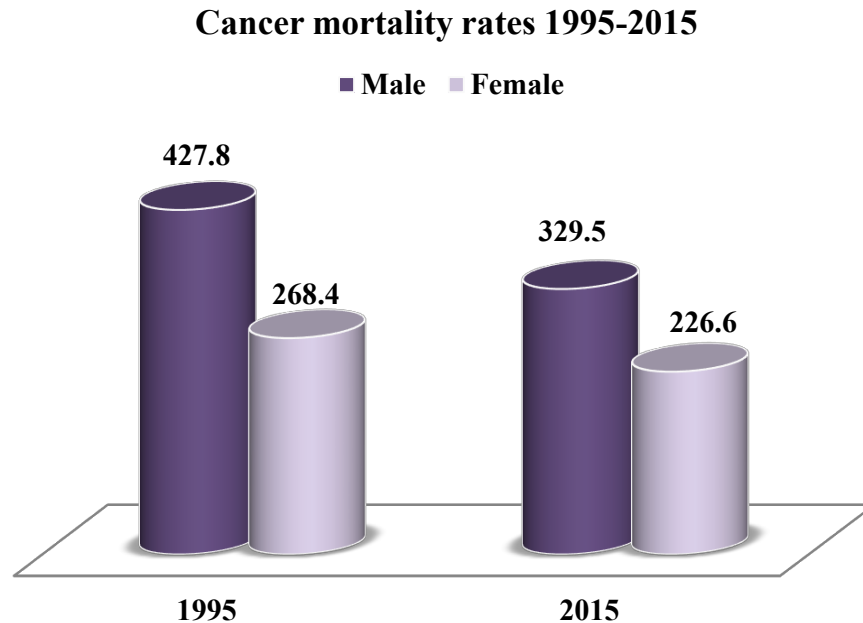
1995

2015

Figure 2. Cancer mortality rates (per 100,000 cases) in England for males and females from 1995 to 2015 (Office for National Statistics, 2017)

2.4 Physical and psychosocial impact of cancer

Receiving a diagnosis of cancer is a significant life event and one that presents itself with several physical, psychological and social challenges for patients to manage, in addition to dealing with the cancer diagnosis itself. Physical symptoms and side effects can begin to emerge at an early stage of a cancer pathway. These can start from symptoms that help identify the cancer itself, through to side effects that develop as a result of intrusive biopsy procedures. For example, in men at risk of being diagnosed with prostate cancer – the most common cancer in males and the third most common cancer in the UK after lung and bowel (Office for National Statistics, 2016) – the process of being tested for a potential prostate problem (e.g. cancer, prostatitis or benign prostate hyperplasia) can cause physical, and sometimes psychological implications for the patient. This is because testing for cancer can produce inaccurate results, especially in cancer types that currently have no national screening programme in place. Therefore, tests can sometimes lead to ambiguity and in some cases, falsely diagnosis patients due to inaccuracies in the testing methods. Research has found that false-positive test results in older men who have been screened for

prostate cancer can, in some instances, reduce the likelihood of men returning for a screening test again in the future (Ford, Havstad, Demers, & Johnson, 2005). Other more recent research, has similarly concluded that women screened for breast cancer were less likely to return for future mammogram tests, if they received a false positive test result compared with a true negative result (Shen, Winget, & Yuan, 2017).

At the point of biopsy; extracting a sample of tissue to test for potential malignant cells, the procedure can be invasive and also has the potential to produce inaccurate results. Research has found that at the point of biopsy, men being tested for a possible diagnosis of prostate cancer can experience increased levels of distress (Macefield et al., 2010). Feelings of depression and anxiety can then also rise when those diagnosed with cancer enter the pre-treatment stage of their cancer journey (Watts el al., 2014). Therefore, for those who experience initial biopsy surgery and post-surgery recovery, they are also challenged with the emotional impact of potentially receiving a cancer diagnosis; causing concern about how cancer may affect themselves and their families in the short- and long-term. Because of this, it is highly important to support and help patients manage the emotional and physical impact of cancer, right from the point of testing, through to treatment and beyond.

Many common side effects of cancer treatment, including nausea, hair loss and fatigue, are mostly expected and managed effectively by the patient themselves alongside their medical team. This can be achieved with medication or specialist products (e.g. anti-sickness medicine for nausea and wigs for hair loss), and appropriate support and advice from health professionals when necessary. The physical impact of cancer treatment and cancer-related surgery, affects every person differently and the severity of impact is often determined by pre-existing factors such as body weight (Amri, Bordeianou, Liliana, Sylla, & Berger, 2014). Side effects of treatment, including cognitive impairment, memory loss and concentration difficulties have been closely associated with emotional distress, fatigue and reduced QOL (Wagland, Richardson, Armes, Hankins, Lennan, & Griffiths, 2015). Although some physical side effects of treatment can be expected and dealt with accordingly, the psychological impact of how patients emotionally deal with cancer is complex and largely heterogeneous between individuals. The psychosocial aspects of cancer

remain a challenge in terms of providing adequate and equal levels of support and information, at the right time, to all people affected by cancer.

Research has found that although the psychological impact of cancer can be highly challenging for patients (Galway et al., 2012), many health professionals are still reluctant to have open discussions with their patients regarding the emotional and psychological side effects of cancer (Bonito, Horowitz, McCorkle, & Chagpar, 2013; Taylor et al., 2011). A systematic review that aimed to assess the effects of psychological interventions on QOL and emotional wellbeing among newly diagnosed cancer patients, found that patients who were offered and accepted psychological support for the emotional impact of their cancer, had a better QOL and improved psychological distress, compared to those who did not receive support (Galway et al., 2012). The findings also highlighted the importance of referring and signposting patients to psychological services. In order for this to become best practice in clinical settings, more work needs to be conducted to raise the profile of psychological support among those in medical communities. However, the review conducted by Galway et al. (2012) was unable to draw firm conclusions and highlight any statistically significant changes in terms of anxiety and depression, which suggests that more long-term studies exploring the impact of psychological interventions for people living with and beyond cancer is warranted.

Patients living with and beyond cancer also experience a number of social issues and concerns that can negatively and significantly impact their lives and relationships with others. Findings from a study that explored the psychological impact of cancer on families highlighted the important role that relatives and carers play in helping to support people with cancer, and how relationships can be challenged by depression and anxiety, during times of difficulty and illness (Edwards & Clarke, 2004). There is also a number of employment and financial issues when a person is diagnosed with cancer. A study found that cancer negatively affected work status and annual earnings by approximately 10% (Jeon, 2017), whilst other findings highlighted that 50% of young adults in full-time employment reportedly experiences problems within the workplace after being diagnosed with cancer (Parsons et al., 2012). Education and relationships with peers may also be negatively affected as a result of cancer, particularly for children, teenagers and young adults (Warner et al., 2016).

A population-based study that compared family members of cancer patients to an age and sex matched control group, found that family caregivers were less likely to be employed, had significantly higher levels of stress and were at an increased risk of experiencing depressive symptoms compared to those in the control group (Lim, Kim, & Lee, 2013). Caring for a person with cancer was also considered to be a highly distressing role (Balfe et al., 2016), which reportedly did not reduce even after prolonged lengths of time (Balfe et al., 2016; Halkett et al., 2017). Therefore, in order to effectively support people living well beyond cancer, it is essential that supportive care services fulfil the needs of every individual affected by cancer, including family members and carers. These potential problems can be effectively managed, if the correct support services are offered at the correct time. However, it is known that many of these services are not always being utilised by those who need the support, and as a consequence of this, many patients are living with unmet psychosocial needs (Okediji, Salako, & Fatiregun, 2017). This means that many individuals are left under supported and unable to resolve their social concerns or worries. Therefore, it is fundamental to investigate and identify gaps in clinical and supportive care provision for people living with and beyond cancer, to ensure that all patients, irrespective of age or socio-economic status, are receiving the support that fulfils their physical and psychosocial needs.

2.5 Survivorship and living well beyond cancer

As the number of people living beyond a cancer diagnosis steadily increases (Office for National Statistics, 2017), the need for supportive care services for those who require long-term support is equally rising. Research has shown that the post-treatment stage is not always a positive experience for all individuals affected by cancer. If treatment is unsuccessful and palliative care for the patient is required, patients can experience feelings of denial that their illness may be incurable (Ghandourh, 2016). However, if treatment is successful and patients enter a remission stage, rather than experiencing feelings of relief or happiness, patients can instead feel overwhelming sadness, loneliness and loss of confidence after their treatment ends (Foster & Fenlon, 2011; Foster et al., 2015). It can be particularly difficult for patients

to return to normality, without feeling burdened by cancer-related worry or fear of recurrence (Costanzo et al., 2007). It is also understood that those living beyond a cancer diagnosis have a range of unmet emotional and physical needs (Allen, Savadatti, & Levy, 2009; Burg et al., 2015; Khan, Evans, & Rose, 2011) and thus feel unable to cope with the transition from treatment back to their normal lives (Baker et al., 2016).

There are currently around two million people in the UK living beyond cancer (Maddams, Utley, & Møller, 2012), many of who are also managing other long-term conditions such as high blood pressure, obesity and cardiovascular disease (Macmillan Cancer Support, 2015). After cancer treatment ends the majority of people will return to normal functioning and live their lives relatively symptom-free; however, for others cancer can have a long-term impact, which causes a range of physical and psychological problems (Stein, Syrjala, & Andrykowski, 2008). For example, research has shown that men living beyond prostate cancer commonly experience problems relating to urinary and bowel functioning (Mols et al., 2009), whilst head and neck cancer patients reportedly experience long-term taste dysfunction (Mclaughlin, 2013) and breast cancer patients frequently report problems relating to sexual functioning and body image (Boquiren et al., 2016). Research has also found that adult survivors of childhood cancer are particularly prone to developing long-term negative side effects, which have been caused directly by their early experiences of cancer and treatment for cancer (Jacobs & Pucci, 2013). Therefore, it is essential that appropriate services and interventions are maintained to the same standard of care, which is received during tests and treatment for cancer. Support must also be available and offered at the correct time, in order to effectively support people living beyond cancer who are in long-term recovery.

In line with the *'National Cancer Survivorship Initiative'* (DH, Macmillan Cancer Support, & NHS Improvement, 2010), the development and implementation of the *'Recovery Package'* was introduced nationally across the UK. The *'Recovery Package'* presents a tailored set of actions that aims to fulfil the individual needs of those who are directly affected by cancer (DH et al., 2010; Independent Cancer Task force, 2015; NHS, 2016). Together patients and healthcare professionals work through the package in order to effectively assess patients' holistic needs and ensure

that treatment plans are carefully considered through a process of shared decision-making (DH et al., 2010; Independent Cancer Task force, 2015; NHS, 2016). Attendance at '*Health and Wellbeing Events'* are also similarly encouraged as they allow care to continue once treatment has ended and ensures that GPs remain connected with the recovery process of each individual patient (DH et al., 2010; Independent Cancer Task force, 2015; NHS, 2016; NHS England, 2016). The latest National Cancer Survivorship Initiative titled *'Living With and Beyond Cancer: Taking Action to Improve Outcomes'* (DH, Macmillan Cancer Support, & NHS Improvement, 2013) reported that the post-treatment *'Recovery Package'* was potentially the most fundamental element required for achieving good cancer outcomes, in addition to promoting healthy lifestyles and independence amongst those living beyond cancer (DH et al., 2013).

2.6 Summary

In order to manage cancer effectively, it is essential that supportive care is addressed in the same way that clinical care and treatment is addressed. As the number of people living beyond cancer continues to rise (Office for National Statistics, 2017) the need for accessible supportive care services is also mounting. Added pressures within the NHS, such as workforce shortages and restricted budgets (de Silva, 2011), contribute towards the difficulty in developing and implementing adequate solutions. As research suggests that the transition from *'patient to survivor'* can be a difficult and challenging time (Allen et al., 2009), it is therefore essential that the high standards of support received during treatment continues post-treatment and beyond into long-term recovery. This will ensure that each individual patient experiences positive outcomes of care such as improved self-efficacy, QOL and a feeling of empowerment (McCorkle et al., 2011).

Chapter 3 - Holistic cancer support

3.1 Overview

Chapter three will explore the concept of holistic care for patients and how it can be integrated into both routine clinical practice and cancer support services. Subsections of this chapter will explore the impact of holistic care on patient experience and what it means to support and identify the patient as a *'whole'* person. The chapter will also explore how self-management techniques can be used in order to implement a patient centred approach to healthcare delivery.

3.2 The meaning of holistic care in relation to cancer

The term *'holistic'* or otherwise known as *'holism'* is associated with the notion of identifying and treating an individual as a whole person, rather than disconnected parts (Johns, 2012). In a concept analysis, the term *'holistic care'* was defined as a "*provision of care to patients that is based on a mutual understanding of their physical, psychological, emotional, and spiritual dimensions…with a view to achieving harmony that transcends physical wellness*" (Jasemi, Valizadeh, Zamanzadeh, & Keogh, 2017). Holism also encompasses lived experiences of healthcare and considers the meanings associated with health and illness (Margereson & Trenoweth, 2010).

Results of a study that explored holism in cancer care, reported that the use of holistic principles had positive outcomes when applied to cancer settings and could significantly benefit patients in terms of QOL and general wellbeing (Blignault et al., 2014). In the UK, the concept of holistic care was featured within the *'National Cancer Survivorship Initiative'* (DH et al., 2010), which identified and suggested five key shifts that would improve the care and support for those living with and beyond cancer in the UK. In a later edition of the report it stated that healthcare providers were required to conduct '*Holistic Needs Assessments*' (HNA) on a routine basis, as part of a move towards patient-centred care (DH et al., 2013). HNA is a process conducted in collaboration with both the patient and the healthcare professional, which requires a method of collecting and discussing information, in order to develop

a mutual understanding of what the person affected by cancer understands and needs (Macmillan Cancer Support, 2014). Although research into the long-term impact of HNA on cancer patients' post-treatment recovery is still minimal, the implementation of HNA is believed to rebuild patients' confidence, self-identity and general wellbeing following treatment (Foster & Fenlon, 2011).

3.3 Self-management and person-centred care

The term *'self-management'* describes an act of patient empowerment, whereby those living with and beyond a cancer diagnosis are encouraged to take more responsibility for the medical, emotional, physical and spiritual elements of their condition (Davies & Batehup, 2010; McCorkle et al., 2011). Self-management is a long-term process that should be accompanied alongside on-going clinical assessment, support and treatment (Davies & Batehup, 2010; The Kings Fund, 2012). Adopting self-management techniques is believed to significantly help cancer patients return to normal life processes and usual levels of general wellbeing after their treatment for cancer ends (Henshall, Greenfield, & Gale, 2017). According to the '*National Cancer Survivorship Initiative'* (DH et al., 2010), four key aspects are essential for successfully promoting self-management: (1) information and education appropriate to suit the needs of the individual, (2) key contacts for cancer and non-cancer related care and support, both in and out of hours, (3) efficient and reliable processes for re-accessing the system, and (4) effective remote monitoring as appropriate.

It is believed that healthcare services will be positively impacted in the future if cultural attitudes can shift towards a more person centred and self-management approach (de Silva, 2011). It is believed that taking a new approach would have a positive impact on financial pressures, population increases and workforce shortages (de Silva, 2011). However, it is also important to remember that self-management should be integrated alongside clinical care rather than used as an alternative to traditional face-to-face interventions. The patient-professional relationship should still remain at the forefront of patient care, especially in cancer services where overall patient experience is fundamental (National Institute for Health and Clinical Excellence (NICE), 2004). When self-management techniques are used in addition to routine cancer care, communication between patient and professional is enhanced

(Dorflinger, Kerns, & Auerbach, 2013), patients feel more involved with treatment decisions (McCorkle et al., 2011) and general wellbeing and self-esteem improves (Braden, Mishel, & Longman, 1998).

There are a number of ways in which self-managed support can be delivered directly to patients. The rise in twenty first century technology and the accessibility of online information is gaining increasingly popular amongst patients seeking higher levels of engagement with their treatment options (Ferguson & Frydman, 2004). These new cohorts of service users are known as '*e-patients*' (Ferguson & Frydman, 2004; Richards, Coulter, & Wicks, 2015). Research has shown that health related information is one of the most frequently sought topics on the Internet (McMullan, 2006), with information communication technology quickly becoming a first point of contact for *'e-patients'* seeking health information straight away (Dedding, van Doorn, Winkler, & Reis, 2011; McMullan, 2006). The transparency of health information available online can significantly improve patients' understanding of diagnosis and enhance levels of self-efficacy when it comes to making informed treatment decisions (McMullan, 2006). Utilization of the internet can also provide patients with the relevant tools to feel well informed, knowledgeable and motivated to care for themselves (Dedding et al., 2011; de Silva, 2011). However, health information can cause problems if quality standards are not maintained, and the information provided is not based on reliable or up-to-date evidence. Patient information, particularly when presented online, can cause further issues if the information contains medical jargon or hard to understand terminology. Therefore, patients should feel supported by clinicians in their quest to interpret and understand health information, regardless of their background or literacy levels (The Kings Fund, 2010).

Using digital technologies to promote and encourage self-management among people living with and beyond cancer has identified a number of positive outcomes for the patient. In an experimental study that evaluated the feasibility and acceptability of a multimedia self-management intervention titled '*Preparing for Lung Surgery'*, it was concluded that the intervention did result in significantly improved QOL amongst both patients and caregivers (Sun et al., 2017). The study also found that the intervention was effective in enhancing patient self-efficacy, surgery-related

knowledge and overall satisfaction with the intervention itself (Sun et al., 2017). Likewise, in a similar study that tested the feasibility and acceptability of an intervention for breast cancer patients titled *'Managing Cancer Care: A Personal Guide',* results found that after patients had completed the seven-module intervention their knowledge for care options increased and levels of anxiety and depression reportedly decreased (Schulman-Green & Jeon, 2015).

However, as research has positively shown that self-management based interventions can be effective at heightening QOL and improving knowledge among patients, other studies have found that digital support interventions are not effective at alleviating cancer-related pain (Koller, Miaskowski, De Geest, Opitz, & Spichiger, 2013). Therefore, a self-management approach to cancer care should be used collaboratively between the patient and their medical team, to ensure that the best support is being offered to the person affected by cancer (Payne, 2016). Improving communication between patient and clinician would ensure that patients do not become overly dependent on post-treatment support services, but instead feel fully empowered and motivated to manage their condition independently themselves (Richards et al., 2015). This would reduce pressures on the NHS and empower patients as they move through their cancer care pathway.

3.4 Impact on patient experience

According to the *'National Cancer Survivorship Initiative'* (DH et al., 2010), an innovative and far-reaching approach to support services is required in order to improve cancer patients' experiences and outcomes of care. For patients to feel empowered and motivated to take control of their health it is vital that adequate support, which suits the individual needs of each patient, is available and readily accessible at the appropriate time (DH et al., 2010). It is believed that cancer patients who receive good quality information and feel supported throughout their treatment are more likely to positively assess their overall care experience (Macmillan Cancer Support, 2012) and feel more engaged with healthcare services in the future (de Silva, 2011). Other recommendations for improving patients' experiences of cancer care include: (1) offering key information at significant points throughout the patient pathway, (2) providing support for effective self-care and self-management, and (3)

involving patients in service development wherever possible (Coulter, 2007). In addition to this, '*The Cavendish Review*' (2013) highlighted the importance of high quality standardised care for all, in order for every patient to have access to a positive and equal healthcare experience.

Research that explored the impact of cancer support and information services found that patients' experience of care was positively affected as a result of their engagement with supportive health care professionals (Boltong, Ledwick, Babb, Sutton, & Ugalde, 2017). The qualitative results identified that patients experienced less worry, fear and burden as a result of receiving reassurance, normalisation and having their individual needs fulfilled (Boltong et al., 2017). A further qualitative study into patients' experiences of cancer support found that having information that demystified the system, realistically managed their expectations and delivered patient-centred care, were all contributing factors essential for positive patient experience (Gotlib Conn, Hammond Mobilio, Rotstein, & Blacker, 2016). Other research similarly identified that poor patient experience occurred when health care professionals were unable to offer information about diagnosis or treatment to patients and their caregivers (Piazza et al., 2017). The findings reported that a lack of reassurance and interpersonal skills contributed towards dissatisfaction amongst patients and their family members (Piazza et al., 2017).

According to Macmillan Cancer Support (2013), patients perceive *'good'* patient experience as one where they feel fully supported, respected and actively involved in all aspects of their care decisions, from diagnosis and beyond. A review identifying links between patient experience and clinical safety found that patient experience was positively associated with treatment adherence, engagement with informative resources, and overall improvements in health outcomes (Doyle, Lennox, & Bell, 2013). Latest results from the *'National Cancer Patient Experience Survey'* (Quality Health, 2016), which was initiated in 2010 to monitor UK national progress and prompt local improvements, highlighted several positive outcomes. Using a scale of zero (very poor) to 10 (very good) on the survey, respondents gave an average score of 8.7 when asked to rate their overall experience of cancer care in the UK (Quality Health, 2016). This positive outcome, which also showed visible improvement

compared to previous years, was reassuring for people affected by cancer and also healthcare professionals working within the field of cancer care.

However, making a positive impact on patients' experience of cancer care does not always require such complex initiatives or interventions. Sometimes the simplest changes can make the most meaningful impact. Integrating the basic act of kindness into routine care is believed to provide fundamental value to the way patients are cared for and supported (Jones, 2010). A study that explored patients' experiences of cancer care in Wales, found that patients regarded personal qualities such as kindness, empathy and respect amongst NHS staff as being significant aspects that contribute towards their overall experience of cancer care (Bracher, Corner, & Wagland, 2016).

"Invoking kindness may not be the whole answer, but avoiding unkindness would certainly be a start" (Jones, 2010).

3.5 Summary

Encouraging patients to self-manage their condition and take more responsibility for their own general health is believed to have beneficial outcomes for both the patient and the healthcare providers (de Silva, 2011). In times of significant pressure and uncertainty for the NHS, shifting attitudes and actively promoting patient-centred care will make meaningful differences to patients' experiences of healthcare and potential relieve some of the healthcare pressures. It has already been identified through published research that patients' QOL and levels of self-efficacy will increase, as their supportive needs are fulfilled and they have more involvement with their care and treatment decisions (Piazza et al., 2017).

Chapter 4 – Support and wellbeing groups

4.1 Overview

The following chapter will mainly focus on wellbeing groups within supportive cancer care settings. The principles of supportive cancer care and the difference they make to people affected by cancer will be discussed. A distinction between group support and individual support will also be explored at length within this chapter. In addition to this, the various methods of delivery and facilitation of such supportive groups will be reviewed. The focus will then shift towards yoga therapy and creative writing, respectively, which are the two key groups in which recruitment for the present study took place. An overview of the two wellbeing activities will be presented generally, followed by an overview of both programmes delivered at University College Hospital (UCH), Macmillan Support and Information Service (MSIS). The aim of these subsections will be to understand how each group works independently to provide a level of therapeutic support for cancer patients who attend.

4.2 Supportive cancer care

Feeling supported and cared for, psychologically and socially, is fundamental to a person's health, their overall cancer experience and should be delivered to the same extent and quality as clinical support and care (Luigi, David, & Michelle, 2017). The idea and definition of support will vary from person-to-person, as this is often determined by individual need and personal circumstance. Supportive cancer care services are rising in terms of the breadth of services offered and awareness of their importance among health professionals and patients. A reduction in stigma around mental health, may also have contributed to peoples' willingness to seek and engage with cancer support services. However, hard-to-reach patient groups and inequality in the availability and accessibility of services across the UK, are still causes for concern and key reasons why many people with cancer are living with unmet psychosocial needs (Okediji et al., 2017). Research has found that low-educated and un-married men, who do not live in a city, are less likely to access psychological support services for their cancer, than well-educated women who live in urban areas (Nekolaichuk,

Cumming, Turner, Yushchyshyn, & Sela, 2011). Therefore, more work needs to be done to ensure that all people affected by cancer are equally offered appropriate support that is right for them. Funding for such services is one of the main barriers that prevents this from happening, however a lack of knowledge and poor awareness among medical professionals may also mean that patients are not being referred or signposted to services that could be available to them.

Peer support can be delivered in several ways, including cancer type specific support groups, online communities and through attending a health and wellbeing event. People directly affected by cancer, who engage with group intervention programmes, have been shown to experience less depressive symptoms than those who do not participate (Schofield et al., 2016). Results from a study that explored the long-term psychological benefits of women with breast cancer that attended a cognitive-behavioural stress management group, found that those who attended reported lower depressive symptoms and better QOL, compared to the control group up to 15 years later (Stagl et al., 2015). Similarly, a systematic review that aimed to assess the effects of psychosocial interventions on QOL and psychological distress, 12 months after an initial cancer diagnosis, found that psychoeducational and nurse-delivered interventions did highlight a small, yet significant change in the QOL of patients who participated (Galway et al., 2012). Other similar research reported that people affected by cancer attended therapist-led groups to express their true feelings (Giese-Davis et al., 2016) and to experience emotional relief and a sense of wellbeing (Hoeck, Ledderer, & Ploug Hansen, 2017).

Health professional-led groups have also been found to have beneficial outcomes in terms of overall survival, up to ten years following participation within a group support programme (Oh, Shin, Ahn, & Kim, 2016). However, it is believed that more psychosocial research in this area needs to be conducted, in order to gain better understanding of the effects of treatments on survival outcomes (Oh et al., 2016). Other research has similarly identified that talking to a trained professional, such as a psychologist or counsellor, about worries or concerns can positively impact a person's ability to manage and deal with their cancer diagnosis and treatment (Banks, Pearce, French, Lloyd, & Lewis, 2017; Matthews, Glackin, Hughes, & Rogers, 2014). In a meta-analytic study that aimed to investigate uptake and adherence to psychological

interventions, among cancer patients experiencing distress, results found that patients were more likely to participate if the intervention was delivered by a nursing professional (Brebach, Sharpe, Costa, Rhodes, & Butow, 2016). However, more research which evaluates how psychological support delivered by trained professionals can be effective at helping patients manage the emotional impact of cancer, is still needed. In turn, this will contribute to long-term recovery and help patients feel supported as they attempt to return back to everyday life after cancer.

Support groups, both online and in-person, offer people affected by cancer with a safe, informal and confidential place to disclose worries, concerns and fears, as well as share and exchange experiences and advice on topics of their choice (Owen, Goldstein, Lee, Breen, & Rowland, 2007). They also provide emotional and social support to those who attend (Owen et al., 2007). An abundance of research, mostly qualitative, has explored the benefits of attending such supportive group interventions. The findings are overwhelmingly positive and mostly highlight beneficial outcomes for patients, however, QOL and mood are two outcomes that have been unable to show any statistically significant change in much of the research (Huber, Muck, Maatz, Keck, Enders, Maatouk, & Ihrig, 2018; Owen, O'Carroll Bantum, Pagano, & Stanton, 2017). This could be due to a lack of long-term, large scale studies and randomised control trials in this area of cancer care, which means that psychological and practical support for patients remain largely over shadowed by clinical cancer treatments.

Patients frequently report feelings of isolation and loneliness when cancer treatment comes to an end. Research focusing on the post-treatment stage of the patient pathway identified how social support services, such as cancer specific support groups, can be effective in enhancing self-efficacy, helping patients cope better, and improving emotional health (Brunelli, Murphy, & Athanasou, 2016; Lee & Suh, 2018; Ramchand et al., 2017). Support groups, particularly in-person group meetings, are believed to create a sense of togetherness and a feeling of a being part of a community (Hoeck et al., 2017). Psychosocial interventions have also shown to be cost-effective for improving health-related QOL, mood and pain, when compared with usual care (Dieng, Cust, Kasparian, Mann, & Morton, 2016). Support groups also offer patients a safe environment where discussions can be held with people who understand and

share similar non-judgemental attitudes about cancer (Hoeck et al., 2017; Owen et al., 2007). Other support interventions that can help patients manage the psychosocial consequences of diagnosis and treatment include group sessions that focus on goal setting and positive thinking; semi-formal education sessions intended to inform and educate patients; and wellbeing sessions involving physical activity, creativity or holism principles. Findings from a study that identified the effects of an education and peer support intervention for women with breast cancer, found that a peer support intervention predicted more life purpose and less depressive symptoms in the short-term among women with breast cancer (Mens, Helgeson, Lembersky, Baum, & Scheier, 2016). This demonstrates further how fundamental psychosocial interventions can be for people living with and beyond cancer.

4.3 Wellbeing group versus individual support

The term *'wellbeing'* has several definitions and interpretations due to the complexity of its meaning (Dodge, Daly, Huyton, & Sanders, 2012). However, The Oxford English Dictionary (2017) describes the term *'wellbeing'* as *"the state of being comfortable, healthy, or happy"*. Therefore, the fundamental aim of wellbeing groups should be to promote happiness and health, in comfortable surroundings for every person who attends. Wellbeing sessions can include yoga therapy, art therapy, creative writing and forms of more rigorous physical activity such as walking, gardening or dance.

The differences between group support and individual one-to-one support are vast. Group constructs, specifically those in clinical based settings, have a range of additional elements that add value for those who attend. Firstly, the social dynamics of a group where people are enabled to meet others and form a sense of togetherness has been identified as a fundamental aspect of group cohesion. Research has found that yoga therapy delivered in a group setting provides a feeling of safety and shared understanding amongst those who engage with the activity (Mackenzie, Wurz, Yamauchi, Pires, & Culos-Reed, 2016). In addition to this, a qualitative study exploring gynaecological cancer patients' experiences of participating in a group yoga programme also found that having a sense of community with other people similar to

themselves was an important element of why they attended the group (Archer, Phillips et al., 2015).

Secondly, as financial pressures on health care services grow and the need for support services rise, delivering supportive care interventions within group settings rather than individually could potentially provide an effective solution to this particular problem. Delivering group wellbeing sessions to cancer patients requires less financial output, as facilitators would have access to more patients at each given time. Groups may also minimize the burden on financial pressures by improving other aspects of patients' wellbeing and overall health, which may therefore mean that there is a lesser need for further clinical input or access to health services in the future. In research that has focused on creative based group sessions, study findings have revealed that being in a group reduces reported levels of anxiety and depression, enhances QOL and general mood, and helps patients manage their illness more effectively themselves (Archer, Buxton, & Sheffield, 2015). In addition to this, the delivery of an art therapy group amongst cancer patients receiving chemotherapy treatment similarly found that patients experienced enhanced QOL and reduced levels of depression as a result of attending a group (Bozcuk et al., 2017).

4.4 Yoga therapy for people affected by cancer

According to Kabat-Zinn (2017), yoga can be *"extraordinarily uplifting, rejuvenating, invigorating, transporting, and just plain relaxing"* which can lead to *"greater strength, balance, and flexibility"* among those who participate. The practice of yoga, meaning *"to unite or join"* in Sanskrit, originates from India approximately 5,000 years ago, and has religious roots in Hinduism and Buddhism (Connolloy, 2007; Pandurangi, Keshavan, Ganapathy, & Gangadhar, 2017). The earliest images of yoga postures were imprinted in soapstone (Pandurangi et al., 2017; Singleton, 2010), which to this day remain popular and widely practiced throughout many cultures worldwide. Yoga is an exercise that involves more than just physical activity. The practice aims to incorporate all aspects of mind and body, together with a combination of physical postures, breathing exercises and meditation techniques (van Uden-Kraan, Chinapaw, Drossaert, Verdonck-de Leeuw, & Buffart, 2013).

Research has found that the use of complementary alternative medicines (CAM) has increased significantly over the past few decades, with almost half of cancer patients believed to have used CAM at some point during their experience with cancer (Horneber et al., 2012). It is understood that cancer patients opt to integrate CAM alongside their clinical care in order to boost immune system, relieve pain and cope with side-effects of treatment more effectively (Cramer, Cohen, Dobos, & Witt, 2013; Mansky & Wallerstedt, 2006). Forms of CAM that have shown positive therapeutic outcomes for cancer patients include acupuncture, hypnosis massage, music therapy and yoga therapy (Mansky & Wallerstedt, 2006). Many patients access yoga therapy groups during and after their cancer treatment ends, in order to help manage the physical and emotional impact of cancer (Sisk & Fonteyn, 2016). The delivery of yoga alongside routine clinical practice is understood to produce better health outcomes for patients than when traditional treatment is delivered alone (Jeter, Slutsky, Singh, & Khalsa, 2015).

Qualitative research into the impact of yoga on relationships found that the practice of yoga can result in personal transformation and increase levels of social interaction (Ross, Bevans, Friedmann, Williams, & Thomas, 2014). It can also help people cope more effectively with relationship losses, bereavement and interpersonal crises (Ross et al., 2014). In a qualitative study, which explored adult cancer patients' experiences of yoga, results found that stress associated with cancer treatment reduced as a result of practicing yoga (McCall, Thorne, Ward, & Heneghan, 2015). The study also reported that the social dynamics of group yoga were an important aspect to patients, and feelings of empowerment and levels of general self-awareness both increased as they took part in the group intervention (McCall et al., 2015). Similar positive outcomes were identified in a meta-analysis that explored the effects of yoga on the psychological health of cancer patients (Lin, Hu, Chang, Lin, & Tsauo, (2011). The analysis found that yoga groups showed significantly greater improvements in anxiety, depression and stress, when compared to a waitlist control group (Lin et al., 2011). However, the results of the review were based on a small number of studies that were rated as either fair or low quality by the researchers. Therefore, this suggests that further work is needed in order to understand the psychological impact of yoga on patients with cancer.

Furthermore, a randomised control trial investigating the effects of yoga therapy among breast cancer patients undergoing radiotherapy treatment, found that yoga had enhanced QOL, increased levels of physical functioning and reduced fatigue among the participant sample (Chandwani et al., 2014). A systematic review that explored the impact of yoga on cancer treatment-related side-effects concluded that participating in a yoga group showed statistically significant changes in overall QOL, depression, anxiety and gastrointestinal symptoms (Pan, Yang, Wang, Zhang, & Liang, 2017). The review also concluded that practicing yoga for longer than 3 months, had a positive effect on anxiety among people affected by cancer (Pan et al., 2017). Although this review highlighted positive outcomes for yoga and the management of treatment related side effects, the review only identified studies that had been conducted with women diagnosed with breast cancer, which means that the impact of yoga on male cancer patients has not been represented in this instance. Other research, which similarly employed all female samples, also found that yoga enhances QOL (Jun, Ke-hu, Jin-hui, & Chun-mei, 2012), improves emotional functioning (Côté & Daneault, 2012; Lotzke et al., 2016) and produces higher quality sleep patterns (Côté & Daneault, 2012). Yoga can also be valuable in helping patients achieve relaxation and perform daily tasks with ease and a restored sense of normality (Ülger & Yagli, 2010).

Patients also practice yoga to help manage the side effects associated with cancer and treatment for cancer. It has been reported that conventional cancer treatment, such as chemotherapy and radiotherapy, can lead to increased fatigue (Wang & Woodruff, 2015) and lack of motivation to carry out moderate to vigorous levels of physical activity (Kwan et al., 2012). Treatment can also result in muscle weakness (Brown, Winters-Stone, Lee, & Schmitz, 2012) and significant changes in body mass index (BMI) (Lønbro, Petersen, Andersen, & Johansen, 2015). This could consequently lead to further health implications in the future. Therefore, maintaining some level of physical activity is essential for those diagnosed with cancer. Research has found that reducing levels of sedentary behaviour by increasing physical activity during and after cancer treatment ends, can help alleviate treatment associated side effects (Albrecht & Taylor, 2012) and positively assist the recovery process post-treatment (van Zutphen et al., 2017; Wilhelmsson, Roos, Hagberg, Wengström, & Blomberg, 2017). Therefore, yoga delivered in clinical settings aimed specifically at people affected by

cancer offers a more relaxed and pleasant alternative to strenuous physical activity, which some patients may find too challenging or unmanageable.

In addition to the physical implications, research has shown that cancer treatment can also negatively impact cognitive capacity (Brown et al., 2012) and heighten depressive emotions such as anxiety and stress (Jim et al., 2011). Further research has identified '*chemotherapy brain*' as a recurring problem, which patients may experience at some point during their cancer experience (Hermelink, 2015; Jenkins et al., 2016). The practice of yoga may therefore encourage and support people to feel calmer and more relaxed, at times of uncertainty and high emotional instability. Learnt breathing techniques and gentle stretching exercises can be applied outside of dedicated classes for patients to utilise at times of need.

4.4.1 Overview of yoga programme at UCH MSIS

The group has been running at UCH MSIS on a weekly basis since 2013 and is facilitated by an experienced cancer nurse and registered yoga teacher. The group is only available for UCH patients (those with a registered hospital number) and booking is essential (due to limited space). Since beginning, the group has risen in popularity with a total number of 403 patients attending in 2016 compared to just 121 in 2013. Furthermore, patients are required to complete a detailed pre-assessment form before they join the yoga programme. The assessment identifies cancer type, any physical limitations, and the patients' main reasons for wanting to attend. Generally, breast cancer patients' uptake the majority of places within the group (28%); however other cancer types who regularly attend sessions at UCH MSIS include gynaecological (13%), lymphoma (11%), sarcoma (6%), head and neck (6%), myeloma (5%), prostate (5%), metastatic (5%), brain (4%) and other (17%). Reasons for attending, as identified in patient pre-assessment forms, generally highlight three main points: (1) to improve physical strength, (2) to relax and/or socialize with others, and (3) to help cope with cancer specific side-effects.

4.5 Creative writing for people affected by cancer

The Oxford English Dictionary (2017) defines the term '*creative writing*' as "*writing, typically fiction or poetry, which displays imagination or invention (often contrasted with academic or journalistic writing)*". The act of writing creatively is believed to have originated in Ancient Egypt and has developed as a cultural innovation throughout the years (Nettle, 2009). Writing allows the outpouring of thoughts and emotions, which may be an effective way of coping with several different long-term conditions, including cancer (Cordell & Poiani, 2014).

Reasons for writing creatively differs between individuals and the mechanisms behind the act have been debated and applied to a number of theories. One potential explanation derives from the emotional exposure theory, initially proposed by Foa and Kozak (1986). The theory implies that emotions are represented by information held within the memory, which prompts feelings of anxiety and danger when the information is disclosed (Foa & Kozak, 1986). Therefore, repeated confrontation and emotional upheaval can consequently lead to familiarisation and potential elimination of the emotions that have been associated with trauma (Foa & Kozak, 1986). This consequently reduces levels of anxiety and improves the ability to function normally (Sexton & Pennebaker, 2009). When the theory has previously been applied to other health conditions such as post-traumatic stress disorder, positive outcomes have also been reported (Stimmel, Cruise, Ford, & Weiss, 2014).

It has also been suggested that creative writing can help people recognise and self-regulate their emotions, which in turn provides greater self-control and the ability to cope more effectively with varying emotional states (Sexton & Pennebaker, 2009). In addition to this, it is believed that cognitive adaptation, otherwise known as the cognitive reframing theory, could also be a contributing factor towards why people participate in creative writing activities (Sexton & Pennebaker, 2009). The concept of cognitive reframing is centred on four key attributes: (1) sense of personal control, (2) altering or self-altering perceptions of negative, distorted, or self-defeating beliefs, (3) converting a negative, self-destructive idea into a positive supportive idea, and (4) the goal for cognitive reframing is to change behaviour and/or to improve wellbeing (Robson & Troutman-Jordan, 2014). Through participation with the above stages,

people will have the ability to cope better and make sense of traumatic life events more effectively (Sexton & Pennebaker, 2009).

The theories mentioned above are among many theoretical explanations that aim to unravel the deeper reasons and meanings behind people's attendance and participation in creative writing sessions; either within groups or independently. However, participation in creative writing tasks can also prompt change on a much more basic level. In a 2006 scheme titled *'Pen & Tonic',* the founders Bridget Shea and Tess Hudson from the North East of England used the term '*writing for health*' to describe a form of free writing (Penfold, 2010). It was suggested that employing creative writing techniques into daily interactions between healthcare professionals and patients could enhance communication and self-esteem (Penfold, 2010).

In support of these claims, research from a renowned cancer centre in the US found that an expressive writing intervention for cancer patients did have a positive impact on patients' ability to tolerate treatment, await results, cope with their illness and manage illness-related anxiety (Corner et al., 2015). Further research also found that expressive writing could improve wound (Koschwanez et al., 2013), boost the immune system (Lowe, 2006), and improve uptake to mental health services among distressed patients (Mosher et al., 2012). Other previous research has similarly found that writing can significantly improve QOL (Craft, Davis, & Paulson, 2013; Pok-Ja & Soo Hyun, 2016), enhance health and wellbeing (Lowe, 2006), and provide a safe space for patients to creatively express important issues (Bolton, 2008). However, despite mostly positive findings that support creative writing programmes for cancer patients, other research has shown less favourable outcomes. In a study that aimed to evaluate the effectiveness of express writing interventions for improving psychological and physical health among people living with and beyond cancer, results found that there was not a statistically significant improvement in neither psychological, nor QOL outcomes, among those who participated in the intervention (Zachariae & O'Toole, 2015). Furthermore, many health professionals from within the medical community have remained unconvinced, and largely unaware of the benefits of expressive writing interventions, which may indirectly influence patients' awareness and participation in such groups. However, Spiegel (1999) has strongly advocated and supported emotional expressive writing in cancer care and has

challenged any hesitant views by stating that health professionals should embrace creative writing in the same way as pharmaceutical interventions.

"It is not simply mind over matter, but it is clear that mind matters" (Spiegel, 1999).

4.5.1 Overview of creative writing programme at UCH MSIS

The creative writing group is one of the most popular groups at UCH MSIS, which began in 2012 when the UCH Macmillan Cancer Centre opened. Like yoga, attendance to the creative writing group has also increased, with a total number of 334 patients attending in 2016 compared to 239 people in 2015. The open-ended group runs on a weekly term-time basis and is co-facilitated by a volunteer (with a specialist background in writing) and a member of the UCH Macmillan Support and Information specialist team. The group is offered to any person affected by cancer (including relatives, friends and carers) and attendees do not need to book or complete an assessment prior to joining. In response to patient demand for more similar groups at the service, occasional one-off workshops (e.g. memoir journal writing) and daytrips (e.g. to local galleries) are organized throughout the year.

4.6 Summary

Attendance at wellbeing groups can enhance patients' QOL, provide an outlet for expression, and assist with long-term recovery after cancer treatment ends (Chandwani et al., 2014; Jun et al., 2012; Sexton & Pennebaker, 2009). Wellbeing groups, which often have a strong therapeutic feel, ensure patients feel cared for, understood and accepted, by similar people that have perhaps shared similar experiences (Bolton, 2008; Ross et al., 2014). Groups are also thought to be a more cost-effective method of delivering supportive cancer care at times of significant financial pressure. With more research and better promotion highlighting the benefits of wellbeing groups, people living with and beyond cancer will have increased opportunities to attend such sessions at all stages in their cancer pathway, in particular the post treatment stage when social support is often most needed.

Chapter 5 - Summary, aims and epistemological stance

5.1 Overview

The aim of this chapter is to provide the reader with a brief research overview and insight into what should be expected in the later chapters of this research study. Sub-sections will highlight the aims and the epistemological stance that was adopted by the researcher. The chapter will also identify the researcher's position in relation to this study and present a justification for the analytical method that was used – thematic analysis.

5.2 Research summary

The following research presents an in-depth qualitative study that aims to offer the reader a unique insight and understanding into a highly important aspect of cancer care that is often overlooked in favour of more clinical based interventions. By interviewing people living with and beyond a cancer diagnosis about their honest experiences and attitudes towards supportive wellbeing groups, it provides valuable and detailed results that an alternative survey or questionnaire based quantitative study would fail to achieve. The present study primarily explores the notion of a wellbeing group and why cancer patients continue to attend them within clinical settings, even after their treatment has ended. Groups included within the study were yoga and creative writing programmes. An inductive approach to thematic analysis (Braun & Clarke, 2006) was used to identify key and recurring themes throughout the research data. The study aims to add value to already published literature within the field of psycho-oncology and hopefully help shape the way people think about supportive cancer care services in the future.

5.3 Research aims

Three significant aims were identified: (1) to understand why people living with and beyond a cancer diagnosis attend groups, (2) explore patients' experiences and attitudes towards wellbeing groups and (3) identify the perceived impact that attending a group may have.

5.4 Epistemological stance and researcher position

Epistemology is a philosophical term that refers to the theoretical underpinning of knowledge and how the theory of knowledge can be applied to research in an attempt to make sense of the world (Willig, 2013). Thematic analysis, which is the approach used within the present study, is flexible and un-attached from theory or epistemology (Braun & Clarke, 2006; Willig, 2013). However, according to Braun and Clarke (2006), research epistemology can still be valuable and help guide how qualitative data is viewed and reported by the researcher. Therefore, it is understood that three key questions in relation to thematic analysis are essential in helping to determine the researcher's epistemological stance. These are: (1) what kind of knowledge does thematic analysis aim to produce, (2) what kind of assumptions can thematic analysis make about the world, and (3) how does it position the researcher? (Willig, 2013). Upon reflecting on these questions in relation to the present study, it seemed appropriate to position the researcher's epistemological stance as a mostly critical realist, with a phenomenological orientation.

Firstly, critical realism is a popular philosophical framework that is often used in social scientific research (Fletcher, 2017). The aim is to generate new knowledge that accurately captures and reflects something that is occurring within the real world (Willig, 2013). Applying a critical realist approach to the present study's data assumes that data requires careful interpretation (Willig, 2013), in order to develop in-depth understanding about motivation, experience, and meaning (Braun & Clarke, 2006). Secondly, regarding phenomenological orientation, the aim of this approach is to produce in-depth knowledge on the subjective experience of participants (Willig, 2013). In some aspects both approaches interconnect. However, a phenomenological approach to research focuses on the quality of participants' experiences, rather than initiating beliefs on the reasons behind thoughts, feelings and perceptions (Willig, 2013). Therefore, both approaches work well together and fit rightfully alongside the present study's aims and chosen methodology. The researcher's social position is also believed to influence what is seen and how information is perceived (May & Perry, 2014). This aspect also needs to be considered before research is conducted (Willig, 2013). Like thematic analysis, the researcher's position can also be flexible and free from restrictive frameworks (Willig, 2013). From a realist approach, the researcher is

required to dig deep in order to interpret more about the data (Willig, 2013). This is achieved when the researcher adopts the role of detective in order to uncover new information through use of their personal skills and experience (Willig, 2013). In the present study, the lead researcher held a professional role at the study's recruitment location for two-years and therefore had formed a good level of pre-existing knowledge about supportive cancer care. Although this could have had a potentially negative impact on data, in terms of skewed or bias results, it also had the possibility to add significant value and depth to research themes, and so therefore should be viewed positively as a research advantage.

With a good level of background knowledge, the researcher was also able to ensure that participants were asked relevant and provoking questions that provided valuable insight into the area in which new knowledge was being sought. In addition to this, a phenomenological approach also required that the researcher thought carefully about the data from a counselling point-of-view (Willig, 2013). The primary aim of the researcher in this instance was to listen empathetically without being restricted or influenced by external factors or feelings (Willing, 2013). This was achieved by ensuring that all data remained as grounded to participants' true responses as possible, whilst also maintaining the thorough interpretive element of realism. Both aspects were implemented alongside each other during the data collection phase, in order to form a strong, well-rounded researcher position.

5.5 Justification for selecting the thematic analysis approach

A number of other analytical approaches were considered prior to selecting thematic analysis for the present study. Other methods of analyses that were carefully considered included Interpretive Phonological Analysis (Smith, 1996) and Framework Analysis (Ritchie & Lewis, 2003). However, the appeal of flexibility and being free from pre-determined theoretical frameworks was the main justification for using thematic analysis above any other methodological approach.

Thematic analysis is a form of pattern recognition whereby emerging key themes develop into categories for analysis (Fereday & Muir-Cochrane, 2006). The analytical approach can be used as a way of seeing and making sense of the world from

relatively unrelated material (Boyatzis, 1998). It also offers flexibility theoretically and in terms of research question, sample size and data collection methods (Clarke & Braun, 2017). The analytical approach can also be used to explore and identify patterns both within and across data sets in relation to participants' experiences, opinions and behaviours (Clarke & Braun, 2017). As suggested by Boyatzis (1998), thematic analysis is a process that involves three distinct stages: (1) deciding on sampling and design issues, (2) developing themes and code, and (3) validating and using code. However, Braun and Clarke (2006) later added to this process by suggesting that six essential steps should be followed. These included: (1) familiarisation of the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the final report (Braun & Clarke, 2006). The latter six-step process by Braun and Clarke (2006) was consulted during the present study's analysis phase.

5.6 Summary

The present study aims to qualitatively investigate why people living with and beyond a cancer diagnosis continue to attend supportive wellbeing groups within clinical settings. The research also explores patients' experiences and their perceived impact of attending a group from a critical realist and phenomenological approach. The researcher applied existing knowledge to the data collection process, whilst also ensuring that participant responses were reflected accurately.

Chapter 6 – Method

6.1 Overview

Within this chapter the methodological details used throughout the present study will be outlined in detail. A comprehensive description of the participant sample and a thorough account of the recruitment process will both be reported. In addition to this, a stage-by-stage account of the procedure that was followed and the materials that were implemented will be accurately recorded. The chapter will close by highlighting some ethical considerations and underpinning a theoretical framework that justifies the chosen method of analyses.

6.2 Design

The present study adopted a qualitative design that used semi-structured focus groups and individual interviews to obtain data about patients' experiences of regularly attending a supportive wellbeing group.

6.3 Sampling

6.3.1 Participants

All participants had been directly affected by cancer at some point in their lives. Several participants were undergoing active cancer treatment at the time of data collection, whilst others were either in remission or being regularly checked/monitored. Time since their diagnosis varied across the participant sample. There was no set limit. A study inclusion criterion included:

- Must have received a cancer diagnosis and therefore be living with or beyond cancer or a red cell condition
- Must have taken part in at least three of the same wellbeing group sessions at University College Hospital, Macmillan Support and Information Service
- Must be an adult over the age of 18 years and have a good understanding of English language
- Must be well enough to consent and take part in a one-off interview.

6.3.2 Selecting suitable wellbeing groups

At UCH MSIS, a wellbeing programme of workshops, groups and courses are available for patients to attend in order to support them through their experience with cancer. In the planning phase of the current study a total of six groups delivered at UCH MSIS were considered carefully for inclusion within the study. These included:

- General oncology support group
- Haematology support group
- Penile and urethral support group
- Helping Overcome Problems Effectively course (HOPE)
- Yoga
- Creative writing.

The study's lead researcher proposed an inclusion criterion for this specific aspect of the study's methodology. The wellbeing group criterion included:

- Must be centred around the notion of either wellbeing, therapeutic or holistic support principles.
- Must allow patients to attend at least three sessions.
- Must be held regularly at UCH MSIS.

Therefore, based on the above inclusion criteria the two most suitable groups, yoga and creative writing, were chosen as the principal groups for recruitment to take place. The remaining four groups were excluded because of three main factors:

- Focus was on support, rather than wellbeing (general oncology support group, haematology support group and penile and urethral support group).
- Group did not run on a long-term continual basis (HOPE course).
- Group had affiliations with other organisations and independent evaluation procedures (HOPE).

It should also be noted that some participants may have attended more and/or been part of additional groups within the service during the time of data collection. If so, participants were only asked questions regarding the wellbeing groups included in the present study; yoga and creative writing. Principle groups were the most popular and well attended amongst service users. As shown in Table 1, both wellbeing groups also displayed a number of contrasting differences, which provide a more extensive insight into patients' experiences of different types of wellbeing groups.

Table 1

Contrasting differences between wellbeing group sessions

Yoga	Creative writing
Physical	Cognitive
Individual	Collective group/sharing
Calmness/peace	Expression/creativity
Instructed	Guided
Booked/prior assessment required	Open to all/drop-in

6.4 Materials

6.4.1 Information and consent

Information and consent forms (Appendix A and Appendix B, respectively) were created and distributed amongst the participants prior to interviews. When creating both documents it was vital that the points were clear and concise. All potential participants were given adequate time to think about their decision before committing to take part in the study. They were encouraged to discuss their decision with other external individuals, for example members of their clinical team, relatives and/or friends. The information sheet also included key contact details for the lead researcher, research supervisor and academic institute (City, University of London), should the participant require any further information.

6.4.2 Demographic information

Basic demographic information was also obtained prior to interviews taking place. This was completed either in-person using the participant demographic form (Appendix C), over the telephone via verbal responses, or through access of the patient records database (only after full consent had been provided by the participant). The demographic information obtained in the present study included name, age, gender, cancer diagnosis, number of sessions attended and type of session attended. The form was aimed to be simple and non-intrusive. All information remained

confidential through secure storage and password protected computer files. Only the lead researcher had access to participant information.

6.4.3 Interview framework

A semi-structured interview schedule was created and utilised during the interview stage. The same framework of questions was applied to both focus groups and individual interviews. As Table 2 presents, each interview typically started by asking participants about their initial reasons for joining the wellbeing group of their choice. This provided participants with an opportunity to discuss their early experiences. Depending on their response, further questions that followed were typically centred on general attitudes towards groups and their perceptions on how attending a group may, or may not have impacted them physically and psychologically. Generally, each interview ended with open-ended discussion about any other feedback and/or opinions regarding either the group itself or the supportive service at UCH. The interview guide worked well and was implemented to merely use as a prompt to ensure that the interview remained on topic. It was flexible, non-restrictive and could easily be adapted to suit each individual participant. The interview schedule was piloted with an initial participant to ensure that the proposed questions were suitable and in fulfilment of the study aims.

Table 2

Interview schedule

Study aims	Example questions
- Patients' reasons for attending a wellbeing group	- Where did you first hear about the wellbeing group that you attended? - What initially attracted you to the group you chose to attend? - Had you done yoga/creative writing before you attended the group here?
- Patients' experiences and attitudes towards attending a wellbeing group	- Groups such as yoga/creative writing take place in a range of different external settings, so what was it about the group here in the hospital, which made you want to return? - The group facilitator is a health care professional; did this make a difference to your experience? - What has the group meant to you? - Would you change or improve anything about the group?
- The perceived impact of attending a wellbeing group	- Since you have been attending the group, have you noticed any changes or has it impacted your life in any way? Prompt: Has it helped you before/during/after your experience with cancer?

6.4.4 Debrief

On completion of all interviews each participant was offered a debrief sheet (Appendix D), which they were encouraged to take home and read carefully. The aim of the document was to debrief participants after they had taken part in the study. A brief overview of the research was provided and important contact details, including those of the lead researcher, were included on the sheet. In addition to the hard copy provided, all participants were also verbally debriefed following their participation. All participants were sincerely thanked for their input and generous time they had committed. In addition to this, all participants were reminded of the strict

confidentiality code that would be followed with their information and details provided. It was also important to re-emphasise to participants that their contribution to the research would not impact or affect any on-going clinical or supportive care that they received at the hospital. All participants were encouraged to contact the researcher if they had any further questions or concerns. If a higher level of support was required, participants were signposted to the UCH Macmillan Support and Information specialist team, who were able to assist them further depending on their individual needs. This however was not required at any point throughout the study.

6.5 Procedure

6.5.1 Recruitment

Participants were recruited through a purposive sampling method via UCH Macmillan Cancer Centre, MSIS. Potential participants (those meeting the inclusion criterion in Section 6.5.1) were specifically approached and informed of the study by a member of the UCH Macmillan Support and Information Specialist team prior or post to them attending a group session. If interest was shown, suitable participants were introduced to the lead researcher who worked within the service and was available to provide additional information if required. After meeting the researcher, participants were provided with written information and advised to think about their decision prior to consenting. Afterwards, participants contacted the lead researcher if they wished to take part in the study, either via telephone (included on the information sheet) or face-to-face during a routine visit to the hospital. At this stage, a convenient date and time was arranged for participation in a focus group, telephone, or face-to-face individual interview. All participants were willing and agreed to take part. No incentive was offered for contribution to the study; participation was voluntary. All interviews were conducted on UCH premises during June 2016 and June 2017. A lone worker policy was consulted where necessary during face-to-face individual interviews.

6.5.2 Pilot interview

At the start of the study before any data collection had taken place (May 2016), a pilot telephone interview was conducted with an individual who fulfilled the participant inclusion criteria. The aim of the short pilot interview was to ensure that all questions

within the interview schedule fulfilled the research aims adequately. It was also an opportunity for the researcher to perfect interviewing technique and identify any gaps within the interview schedule. It should be the noted that the schedule did not change significantly as a result of the pilot interview. Only minor changes, such as wording and phrasing of questions took place.

6.5.3 Focus group data collection

Initially, focus groups were proposed as the main data collection method and two successful focus groups were conducted (3 and 7 participants respectively). Focus group interviews lasted for 44 and 47 minutes respectively. However, after numerous unsuccessful attempts to arrange additional focus groups, the decision was finalised by the lead investigator to recourse data collection methods to solely individual interviews (face-to-face or via telephone).

6.5.4 Individual face-to-face and telephone interviews

After collecting data from 10 participants in two separate focus groups, a further 10 individual interviews (3 face-to-face and 7 telephone), were conducted successfully. Due to the nature of participants used within the present study, in which some were undergoing active treatment at the time of data collection, individual interviews proved significantly more effective and convenient. Individual interviews lasted for between 15 minutes and 58 minutes.

6.5.5 Process

At the start of data collection all participants were politely greeted and briefed on the key points from the information sheet. Participants who conducted their interview via telephone were unable to collect an information sheet and sign a consent form in-person. Therefore, a more in-depth summary of the study was provided to these participants before any interview questions were asked. These specific participants were also asked to provide verbal consent over the telephone. They were informed about: (1) their right to withdraw, (2) answer only the questions that they so wished to answer, (3) their details and personal information remaining confidential, and (4) the interview being audio recorded. The researcher deliberately asked questions clearly

and slowly to ensure that each participant understood. Questions were open-ended and the researcher prompted participants to expand their answers on several occasions. Upon completion of interviews, participants were thanked for their time and debrief sheets were distributed. For those who conducted their interview via telephone, a research debrief was completed verbally.

After conducting two separate focus groups containing a total of 10 participants and then undertaking a further 10 individual interviews, it was determined that data saturation had been completely reached. This conclusion was reached based on the lead researcher's judgement and evident across the responses of 20 participants; it was clear that no new information that fulfilled the study's aims was being identified. In addition to this, further information that went beyond the study's main aims and was deemed of particular interest to the lead researcher was also not being identified. Therefore, based on this awareness, recruitment to the present study was closed. The lead researcher then proceeded to transcribe all audio data verbatim and manually into individual Microsoft Word document files. Participants' real names were replaced with unidentifiable pseudonyms for the purposes of confidentiality. Only the lead researcher had access to participants' real names, which were stored on a password-protected file. The lead researcher maintained high ethical standards and adhered to professional codes of conduct, as outlined by the BPS (2009) and HCPC (2008), throughout the duration of the study.

6.6 Method of analysis

6.6.1 Familiarisation of data

After transcriptions of audio recordings were complete, the interview transcripts were read several times by the study's lead researcher before an inductive approach to thematic analysis was employed. In addition to this, the audio recordings were repeatedly played several times during this phase in order to gain further familiarity with the data.

6.6.2 Generating initial ideas

During initial stages of analysis, the interview transcripts were coded by hand in order to identify preliminary ideas and recurring concepts throughout (Appendix E). At this preliminary stage of analysis, any thoughts or initial ideas regarding recurring concepts were hand written on the right-hand side margin of all interview transcripts. In order to ensure validity of codes at this stage, 20% of interview transcripts (n=4) were secondary coded by an accredited health psychologist. Codes identified through the second coding process were compared to those identified at the initial coding stage. Generally, codes identified were similar, but wording and naming of codes differed slightly. These were combined with the original naming of codes in order to develop innovative descriptions and interpretations. It should also be noted that the transcripts were analysed using an inductive approach to thematic analysis, whereby the lead researcher analysed the data without being informed by a pre-determined theoretical coding framework (Willig, 2013). Instead the themes remained closely grounded to the original data, which added to the validity and reliability of results.

6.6.3 Searching for themes

After preliminary coding had been completed, all thoughts and ideas were considered carefully and transcripts were re-read again. The lead researcher conducted the majority of this stage manually by dismantling interview transcripts and organizing codes into relevant groups. This helped to make sense of initial codes and search for more defined and meaningful themes. By dismantling paper copies of interview transcripts into different patterns and arrangements, the researcher was able to continuously and flexibly move and adapt codes until rich and distinct themes had been established.

6.6.4 Reviewing themes

Upon completion of secondary analysis, the researcher focused on reviewing and arranging themes according to relevant content and meaning (Braun & Clarke, 2006). At this stage a mind map using NVivo 10 software was created in order to visually present and review the broad range of themes that had been identified (Figure 3). At this specific stage a total of 7 themes and 17 sub-themes had emerged. The visual

mind map helped to visualize themes and identify elements that required more specific attention and/or interpretation.

6.6.5 Defining and naming themes

In a final stage of analysis, all codes were re-arranged, defined and structured. Finally, they were all labelled with appropriate titles that reflected both the meaning and interpretation accurately. Themes were accurately named based on genuine participant responses, by integrating specific words that recurred throughout interview transcripts within theme titles wherever possible. This helped to ground themes to original data, which therefore ensured that results were both strong and truthfully representative. Consequently, 3 key themes and 9 sub-themes were established (Figure 4).

6.6.6 Producing the final report

Upon conducting a thorough stage-by-stage analysis on the present study's data set, the final key themes and sub-themes where written into a final report. Established themes were presented alongside detailed interpretation and relevant participant quotations to support the proposed findings. Visual representations of all key findings were produced using both NVivo 10 and Microsoft Word software packages. These were then incorporated within the final report to add depth and clarity to the results section. In addition to this, using images to display the step-by-step approach that was adopted during the analysis stage will help the reader visualise the process and understand how the final themes were created.

6.7 Evaluating qualitative research

Generally, qualitative research is criticised and perceived as being inferior to alternative quantitative research methods, especially amongst many health service researchers who lack understanding for the methodological approach (Guest, MacQueen, & Namey, 2012; Mays & Pope, 2000). Claims have suggested that qualitative methodologies fail to attain scientific rigour, lack strong rationale and produce results that offer poor levels of transparency (Rolfe, 2006). According to

Noble and Smith (2015), '*Evaluating the quality of research is essential if findings are to be utilised in practice and incorporated into care delivery'*. Therefore, criteria highlighting seven aspects essential for ensuring excellent qualitative health research will be followed throughout the present study: (1) ethical procedures, (2) importance of research, (3) clarity and coherence, (4) use of appropriate and rigorous methods, (5) reflexivity or attending to researcher bias, (6) validity or credibility, and (7) verification or reliability (Cohen & Crabtree, 2008). The present study's lead researcher will consider these evaluative points carefully during three key stages: (1) criteria, (2) process, and (3) writing (Gómez, 2009). However, evaluating qualitative research with a structured set of criteria is not intended to be taken purely at face value, instead the evaluative assessment points should be approached with flexibility and a level of informality (Yardley, 2017; Yardley, 2008). Adopting a flexible approach to the research evaluation will ensure that findings are strong and reliable. Finally, conducting evaluation also allows the lead researcher to act reflectively on the data and will firmly ground the study's chosen method and theoretical framework.

6.7.1 Triangulation of data collection methods

Within the present study, a combination of focus groups, individual face-to-face interviews and individual telephone interviews took place. Therefore, the integration of these three data collection methods needs to be considered to ensure that results are reliable and do not lack validity. Consequently, the evaluation method of triangulation, otherwise known as '*integrating'* or '*combining'* methods of research (Moran-Ellis et al., 2006), will be consulted within the present study. Triangulation offers the potential to '*know more*' about a topic where new knowledge is being sought (Moran-Ellis et al., 2006) and helps the researcher identify new patterns or validate existing interpretation (Mays & Pope, 2000). It provides an additional method of evaluation and helps to establish rigour and strength.

6.8 Ethical considerations

6.8.1 Ethical considerations

Gaining ethical approval from the relevant professional bodies, prior to any data collection was a fundamental stage in the research process. Ethical procedures in psychology have grown in both awareness and rigor over the past few decades (Sinclair, 2017). However, new ethical challenges have arisen in recent years due to a number of factors including advances in technology, multidisciplinary collaboration of research, and an increase in legal expectations worldwide (Sinclair, 2017). It is therefore vital that all ethical aspects of a research study are considered carefully and acted upon with professionalism and efficiency.

Qualitative studies often require additional ethical attention for a number of varying reasons. Peter (2015) suggested that the following aspects need to be ethically considered in order to maintain best practice and protect human participants: (1) data collection methods such as in-depth interviews can create a sense of vulnerability amongst participants, (2) natural observation can potentially challenge privacy and consent, and (3) identifiable results raise concern regarding confidentiality. Considering the points proposed by Peter (2015), the present study was designed with the participants at the centre of all ethical decisions. Due to the nature of the sample used it was additionally important to consider participants' needs and ensure that harm and/or distress was completely avoided at all costs.

Conducting research with people living with or beyond a cancer diagnosis prompted more concerns over ethics. Using a sample of patients from an NHS trust required that a strict ethical code of conduct was understood and maintained throughout. The present study's lead researcher made numerous efforts to install a feeling of safety and care during the time of data collection. In addition to this, the researcher created a feeling of trust with all participants by building rapport and displaying genuine compassion. The nature of the study's topic was deemed neither sensitive nor taboo, and therefore it was not anticipated that the key questions featured within the interview framework would raise any concern. However regardless of this, the lead researcher still ensured that a number of well thought out strategies were considered carefully beforehand. Strategies included: (1) verbally reminding participants of their

right to anonymity and withdrawal (up until transcription phase), (2) immediately stopping any interview in which distress was clear and signposting appropriately, and (3) creating a welcoming and calm environment (for example, offering water and comfortable chairs).

6.8.2 Ethical approvals

Prior to commencing the study, ethical approval was obtained from the relevant professional bodies. Due to the nature of the present study and the data collection site that was being used (people affected by cancer and seeking care at NHS foundation trust hospital), it was essential that ethical approval was sought via the relevant NHS ethical procedures. The Integrated Research Application System (IRAS) was used to submit the ethics application. Approvals gained for the present study include:

- NHS Research Ethics Committee (16/EE/0143)
- Local Research and Development (R&D) office obtained for the specific site in which the research was carried out - University College London Hospitals NHS Foundation Trust
- As part of the site-specific ethical approval process, an application submission to the Cancer Governance research group at UCLH was also required in order to ensure that best practice was adhered to and maintained from the offset and throughout (see evidence folder for all of the above).

6.9 Summary

A qualitative study using an inductive approach to thematic analysis will be employed. Through a combination of focus groups, face-to-face interviews and telephone interviews, participants will be asked a series of questions that aim to explore their experiences of attending a wellbeing group. An in-depth step-by-step process will be followed during the analysis stage, in order to establish valid and emerging themes. Finally, ethical considerations will carefully be implemented throughout, which will protect participants and minimise vulnerability.

Chapter 7 - Results

7.1 Overview

The following chapter aims to clearly and concisely present the study's key themes and interpretation of all study data. Upon completion of data collection and analysis, chapter seven will identify the findings that emerged as a result of the in-depth thematic analysis that took place. A range of quotations to support the results will also feature within this chapter and a participant demographic table will detail key information about the study's sample. Furthermore, the use of visual imaginary will be used to highlight the analytical process. Firstly, a mind map displaying the initial identified codes will be presented (Figure 3), followed by a diagrammatic representation of the study's final themes (Figure 4).

7.2 Summary of participant demographics

As table 3 presents, a total number of 20 participants took part in the present study all living either with or beyond a cancer diagnosis consented to take part in the study. Originally, a total of 22 people were approached to take part in the study and from this only two potential participants, of whom initially agreed to take part in the study, did not undertake an interview or focus group. The primary reason for both individuals was difficulty finding a suitable time to complete an interview.

Generally, more female participants (n=17) took part in the study compared to males (n=3). Participants had a mean age of 53.6 years (SD = 12.3). Furthermore, a vast range of cancer types and red cell conditions are diagnosed and treated at UCH Macmillan Cancer Centre every day. The sample of participants used within the present study is largely reflective of this. Breast cancer patients accounted for the majority of participants (n=11), whilst other cancer types included, lymphoma (n=4), glioblastoma (n=1), prostate (n=1), bladder (n=1), thalassemia (n=1), nasopharyngeal carcinoma (n=1), ovarian (n=1), oropharyngeal (n=1), thyroid (n=1), adenoid cystic carcinoma (n=1).

Finally, participants were recruited from a yoga group (n=11), creative writing group (n=8), or both (n=1). Data collection methods included focus groups (n=10), individual telephone interviews (n=7) or individual face-to-face interviews (n=3). Generally, participants' attendance to groups was high and went beyond the study's minimum requirement of three group sessions. Many participants had attended in excess of 8 group wellbeing sessions (n=14), whilst others attended a reported 6 sessions (n=3), 5 sessions (n=2) and 3 sessions (n=1).

Table 3

Participant demographic information (sex, age, group attended, number of sessions attended, diagnosis and data collection method)

Participant (Pseudonym name)	Sex	Age (years)	Group attended	Number of sessions attended	Diagnosis	Data collection method
1. Elaine	F	59	Yoga	3	Glioblastoma	FG
2. Tara	F	42	Yoga	>8	Breast	FG
3. Ben	M	52	Yoga	6	Prostate	FG
4. Caroline	F	78	CW	>8	Bladder	FG
5. Joseph	M	46	CW	>8	Thalassemia	FG
6. Chris	M	43	CW	>8	Lymphoma	FG
7. Jenny	F	71	CW	>8	Breast	FG
8. Kara	F	66	CW	>8	Nasopharyngeal carcinoma	FG
9. Victoria	F	64	CW	5	Breast	FG
10. Eve	F	55	CW	>8	Lymphoma	FG
11. Hannah	F	45	Yoga	6	Ovarian	TI
12. Gill	F	60	Yoga	>8	Breast	TI
13. Sophia	F	28	Yoga	6	Lymphoma	TI
14. Krishna	F	49	Yoga	5	Breast	TI
15. Eliza	F	50	Yoga & CW	>8	Breast	TI
16. Amanda	F	64	Yoga	>8	Oropharyngeal	FI
17. Talia	F	34	Yoga	>8	Lymphoma	TI
18. Faye	F	62	CW	>8	Thyroid	FI
19. Annika	F	50	Yoga	>8	Breast	TI
20. Sally	F	54	Yoga	>8	Adenoid cystic carcinoma	FI

Note. M/F = male/female; CW = creative writing; FG = focus group; TI = telephone interview; FI = face-to-face interview.

7.3 Findings
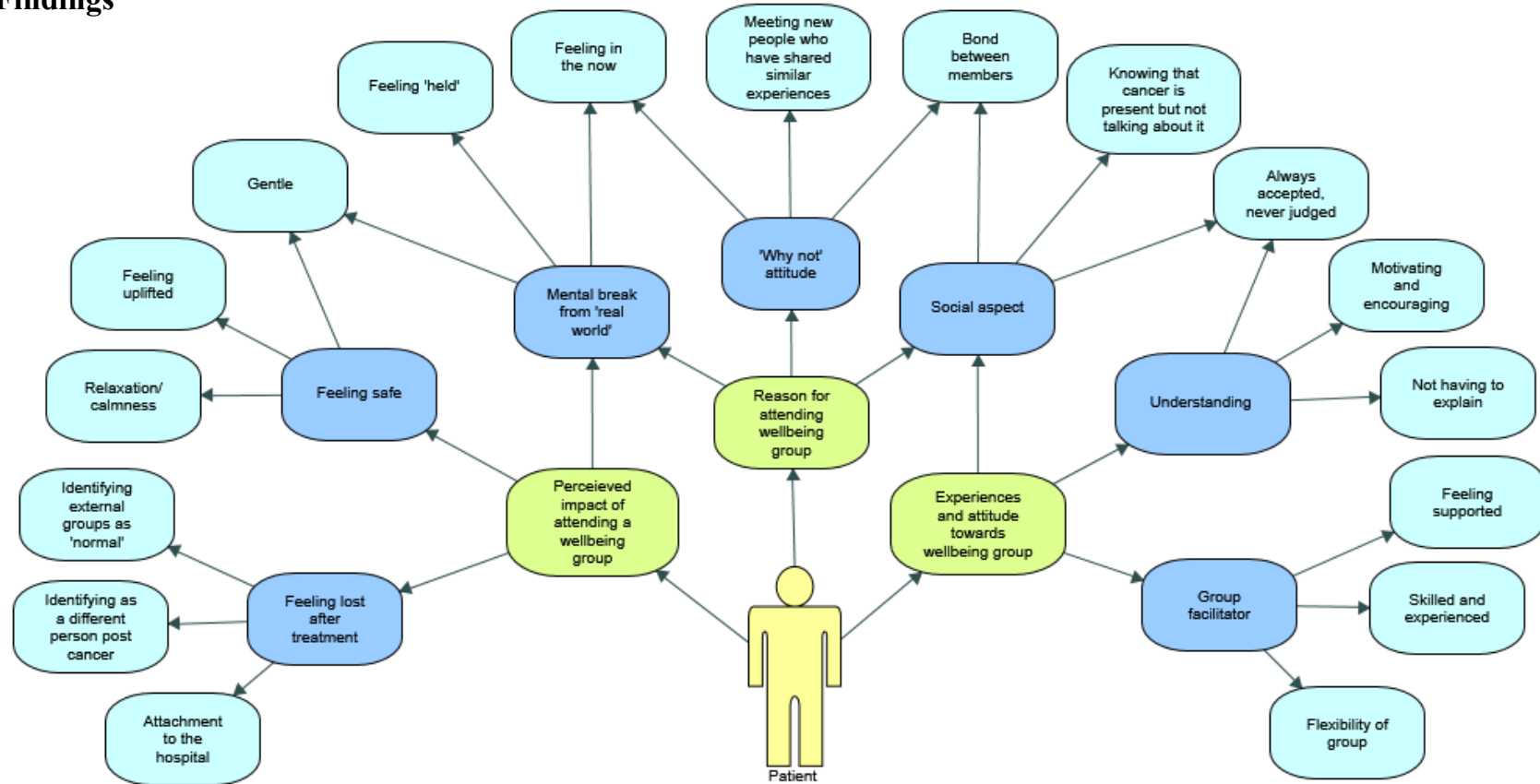
Figure 3. Mind map representing initial codes identified during early stage analysis
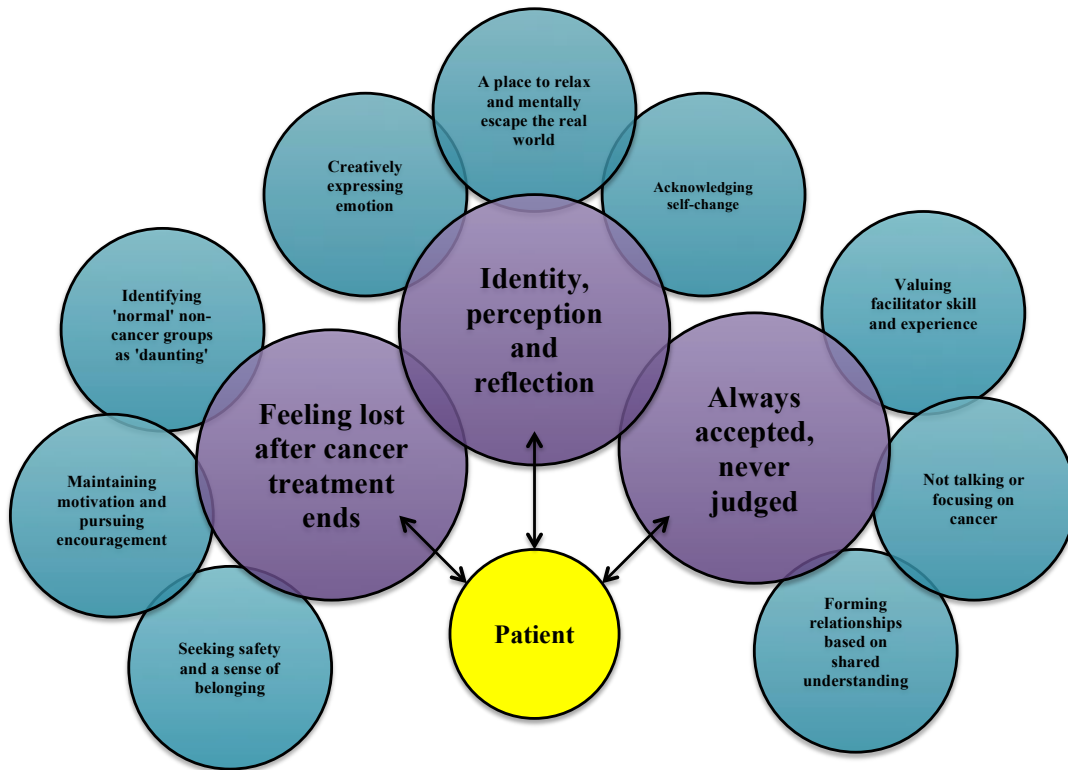
Figure 4. Visual representation of final themes identified

The above diagrammatic representations highlight elements of the analytical process that was conducted upon completion of all data collection, transcription and preliminary data coding (Appendix E). Initial codes were typically created broadly and remained closely grounded to the participants' responses during interview. Through a process of in-depth analysis and interpretation, codes were narrowed and defined into structured and meaningful themes. For each key theme and sub-theme identified, relevant participant quotations were identified from data transcripts and presented in a table format (see evidence folder). From the quotes identified, the most suitable examples were selected to feature within the main research report.

Three key overarching themes were established during this process: (1) Identity, perception and reflection, (2) Feeling lost after cancer treatment ends, and (3) Always accepted, never judged. From these main themes, a further 3 sub-themes were identified for each. Therefore, a final three key themes and nine sub-themes have been established within this study. All final themes identified within Figure 2 have been presented using overlapping shapes and arrows, in order to highlight the fluidity and

interconnectivity of both the key and sub-themes. Although all findings were separate from one another and have individual interpretation and meanings attached, it should be noted that clear links and associations remain amongst the majority of themes identified within this research. All key themes and sub-themes will be presented below and will feature alongside detailed interpretative explanations and relevant participant quotations to support. Corresponding participant pseudonym names and transcript line numbers will be provided in parentheses alongside each quotation.

Bar chart graphs detailing the exact number of times each participant directly spoke about each sub theme have been created and presented below.

Theme 1: Identity, perception and reflection
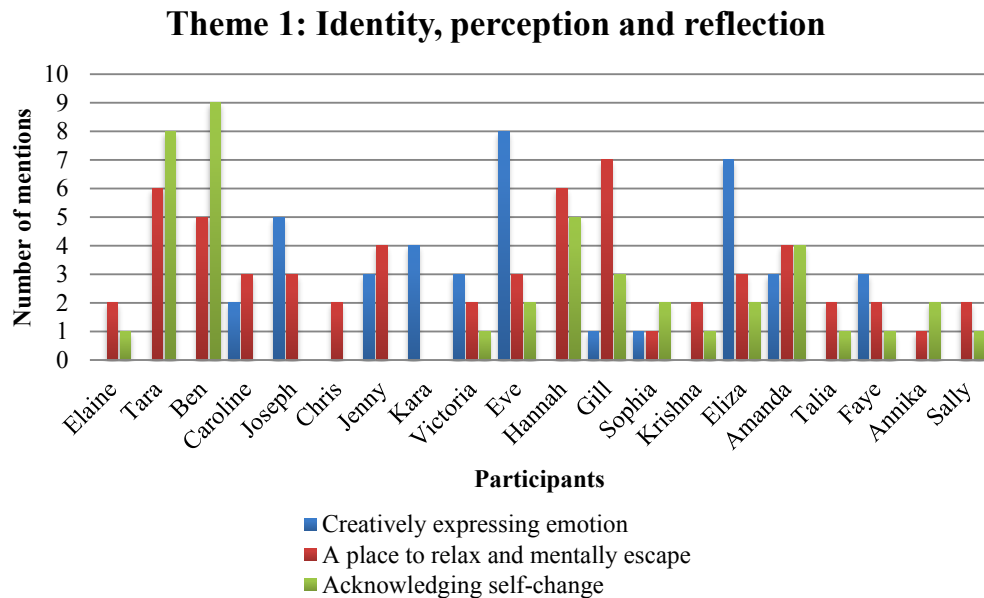
Figure 5. Bar chart graph identifying number of times each participant spoke about theme one.

Theme 2: Feeling lost after cancer treatment ends
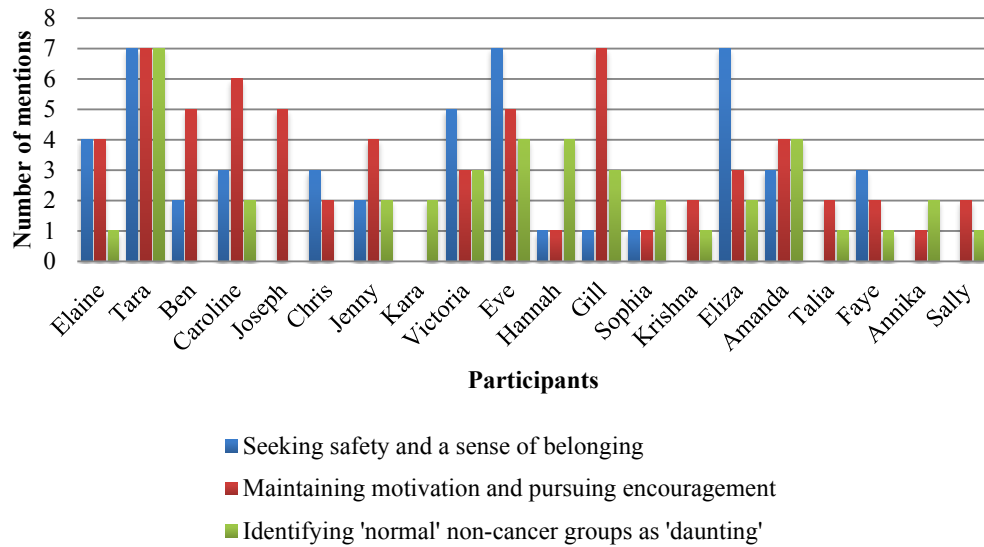
Figure 6. Bar chart graph identifying number of times each participant spoke about theme two.

Theme 3: Always accepted, never judged
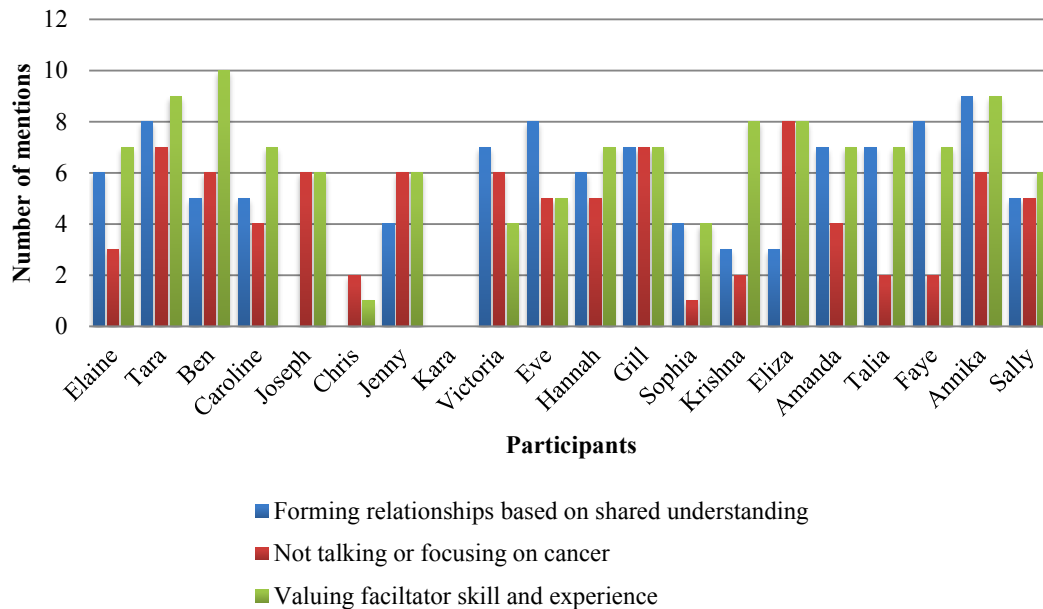
Figure 7. Bar chart graph identifying number of times each participant spoke about theme three

7.3 Theme one – Identity, perception and reflection

7.3.1 Overview

This key theme fundamentally identifies and represents the emotional aspects of managing cancer and the side effects associated with cancer treatment. Theme one, *'Identity, perception and reflection'* has been successful at capturing participants honest reflections and accounts, which provides the study with an insightful and rich finding that goes beyond initial study aims. The theme also represents how participants felt emotionally supported by regularly attending a wellbeing group. In addition to this, patients' self-identity and perception of the world changed as a result of experiencing cancer first-hand, and this was highlighted under this specific finding. Interview data also identified participants' ability to peruse and engage with available support services in order to acknowledge and challenge their personal self-changes. Theme one has been separated into three separate, yet interlinked sub-themes. These include: (1) Acknowledging self-change, (2) Reflecting and creatively expressing emotion, and (3) A place to relax and mentally escape the real world. Each sub-theme will be explained and justified below, using relevant participant quotations to support.

7.3.2 Acknowledging self-change

It became clear during the data collection phase that many of the participants had experienced profound changes in the way they perceived both themselves and also society since receiving their cancer diagnosis. This was a somewhat significant finding to emerge from the data, which added a great level of depth, understanding and possibility to interpret the data beyond the primary aims. It also provided valuable insight into cancer patients' outlooks, reflections and emotions in relation to their experience with cancer, and how these shifts in self-identity had impacted their everyday lives. Participants revealed how attendance to a wellbeing group had helped them to acknowledge their feelings and subsequently adjust to their new perceived self-identity and way of thinking about the world. Many participants talked about experiencing a *'change'* or an overwhelming feeling of being different post-cancer, in comparison to their previous cancer selves:

"...there was the person you were before, and then the person after, you've completely changed" (Ben, 392-393)

"...I think that where my life has changed and things are different, it just makes me feel calm and like myself again" (Hannah, 87-89).

The above quotations demonstrate how participants verbalised their thoughts and emotions about feeling '*different*' since being diagnosed with cancer. The quote from Ben showed how he identified as two different people; a pre-cancer Ben and a post-cancer Ben. He stated that he had *'completely changed'* since being diagnosed with cancer. This was typical of other study participants who similarly stated that they felt different as a consequence of receiving a cancer diagnosis. The quotation from Hannah similarly identifies a feeling of self-change, yet also specifies how attending a wellbeing group had helped her in relation to this feeling. She stated that the group had made her feel *'calm'* and *'like myself again'*. This provides clear and positive validation for the premise of holistic cancer support, specifically in the form of wellbeing groups. In addition to acknowledging self-change as a result of attending wellbeing groups, participants also discussed the impact of cancer specifically on levels of confidence and self-esteem:

"...from the cancer treatment my sense of myself was trashed, suddenly I'm not doing 99% of what I valued in myself and to have some sort of restoration of me as a person, and it's not there yet, there's a sense of a different way of being that I take with me..." (Amanda, 223-227)

"Yeah well for me my confidence was knocked unbelievably by this diagnosis which came about at the same time as a lot of other things and so to find anything that I could do and feel okay about, and in a group, in a situation where I was accepted for just being here and the fact that I was just sat here around the table was erm, it's really strange that this has been the only place where I've found that, the only place, I've explored all sorts of things actually but this is the only group that has stuck actually, which is really strange you know because so little happens in a way, you know there's no great talking that goes on, you know we just write little short things and read them out and with very little structure on the face of it, but it's been the only thing, and I

can't tell you how supportive it's felt, it's been the most ridiculously

supportive thing really when I think about it" (Victoria, 717-728).

Both of the above quotations show how each participant firstly acknowledged a change within their sense of self-identity, and secondly identified how attending a wellbeing group had helped them in relation to this feeling. Both participants commented on how cancer had significantly impacted their confidence and levels of self-esteem in an immensely negative way. Within the first quote, Amanda said her sense of self had been *'trashed'* and within the second quote, Victoria stated that her confidence had been *'knocked unbelievably'*. They both equally recognised that gaining therapeutic holistic support in the form of wellbeing groups had positively helped to support and restore a sense of what was normal for them. They both reported positively on their experiences of attending a group. Both participants confidently suggested that the group had been highly valuable in their attempts to recover and restore their sense of self-identity and self-confidence.

7.3.3 Creatively expressing emotion

During data analysis, it frequently emerged that participants viewed the group as a place to reflect and creatively express their thoughts, feelings and emotions. Many participants discussed the difficulties and implications associated with verbalising and articulating their thoughts in normal everyday life, however attending a wellbeing group within a clinical setting was identified as an effective and valuable refuge for patients to overcome this challenge. Patients chose to express their emotions differently and it was clear that each participant had a different way of coping with their problems. Attending a wellbeing group, as a result of cancer induced self-change, evidently helped many of the participants to feel listened to and heard. It was also clear amongst many of the participants that a wellbeing group had helped them feel safe and relaxed. This subsequently resulted in participants using the group to emotionally disclose personal and sometimes *'very deeply buried'* information:

"...I can't express my feelings very easily just from my head to speaking, it

needs to go through some form of creative form, if I write or paint them, then I

can talk about what I've drawn or written, so obviously there seems to be some disconnect with me, but that's just me, that's how this group helps me" (Eve, 675-679)

"...the writing group is a kind of outlet, because I have written in the past, different types of writing and I think erm it's one of the things with an illness, it can make you feel very inarticulate and helpless, so I wanted to open up that channel and the very first group I went to I wrote something that was very personal, autobiographical and I was just quite curious, and I said 'oh wow I didn't go into this thinking I was going to write that and thinking it would have that affect', but I thought 'okay it's had that affect so I should come back', because it was clearly opening up something and it was allowing me to express something that was there that had been very deeply buried, I haven't been nearly as emotional since, but every time I've gone I've thought 'oh I'm expressing something, I'm articulating something'...none of it has been expressly or directly about cancer or my experience of cancer but they're expressing emotions and so all of them are memories and emotions, and things that I feel are probably quite healthy to express, and there's something about being in a group you know...it's not like I've gotten amazing specific feedback on my writing or anything and it's just a general feeling of you're choosing to share something, you're in a group, there's something powerful in that and helpful, and sometimes some of the tutors will say something you know, just in passing or outside the group, 'oh I really liked that piece you wrote', or something, which is really nice, it's nice to be validated you know and encouraged, erm so you know that's very helping in some way, in the healing process" (Eliza, 288-319).

The first quotation from Eve shows how she recognised and reflected upon a feeling of inability to articulate and process thoughts into verbal responses. A disconnect between the two processes, which other participants similarly identified as a challenge, had left Eve feeling unable to express and communicate her feelings easily. By reflecting upon this, she stated that attending a wellbeing group had positively supported her to overcome these self-identified barriers. In addition to this, the second quotation also demonstrates how wellbeing groups can support people living with or

beyond a cancer diagnosis to feel enabled and empowered to express their thoughts creatively. Eliza perceived the group that she attended as an *'outlet'* for expression and communication, in which she had the opportunity to safely and confidentially articulate momentous experiences from her life. She also commented on how the group had helped her to feel *'validated'* and *'encouraged'* through receiving positive feedback on her work she had produced within the group. She believed that this had aided and supported her, in what she described as the *'healing process'*.

7.3.4 A place to relax and mentally escape the real world

Participants frequently spoke about wanting to seek some level of relaxation throughout their experience with cancer, either during active treatment or whilst managing long-term recovery. They sought this for a number of reasons but mainly to feel better within their sense of self and take time away from their worries. Many suggested that attending a wellbeing group, within a supportive care service, helped them to feel more relaxed:

> *"...I seem to have a lot on my mind and erm, I feel like I'm being pulled in lots of different directions, with like this cancer, work and then other stuff you know and yeah, it just is calm and one of the only things really that I actually do for myself, it's just some time out really and it's nice, it's relaxing, also it's nice, well I think it's nice just being with other people who all have this kind of shared understanding you know"* (Hannah, 93-98)

> *"...it was one of the few times that I had felt actually free from the anxieties, the pain, you know I could just really go to a different space, just coming to focus on whatever could be possible, I allowed myself to relax into that and leave sort of the shell of the body and the shell of all the feelings of tremendous uncertainty… so it was very important to me that I had this feeling where actually I would start to feel not only better, but good…"* (Amanda, 41-47).

The above quotations suggest that people living with or beyond cancer have a number of fears, stresses and anxieties that all run in parallel with one another. In addition to

dealing with a cancer diagnosis, it is possible that other participants and cancer patients alike may have also experienced additional non-related health concerns such as work stresses, financial pressures and/or relationship difficulties. This is evident within both of the above quotations. Hannah commented on feeling *'pulled in lots of different directions'*, which she stated was in relation to work and various other personal matters. With this in mind, she said that the group installed a feeling of calm and she perceived her attendance at the group as something that she did solely for herself. The second quotation from Amanda equally highlighted a need for relaxation at a time that she associated with anxiety, pain and uncertainty. She spoke about using the group to enter a *'different space'* and *'leave the shell of the body'* in an attempt to feel both better and good. Many participants also said that attending a group felt like they were being *'held'*. This was outlined several times by a number of participants:

> *"I wonder if it's the two hours we're held in this bubble, there's just a few of us engaged in this activity, the world's going on around us, things happening god knows where, but we are just in this place…"* (Joseph, 745-747)

> *"…it feels like a hugely deep group…it feels like a whole consciousness being held is all I can say, it sounds a bit over the top, it feels it, I don't know, the world is held, you know it is very different and I have been to lots of groups and I don't really do a lot else in my life but I come to this and it's two hours that I would prioritize over everything else in my week and I don't understand why, I can't explain it… yes it's funny isn't it, there's something about holding and it is a high point in my week"* (Eve, 736-756).

One of the study participants, Joseph, compared the group to a *'bubble'* and said that he felt held within it for the duration of the group. He implied that being engaged within the group felt like an escape and a break from everything else happening in the outside world. Similarly, within the second quotation, Eve said that she felt as though her *'whole consciousness'* was being held for the time that she spent participating within the wellbeing group of her choice. She was unable to explain her reasons for feeling this way, but it could be interpreted that she perceived the group as a place to relax and mentally escape from all other thoughts and emotions that were dominating her consciousness. Feeling *'held'* was a word that reoccurred a number of times

amongst many of the participants within the present study. Many of the participants had attended a significant number of group wellbeing sessions and therefore had devised an understanding and expectation of what the group represented and how it would make them feel. In comparison to other external factors that were perhaps having a negative impact, the group offered an alternative escape, in a place that felt relaxed and safe for a short duration of their prioritised time.

7.4 Theme two – Feeling lost after cancer treatment ends

7.4.1 Overview

This key theme focuses specifically on when cancer treatment ends. Similarly, with theme one, this second finding was relatively unanticipated in relation to the outlined study aims. It was expected that post-cancer recovery would occur as a somewhat prominent topic of discussion, but the extent to which participants centralised the matter and the number of times it recurred throughout the interview transcripts was significantly higher than expected. In addition to participants expressing how they felt after their treatment for cancer had ended, the theme also identified how attending a wellbeing group had helped participants to feel more supported during this phase. Theme two has been separated into three overlapping sub-themes. These include: (1) Maintaining motivation and pursuing encouragement, (2) Seeking safety and a sense of belonging, and (3) Identifying 'normal' non-cancer groups as 'daunting'. Each of the sub-themes will be explained and rationalised below, using relevant participant quotations to support.

7.4.2 Maintaining motivation and pursuing encouragement

Throughout a clear majority of interviews, participants stated that during the recovery phase after their cancer treatment had ended, they often felt unmotivated and unenthused by certain things in their life that they once valued and enjoyed. This sub-theme connected strongly with key theme one, *'Identity, perception and reflection'*, whereby patients' self-identity and perception of how they viewed and related to the world had changed as a result of their cancer diagnosis. Many participants honestly

disclosed their feelings and experiences during this post-treatment phase and presented how a wellbeing group had made a positive impact:

> *"...it's like you can kind of lose enthusiasm for everything and you can kind of drift, well I found that I just sort of drifted, sat at home day after day and sometimes you kind of need things to get you out the house and get you going..."* (Tara, 461-464)

> *"It gets you out of the house and gets you doing things and being with other people, because when I was first diagnosed it was a shock and I didn't really know what to do but being in that group for just the few sessions I went to did really motivate me and it actually did encourage me to do more exercise and yeah, like I said it made me appreciate things more"* (Gill, 105-109).

The above quotations demonstrate how participants felt hugely unmotivated both during and after their treatment for cancer had ended. In the first quote, Tara hinted that she had experienced a sense of loss after her treatment finished and stated that she lost enthusiasm and *'drifted'* as a result. Equally, Gill commented on feeling shocked and suggested that she had also felt lost during her experience of being diagnosed with cancer. Although both example quotes represent different phases of the participants' respective cancer journeys; both suggest similarly that they sought an opportunity to get *'out of the house'*. They both implied that the group had provided them with necessary levels of motivation. As a result, participants claimed that the wellbeing group had made them feel supported and strong. A further finding from within this sub-theme highlighted participants' need for encouragement in their attempts to self-manage long-term recovery:

> *"...it's a warm and open group and I think that was so important, well it was important for me anyway because it's a positive environment at a frightening time of your life, you need that encouragement and that feeling of being welcomed, I don't know it just helps"* (Gill, 127-131).

Gill commented on how important it felt to her that the group was *'warm and open'*, which perhaps indicated why she continued to attend the wellbeing group.

Interestingly, she also likened the group to *'a positive environment at a frightening time'*, which also may help to understand why she and other participants continued to attend wellbeing groups within clinical settings. It also helps to establish how a wellbeing group can make a positive contribution towards patient experience. In her response, Gill added that the group felt welcoming and encouraging, which she implied was helpful. It should also be noted that whilst participants generally and genuinely enjoyed participating in a group delivered at an NHS cancer centre, some participants (n=4) stated that some form of online digital content, that offered elements of wellbeing support, which they could access at home, would add value to their supportive care experiences. One participant, Hannah, said that having the option to access simple yoga tutorial videos online would help her keep active and enable her to 'practice the moves' she had learnt at the group session. Another participant, Talia, also added that online videos would help when she was unable to attend a class in-person. Similarly, Annika added that short online writing exercises that were updated frequently would be a 'good feature' that she would access at home. However, participants that discussed online content were clear in their preference to still maintain physical group sessions. It was obvious that the addition of web based holistic support would be preferably offered alongside group sessions as either an added extra or as a way for new patients to trial if they were interested. Participants discussed the idea of web-based content with enthusiasm and implied that having access to online support would motivate and support them after their treatment had ended.

Many of the participants also spoke about their desire to attend more sessions and their disappointment that the service limited the attendance for some groups (yoga). One participant, Annika, commented that although the group facilitator had been 'kind and flexible' in allowing her to continue having yoga sessions beyond the usual set limit, she expressed a strong wish for 'many more'. She explained how the group helped her manage the side effects of her treatment and enabled her to meet others who had shared similar experiences. She also added that external yoga classes were 'too expensive' and so the group at UCH MSIS provided her with the opportunity to practice yoga which otherwise would not be financially possible. Other participants (n=3) also spoke about their wish to continue having more sessions.

7.4.3 Seeking safety and a sense of belonging

In relation to feeling a sense of loss after cancer treatment ends, it emerged during analysis that participants also recurrently talked about a need to remain connected in some way to the hospital in which they were treated for their cancer. Many spoke about receiving high levels of care, support and attention during active cancer treatment, from both medical professionals and also friends and relatives. Some participants suggested that much of this support appeared to stop suddenly after their treatment was over. As a result, it was a recurring comment that participants often felt lost and/or abandoned. This sub-theme can also relate to key theme one, *'Identity, perception and reflection'*, as the finding suggests that participants frequently perceived and viewed society differently since their cancer diagnosis. It also implies that their relationships with both themselves and also others had been directly affected as a consequence of their cancer diagnosis. Furthermore, this sub-theme can also be linked to theme three, *'Always accepted, never judged'*. The connection to theme three is based on the understanding that participants choose to build new relationships, with unfamiliar people, based on a foundation of shared understanding. Participants repeatedly described feeling lost after their treatment was over, and therefore consequently sought a sense of belonging in a place that felt *'safe'* and *'comfortable'* to them:

> *"...that's definitely an aspect of coming here, I remember when I first finished my treatment I thought 'ooh I'm kind of a bit lost now'...it felt like a safe place"* (Tara, 401-408)

> *"...in some ways you tend to cling, I mean I love this hospital and these buildings because you know, they feel familiar to you...you get comfortable"* (Ben, 397-399).

Both quotations represent how participants sought a sense of security and feeling of connectedness to what once were familiar surroundings. In the first quote from Tara, she said that the group felt like a *'safe place'* and it was *'definitely'* an aspect of why she continued to attend the group that was based within a clinical setting. She openly admitted to feeling lost after her treatment ended and suggested that as a result of this

feeling she sought a sense of belonging from safe and familiar surroundings. Equally, Ben also expressed his desire to stay connected to the hospital premises. He claimed that he tended to *'cling'* to the hospital buildings, because they were both *'familiar'* and felt *'comfortable'* to him. This explains why people continuously choose to attend wellbeing groups in hospital settings. Attending and committing to a group session ensures that ties between hospital and patient are not abruptly cut. A wellbeing group bridges this gap and also helps to support, encourage and provide safety to patients who enter the recovery stage after their cancer treatment ends. However, some participants also spoke about the need for more physical space to conduct such group activities within clinical settings. Some participants (n=2) acknowledged that although attending a group within the hospital where their treatment was conducted had significant benefits, it also caused problems because of a lack of room availability at the busy hospital. One participant, Krishna, commented that the group could sometimes feel 'a little crowded' and 'a bigger room with more space' could add even more value to her experience of attending the group. However, they recognised that hospital space was usually prioritised for clinical care rather than holistic patient support.

Furthermore, some participants added that whilst wellbeing groups did fulfil a need to feel safe and connected to clinical settings, this was achieved by offering support in non-clinical areas. Participants were clearly able to distinguish between the two aspects of care:

> *"I go to the hospital to have hospital appointments but I go to the Living Room to kind of do more social things, more chilled things, things that kind of allow me to move beyond being a patient, allows me to move beyond something that just gets operated on, or probed, or scanned, or something and it's a very, very welcoming space and the people who work there are very kind and some of them are participating in these groups as well, so it never feels like doing a group there is like a medical thing, it's not like we're being medicalised or objectified, or you know, there's a word I'm looking for… you're able to sort of nurture yourself and nourish yourself there, so I wouldn't only go to groups there, there's other things that I like doing that aren't in hospitals, but since I am a patient it makes sense to have something*

to do there that not only is it taking account of the limitations of your body but it's also very calming…" (Eliza, 126-138)

"Also, I come here anyway and so the sense of being able to do something that could be appreciative of my variability in the course of a day, but also a nice thing to do in a place that often is associated with less than comfortable experiences" (Amanda, 22-24).

The first quotation from Eliza interestingly states that attending a wellbeing group within a clinical setting never felt like a *'medical thing'*. She also added that attending a wellbeing group never made her feel *'medicalised or objectified'*, but instead she felt regarded as a person rather than a patient. Eliza also stated the group felt welcoming and calm, which allowed her to *'nurture'* and *'nourish'* herself during the post-treatment phase. In addition to this, it was suggested that the group enabled her to move beyond being a patient, something that was clearly appreciated and valued by the participant. It was also implied that returning to familiar hospital premises felt different depending on the reason for attendance. For example, attending a wellbeing group was identified as being a positive experience, whereas attending a clinic or other medical appointment was mostly identified as a negative experience. Participants' perceptions of clinical departments were perhaps negatively skewed by their previous experiences. Within the first quote, Eliza suggested that her associations of clinical areas were mostly of being *'operated on', 'probed'* and *'scanned'*. In addition to this, the second quotation from Amanda similarly identified a level of awareness for these two distinct aspects of cancer care; the medical care and the supportive care. She claimed that a wellbeing group felt like a *'nice thing to do'* in a place associated with *'less than comfortable experiences'*.

7.4.4 Identifying 'normal' non-cancer groups as 'daunting'

It was a common theme throughout that participants identified external non-cancer classes or groups as being *'normal'*. Once again this links significantly to theme one, *'Identity, perception and reflection'*, as it reflects how the participants frequently viewed and related to the world since receiving their cancer diagnosis. Somehow, participants were under the assumption that non-cancer wellbeing groups such as

yoga would be too difficult, demanding and/or challenging. In addition to this, many of them believed that the pace of a normal non-cancer group would be too rigorous or intense. Feeling *'pushed'* and under *'pressure'* were both fundamental features of an external class that participants perceived as unappealing:

> *"Not being pushed too much, well knowing that there wasn't any pressure and things were done at my own level…I never felt pushed you know, it was always doable and more relaxing really than anything"* (Hannah, 73-76)

> *"You're not pushed, erm, it's very, it's not competitive and you can go at your own pace, the teacher knows everyone's strengths and if someone has certain difficulties or problems, everyone is individual even though it's a group class you know, erm there's no rush, we're never rushed to do all the things together, everything is at our own pace and in our own time which is what probably makes it feel so relaxing as well…I just don't know if going somewhere else would be like that, I don't think you could ever get that sort of one-to-one attention when you're still in a group… it's a very stressless environment which again I don't know if you would always get if you went somewhere else, erm you don't feel pressure like you might do in other classes you know, to keep pushing yourself forward to do all the moves really well, that's not what this class is like…"* (Gill, 63-79).

The above evidence displays participants' desires to engage in wellbeing groups that enables them to set their own gentle pace, whilst feeling restored and relaxed in a *'stressless environment'*. Gill stated that whilst attending a wellbeing group in the safety of a hospital setting, she never felt pressurised or rushed into going beyond both her physical and mental limitations. Other participants equally agreed. Many of their assumptions were based on a comparison between their perceived personal limitations and their expectations and beliefs about external non-cancer wellbeing groups:

> *"…I just think that if I had gone to a normal class, like well I could have, you know I could go to a class at a gym near where I live, but I actually think that*

would be quite daunting because you know, I can't do a lot of stuff that I used to do…" (Hannah, 80-83)

"Yeah I wouldn't have done a normal yoga group, because I would have found it too much, this one seemed the right thing" (Tara, 93-94).

Both quotations demonstrate how participants perceived non-cancer groups delivered in non-clinical settings to be *'daunting'*. Within the first quote, Hannah acknowledged an element of self-change that had occurred as a result of her cancer treatment. She therefore suggested that a wellbeing groups delivered in the safety and comfort of a familiar clinical setting would help her feel encouraged and connected to familiar hospital surroundings. Tara also identified external groups as *'normal'*, which was common amongst many of the other participants within the present study. The second quote presents how a normal non-cancer group would be *'too much'* for a person living with or beyond a cancer diagnosis, but a group delivered within a hospital setting would be the *'right thing'*. This finding can also be connected to a number of the other themes identified within the present study. Perhaps participants felt daunted by the idea of attending an external wellbeing group because the *'normal'* people that would also be participating within the *'normal'* group, could possibly judge, lack understanding and/or set an unrealistic pace:

"…unless you have experienced a similar thing, like first-hand you know, I just don't think people really get all those feelings, but here people do and they just know, so erm, there's no pressure and there's no competition, it's not intimidating like I think it would be if I went somewhere else, it's calm and relaxing and that's why I like it to be honest" (Hannah, 128-132)

"I think from what I've heard from other people, you know like yoga normally sounds quite intense, whereas at the hospital they can consider all your aches and with things like chemotherapy as well, they kind of know what you're going through, I feel like it's more relaxed, I mean I haven't really tried another session but I think with how I feel I would find it too intense…"
(Talia, 46-50).

Both supporting quotations identify that other people, in particular people that have not been directly affected by cancer, play a crucial role in why patients chose to attend wellbeing groups within clinical settings rather than go elsewhere. Hannah claimed that people who have not experienced cancer first hand lack true understanding for the feelings that are associated with living with or beyond cancer. She recognised that when groups are conducted in clinical settings with others who have shared similar first-hand experiences, there is an expectation that the group will feel neither competitive nor intimidating. Ensuring that a group felt *'calm and relaxing'* was also a fundamental aspect of why people enjoyed and continued to return to supportive wellbeing groups. Similarly, within the second quote Talia also commented on the importance of relaxation. It was identified that non-cancer groups would be too *'intense'* for people either undergoing cancer treatment or recovering post-treatment. Across the majority of all participants within the present study this same sub-theme emerged frequently. Many also stated that groups facilitated on hospital premises felt safer, more inclusive and relaxed.

7.5 Theme three – Always accepted, never judged

7.5.1 Overview

Whilst conducting thematic analysis on all study data, it was clearly evident that participants commonly shared the belief that being in a group with other cancer patients was an essential reason for joining a wellbeing group. Secondly, it was frequently highlighted that participants' experiences and attitudes towards attending a wellbeing group was that they never felt judged, neither by other group attendees nor the group facilitator. Instead participants reported feelings of complete acceptance and understanding by everyone involved. These feelings occurred for several reasons, however the skill and expertise of the group facilitator and the fact that cancer was not always a central topic of group conversation were the main two reasons. Overall, theme three, *'Always accepted, never judged'* was the most dominant theme to recur throughout all interview data. All participants referred to this theme at some point during their study interview. The third theme has been divided into three distinct, yet somewhat overlapping sub-themes: (1) Forming relationships based on shared understanding, (2) Valuing facilitator skill and experience, and (3) Not talking or

focusing on cancer. Each of these sub-key themes will be presented below with relevant participant quotations to support.

7.5.2 Forming relationships based on shared understanding

Many of the participants spoke about the importance of being with other people who had perhaps shared similar experiences. Many suggested that this aspect of supportive care had been immensely important to them. It was apparent from participant responses that there was a strong sense of togetherness and attachment between group members. This level of close interaction between group members was perhaps valued highly by participants due to a lack of informal communication in other areas of the hospital, for example busy clinic waiting areas. Therefore, wellbeing groups provide a convenient and comfortable environment for people affected by cancer to form new friendships based on mutual understanding and a shared level of acceptance:

> *"Being around people who are in the same boat"* (Tara, 115)

> *"Well I think it's the old soldier thing isn't it? I suppose we've all been through a particular war that we understand, we all have different types of cancers, so I think there is that connection…there's the gel isn't there, the people coming together…"* (Faye, 138-142)

> *"...we became our own sort of family in one sense"* (Joseph, 802-803).

As the above quotations show, participants valued being around others that were all in '*the same boat'*. Joseph stated that the group felt like a *'family'* and Faye described the group members as *'soldiers'* who together had a *'connection'*. Most of the relationships formed within these wellbeing groups, were formed because of a shared understanding and first-hand experience of living with or beyond cancer. In addition to creating friendships and a sense of *'community'* within these wellbeing groups, participants also talked about using the group and the newly formed relationships as a way of simply seeking reassurance and supportive information from peers:

"I think it's quite reassuring and nice to talk to other people that have kind of gone through something similar as you have…it's nice to make friends and you see the same regular faces every week so that's quite nice, you feel like a little community in there I guess, because you don't really know what cancer's like or the chemotherapy unless you've gone through it, you can sympathize, but if you talk to other people as well you don't feel like you're alone in what you're going through" (Talia, 70-79)

"…sometimes you can get to talk to other patients and for me when I was, I was, well being a man and you get to talk to people who are maybe further down the road than you who have joined the prostate cancer club [laughs], and you've got that mutual support as well and you can say 'oh this happened to me', because I found that you want to ask someone else who's been through it in a way, you know, and 'how did it affect you' and 'how did this happen' and you can just get sitting and chatting to someone who you'll never see again you know, I find it very good as well" (Ben, 651-658).

The first quotation from Talia describes how she felt reassured by being in a group with other similar people. She also added that it was *'nice to make friends'* with people who shared a mutual understanding of cancer from a first-hand perspective. This was a recurring theme throughout, with most participants also stating that being with other cancer patients often felt more supportive than being with relatives or friends. Talia also added that regularly attending a wellbeing group felt like a *'community'*, which similarly aligns with other participant responses who also implied that the group created a sense of togetherness and closeness between members. In the second quotation, Ben reflected on his experience of being a male patient who attended a wellbeing group. He commented on his previous interactions with other patients who he said had also joined the *'prostate cancer club'*. Like many of the other participants, Ben suggested that sharing information, advice and personal stories with other patients, had significantly helped him during his experience of living with and beyond a cancer diagnosis.

However, despite the participants identifying the formation of new friendships as a key reason for wanting to join and maintain attendance at wellbeing groups, it is

worth noting that a small number of participants (n=3) commented on how the groups could sometimes feel unhelpful. One of the participants from the present study, Amanda, said that the wellbeing group occasionally felt that there was *"a great deal of competition"* between some of the core group members. She also added that core members who overpower or take control could sometimes dominate groups; she described this as people *"who tend to suck the oxygen out of the air"*. A further participant, Eliza, suggested that the wellbeing group she attended *"can sometimes feel a bit cliquey"*. Similarly, Eve who took part in a focus group said that before she attended a wellbeing group she assumed that it *"might be quite cliquey"*. Interestingly, this comment from Eve was quickly challenged by another participant who responded by saying *"yeah but it's just not like that"*. Generally, these comments were infrequent throughout the dataset, but worth noting as it provides an unbiased view on groups and a learning opportunity that can be used by healthcare providers who may consider delivering similar groups to patients in the future.

7.5.3 Valuing facilitator skill and experience

Participants revealed that the feeling of always being accepted and never judged occurred not only amongst the other patients, but also the primary group facilitator. Many of the participants stated that the group facilitator was a key and fundamental reason why they continued to return to a wellbeing group. Several participants claimed that having awareness that the facilitator was a skilled and experienced health care professional was highly valuable and added to their overall feeling of safety within the group. Participants also compared group facilitation from wellbeing groups in clinical settings, to wellbeing groups in external non-cancer settings. This linked closely to theme two, *'Feeling lost after cancer treatment ends'*. Participants believed that skilled and qualified group facilitators provided the group with a sense of reassurance:

> *"...she's very understanding of what people are going through and what their limitations are, so I think it's definitely helpful that she has that understanding"* (Sophia, 53-55)

"Absolutely, I think so because writing stuff can bring up or you might just feel unwell for a bit, or something might have hit you in a particular way or stuff you've been going through might hit you, and so then you might need to take five, so yes I think it's important, the main facilitator can't do everything" (Faye, 238-241)

"...the leader is sensitive to what people can and cannot do, so I can trust that the leader evaluates risk from the moment we start, well before we started, there is an eye of endless duty and care, and it's exercised and it's really lovely because I can relax into it in a different way, if it's me for example, one time she knew that something is difficult for the neck and she just said, 'you might want to' and whatever, you know and I thought it's really delightful…" (Amanda, 110-116).

As the above quotations present, participants all demonstrated a high level of awareness for how group facilitators added value to wellbeing groups. Participants acknowledged that whilst group facilitators may not have experienced cancer first-hand, many had a strong understanding about cancer from their many years of working within clinical cancer settings. This level of professionalism, competence and efficiency made participants feel safe, understood and cared for whilst they engaged within a wellbeing group. Sophia stated that in her experience of attending a wellbeing group, the group facilitator took account of her *'limitations'* and showed a distinct level of *'understanding'*, which Sophia said was *'helpful'*. Similarly, Faye agreed and implied that she felt safe in the company of a health care professional in the event of needing *'to take five'*. Finally, Amanda described the group facilitator as being *'sensitive'* and claimed that the group was conducted under *'an eye of endless duty and care'*. In addition to this, Amanda emphasised how important it was to her that the group facilitator understood her cancer related physical limitations. By caring and implementing safety in this way, which had been gained through practice and skill, Amanda suggested that the group felt more relaxed.

7.5.4 Not talking or focusing on cancer

This sub-theme relates to the understanding that wellbeing groups felt like supportive communities, where the focus and central topic of discussion was not always necessarily about cancer. This connects strongly to other themes identified within this research. Many participants stated that whilst they attended a wellbeing group there was a clear awareness for the fact that cancer was present within the room. However, this often appeared to provide enough comfort and support for participants. It was assumed from participant responses that wellbeing groups were viewed not only as places to mentally escape, but also to verbally rest from the topic of cancer. Some of the participants stated that the groups felt like a support group *'without the focus being on cancer'*:

> *"I think for me my life was, at the time I joined, completely dominated by hospital appointments, scans, nutrition lectures, this thing, that thing, everything about cancer, and coming to this group erm, people knew what you were going through but you weren't specifically focused on cancer and so it was, they understood that you were feeling rotten and you had your chemo and it was sort of like, it became like a sort of support group without the focus being on cancer"* (Jenny, 145-148)

> *"So being with other people yeah is definitely important and even though we're all there at the same place, at the same time, it's just not actually having to talk about the cancer which is a bit of a relief, and yeah like a break from it all I suppose…everyone kind of knows but without having to say what is obvious, if that makes sense"* (Hannah, 116-124).

As Jenny describes in her response outlined above, the wellbeing group that she attended helped her significantly during a time *'completely dominated'* by medical and clinical appointments. Equally with other participants who responded in the same way, Jenny suggested that her life had been totally consumed by cancer and the treatment she received. The group therefore provided her with a calm space to think and rest, alongside other people who had shared similar experiences. It is evident from this finding that wellbeing groups conducted within clinical settings enable

people living with or beyond cancer, to engage with an enjoyable activity for a short duration of time. During a group session, patients' focus and attention is diverted away from the negative associations related to their cancer. For those who attend, the groups are *'definitely important'* and provide *'relief'* from always having to talk about cancer. This is achieved by both the skill and experience of the group facilitator, and also the other attendees who attend similar wellbeing groups:

> *"Yeah I wouldn't do the class if it wasn't for the group of people, and there's also the support you know, you're meeting other people who are going through similar things, so even if you're not actually talking about what you've been through, it's just that sense that you're in a place where people get you, get what you're going through, you don't need to verbalize what you're going through, but you're just being understood, it's a common understanding"* (Krishna, 116-121)

> *"Although it is very much sort of there in the room with us, but not in an obvious way, people can talk about it if they want to, or make reference to it, and that in itself is quite a relief because you can't talk about it to ordinary people or even your family because they don't know, they don't know the score but everybody around that table knows the score in one way or another and that is a great blessing for me anyway, it's not like we want to blabber on about it but it's nice to know you've got that safety guard if you need it…"*
> (Caroline, 152-158).

Both of the above quotations confirm the finding that peer support is a fundamental aspect of wellbeing groups. Participants never felt as though they were being judged for not wishing to talk about their cancer. Instead, they simply felt accepted. It also emerged that participants felt less obliged to explain their cancer to other patients within a wellbeing group, compared to relatives or friends that had not experienced cancer directly. Krishna suggested that she valued being in a group where *'people get what you're going through'* even though *'you don't need to verbalise'*. This was a very powerful finding that was supported by several other participants. Caroline similarly added that *'other people'* did not understand about cancer in the same way that those in the group understood. She stated that *'it's not like we want to blabber on'*

but implied that it was reassuring to know that the option was there if she felt the need to talk about her cancer.

7.6 Results summary

After inductively analysing the data, three key themes and nine sub-themes were identified. Key themes included: (1) Identity, perception and reflection, (2) Feeling lost after cancer treatment ends, and (3) Always accepted, never judged. Generally, results reported positively that wellbeing groups did make a significant difference to patient experience. Groups offered a safe, relaxed and non-judgmental environment for those living with and beyond cancer to mentally escape. It was also identified that groups enabled patients to feel connected to clinical surroundings even after treatment had ended. A further key finding also highlighted that the group facilitator's skill and experience was a fundamental aspect to the general group dynamic. Furthermore, attendance to a wellbeing group was found to effectively fulfil patients' social needs by helping to build new friendships based on shared understanding and past experiences.

Chapter 8 - Discussion

8.1 Overview

Chapter eight aims to inform and provide the reader with a concluding overview of the present study. A summary of key findings will open the chapter, followed by a sub-section that will present the study's outcomes in relation to already published literature, which featured earlier in the introduction chapters of this study. The discussion will then explore how holistic support can be effectively integrated into routine cancer care, and the implications that are associated with these. This section will also offer recommendations for further research, which could be conducted in the future in order to add value and more depth to existing knowledge within this area of health psychology. In addition to this, the study's strengths and limitations will be identified, which will hep shape future research and practice. Finally, the discussion chapter will close with a section of reflectivity that will highlight positive and challenging aspects of the study, from the lead researcher's perspective. A final conclusion that draws together all aspects of the present study will conclude this research thesis.

8.2 Summary of study findings

This study set out to explore and understand why people living with and beyond a cancer diagnosis regularly attend supportive wellbeing groups, even after their treatment for cancer has ended. The study also aimed to identify participants' experiences, attitudes and perceived impact of attending a wellbeing group, such as yoga or creative writing, within a clinical setting. In order to achieve these aims an interview schedule was designed to fulfil each main objective. Data collection took place with participants (n=20) during focus groups, face-to-face interviews and telephone interviews. In general, the sample was representative of wider cancer patient audiences. In the current study, a higher number of female participants took part in the study compared to males, which supports existing research that suggests women are more likely to access additional psychosocial support for their cancer, compared to male patients (Merckaert et al., 2010). In addition to this, a report from the Office for National Statistics (2017) stated that cancer incidence rates were

highest in woman between the ages of 20-59 years. This key statistic also similarly aligns with the present study, which used a female majority sample with an average age of 53.6 years.

After all data collection had been completed for the present study, interview data was analysed using an inductive approach to thematic analysis in order to highlight recurring themes. Three key themes and a further 9 sub-themes emerged. Key themes included: (1) Identity, perception and reflection, (2) Feeling lost after cancer treatment, and (3) Always accepted, never judged. Each theme represented a different topic that had occurred throughout the dataset. However, it should be noted that many of the themes interconnected with one another and this was represented using visual images within the results section.

In theme one, *'Identity, perception and reflection'*, participants disclosed their feelings and reflections about their cancer experiences. Many acknowledged that they had experienced a level of self-change as a result of their cancer diagnosis. They suggested that attending a wellbeing group had given them a calm and relaxing space to feel safe whilst they reflected on their experiences and new ways of thinking about the world. Theme two, *'Feeling lost after cancer treatment'* related to participants who had completed their treatment and who were subsequently living beyond their cancer. Many commented on how the experience of completing treatment had made them feel lost or abandoned. Participants also commented on how the transition from patient to *'normal'* person was a particularly challenging time. Consequently, participants said that attending a wellbeing group had helped them to develop a sense of belonging and also remain motivated during the recovery phase after treatment. Finally, theme three, *'Always accepted, never judged'*, refers to participants' experiences and attitudes towards supportive wellbeing groups. Many said that they attended a wellbeing group within a clinical setting because of the supportive atmosphere from the other group members and the facilitator. It was evident that being with others who had shared similar experiences, had led to a feeling of acceptance and comfort for those participating within a group. Many added that a wellbeing group felt supportive, without the focus or topic of discussion always being about cancer. This was also identified as a fundamental reason why participants

repeatedly chose to attend a wellbeing group within a clinical environment, even after their treatment for cancer had ended.

8.3 Findings in relation to previous research

Present study findings show that being in the presence of others, who had perhaps shared similar experiences, was a fundamental reason why many attended a wellbeing group. This finding strongly aligns with other published research which similarly concluded that those living after cancer treatment who participated in a 7-week yoga intervention programme alongside others who had been affected by cancer, reported feeling a sense of safety and shared understanding within the group (Mackenzie et al., 2016). This research paper employed a qualitative methodology and used a similar sample size to that which was used within the present study. However, the study solely focused on a yoga programme, which focused on yoga principles rather than the impact and value of the group construct. Research that investigated the effectiveness of support groups for people living with chronic health conditions, including cancer, did report positive outcomes for factors such as psychosocial functioning, self-efficacy and QOL, among those who participated within a group (Brunelli et al., 2016). Similar psychosocial interventions for women with breast cancer have likewise reported promising findings, such as positive short-term effects on general wellbeing, less depressive symptoms and more life purpose (Mens et al., 2016). These findings relate to results from the present study, which reported that people living with and beyond cancer, who regularly attend group sessions, experience change in self-perception, identity and awareness regarding how their lives have changes since being diagnosed with cancer. It also supports the finding that wellbeing is improved and people affected by cancer attend groups in order to feel better and more relaxed.

Other previous research conducted within the field of psycho-oncology similarly provides more support for the key findings identified within the present study. Participants from a qualitative study compared wellbeing groups to communities (Ross et al., 2014), whilst other research found that groups provided safe and relaxed spaces for people affected by cancer to feel supported (van Zutphen et al., 2017). However, unlike the present study, this previously published literature has generally

been conducted using single cancer population types. This is evident in the study conducted by Archer, Philips, et al. (2015), which used a specific sample of female gynaecological cancer patients only. Findings from this study concluded that participants liked feeling part of a community, however the findings are not representative of wider cancer-related population and this therefore limits the generalisability of the study's findings.

As well as finding value in being surrounded with other similar people, the present study also identified that being part of a wellbeing group made participants feel restored, happier and more supported during their cancer experience. Throughout all key themes, participants commented on how attending a wellbeing group had encouraged, motivated and uplifted them during uncertain and frightening times. This finding supports previously published literature which has similarly identified that supportive wellbeing groups for people affected by cancer can enhance QOL, mood and general wellbeing amongst those who participate (Archer, Buxton, et al. 2015; Bozcuk et al., 2017; McCall et al., 2015). However, the review of literature by Archer, Buxton, et al. (2015) included a number of studies that were assessed as satisfactory or poor, according to the quality assessment tool that was applied. This therefore suggests that the review findings were not completely reliable. In addition to this, findings from the comparative study that explored the effect of art therapy on patients undergoing active cancer treatment were largely based on a biased and non-randomized sample (Bozcuk et al., 2017). This also suggests that the findings were non-reliable. Therefore, a large proportion of previous literature about group support for people affected by cancer should be taken with a level of caution.

Results from a further qualitative study identified that patients who engaged within a therapeutic yoga group did so in order to seek a non-medical approach to their cancer support. This consequently led to participants reportedly self-identifying as healthy people rather than patients. This also supports findings from the present study and links closely with theme one, *'Identity, perception and reflection'*. In the same study by McCall et al. (2015), hurdles and barriers to practicing yoga were raised during data collection. The participants highlighted some concern about feeling stigmatized in public yoga classes, compared to classes delivered in exclusively in clinical settings. This finding was notably similar to present study findings, which also

highlighted participants' perceived attitudes towards *'normal'* wellbeing groups, with participants labelling them as *'daunting'*. In regards to expressive writing for people affected by cancer, a study that explored the impact of writing on psychological and physical health outcomes of patients, found no statistically significant change in either effects (Zachariae & O'Toole, 2015). Although this finding failed to offer any statistically proven support for expressive writing, the authors of the paper did conclude that writing groups could still be valuable for people living with and beyond cancer, due to the practical and inexpensive nature of delivering such groups. They also added that further research should be conducted in order to understand the impact of writing further.

Another significant finding from the present study was the importance of highly skilled group facilitation. This was evident within key theme three, *'Always accepted, never judged'*. When the present study's sample were asked about the wellbeing group's main facilitator, all participants agreed that having an experienced and qualified healthcare professional added substantial value to the group. For many it was a key reason why they continued to attend. In support of this, other research has equally reported that professional facilitation of groups can make a significant difference and a positive contribution to overall patient experience (Boltong et al., 2017). Findings from the present study found that group attendance, delivered in a clinical setting and facilitated by a healthcare professional, helped to fulfil patients' supportive care needs. This also aligns with qualitative study findings from Boltong et al. (2017), who reported similar outcomes. Likewise, in a study conducted by Schofield et al. (2016), which investigated the benefits of a group nurse-led intervention, results found that men with prostate cancer experienced a significant beneficial effect on their depressive symptoms after they had taken part in the group intervention. However, authors of the paper concluded that more work was needed in order to evaluate and assess the cost-effectiveness of using health professionals, such as nurses, to deliver patient-facing group interventions. This also presents a potential implication for the present study, which reported generally positive outcomes on the impact of wellbeing groups, when facilitated by health professionals, to people living with and beyond cancer.

In addition to this, feeling accepted and welcomed into a wellbeing group by the facilitator and other patients, was an important finding to emerge from the present study's dataset. Many of the participants implied that supportive care services in clinical settings felt kind, warm and open, in comparison to clinical settings, which were associated with less than pleasant experiences. Previous research aligns with this finding by also concluding that kindness, especially when shown by healthcare professionals, was important and ensured that patients felt cared for and supported (Jones, 2010). Other supporting literature revealed that kindness and empathy shown by NHS staff were essential and contributed significantly towards patients' experience of healthcare (Bracher et al., 2016). However, this study by Bracher et al. (2016) was conducted using free-text responses, where participants were required to comment about their cancer care experience in Wales, using a text box provided. This therefore may suggest that data was not as in-depth as other forms of qualitative data collection methods, such as individual interviews. The study was also based solely on Welsh cancer care services, which may suggest that the findings will be difficult to apply to other healthcare settings and participant populations elsewhere.

8.4 Integrating holistic cancer support into routine practice

Based on a small number of participant responses outlined in theme one, 'Identity, perception and reflection', some key recommendations for future practice have been outlined. In principle, some wellbeing group sessions were limited in order to allow other patients to have equal access and also encourage individuals to move on and detach from hospital services when the time was right. This was not always implemented and therefore some patients found it difficult to leave. Participants who recommended that healthcare services remove the cap on group sessions, were perhaps unaware of the implications associated with patients who avoid moving beyond long-term support in clinical settings. Instead, those who attend wellbeing groups for several years after their treatment has ended, should be given appropriate encouragement and support to self-manage and seek support elsewhere. This will help them to fully restore a sense of normality and form new relationships in non-cancer environments. Some participants in the present study also suggested that more physical space was needed. This element of group delivery was not always feasible due to hospital restrictions and limited room availability. However, healthcare

providers should still consider this recommendation when thinking about the implementation of holistic care services, such as wellbeing groups, into routine practice. Maintaining a calm, welcoming and relaxed space where patients feel comfortable and safe is essential. Many participants said that having a calm space to mentally escape was a primary reason for continuing to attend wellbeing groups.

A finding that was highlighting in theme two, 'Feeling lost after cancer treatment ends', highlighted a potential need for support to be delivered in an online digital format, such as video tutorials of exercises and/or short creative writing activities. Some participants suggested that the use of online platforms to access support at home would help maintain motivation after cancer treatment ends. This aligns with previously published research, which suggests that patients are increasingly accessing health information online (Dedding et al., 2011; Ferguson & Frydman, 2004; McMullan, 2006). Although this would be costly and further research would be required to justify the development of online content, it may help to connect and provide support to those unable to attend a group session in-person. It is fundamental that supportive care services centred on the principles of holism are easily accessible to all people affected by cancer. However, in a study that aimed to evaluate the effects of a 12-week online social networking intervention, for people affected by cancer, results found that it did not improve outcomes related to depression, mood disturbance, or trauma-related anxiety among those who took part (Owen et al., 2017). Similarly, Huber et al. (2018) reported no significant differences in anxiety, depression, and QOL, among prostate cancer patients who participated in an online peer support group, compared to a face-to-face peer support group. It is also believed that patients who access online peer support groups are more likely to change their initial treatment decision and experience greater levels of distress, compared to those who access face-to-face group support (Huber et al., 2018). Online support services would also eliminate the social element of groups, which many participants have rated as a highly important aspect. Therefore, this should be considered wisely and more research into online support for cancer patients should be conducted.

In addition to supporting people living with or beyond a cancer diagnosis, it is also important to consider the needs of carers, relatives and friends of people diagnosed with cancer. Many caregivers also take responsibility or play a fundamental role in

the care and/or treatment decisions of their loved one. Therefore, it is essential that resources are also accessible to carers and relatives of people with cancer. This will help to raise awareness and inform people affected by cancer about available support services. This can be achieved using promotional materials and informative information. Information such as leaflets, posters and flyers should be entirely jargon-free and available in a variety of formats, such as large-print and non-English languages. This will ensure that every person affected by cancer is well informed and feels confident to access supportive care services within clinical settings.

A further recommendation, based on the finding that health professional-led groups add significant value to patient experience, should be the consideration of professional involvement wherever possible in the development, implementation and delivery of group support sessions. Patients frequently report feelings of loss and abandonment after their cancer treatment ends (Foster & Fenlon, 2011; Foster et al., 2015). Therefore, the continuation of professional care, delivered in the form of a wellbeing group, could help patients alleviate these negative feelings after their treatment ends. However, this will have cost implications if healthcare providers chose to employ qualified professionals, rather than volunteers or non-registered professionals to facilitate groups. Regardless of cost implications, support for people after treatment is essential for patients as they transition back to their normal everyday routines. In the UK, there is a current focus on the post-treatment phase, which is evident in the recent implementation of a national initiative known as the *'recovery package'*. The package requires patients to attend *'Health and Wellbeing Events'* (DH et al., 2010; Independent Task Force, 2015; NHS, 2016), which are aimed at those who have completed or who are approaching the end of their treatment. The purpose is to inform, engage, support and provide patients and their carers with the appropriate tools to self-manage their side-effects themselves. Although the events are viewed as a positive addition to the recovery phase after treatment, future research should be conducted in order to assess the long-term impact of attending these events.

8.5 Implications for future practice

Although present study findings largely concluded that wellbeing groups were highly beneficial for people living with and beyond a cancer diagnosis, the study data did highlight some negative aspects to attending groups. This finding was presented within theme 3, 'Always accepted, never judged'. Therefore, considering that a downside to wellbeing groups had been briefly disclosed during data collection, future practice should wisely consider monitoring patients' use of supportive care services. Ensuring that people who have been affected by cancer do not become dependent or attached to hospital support services is essential when healthcare providers think about integrating holistic support alongside routine cancer care. Patients should be encouraged to self-manage better and take more control of their health. When patients independently self-manage their side-effects, it is believed to assist the recovery process and support patients in their attempts to install a sense of normality (Henshall et al., 2017). Therefore, professionals should consequently view supportive wellbeing groups as tools to help patients feel more supported, rather than allowing patients to use groups continuously or perhaps in replacement of clinical attention that was lost after their cancer treatment ended. Whenever possible, group *'ground rules'* should be implemented and patient expectations regarding how a wellbeing group can provide support, should be established and maintained.

A key finding of the present study focused on the skill and expertise of the group facilitator, of who was a healthcare professional by background. Participants frequently discussed the importance of their input and contribution to the group and the value they added as a result. In order to deliver such successful and meaningful groups for people affected by cancer, it was clear from the study data that the group facilitators had knowledge, comprehensive understanding and awareness of holistic support in cancer settings. However, this positive finding contrasts with other previous research, which dissimilarly found that healthcare professionals lack awareness, and understanding of the benefits of providing holistic care to patients and their families. In a study that combined conventional treatment alongside complementary therapies such as yoga and art therapy, findings identified that there was a clear lack of awareness for alternative therapies amongst many health care professionals (Blignault et al., 2014). Other research similarly found that healthcare

professionals working within the field of cancer care, such as nurses, lacked complete understanding of holistic patient care (Bahrami, 2010). As a result, this may cause implications for future practice and it is clear that more work needs to be done in order to improve understanding and awareness for alternative therapies amongst medical communities. Therefore, unless this problem is challenged, healthcare professionals uncertain about how alternative therapies can make a positive contribution towards patient experience will misinform patients or fail entirely to deliver information about holistic support. In order to raise awareness, it is fundamental that healthcare professionals are educated about the importance of supportive care services for people affected by cancer. This could be achieved through in-depth published research highlighting the value of supportive wellbeing groups, which should then be disseminated appropriately to the relevant medical communities. A further implication associated with future practice, is the cost and funding allocation to cancer support services. As the media reports on growing financial pressures in the NHS and cutting-edge treatment technologies that prioritise budgets, there is a worry that support services for people affected by cancer will be unrecognised and viewed as less important. Therefore, raising awareness and demonstrating the value of holistic support is a crucial next step.

8.6 Study strengths

The present study has several noteworthy strengths, which have contributed to both the successful completion of the study and also the insightful key findings that have been identified. One of the first strengths derives directly from the mix of participants that were used within the study. A heterogeneous data set allows findings to be drawn from different cancer types, varying cancer stages and different participant demographics (such as age and gender). As a result, the data is broader and can be generalised to more population types. A further strength of the study is the sample size. In total 20 participants completed an interview for the present study, in addition to one pilot interview that was conducted initially with the purpose of identifying flaws in the interview schedule. Based on other similar studies that also employed qualitative methodologies, the present study's sample size (n=20) is equally comparable and proves relatively strong. Data saturation was also achieved, which identifies an additional strength. Data saturation was evident at the point when neither

new, nor original themes emerged from participant interviews. As data saturation was achieved within the present study, this suggests that key findings are strong and reliable.

A further strength is that the research was conducted in an NHS flagship supportive cancer care service. The service offers a wellbeing programme of groups, courses and workshops in order to support people affected by cancer. Therefore, it was an excellent location for recruitment due to the range of wellbeing groups available and the number of patients, with a range of cancer types, who were happy to participate within the study. In addition to this, the study's lead investigator worked for two consecutive years within the clinical setting where recruitment for the present study took place. This was a noteworthy advantage over other previously published literature, as the researcher had experience of working directly with people who had been affected by cancer and had the opportunity to observe the inner workings of a flagship supportive cancer care service on a daily basis. This positively impacted the study outcomes as the researcher had a thorough understanding and awareness about the services at UCH MSIS. The lead researcher also understood about the development, promotion and facilitation of wellbeing groups. This advantage enabled the researcher to recruit participants relatively easily, which consequently sped up the recruitment process.

Finally, the study's topic area and interview schedule both posed minimal threat of causing participant distress. Thus, all participants expressed eagerness to participate within the study. There was zero dropout and withdrawal from the study, which highlights a further significant strength. The study also focused on a relatively under researched aspect of psycho-oncology literature. As the study rationale stated, research into wellbeing groups where the focus is on the group construct, rather than the specific content, is relatively minimal. There is also a clear lack of research that has been conducted about wellbeing groups in the UK. This study therefore provides a new perspective and an original insight into this essential element of supportive cancer care. As a result, the research creates opportunities to expand and build on present study findings with additional research in the future.

8.7 Study limitations

In general, the present study was conducted efficiently and with no cause for concern. However, upon completion of the study, the lead researcher engaged in reflective practice and identified some noteworthy limitations, which could help inform future research and practice. Firstly, the study only accounted for the experiences of people who had repeatedly engaged with wellbeing groups. As participants regularly attended a wellbeing group and utilised cancer support services, it may already suggest that they enjoyed, valued and benefitted from attending a group. Therefore, the research did not gain the experiences of people who had attended less than three wellbeing sessions and then subsequently made the decision not to return. It also did not account for those people living with and beyond cancer who did not access supportive wellbeing groups in any capacity. Therefore, this may suggest that the present study's key findings were skewed and collected from a one-sided perspective. However, the study did not set out to identify why people choose not to attend or return to wellbeing groups, but future research that targets these specific individuals could potentially add to understanding and knowledge in this area of psycho-oncology.

A further limitation occurred during the study's data collection phase. Initially, focus groups were proposed in an attempt to interview a large number of participants at one given time. However, due to the nature of participants used, some of which were undergoing active treatment for their cancer (typically either chemotherapy or radiotherapy), arranging focus group interviews proved to be extremely challenging. As a result, a combination of individual interviews and telephone interviews were employed in order to complete data collection. Employing different methods of data collection has a number of limitations. It is possible that participants responded differently within focus groups, compared to individual interviews. Many of the participants who participated in a focus group interview alongside their friends (of whom also attended the same wellbeing group) may have altered their responses in an attempt to provide socially desirable answers. The method of triangulation was employed during the analysis phase in an attempt to combine the data from all collection methods and eliminate any social desirability bias. However, conducting the research from one single method of data collection would have minimised bias

and potentially been more reliable. Therefore, this is something to consider in future research projects. It should also be noted that a few core group members appeared to dominate focus groups that were successfully completed within the present study. This observation supports the opinions from the minority of participants who implied that wellbeing groups could also have a negative quality, such as group cliques or overpowering individuals. For example, in one of the focus groups conducted, a participant named 'Kara' featured only seven times within the focus group interview, whereas more dominant participants commented over sixty times. This possible limitation may be due to the heterogeneity of participants that were used. Participants during active cancer treatment may have been less vocal in their responses due to physical and/or psychological demands of their cancer treatment. Other participants also had long-term implications relating to their cancer and treatment, including difficulties with speech and communication. Therefore, this may have also contributed to some participants' lack of comments during focus group interviews.

The level of heterogeneity amongst the study's sample may also raise some concern over the study's ability to establish understanding and associations between specific cancer diagnoses and experiences' of attending a wellbeing group. The sample featured a range of cancer types including gynaecological, head and neck, and red cell conditions. It also included people at different stages during their experience with cancer. Some participants were undergoing active cancer treatment at the time of data collection, whilst others were being monitored or on follow-up. It should also be noted that some participants had also been in remission for a number of years and were employing self-management techniques to help feel supported with the long-term physical and emotional effects of treatment. Although this positively shows that wellbeing groups are inclusive to all and can be accessed by an extensive range of individuals, it may also have limited the study's scope to analyse data and draw conclusions between group attendance, cancer stage and cancer type. This again is something that should be considered in future research. In addition to this, the study also only focused on yoga and creative writing, as forms of supportive wellbeing groups. There are a number of other groups that are based on the principles of holism and perhaps further research could open the recruitment criteria to additional wellbeing groups in order to create more generalisable results.

Finally, the lead researcher's role in the setting where recruitment and data collection took place could also be viewed as a potential bias and disadvantage for the current study. Although this element of the study impacted the research in a mostly positive manner, the researcher's role at UCH MSIS and familiarity with some of the participants, could have led to skewed data as a result of social desirability bias. However, this limitation was acknowledged early in the research process, and effectively controlled and managed throughout by the researcher. This was achieved by conducting the study's method professionally and ethically. All participants were fully briefed and informed about the study with the relevant participant information. Trust was built and maintained between researcher and participant, which encouraged the participants to disclose honest responses to the questions asked during one-to-one interviews and /or focus groups. This ensured that all data collected was accurate and reliable, and any risk of bias was minimised as much as possible.

8.8 Recommendations for further research

Based on the identified study limitations, there are a number of gaps that could be fulfilled by conducting further research within the field of psycho-oncology. Firstly, exploring why people do not use groups or choose not to continue attending would be advantageous to both future patients and healthcare providers. It could add value to already published literature by exploring the notion of wellbeing groups from a different perspective. Producing more evidence to support holistic cancer care services, could also help guide future practice and raise awareness amongst healthcare professionals who are uncertain or unconvinced by the notion of holistic support in cancer care. A further direction for future research could potentially consider incorporating healthcare professionals within the sample. This would also offer a different perspective and alternatively explore healthcare professionals' attitudes and experiences of facilitating wellbeing groups. It could also help to establish healthcare professionals' level of awareness and knowledge about holistic wellbeing groups. This could consequently lead to the development of education programmes aimed at informing and raising awareness amongst healthcare providers about the benefits of providing support to people living with and beyond a cancer diagnosis.

Other research, which could perhaps enhance supportive care services in the future, should consider exploring the impact of wellbeing groups on people with advanced cancer and/or with significant long-term side-effects as a result of their cancer treatment. It may also be helpful for further research to also only focus on one type of cancer and expand the range of wellbeing groups included. Research into the impact of holistic support for children and adolescents would additionally provide more understanding of the topic area and help support more people affected by cancer in the future. Finally, research that focuses solely on men living with and beyond cancer, who seek support through attendance at wellbeing groups, would add substantial weight to minimal research conducted with male participants. Generally, research in this area is typically governed by female dominated samples. Previous research has shown that women are more likely than men to seek support for their cancer diagnosis (Merckaert et al., 2010). Therefore, in-depth qualitative research that explores why men affected directly by cancer do not seek support for their cancer would provide further understanding and knowledge to this research area. It would also enable healthcare provides to tailor support services, such as wellbeing groups, to those who engage less with services. This would ensure that more people have access to equal support during their experience with cancer.

8.9 Reflections

Upon completion of the present study, the lead researcher took some time to reflect on the process whilst paying particular attention to some of the challenges and also the aspects that went particularly well. Firstly, at the start of the study ethical approval was sought from the relevant professional bodies. This was conducted via IRAS and was a considerably lengthy process that proved challenging at times due to the complexity of the application. As an early career researcher, unfamiliar with the process, it was difficult and caused a feeling of slight disappointment when the process took longer than anticipated. This also delayed the start of recruitment and data collection. However, in hindsight the process was an excellent learning experience. Moving forward as a researcher, the ethical approval process will be completed more confidently and efficiently. Other challenges that have briefly been mentioned earlier within the research report included difficulties with focus group recruitment and attendance. At times this difficulty was disheartening and caused

setbacks in the data collection stage of the present study. However, upon reflection and completion of the study, it is now clear that the combination of various data collection techniques has added to the study's strengths and provided a diverse dataset.

In addition to this, it was also important to acknowledge that the research was a continuously evolving process that was consequently adapted a number of times throughout the study duration. Accepting this was also challenging at times, as the originally proposed protocol, study aims and focus of the research changed considerably over the past two years. However, rather than viewing this as a negative aspect, it instead should be viewed positively. The research consequently developed into a strong and well-defined study that fulfilled study aims and highlighted interesting and innovative findings. These will help shape both future research and practice for people affected by cancer. In addition to this, qualitative research is naturally more flexible than quantitative methodologies. Therefore, the present study had a sense of openness and flexibility that was beneficial particularly during the data collection and analysis stages. At first, it took time to establish the direction and focus of the research and this also changed as data collection began and findings started to emerge. Participants and their responses helped to guide the research process and it was important that this was represented well during the present study's results section.

After analysis, it was a challenge to select participant quotations to include within the final report in order to support key themes. It was challenging due to the vast amount of rich data that had been collected and analysed; all of which was relevant and worthy of inclusion. Therefore, a future aim is to publish this main research and also utilize parts of the dataset that were not included in the main report in order to publish additional parallel papers (such as data relating to yoga and creative writing specifically). As well as this, it is also hoped that this research will be presented at national conferences, to appropriate and wide-ranging audiences, in order to disseminate the findings. An abstract has already been submitted for presentation at the UK Society of Behavioural Medicine annual conference, which is due to take place in Liverpool during December 2017. By engaging with an audience of esteemed academic experts, healthcare professionals, students and researchers; all from a range of health and psychology related backgrounds, it will inevitably help to guide the

research further in preparation for publication and raise awareness of the study's topic area.

It was also highly important to feel supported and encouraged during the past two years whilst undertaking this research study. Both the academic and the workplace supervisors were incredibly motivating, reassuring and supportive throughout. Acknowledging barriers and challenges was fundamental, but also allowing supervisors to help and advice was also equally important. Conducting this research developed stronger teamwork and communication skills, which both add to the requirements of a successful health psychologist. Finally, this research represents two very inspiring and immensely valuable years of training within an NHS flagship cancer support service. After completing the research and reading through the written report, there is an overwhelming feeling of pride. This research is the only large-scale qualitative study that has been conducted within the supportive cancer care service at UCH. Therefore, this adds even more significance to the findings that emerged. Overall, the experience of conducting a research study within an NHS trust, with a sample of people living with and beyond a cancer diagnosis, has been a complete pleasure and an exceedingly worthwhile learning experience.

8.10 Conclusion

To conclude, an innovative and original research study exploring the notion of supportive wellbeing groups for people living with and beyond cancer was required. The rationale was based on a lack of existing literature and a rising need for supportive cancer care services. Cancer is considered a long-term condition and many people affected have advanced support needs during and after their treatment ends. The post-treatment recovery phase is particularly important, as research has concluded that the transition from *'patient to survivor'* is highly challenging (Allen et al., 2009). It is therefore essential that the supportive needs of patients are fulfilled at the appropriate time, in order to improve patients' QOL and levels of self-efficacy (Piazza et al., 2017). Self-management principles should also be employed wherever possible to ensure that patients feel in control of their own health and able to manage the side-effects of their treatment. Holistic support in cancer care can be delivered to patients in numerous ways. However, supportive wellbeing groups offer a low-cost,

comfortable and welcoming environment for patients to feel cared for and supported. Wellbeing groups fulfil patients' needs to socially interact with others and are believed to enhance patients' QOL by providing a non-judgemental outlet for creative expression.

The present study aimed to qualitatively explore why people living with and beyond a cancer diagnosis continued to attend supportive wellbeing groups within clinical settings. The research also set out to understand participants' attitudes and experiences towards wellbeing groups and their perceived impact of attending a group. This was researched from a critical realist and phenomenological approach, using a combination of focus groups, individual interviews and telephone interviews to collect participant data. All participants had been directly affected by cancer and were all living with or beyond a diagnosis. An inductive approach to thematic analysis was employed in order to identify key recurring themes from participant responses within the dataset. Ethical guidelines and procedures were followed strictly throughout, paying particular attention to the NHS, BPS and HCPC codes of conduct.

Generally, the present study's sample represented a broad range of cancer types and stages of illness, including during treatment and post-treatment. After analysis, results highlighted three key themes and nine sub-themes. Key themes included: (1) Identity, perception and reflection, (2) Feeling lost after cancer treatment ends, and (3) Always accepted, never judged. In brief, the results concluded that wellbeing groups do provide significant levels of support to people living with and beyond a cancer diagnosis. It helps people feel safe, connected, motivated and accepted. Regular attendance at wellbeing groups also allows patients to form a sense of togetherness and build new friendships based on shared understanding. In addition to this, findings also identified that a skilled and experienced group facilitator added value and a feeling of safety to wellbeing groups. Finally, participants also suggested that wellbeing groups felt supportive in a non-clinical and medicalised way. Therefore, ensuring that wellbeing groups did not focus entirely on cancer related topics was as an additional key reason why patients continued to attend and positively rate wellbeing groups.

Moving beyond the present study, the findings should be used as a starting point for future research to follow. Further research projects could potentially recruit participants who have not accessed wellbeing groups, or those who choose not to return to a group after less than three sessions. This would help to understand why people do not attend. In addition to this, the inclusion of healthcare professionals who facilitate wellbeing groups would also add more knowledge to this area of psycho-oncology and subsequently help to raise awareness amongst medical communities. Findings from the present study could also be used to help inform future practice and additionally shape how holistic cancer support is integrated alongside routine cancer care in the future. Having rich qualitative evidence to support the delivery of wellbeing groups in clinical settings, for people affected by cancer, will provide justification for future funding and also educate people about the positive benefits of wellbeing groups.

Word count: 30, 160

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Appendix A: Participant information sheet
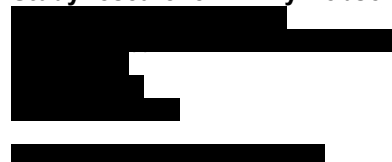
CITY UNIVERSITY LONDON

Study researcher: Emily Robson

Title of study:

A qualitative study exploring the impact of receiving group interventions within a cancer care setting

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?
The primary purpose of this study is to gain a greater understanding and awareness about the impact of receiving wellbeing group intervention sessions within a cancer care setting, among people affected by cancer.

Why have I been invited?
You have been invited to take part in this study because you have previously attended wellbeing group sessions (e.g. yoga and/or creative writing) at the Macmillan Support and Information Service. The study is open to all patients being treated for a cancer diagnosis at UCLH and who have attended at least three group sessions at the centre.

Do I have to take part?
Participation within this study is entirely voluntary and will not affect any future treatment or care that you receive. Participants may withdraw at any stage or avoid answering questions that might be considered too personal or intrusive. Confidentiality and anonymity of patient details and data will be strictly maintained throughout.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason.

What will happen if I take part?

- You will be asked to take part in a focus group interview that is expected to last between 60 and 90 minutes. One-to-one interviews can be arranged if the participant prefers this.
- Data collection will take place over a time period of around 5 months, however you will only be required to attend one focus group interview.
- Participants will meet the researcher on one occasion only.
- The researcher will ask for some basic demographic information prior to the focus group interview. The interview will involve between 4 to 8 participants.
- All interviews will be audio recorded (for the researchers use only) and later transcribed.
- Research will take place within the Macmillan Support and Information Service (in the Living Room) at UCH Macmillan Cancer Centre.

What do I have to do?
You will be asked to attend a focus group (or individual interview if preferred) at a suitable and convenient time (this may be before or after your regular scheduled group session, or at an alternative time).

What are the possible disadvantages and risks of taking part?
There will be minimal risks when taking part in this study. Participants are under no obligation to answer questions and can pause or leave the study at any given time.

What are the possible benefits of taking part?
This study will contribute to already existing knowledge about group interventions in clinical cancer settings. Findings from this research will benefit future patients' experiences of group sessions and in turn improve quality of life for themselves and their family members.

Data from some focus group interviews may also be used as part of service evaluations at the Macmillan Support and Information Service. Such evaluations will contribute towards ongoing service improvement and in turn improve the experiences of care that future patients receive at UCLH.

What will happen when the research study stops?
Upon completion of the study, participant data will be stored securely, on a password-protected file, for a total of 3 years. Participant details (included name and contact details) will remain anonymous and confidentiality will be maintained.

Will my taking part in the study be kept confidential?

- Only the lead researcher will have access to participant information (details disclosed within the pre-interview questionnaire).
- Audio recordings will be stored on a password-protected file on the lead researcher's personal computer.

- Data may be used within the three years after completion of the main study, but all participant information will remain anonymous.
- Direct quotations may be used in the final report, but identifiable information (e.g. participant name) will always remain anonymous.
- Data may be used for future service evaluations, but participant details (include name and contact details) will always remain anonymous and confidential.
- The lead researcher may have to break the confidentiality agreement if an individual is in danger of violence, abuse, self-inflicted harm, harm to others or criminal activity.
- All data records will be stored on a password-protected file on the lead researcher's personal computer. All information will be destroyed after 3 years.

What will happen to the results of the research study?
Results of the study will be used for a doctorate award in Health Psychology.

What will happen if I don't want to carry on with the study?
The participant is free to withdraw from the study without an explanation or penalty at any time. After participants have completed their focus group interview (or open-ended questionnaire) they will be unable to withdraw their data, however confidentiality (including name and contact details) will be strictly maintained.

What if there is a problem?
If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: A qualitative study exploring the impact of receiving group interventions within a cancer care setting

You could also write to the Secretary at:

██████████████

Secretary to Senate Research Ethics Committee

████████████████████
██████████████████
███████████
███████

Email: ███████████████████

City University London holds insurance policies that apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If

you are harmed due to someone's negligence, then you may have grounds for legal action.

Who has reviewed the study?
Cambridge East Research Ethics Committee has reviewed this study and provided ethical approval (REC reference: 16/EE/0143).

Further information and contact details
Emily Robson (Lead Researcher): emily.robson@city.ac.uk
███████████ (Academic Doctorate Supervisor): ████████████████
███████████ (Workplace Doctorate Supervisor): ██████████████

Thank you for taking the time to read this information sheet.

Appendix B: Participant consent form

CITY UNIVERSITY LONDON

Study researcher: Emily Robson

Title of Study:

A qualitative study exploring the impact of receiving group interventions within a cancer care setting

Ethics approval code: [16/EE/0143]   Please initial or circle where applicable

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records. I understand this will involve:	
	Being interviewed by the researcher (as part of a focus group).	
	Allowing the interview to be audio recorded.	
	Completing a pre-interview questionnaire with demographic information.	
	Allowing direct quotes given within an interview to be used in the final report (your name will remain anonymous).	
2.	This information will be held and processed for the following purpose(s): To answer the research question. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I would like to be contacted after the study has ended and asked if I would like a copy of the study results.	Yes/No
6.	I agree to take part in the above study.	

_____   _____   _____

Name of Participant   Signature   Date

_____   _____   _____

Name of Researcher   Signature   Date

Appendix C: Participant demographic questionnaire

![City University London logo]

Pre-focus group demographic questionnaire

Thank you for agreeing to take part in this study about participation within wellbeing group interventions. Please complete this short questionnaire before taking part in the focus group interview. All of your answers will remain completely confidential. You have the right to pass questions or withdraw from the study at any time, without penalisation or compromise to your care that you receive at University College London Hospital.

Name:

Date of birth:

Gender:

Diagnosis:

1. Name of group session that you attended at the Macmillan Support and Information Service:

2. Duration of time that you spent in the group (approximately):

Thank you for taking the time to complete this questionnaire.

Please hand completed questionnaires to Emily Robson (Lead Researcher) or a member of the living room team.

Appendix D: Participant debrief sheet

CITY UNIVERSITY LONDON

A qualitative study exploring the impact of receiving group interventions within a cancer care setting

DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

The study's main aim was to gain a greater understanding and awareness about the impact of receiving wellbeing group intervention sessions within a cancer care setting, among people affected by cancer. We hope that the study will also contribute towards on-going service improvement and in turn, improve quality of life for future patients and their family members at UCLH.

If this study has raised concerns for you, please feel free to call into the Macmillan Support and Information Service, to speak with a member of the specialist team (or call 020 3447 8663).

We hope you found the study interesting. If you have any further questions please do not hesitate to contact us at the following:

Emily Robson (Lead Researcher): emily.robson@city.ac.uk
████████████ (Academic Doctorate Supervisor): ████████████
████████████ (Workplace Doctorate Supervisor: ████████████

Ethics approval code:[16/EE/0143]

Appendix E: Preliminary hand-coding of transcripts

113 **Interviewer**
114 (yeah)

115 **HANNAH**
116 so being with other people yeah is definitely important and even though we're *Being with*
117 all there at the same place, at the same time, it's just not actually having to talk *other people is*
118 about the cancer which is a bit of a relief and yeah like a break from it all I *important*
119 suppose...

'relief' and 'a break'

120 **Interviewer**
121 (yeah)

122 **HANNAH**
123 everyone kind of knows but without having to say what is obvious if that makes *knowing that*
124 sense *cancer is present but not talking about it.*

125 **Interviewer**
126 yeah, no that makes sense completely

127 **HANNAH**
128 you know because unless you have experienced a similar thing, like first hand *First hand experience*
129 you know, I just don't think people really get all those feelings, but here people *↓*
130 do and they just know, so erm, there's no pressure and there's no competition, *understanding*
131 it's not intimidating like I think it would be if I went somewhere else (pause) it's *-'no pressure*
132 calm and relaxing and that's really why I like it to be honest *-'no competition'*
- 'Somewhere else'
-'Calm and relaxing'

133 **Interviewer**
134 yeah

135 **HANNAH**
136 but I mean we don't socialize or you know I don't really know any of them
137 outside the group (pause) they're all very welcoming and it is nice to be together *-Welcoming*
138 just for that time because like I said there is that understanding there *-'nice to be together'*
-understanding

139 **Interviewer**
140 yeah no it's interesting that you say that

50 GILL
51 and I haven't been able to go because I've been really ill with the chemo but it
52 definitely has a really positive influence and yeah it's excellent, I'm definitely   'positive influence'
53 going back after to do more of the sessions, it is only that I've not been well that
54 I've not gone, no other reason   'it's excellent'

55 Interviewer
56 okay so what is it about the group that you really like (pause) because obviously
57 there's other yoga classes external, you know outside of the hospital...

58 GILL
59 (well) you're not pushed   'not pushed'
                                   ↓
60 Interviewer   unlike other classes.
61 you're not pushed?

62 GILL   'own pace'
63 you're not pushed, erm, it's very, it's not at all competitive and you can go at - non-competitive
64 your own pace (pause) the teacher knows everyone's strengths and if someone - Teacher is
65 has certain difficulties or problems, everyone is individual even though it's a   aware
66 group class you know, erm there's no rush, we're never rushed to all do things - No rush
67 together, everything is at our pace and in our own time which is what probably Doing things
68 makes it feel so relaxing as well (pause) and the teacher, she's so attentive and   together
69 she knows when or if you're struggling and I just don't know if going somewhere - Relaxing
70 else would be like that, I don't think you could ever get that sort of one-to-one · Teacher is
                                                                                         attentive
71 attention when you're still in a group   · 'I don't know if going somewhere
                                                   else would be like that'
72 Interviewer   - 'one-to-one attention'.
73 yeah

74 GILL
75 and also, it's a very stressless environment which again I don't know if you 'Stressless
76 would always get if you went somewhere else (pause) erm, you don't feel   environment'.
77 pressure like you might do in other classes you know, to keep pushing yourself No pressure
78 forward and learning to do all the moves really well, that's not what this class is 'Other
                                                                                            classes'
79 like (pause) and it's nice I think to be in quite small groups   Small groups

130

Appendix F: Supervision plan

Supervision Plan - research

Supervisee: ___Emily Robson_____

Supervisor: _____█████████████_____

Research	Area of work (*outside of normal work)	Supporting evidence	Changes
Research thesis	**Setting**: Patients living with and beyond a cancer diagnosis and who regularly participate within a wellbeing group (such as yoga or creative wring) at UCH MSIS, part of University College London Hospitals NHS Foundation Trust. **Description**: 20 qualitative semi-structured interviews with people living with and beyond a cancer diagnosis. Participants have a range of cancer types and are all at different stages of their cancer experiences. Key study aims include: 1) To understand why people living with and beyond cancer choose to regularly attend wellbeing groups in clinical settings 2) Explore patients' experiences and attitudes towards attending wellbeing groups 3) Identify the perceived impact that attending a group may have on those who attend. Focus groups will be employed to collect data, using semi-structured interviews with all participants. Interview audio recordings will be transcribed and then analysed using an inductive approach to thematic analysis. This will highlight any key recurring themes from within the dataset.	Thesis of 30,000 words + 2 publishable papers, approx. 10,000 words)	Due to difficulty with focus group recruitment and attendance, data collection methods were changed to focus groups, individual face-to-face interviews and individual telephone interviews.
Systematic review	The effectiveness of mindfulness techniques for adults with recurring chronic headaches and migraines: A systematic review	Systematic review (6000 words) – to also be used as an example of a publishable paper	

131

SECTION C: PUBLICATIONS

Publishable paper 1: A qualitative study exploring mothers' views on sugar and hidden sugar in their children's diets

Abstract

Background: Excess sugar consumption within children's diets is believed to be a contributing factor towards the prevalence of childhood obesity, tooth decay and fatty liver disease. Guidelines have stated that sugar consumption should only account for 5% of total dietary intake. However, research has shown that many children consume above the recommended amount, typically through food products that contain hidden and added sugars.

Aim: To explore mothers' views on sugar and hidden sugar in their children's diets.

Methodology: A total number of 11 participants were recruited; all mothers from the United Kingdom (UK) with at least one child between the ages of 2-12 years of age. Data were collected using one-to-one semi-structured interviews, which were later transcribed and thematically analysed to identify recurring themes.

Results: In total, four key themes and eight sub-themes were identified from the data. Main themes included: (1) Mum in a buffering role, (2) External support systems, (3) Compromise in social contexts, and (4) Confusion and misunderstanding. Themes were interconnecting and layered, which is shown in a conceptual model (Figure 1).

Conclusion: A number of factors contribute to the consumption of high-sugar food items and the mother adopts a buffering role in order to protect the child. Improved education and/or advice for parents are warranted, in addition to wider scale efforts such as government legislation changes. Future research should incorporate the views of other family members (e.g. fathers and grandparents), in order to keep up-to-date with modern societal changes and understand the research question further.

Keywords
Childhood; obesity; sugar; parent; awareness; knowledge.

Introduction

Obesity is a wide scale global health issue that affects millions of individuals each year. Over the course of three decades obesity rates have significantly increased and been labelled a major health epidemic (Han, Lawlor, & Kimm, 2010; Hruby & Hu, 2015). In the UK alone, reports estimate that obesity related illnesses could cost the National Health Service (NHS) approximately £49.9 billion per year by 2050 (McPherson, Marsh, & Brown, 2007). Obesity amongst children also raises equal levels of concern (Drotz, 2012; Fisher et al., 2015). According to the World Health Organization (WHO, 2016) the number of overweight and obese infants (0-5 years of age) reached a total of 41 million in 2014. Without effective intervention, obese children are highly likely to remain obese throughout the duration of their lives (WHO, 2014; WHO, 2015). Childhood obesity is associated with the premature onset of illnesses typically associated with adulthood such as coronary heart disease, certain types of cancer and Type-2 diabetes (Hruby & Hu, 2015; Kell, Cardel, Bohan Brown, & Fernández, 2014; Llewellyn, Simmonds, Owen, & Woolacott, 2016; WHO, 2014). In addition to the physical health implications, it is also believed that overweight or obese children are more likely to experience negative psychological trauma such as stigmatization, low self-esteem and potential isolation from peers (DeSmet et al., 2014).

Recent media has focused less on issues relating to fat, salt and portion size and instead redirected focus towards sugar. The Scientific Advisory Committee on Nutrition (SACN, 2015) advised that the total intake of *'free sugars'* should not exceed 5% of total dietary intake. The term *'free sugars'* defines any additional sugar added by a manufacturer (Malnick, 2014). For children aged between 4-6 years the total intake of sugar should not exceed 19 grams per day, and for children aged between 6-10 years, the total amount is 24 grams (SACN, 2015). However, daily sugar intake among children is largely dependent on parental awareness and their willingness to implement dietary changes. Research has shown that parents transfer nutritional knowledge and significantly contribute to the formation of their children's food preferences (Zarnowiecki, Sinn, Petkov, & Dollman, 2012). Research exploring snacking behaviour amongst children found that parents perceived regular sweet treats as normal and admitted to using sugary food items as rewards for good behaviour (Pescud, Pettigrew, & Henley, 2014). In similar research, Fisher et al.

(2015) found that parents also enjoyed eating high-sugar snacks and did not consider such products as *'real'* food.

There is now a growing public awareness for hidden sugars, in which foods typically perceived as *'healthy'*, such as smoothies, yoghurts and pre-made pasta sauces, often contain unknowingly high quantities of sugar. In a study that explored sugar content in products aimed at children, findings revealed that the sugar in fruit juices, juice drinks and smoothies was unacceptably high with over 40% of products containing at least 19 grams of sugar (Boulton et al., 2016). Further research has found that sugar-sweetened beverages contribute significantly towards weight gain, fatty liver disease and metabolic syndrome (Bray & Popkin, 2014). Other research has similarly concluded that snack food items such as biscuits, sweets and desserts typically contain high levels of added sugars when purchased from stores (Drewnowski & Rehm, 2014). Amongst children, a high intake of added sugars has been associated with lifestyle factors such as eating outside of the home and eating in front of a screen (Farajian, Risvas, Panagiotakos, & Zampelas, 2016).

The main aim of the current study is to explore mothers' views on the health implications associated with excess sugar consumption in their children's diets. The study also aims to understand how mothers' attempt to manage their children's daily intake of sugar and hidden sugar.

Method

Participants

The sample included 11 mothers with children aged between 2-16 years of age. However, the study only focused on exploring mothers' views on sugar consumption in their children under the age of 12 years. An opportunity sample was used to recruit mothers from different regions across the UK. All participants volunteered to take part.

Materials

Prior to the qualitative interviews taking place, ethical approval was sought and granted from the Ethics Committee in the Psychology Department at City, University of London. All participants were given a detailed information sheet and asked to sign

a consent form in order to indicate that they understood what was required. During data collection, the lead researcher conducted all interviews via telephone and employed a semi-structured interview schedule that asked participants open-ended questions. Upon completion of all interviews, participants were given a debrief sheet.

Procedure

Key questions within the interview schedule focused on levels of children's sugar consumption; awareness of sugar content in foods; parental and school responsibilities, and support that should be made available to educate parents. All interviews were audio recorded and transcribed verbatim. An inductive approach to thematic analysis (Braun & Clarke, 2006) was then undertaken in order to establish emerging themes.

Results

As Table 1 shows, participants were recruited from three key regions in the UK including the North East (N=1), Midlands (N=8), and London (N=2). All mothers had at least one child within the specified age criteria of the study. Most participants were in part-time employment at the time of data collection (N=5), whilst others were in full-time (N=2), maternity leave (N=2), or undertaking higher education courses (N=2). All interview transcripts were inductively analysed using thematic analysis, which identified four key themes that emerged consistently throughout (see Table 2).

Table 1

Participant demographic information (employment status, location, number of children, child gender and age)

Participant	Employment status	Location	Number of children	Child gender (age)
1	Maternity leave	North East	1	Girl (3)
2	Maternity leave	Midlands	2	Girl (6), Girl (8)
3	Part-time	Midlands	2	Boy (7), Girl (10)
4	Part-time	Midlands	2	Boy (10), Boy (14)
5	Part-time	Midlands	2	Boy (2), Girl (10)
6	Part-time	Midlands	2	Girl (8), Boy (16)
7	Full-time	Midlands	2	Boy (9), Boy (12)
8	Full-time	Midlands	2	Boy (10), Boy (12)
9	Student	London	2	Girl (7), Boy (10)
10	Part-time	Midlands	2	Boy (6), Girl (8)
11	Student	London	2	Girl (5), Girl (7)

Table 2

Superordinate and subordinate themes

Theme Number	Superordinate themes	Subordinate themes
1	Mum in a buffering role	- Attempt to install structure - Managing a balance - Willingness to take responsibility
2	External support systems	- Trust for authoritative figures - Socio-economic factors
3	Compromise in social contexts	- Occurrence of social traditions/activities - Influence of grandparents
4	Confusion and misunderstanding	- Feelings of confusion regarding nutritional guidelines

Theme 1: Mum in a buffering role

Thematic analysis revealed the complexity of the mother's role as the primary caregiver; the mother displayed buffering style behaviours in order to protect the child from a range of factors contributing towards excess sugar consumption. Theme one is central to all other subsequent themes and provides a basis for the conceptual model. Theme one has three sub-themes:

Attempt to install structure

Mothers had frequently displayed clear attempts to install structure and boundaries to their children's eating habits, in particular their access and consumption of high-sugar food items. Mothers' awareness for current media attention regarding sugar consumption was potentially the reason why parents installed boundaries; most participants did show some level of knowledge regarding the implications associated with excess sugar and hidden sugars in children's diets. Parents discussed their efforts to limit such foods (e.g. sweets, chocolate and cake) to weekends exclusively or after meals. For example,

> *"Really I suppose the only other time they really have sweets at home is at the weekend."*

Managing a balance

Mothers similarly discussed their efforts to ensure that *'ideal'* foods (e.g. fresh fruit and vegetables) were consumed first by the child, in order to justify a sweet treat afterwards. This was a theme that re-emerged several times by a number of parents often defined as *'finding a balance'* and a means of ensuring that a healthy, well-rounded diet was achieved for their children. In addition to seeking balance, the mothers also discussed moderation as a contributing factor to their decision making process. One participant reported:

> *"As long as they can have a little bit of what they fancy now and again as a treat, after a meal...it's just moderation."*

Willingness to take responsibility

A willingness to take responsibility was one of the most significant themes to surface from the data. When questioned about parental responsibility and propositioned with the idea that parents were being blamed, all eleven participants agreed that parents should take responsibility for what their children eat, including monitoring and controlling the level of sugar consumption. Furthermore, mothers revealed that they frequently acknowledged health information and adapted it to suit the needs of their family. For example,

> *"I would say that ultimately it is the parent's responsibility."*

Theme 2: External support systems

External support systems were identified as a major contributor to parental awareness, both positively and negatively. It was revealed that mothers have trust for some support systems (e.g. figures of authority), but hold some feelings of dissatisfaction for others (e.g. media and food industry). Socio-economic status was also identified as an external support system, which is a further obstacle for the mother to overcome and adds to her buffering role previously identified. Two sub-themes have been identified for this over-arching theme.

Trust for authoritative figures

Parents discussed their feelings of trust for authoritative figures (e.g. health care professionals such as school nurses, doctors and dentists) and genuine belief for health advice that was provided by them. One mother stated:

> *"I've probably taken the most information from the dentist actually…or the doctor."*

In contrast, participants conveyed a clear lack of trust for the media and food industry. Parents were inclined to believe that *'advice'* provided by external support systems such as the food industry or media were bias and had an agenda, unlike health professionals who were perceived as impartial and dependable sources. Many of the mothers demonstrated awareness for hidden sugars in products that the food industry frequently market as healthier options, such as yogurts and fruity breakfast bars. One mother commented:

> *"I think some of the treats are misleading."*

Socio-economic factors

Parents frequently discussed supermarket pricing of *'junk'* foods in comparison to *'ideal'* foods. Mothers claimed that supermarket offers were enticing and often more cost effective than purchasing ideal food items. Most parents admitted to regularly purchasing high-sugar products on special offer and therefore having these types of food items readily available for children to access at home:

> *"I think sometimes you go to the supermarkets and the fruits really expensive and sweets and things like that are cheap."*

Theme 3: Compromise in social contexts

Thematic analysis revealed that certain social situations do contribute to the consumption of extra sugar. Embedded social norms and traditions yet again challenge the mother as she adopts her buffering role, which often results in difficulty and/or failure to install structure. Visiting grandparents and attending social activities caused parents to compromise their boundaries. Theme three has two sub-themes.

Occurrence of social traditions/activities

Regardless of any efforts to install structure, parents repeatedly made associations between out of school activities (e.g. swimming or running) and the consumption of high-sugared food and drink items. In addition, parents displayed negotiation style behaviours as social activities were used as justification for excess sugar consumption. Mothers also spoke about the need to conform in certain social contexts such as at *'parties'* and *'days out'* when children often expected to consume high quantities of sugar rich foods:

> *"Obviously treats if they go out to a party or if you're out and about."*

Influence of grandparents

The influence of grandparents was also identified as a contributing element to sugar consumption and influential towards the lessening of any structure or boundaries implemented by the mother. An acceptance that sugar consumption amongst children would increase as a result of spending time with grandparents was evident amongst many of the participants. One parent reported:

> *"At weekends when we go to their grandparents ... obviously then they do have more."*

Theme 4: Confusion and misunderstanding

It emerged that some levels of confusion and/or misunderstanding towards nutritional guidelines was present amongst the participants. Although most mothers had a level of awareness for the health issues associated with sugar consumption, some said that they had experienced feelings of uncertainty about what they should and should not be feeding their child, based on information they had read and/or heard. This was particularly evident during discussions about the media and food industry. Within this key theme, an addition sub-theme also emerged.

Feelings of confusion regarding nutritional guidelines

Mothers said they often felt confused and annoyed over constantly changing health advice, which participants claimed was conflicting and unsupportive. Generally, mothers were aware of the media coverage regarding sugar consumption, but believed

that more could be done to simplify information for parents. Furthermore, an inconsistency between nutritional advice and school dinners was a cause for concern amongst many of the participants. Mothers explained that although school rules had prohibited high-sugar food items from lunchboxes, sweetened puddings had still remained a regular norm within school dinners. Parents commented on their confusion regarding this particular issue by one stating:

"There are times when certain things in lunchboxes get taken off children, but then if they have a hot meal you can have cake and custard every day."
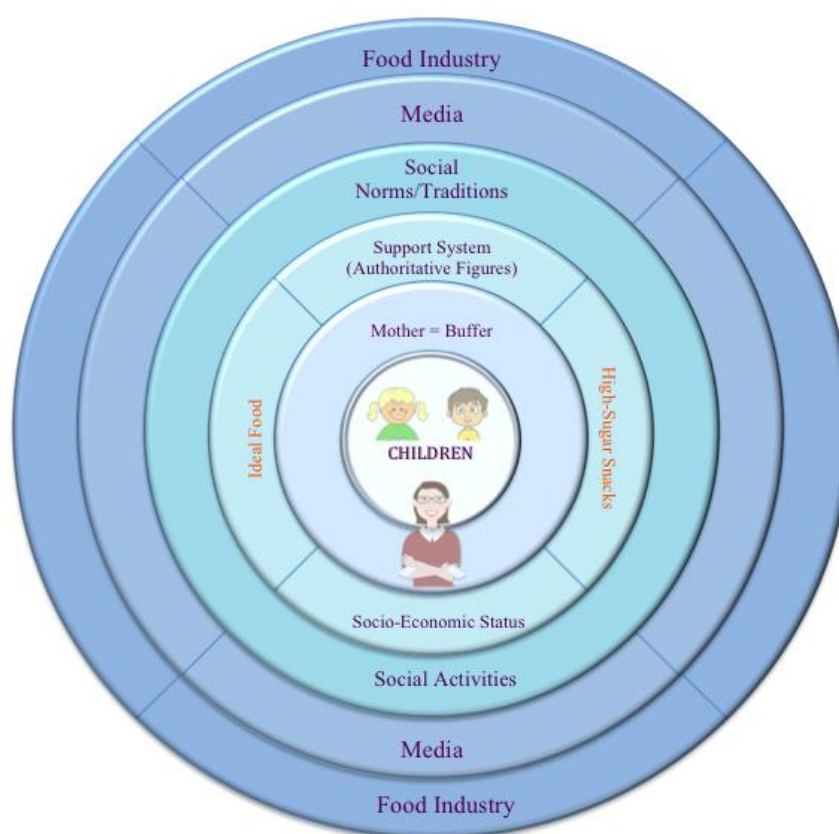
Figure 1. Conceptual model of interconnecting themes

As Figure 1 shows, all themes identified within the present study are related and interconnect to some degree. The conceptual model proposes a framework of how each theme is interrelated. The model represents the relationship between the mother, environment and consumption of sugar. Children are at the centre and exposed to a range of external factors that influence the prevalence of excess sugar consumption within their diets. The mother's role is to then act as a *'buffer'* against the external

141

factors in an attempt to balance high sugar food items with ideal food items. However, the mother has to contend with factors that are closely connected to the family including socio-economic status (e.g. the family's financial situation) and external support systems (e.g. access to trustworthy and reliable information). The second layer of the model represents social norms/traditions and extracurricular activities. Parents have to contend with the expectation that *'treat'* foods are acceptable in certain social surroundings. Furthermore, the third and fourth outer layers represent the media and food industries that respectively contribute to mothers misunderstanding and confusion (e.g. marketing products towards children with unknowingly high quantities of added and hidden sugars).

Discussion

Summary

Four key themes have been established from the present study: (1) Mum in a buffering role, (2) External support systems, (3) Compromise in social contexts, and (4) Confusion and Misunderstanding. Each theme is layered with *'Mum in a buffering role'* at the centre. The conceptual model (Figure 1) depicts the complexity of the mother's role. Findings revealed that mothers do have a good awareness for the implications associated with excess sugar consumption and do make clear efforts to manage the amount of sugar that their children regularly consume. Findings also identified that mothers are willing to accept responsibility for the levels of sugar that their children consume, by generally insisting that their role as primary caregiver gives them the final choice and ultimate responsibility.

The association between parental awareness and children's diet has been explored in previous research. According to Fisher et al. (2015) low-income mothers perceived snack food items as tools for managing behaviour, instead of providing nourishment for the child. Similarly, the consumption of *'extra foods'* was viewed as acceptable by parents who identified moderation and balance as two key aspects of their children's diets (Petrunoff, Wilkenfeld, King, & Flood, 2014). Results from the current study align with these previous findings. Study outcomes identified the importance of managing a balance between high sugar snacks and ideal food items. In support of this, previous research has found that parents play a critical role in the prevalence of childhood obesity (Lindsay, Sussner, Kim, & Gortmaker, 2006) and as a result, the

home environment is an ideal setting for future interventions to take place (Ansem, Lenthe, Schrijvers, Rodenburg, & Mheen, 2014).

Participants within the present study also conveyed feelings of confusion and misunderstanding for certain nutritional guidelines. Similarly, a previous study that surveyed 1,000 British parents found that parents were also confused and had experienced levels of frustration over inconsistent nutritional advice (Fruit Heros, 2014). To be precise, 84% of parents were concerned about their child's diet and almost 50% did not believe that nutritional guidelines were clear. Parents similarly claimed that a lack of knowledge was a significant barrier and often resulted in poor food choices (Fruit Heros, 2014). However, this was a relatively small-scale survey conducted by a food manufacturing company, which therefore may suggest that results are not entirely reliable and generalisable to wider populations.

Recommendations

Current study findings imply that better education and/or training for parents is justified. Therefore, if current nutritional guidelines were simplified and made consistent, parents' knowledge would improve and children would be positively affected as a result. For example, the SACN (2015) which advised that total dietary intake of free sugars should be lowered to 5% was summarised for the public by the NHS (2015). However despite such efforts to simplify information, the material reported still remained largely unclear. Therefore, future research should evaluate the effectiveness of these efforts and consider other ways in which complicated terminology can be simplified further for parents. Nevertheless, this is an encouraging start and parents would positively welcome more efforts to implement change in the future.

A rise in *'working families'* has resulted in busy parents passing more child-care responsibilities over to grandparents (Hinsliff, 2015). Present study findings also identified that grandparents play a significant role in children's eating behaviour. Consequently, future research could focus heavily on the role of grandparents. This will provide a thorough and greater understanding of the present issue, from a perspective that has been relatively under researched. It will also ensure that findings are generalisable and consistent with societal changes. In addition to grandparents,

fathers should also be considered more in future research. Research in this area typically recruits all female participants (Fisher et al., 2015; Spinks & Hamilton, 2015; Walsh et al., 2015; Pescud & Pettigrew, 2014) and rationalisation for excluding male participants is relatively unclear. However, research has suggested that females still tend to have the majority of responsibility for cooking and purchasing food for the family (Walsh et al., 2015; Ipsos Global Trends Survey, 2014). In today's society the family construct is complex and diverse. Therefore, research should reflect these societal changes.

Limitations

Social desirability bias is a potential limitation of this study. Parents' dislike being the target of judgment, with research suggesting that being called a *'bad parent'* is the most offensive criticism (Home-Start UK, 2013). Therefore, in an effort to gain social acceptance and create a *'perfect parent'* image, it is possible that some participants in the present study provided dishonest responses, which could have skewed data and created unreliable results. However, during data collection all efforts were installed to ensure that social desirability bias remained absent from participant responses. Secondly, it should be noted that the current study used a sample of mothers only. Although this may be considered as a potential limitation of the study, a clear gap within previous literature did provide a rationale for the study. Finally, the use of thematic analysis within this study could also be viewed as a possible limitation. The thematic process of analysing qualitative data does not possess wide scale kudos unlike other forms of analytical methods (Braun & Clarke, 2006). In addition to this, some researchers who lack familiarity for qualitative methodologies may believe that thematic analysis is too flexible and unstructured (Braun & Clarke, 2006). However, thematic analysis was identified as the best form of analysis for the current study. Clear and strong themes were established, which reflect both reality and embedded meanings from within and across the data set.

Conclusion

Interlinked themes have emerged from the results of this study, which have significantly added to understanding of this topical issue and set a basis for future research to follow. While the study did conclude that parents held some level of awareness for the health implications associated with sugar and hidden sugar, findings

suggested that clearer nutritional advice aimed at parents is still warranted. Themes were relatively layered, however the distance between the mother and external factors such as media and food industry could be narrowed. Therefore, wide scale efforts such as government legislation changes would initiate a promising start. In addition to this, future research efforts should consider studying fathers and/or grandparents in relation to their awareness of sugar consumption. Subsequently, this would mimic societal changes and offer more in-depth understanding into children's daily sugar intake.

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Human and animal rights

The work described has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki).

Editorial style

Throughout this paper the 6th edition of the American Psychological Association was employed.

Declaration of interest

Conflicts of interest: none.

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Publishable paper 2: The effectiveness of mindfulness-based techniques for adults with recurring chronic headaches and migraines: A systematic review

Abstract

Introduction: Chronic headaches and migraines are amongst the top three common causes of disability worldwide. Symptoms can cause debilitating pain that interfere with everyday tasks and quality of life (QOL). Unpleasant side effects from taking pharmaceutical drugs to manage pain have led to an increased uptake in alternative therapies (e.g. mindfulness). Mindfulness has been associated with improved mental health and reduced stress.

Aim: Identify and assess the effectiveness of mindfulness techniques for adults managing recurring chronic headaches and/or migraines.

Method: A search of English, peer-reviewed literature published between 2007-2017 was conducted within 11 databases. Key words included *'mindfulness'*, *'headache'* and *'adult'*. Inclusion criteria consisted of adults aged over 18 years, diagnosis of headache and/or migraine, randomised control trial (RCT), and use of an intervention that applied mindfulness-based techniques. A quality assessment tool was applied.

Results: After initial searching, 369 studies were retrieved. Following screening and eligibility checks, 9 RCT studies remained. Interventions that applied mindfulness-based stress reduction techniques (including relaxation and breathing exercises) occurred most frequently. Results reported favourably for the effectiveness of mindfulness-based interventions. Headache and migraine frequency decreased and QOL improved.

Discussion and conclusion: It is fundamental that alternative treatments such as mindfulness are offered as part of pain management interventions more frequently. Future reviews should focus on mindfulness for children and/or adolescents with headache, and also qualitative study-designs exploring patient experience should be included. Whilst this review presents preliminary findings, more rigorous RCTs should be conducted in the future in order to explore the research question further.

Keywords

Mindfulness, headache, migraine, randomised control trial, adult

150

Event Review

Presenting research for the first time at the 2016 EHPS/DHP joint annual conference

Emily Robson
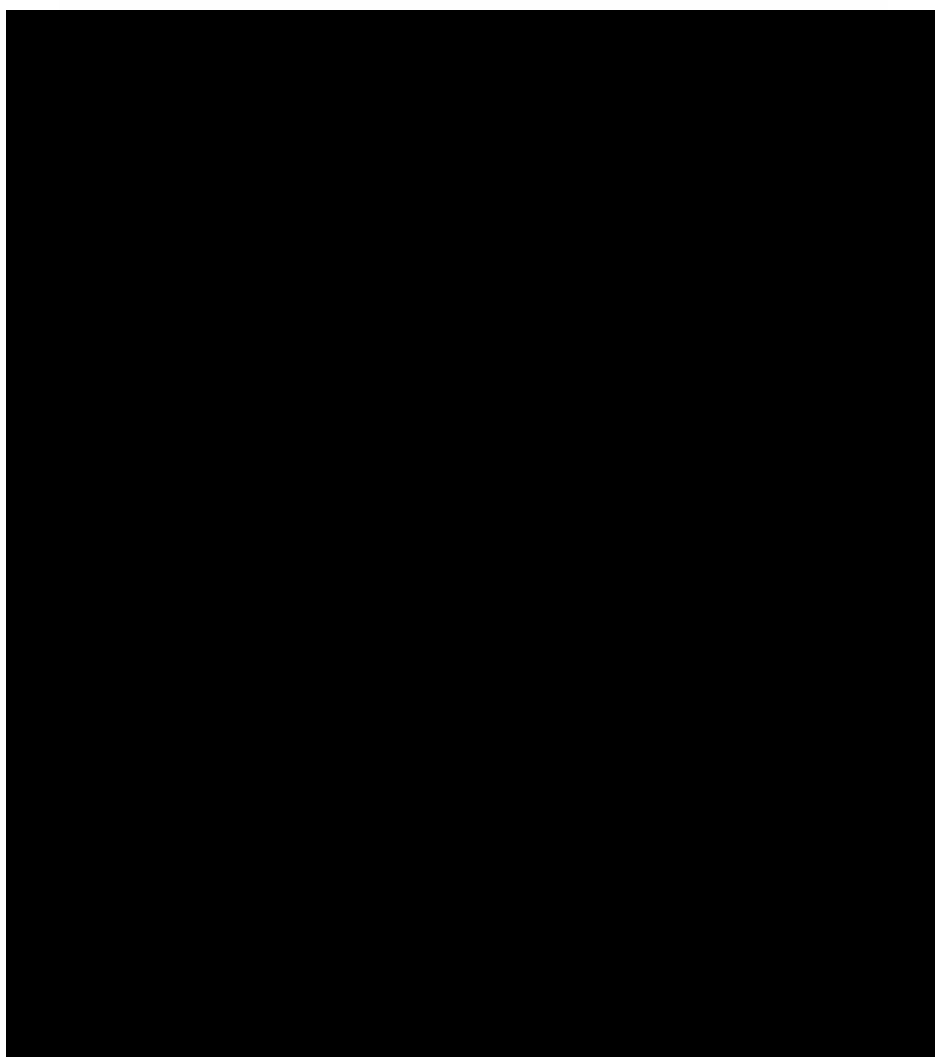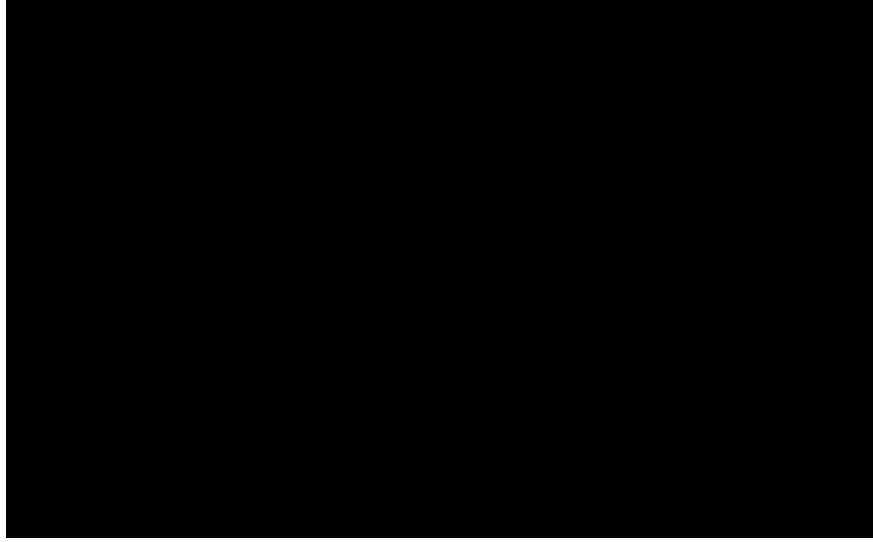
SECTION D: PROFESSIONAL PRACTICE (COMPETENCIES)

UNIT 1: GENERIC PROFESSIONAL PRACTICE

Introduction

Since I began my training, which started initially with the completion of an MSc in health psychology, I have learnt more than I ever thought I could and exceeded all of my own expectations. I have developed knowledge and acquired skills through a range of different professional and academic experiences. However, most of the work evident within this portfolio has been completed during my role as trainee health psychologist, based within UCH MSIS (workplace documents can be found in Appendix A). Throughout the two years in this role I received excellent support, guidance, opportunities and encouragement. In addition to completing the majority of professional competencies in this role, I also had the privilege of undertaking a research study at the service. The research aim was to identify and understand patients' experiences and reasons for attending supportive wellbeing groups in clinical settings.

In addition to research and professional competencies, the day-to-day role was recorded in a daily activity log (see evidence folder). I used the daily log as an opportunity to self-reflect on my experiences and to record my progress. My role and position at the service differed each day and as the only trainee health psychologist within the service it was sometimes difficult, particularly at the beginning, to define my role. However, I worked hard to establish my position and typically worked alongside the support and information specialist team to assist and support with the daily running of UCH MSIS. Whilst training at UCH MSIS, I was presented with a number of excellent opportunities to develop both professionally and personally. I worked closely with many healthcare professionals across the trust, engaged with service users daily and was trusted to independently make key decisions. During my role I was also presented with opportunities to lead groups of people. This was particularly evident within the behaviour change intervention and teaching and training competencies. These specific activities, which required presenting information and directing group tasks, significantly strengthened my communication skills and general confidence. The drop-in service at UCH MSIS offered in-the-

moment emotional and practical support to any person affected by cancer or red cell condition including patients, relatives, friends and carers. In addition to an extensive library of written information, visitors were also encouraged to use the informal space, known as the *'Living Room'*, to gather their thoughts or talk through their concerns and worries with a member of the specialist team. All specialist staff were qualified and registered health care professionals. The service additionally offered complementary therapies, welfare rights advice, psychological and counselling services, dietetic advice, and a wig and scarf-tying service.

This case study will outline and summarise my experiences of completing the stage two training programme in just two years, whilst undertaking a full-time role as a trainee health psychologist. I will document some of the key projects I contributed towards whilst undertaking the training role. I will also outline my continued professional development (CPD), outreach project contributions, and highlight my current published articles. This case study will also reflect upon the challenges and barriers I faced and consider ways in which I will use the skills I have gained to make an impact in the real world. Generally, the portfolio of work that is presented follows a theme of psycho-oncology, which focuses specially on holistic support and self-management. However, I have also attempted to cover as many other health psychology related topics as possible, which demonstrates my ability to practise as a well-rounded and skilled health psychologist. As Figure 1 shows, the doctoral portfolio reflects a broad range of health psychology related topics.

Figure 1. Diagram representing the broad range of topics covered throughout the portfolio of work presented.

Implementing and maintaining legal, ethical and professional standards in applied psychology

As a trainee health psychologist working within the NHS, it was essential to abide by the trust's core values (kindness, safety, teamwork and improving), whilst also maintaining the BPS code of ethics (BPS, 2009) and the HCPC standards of conduct (HCPC, 2008). Firstly, as outlined by the HCPC (2008), it was fundamental to always act in the best interests of the service users. Throughout this portfolio of work, each competency was conducted with the service user at the centre of all decisions. Each element of work was conducted professionally and aimed to improve patient care. The HCPC (2008) document also advises professionals to continually maintain and develop professional knowledge and skills. This is evident throughout. I continually aimed to engage with extra-curricular activities such as workshops, training sessions and seminars whenever possible. I also actively presented research papers and posters at a number of academic and professional conferences. Accepting feedback and

communicating with other practitioners was also a fundamental aspect of the training process to become an applied psychologist (HCPC, 2008). I fulfilled this by working as part of a large multidisciplinary team and working collaboratively across teams in order to support service users and contribute towards excellent patient care within the trust. During the two-year training period, I built strong working alliances and engaged with a range of health professionals, both internally at UCH MSIS and externally. This is particularly evident in the consultancy, behaviour change intervention and training competencies within this portfolio. Outside of my role at UCH MSIS, I also worked collaboratively with professionals in the education sector, which is evident within the teaching competencies in this portfolio.

I also maintained legal standards, which is particularly evident throughout the research components of this portfolio. I sought full ethical approvals from the relevant professional bodies and maintained participant confidentiality throughout. I also adhered to NHS procedures regarding access to patient databases and other personal service user information. Finally, both documents clearly highlight the importance of integrity whilst working as a registered professional. The BPS guidelines state that psychologists should *"value honesty, accuracy, clarity, and fairness in their interactions with all persons"* (BPS, 2009, page 21). I believe that I demonstrated these behaviours continuously throughout the two-year training programme. I did this by working professionally at all times, independently and alongside colleagues at UCH, to deliver a high standard of equal care and support to all patients and their families. I also maintained high standards of accuracy and fairness when conducting the research element of this portfolio. I ensured that all correct procedures were strictly adhered to at all stages of the research process in order to protect patients' safety, wellbeing and confidentiality, and also to ensure that the research findings were correct and reliable. I aim to continue practising by these ethical codes of conduct as I move beyond the doctoral training programme.

Continuing professional self-development

Throughout the stage two training programme, I presented poster and oral presentations at several national conferences. It was essential that I utilised conferences as platforms to showcase the work I was producing both independently

and through my placement at UCH MSIS. Conferences provided excellent opportunities to network with peers, colleagues, fellow academics, researchers and professionals in a range of health psychology related fields. My skill and ability to prepare an academic poster presentation and an oral presentation developed significantly as I progressed through the doctoral training programme.

Firstly, there were a number of opportunities to create academic posters on behalf of UCH MSIS. These mainly included service evaluation posters, which I produced and presented at internal conferences hosted by University College London Hospitals NHS Foundation Trust. In February 2016, I assisted with the development and presentation of an academic poster, which won first prize at the Centre for Nurse and Midwife Led Research (CNMR) annual conference (see evidence folder). Furthermore, at the same conference in 2017 I took the lead on developing two posters; an evaluation of a creative writing group and an evaluation of yoga classes, both for people affected by cancer. I was awarded '*highly recommended*' by the University College London Hospitals NHS Foundation Trust chief nurse for my poster regarding creative writing for people affected by cancer (see evidence folder). In addition to the posters developed for the CNMR conferences, I also produced an academic poster for the 2016 UCH cancer division conference. The poster focused on a core University College London Hospitals trust value, *'kindness'*, and how kindness can impact patient experience (see evidence folder). The poster was received with positive feedback. Furthermore, I also supported with the development of an academic poster for the European Oncology Nursing conference (Dublin, October 2016). This poster gave an overview of the services at UCH MSIS, and was presented by a colleague who attended the conference on behalf of the wider team (see evidence folder).

However, in terms of professional and personal development I believe that presenting a paper for two consecutive years at the DHP annual conference was the most important and also my proudest achievement. At the 2016 DHP and EHPS joint annual conference (Aberdeen, August 2016), I delivered an oral presentation relating to research about children's health (see evidence folder). In 2017, I presented findings from the systematic review I had conducted on the effectiveness of mindfulness for adults affected by headaches and/or migraine, at the annual DHP conference (Cardiff,

September 2017) (see evidence folder). Both presentations helped to shape and develop the papers in preparation for publication and further dissemination.

Throughout the doctoral training programme, I actively sought opportunities to engage with additional learning events, in order to expand my personal and professional development as a health psychologist. Regular attendance at CPD training events and workshops provided valuable opportunities to network with peers and colleagues from other institutions and organizations. A recorded list of all CPD training can be found in the CPD log (Appendix B). Throughout the programme, I attended all compulsory workshops facilitated by City, University of London. They included:

- Ethics and code of conduct
- Conducting a systematic review
- Consultancy
- Teaching and training
- Conducting both qualitative and quantitative research
- Psychological interventions – introductions to cognitive behavioural therapy, acceptance and commitment therapy and tele-health
- Importance of service user involvement.

In addition to these I also attended many other educational seminars and guest lectures that were hosted at the university throughout the year. These included, '*The cost of traumatic brain injury'* seminar by Dr Michael Parsonage (Chief Economist and Senior Policy Advisor at the Centre for Mental Health) and a CBT introductory session. Furthermore, the CPD opportunities at University College London Hospitals NHS Foundation Trust were also highly valuable to my overall training experience. Additional CPD sessions included:

- Attendance at monthly educational seminars at UCH Macmillan Cancer Centre focusing on suicide prevention among cancer patients, complementary medicine and cancer, the importance of patient information, cancer patients' welfare rights, cancer and genomics, and spotting the signs of domestic violence
- Attendance at a health psychology focused CPD event at the National Hospital for Neurology and Neurosurgery about managing patients with chronic sleep problems

- Attendance at Sage and Thyme workshop - learning how to manage difficult conversations with people in distress
  Attendance at an all-day training workshop for motivational interviewing and health coaching hosted by The Academy for Health Coaching.

Providing psychological advice and guidance

A large proportion of my work focused on outreach and engagement with individuals from a number of backgrounds. A vast majority of these outreach activities were conducted outside of my primary role as a trainee health psychologist at UCH MSIS. Working independently on additional outreach projects provided many opportunities to practise as an autonomous professional. It also ensured that I used my own judgement to make confident and key decisions. Firstly, in November 2016 I was invited to speak at an educational careers session for pupils and staff members at a secondary school in Central London. The session was titled, '*An overview of studying and researching in the field of Health Psychology*'. In the hour-long session, I talked to students (age 11-16 years) and teaching professionals about health psychology as a general subject. I discussed the benefits and career opportunities that can arise from studying health psychology and shared my personal experiences of being a trainee health psychologist. I also informed the audience about my research and role at UCH MSIS. In addition to this, I was invited to present at a careers lecture to health psychology masters students at City, University of London (School of Health Science) (March 2017). The aim of this session was to inform students about my experiences of working as a trainee health psychologist within an oncology setting. I used the allocated time to discuss with students, and staff members, about the advantages and challenges of applying health psychology principles to an oncology clinical setting. The session featured alongside various other short talks from other health psychologists working in a variety of settings such as consultancy, academia and brain injury rehabilitation.

During my time at MSIS I was also involved in many outreach projects. Generally, the aim of these projects was to ensure that UCH patients were aware of the support services available to them. Firstly, I led an awareness project in collaboration with the

gynaecological cancer clinic at UCH, which aimed to improve access and awareness of supportive care service among women with a gynaecological cancer diagnosis. In order to achieve this, I worked collaboratively with the UCH gynaecological clinical nurse specialist (CNS) team each week during allocated clinic hours. The main aim was to link the supportive cancer care service with the medical teams. The project involved liaising with the CNS team to identify patients whom required additional support or advice. I used my skill set to communicate, build rapport, and establish the patients' needs. The project was long-term and had been successful in raising awareness for the supportive care service at UCH among both clinical professionals (mostly the CNS team) and gynaecological cancer patients and their families.

Providing feedback to clients

The training placement also provided opportunities to assist with ongoing service evaluation at MSIS. As well as in the moment drop-in support, the service also offered people affected by cancer with a wellbeing programme of groups, workshops and courses. It was essential for these groups to be continually evaluated for improvement purposes and as a basis to remain available. During my time at MSIS, I contributed towards a monthly evaluation steering group meeting, which comprised of multi-disciplinary healthcare professionals. The aims of the evaluation group meetings were to discuss new and innovative methods of evaluation, in order to gain patient feedback on the services available. My knowledge and personal awareness of service user feedback and evaluation, developed significantly as a result of attending the evaluation steering group at MSIS.

As a consequence of the evaluation steering group, I took primary responsibility for a number of evaluation projects including a patient awareness survey. The aim of the MSIS awareness project was to understand patients' reasons for non-attendance to supportive cancer care services at UCH. Raising awareness and increasing viability of services was essential and made a significant impact to overall patient experience. As a result of the project, I found that a high number of patients visiting the UCH Macmillan Cancer Centre had failed to visit the supportive care service. Despite numerous efforts to increase service viability across the hospital trust, the survey revealed that many patients were unaware of the service and had little understanding

about what was available. Overall, the MSIS awareness project made a positive contribution and helped to understand the reasons for patients' non-attendance to support services. In total, 97 patients completed the survey. As a result of this specific project, I created a paper version of the survey, based on patients' reasons for non-attendance, with the intention for it to be conducted annually at UCH (see evidence folder for information relating to the MSIS awareness project).

Throughout all professional competencies presented within this portfolio, I attempted to prepare and present feedback to clients wherever possible. For teaching case studies, an evaluative feedback form was created and distributed to clients. The aim of the form was to gain constructive feedback and to measure if levels of knowledge had increased. This helped significantly with my professional development as a trainee health psychologist. In addition to this, the behaviour change intervention similarly employed evaluation feedback forms that measured clients' perceived motivation and confidence levels, pre- and post- intervention. However, due to the nature of some cases studies and some systemic issues that presented challenges, it was not always possible to obtain evaluative feedback. In these instances, I included detailed information about how evaluation could be obtained in the future and presented evidence to support the ethical and professional conduct of the competency. Evidence included observer reports, workplace supervisor reports, certificates, and/or any materials used directly with the clients.

Reflection and moving forward

Since completing an exceptionally busy and sometimes challenging two years, I have since had chance to reflect on the experience as a whole. I have always taken time to reflect intently on each individual component of the portfolio, in particular the professional competencies. It was important that I allowed time to think about the elements of my training that had gone well and those that had not. I kept detailed accounts of my activities throughout the stage two training programme, which I have used as a tool to reflect (see evidence folder). In general, the stage two training programme has been an immensely positive experience. The course has strengthened my knowledge about health psychology, improved my ability to conduct meaningful

research, supported my ambition to work as a professional, and positively enhanced my ability to self-manage a demanding schedule. I have also had an abundance of opportunities to network alongside an extensive range of professionals within academia and healthcare sectors. Subsequently, through these opportunities I have been able to make lifelong friends. I have also highly valued the frequent supervision sessions from both my academic and workplace supervisors. Regular meetings with my supervisors have offered a safe space to disclose my worries, concerns and problems. Recording details of supervision sessions within Research and Progress (RAPS), has helped to monitor and track progress throughout the two years. In addition to meeting regularly with both supervisors, it has also been important to meet frequently and stay in contact with my peers at the same stage of training. Receiving continual support from fellow students has helped significantly with maintaining motivation throughout my training.

Since approaching the completion phase of my studies, I have occasionally felt overwhelmed by the prospect of moving beyond the training programme. Health psychology is a broad subject that can be applied in a number of different settings. Therefore, I will be required to consider ways in which I can utilise my skill set and apply my professional experience to a setting where I will have the ability to make a meaningful impact and a lasting change. I will continue to raise awareness and increase visibility for health psychology principles by conducting more research in the future and disseminating to appropriate and far-reaching audiences. I would like to conduct further research around the topic of long-term conditions, such as cancer and obesity. I particularly enjoy applying qualitative methodologies; however, my future goals are to become more confident with conducting quantitative research. Although the body of work that I have produced for this portfolio is extensive and covers a range of health psychology related topics, in essence it represents the start of my career and provides a strong foundation for my future work to follow.

Word count: 3,207 words

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Appendix A: Workplace documents

CITY UNIVERSITY LONDON

Department of Psychology
City University
Northampton Square
London EC1V OHB
Programme Director – ███████
██████
Email: █████████████████
Tel: ██████████

Doctorate in Health Psychology
Placement Registration Form

Details	
Trainee's Name: Emily Robson	Personal Supervisor's Name: ████████
Trainee's Email:	Personal Supervisor's Email:
Trainee's Telephone Number:	Personal Supervisor's Telephone Number:

Placement Details

Placement Name: ████████

Placement Address:

Placement Email Address: ████████   Placement Telephone Number:

Placement Line Manager's Name and Occupation: ████████

Work Place Supervisor's Name:

External Supervisor's Name: External Supervisor's email:
(If no internal HCPC registered supervision provided)

CV of supervisor checked in the last 12 months: Yes ☐ No ☐

Registration of supervisor checked in the last 12 months: Yes ☐ No ☐

Copies of equality and diversity policies checked in the last 12 months: Yes ☐ No ☐

Placement Start Date: 26.10.2015

Placement Duration:

Placement Summary
Please give a brief outline of the placement, including type of setting (e.g. NHS primary care/GP practice, IAP Community Mental Health Team, Older Adults, Specialist Service (e.g. tier 3 personality disorder service)), in setting; HM Prison Service (male/female, security level); Voluntary/Third Sector; Private Organisation (nature description), Other (specify):

NHS Macmillan Cancer Care Centre

Supervision Arrangements
Please indicate here what the placement offers in terms of supervision

Frequency Session length
monthly supervision & when needed

Additional Requirements

Please outline any additional agreed requirements, responsibilities or expectations of the trainee or other spe[...]
Arrangements

Variety of projects that map on BPsych
competencies

Line Manager's signature:	Date:
Work Place Supervisor's signature: ▮▮▮▮▮	Date:
External Supervisor's signature (where applicable):	Date: 11ᵗʰ November 2015

City University Approval

Personal Supervisor's signature:
Date:

16

CITY UNIVERSITY LONDON

Department of Psychology
City University
Northampton Square
London EC1V 0HB
Programme Director – ███████████
████████
Email: ████████████████████████
Tel: ███████████

Professional Doctorate in Health Psychology
Work Place Contract

Trainee's name:	Emily Robson
City University Supervisor:	████████████
Work place Supervisor:	████████████
Work place address:	UCLH Macmillan Cancer Care Centre, Huntley Street, London, WC1E 6AG
Work place email:	████████████████
Work place telephone:	████████████

Declaration

- I am willing to act as a work place supervisor for the Trainee named above with respect to their doctorate training in health psychology.
- I confirm that I meet the criteria for being a work place supervisor as outlined in the placement provider and supervisor handbook.
- I agree to act as a link person between City University and the above named trainee's place of work.
- I agree to familiarise myself with content of the training programme through attendance at the Induction and/or viewing the online training provided by City University.
- Study leave will be negotiated and I understand the recommended amount of study leave required. The trainee will be permitted to attend the core workshops. The dates of the core workshops will be provided to me before the start of each academic year.
- I agree to complete a report relating to the trainee's performance on certain professional competences where the personal supervisor has not been directly involved.
- I will complete the required health and safety assessment of the trainee's workplace.
- I agree to liaise with the University regarding the trainee's progress in general, and urgently if I have any concerns about the competency, progress or fitness to practice of the trainee.

Signature: ████████████ Date: 26' October 2015

14

CITY UNIVERSITY LONDON

City University Work Place Contact Questionnaire

Trainee's Name   Emily Robson

1. Health and Safety at Work Etc Act 1974

	YES	NO
Does the company have a written policy for health, safety and welfare at work.	✓	
Is the policy and revisions brought to the attention of the employees.	✓	
Is the company registered with the HSE or local authority	✓	
Will the activities and locations in which the placement will be involved be assessed for the risk to health and safety.	✓	
Will the placement be informed of the precautions to take and of what to do in an emergency.	✓	
Do you provide training, supervision and controls identified by the assessment.	✓	
If the answer to any of the above questions is NO please state why.		

2. Management of Health and Safety at Work (emergency arrangements)

	YES	NO
Do you operate a procedure for investigating work related accidents.	✓	
Are accidents at work recorded in an accident book (BI510) and notified as necessary to the enforcing authority, in accordance with RIDDOR 1995.		✓
Are first-aid facilities appropriate to the class of risk identified.	✓	
Are fire and activity related emergency plans maintained; are employees informed of the action to take in an emergency.	✓	
Are reports of accidents and dangerous occurrences notified to senior managers / executives and investigated internally.	✓	
If the answer to any of the above questions is NO please state why.	all accidents recorded electronically & investigated	

No actual BI515

Appendix B: CPD training log

CITY UNIVERSITY LONDON

Professional Doctorate In Health Psychology Training Programme
Continuous Professional Development (CPD) Log

Trainee's Name: Emily Robson	
Supervisor's Name: ████████████	

Date	Activity Name	Length of activity	Type of activity
16/07/2015	Safeguarding Adults Level 1	0.5 day	CPD online course
16/07/2015	Safeguarding Children Level 1 – Patient Facing	0.5 day	CPD online course
12/10/2015	Professional Skills – Ethics	1 day	Core workshop at City, University of London
02/11/2015	Consultancy	1 day	Core workshop at City, University of London
09/11/2015	SAGE & THYME	1 day	CPD workshop at UCLH
07/12/2015	Quantitative Research Methods	1 day	Core workshop at City, University of London
19/01/2016	Urology services at Westmoreland street	1 hour	UCH Cancer Centre Seminar
01/02/2016	Qualitative Research Methods	1 day	Core workshop at City, University of London
07/03/2016	Writing Systematic Reviews	1 day	Core workshop at City, University of London
19/04/2016	Complementary Therapy at UCH	1 hour	UCH Cancer Centre Seminar
21/04/2016	Assessment and self-management strategies for working with sleep difficulties in a health psychology context	2 hours	CPD workshop at The National Hospital for Neurology and Neurosurgery
09/05/2016	CBT Skills	1 day	Core workshop at City, University of London

06/06/2016	Teaching and Training	1 day	Core workshop at City, University of London
07/11/2016	Involvement of service and/or carers	1 day	Core workshop at City, University of London
23/11/2016	Motivational Interviewing and Health Coaching	1 day	CPD training course
22/03/2017	"Individualised Yoga Intervention – It's Role & Potential in Public Health"	3 hours	CPD convention at The Nehru Centre, London
03/04/2017	Qualitative Research Skills	1 day	Core workshop at City, University of London
13/04/2017	City, University of London, School of health Sciences, Disability and Social Inclusion Seminar – "The costs of social care"	2 hours	Seminar
08/05/2017	Psychological Interventions	1 day	Core workshop at City, University of London
22/06/2017	PhD Employability Series: The Strategic PhD Student	1 hour	Seminar at City, University of London

Appendix C: Supervision plan

Supervision Plan – Generic Professional competency

Supervisee: ___Emily Robson_____

Supervisor: ___█████████████_____

Generic professional competency	Area of work (*outside of normal work)	Supporting evidence	Changes
Supervised practice	All	Practice (daily activity) log Workplace contract	
Generic professional case study	Setting: UCH Macmillan Support and Information Service (MSIS) Description: I work as a Trainee Health Psychologist at UCH MSIS in a predominately patient-facing role. The service provides in-the-moment emotional advice, as well as practical information for any person affected by cancer. The service also offers a wellbeing programme of groups, courses and workshops for patients to attend. My role consists of supporting the specialist team with the daily running of the service and supporting service users and signposting when appropriate. I also assist with on-going service evaluation and awareness projects. In addition to this, I attend conferences and present research on behalf of the team at MSIS. I will attend as many CPD opportunities as possible during my training duration. Externally, I will also attend seminars, conferences and workshops whenever possible.	Supplementary study report (3000 words) Attendance certificates CPD log Conference attendance log	

UNIT 2: CONSULTANCY COMPETENCY

Using technology to support self-management: A review of online educational resources for people affected by cancer

Introduction

At UCH MSIS, an on-site wellbeing programme was offered to all service users and any other person affected by cancer including the patient, relative, friend or carer. Services include a range of workshops and courses, designed to educate and inform service users about cancer and encourage patients to actively self-manage their illness and its subsequent side-effects. A new web-based service that applied the same self-management principles was proposed in order to reach a wider target audience and keep up-to-date with other healthcare providers and rapidly changing demands in patient preferences for online health information and support.

According to the *'National Cancer Survivorship Initiative'* (DH, Macmillan Cancer Support & NHS Improvement, 2010), an innovative and extensive approach to cancer care is fundamentally required in order to improve the future outcomes for patients. In addition to this, the University College London Hospitals NHS Foundation Trust Cancer Strategy (2015) emphasised the significance of information communication technology (ICT) development within the trust and added that the improvement of ICT should improve cancer care for people living in Central London and surrounding areas. Presenting easily accessible information and other educational materials in a digital format was believed to increase patient knowledge and lead to a feeling of empowerment amongst patients (Macmillan Cancer Support, 2012). Health information is also understood to be one of the most frequently sought topics on the internet (McMullan, 2006); online health information can improve patients' understanding of their diagnosis, increase self-efficacy and allow patients an opportunity to be well informed (Dedding, van Doorn, Winkler, & Reis, 2011). It also has the potential to improve physical and mental wellbeing and alter how patients use healthcare services in the future (de Silva, 2011).

The term *'self-management'* is defined as a process of patient empowerment, achieved through encouraging individuals to take responsibility for their own condition, assisted by the appropriate clinical assessment, support and treatment (Davies & Batehup, 2010). According to the *'National Cancer Survivorship Initiative'* (DH, Macmillan Cancer Support & NHS Improvement, 2010), four key aspects are essential for successfully promoting self-management: (1) information and education, (2) key contacts for cancer and non-cancer related support, both in and out of hours, (3) efficient and reliable processes for re-accessing the system, and (4) effective remote monitoring. The use of self-management in health care settings could potentially reduce the pressure on health care services in terms of constricted budgets, population increases, workforce shortages and a rising demand for supportive services (de Silva, 2011). However, it is also important to remember that whilst patients should be equipped with the relevant tools needed to successfully self-manage their illness themselves, the delivery and maintenance of clinical care should remain a key priority for healthcare providers and policy makers.

However, it is likely that not all cancer patients will need to be directly encouraged to self-manage. Many may already feel motivated and encouraged to take some level of control over the management of their health. This will be particularly apparent among a new cohort of service users known as *'e-Patients'*, who have already adopted a self-management approach to their cancer care experience. This movement in patients is particularly prevalent within oncology settings and involves patients who are growing increasingly engaged in learning about their treatment options and demonstrating a willingness to be involved more in the decision-making process (Ennis-O'Connor, 2014). Considering the positive evidence that supports the notion of self-management and implementation of online resources within healthcare settings, a support and information specialist at MSIS created a wish list document outlining key details for a proposed project titled *'The Wellbeing Workroom'*. In order to present the document to higher tier management at University College London Hospitals NHS Foundation Trust, for consideration, discussion and funding, the document required a concise rationale. Therefore, a thorough review of literature (of approximately two thousand words), highlighting research to support the use of self-management techniques within health care settings was required. The consultancy project also aimed to

identify the benefits of using digital technologies as a method of communication with oncology patient cohorts.

Assessing the consultancy request

As a trainee health psychologist working within UCH MSIS, I was aware of the online education project that had been proposed within the department. Online web-based projects, specifically within a health psychology context, were of particular interest to myself and I actively demonstrated enthusiasm to contribute towards the project. After making my interest known, my line manager initially approached me in a consultancy capacity. It was understood that the divisional management team at University College London Hospitals NHS Foundation Trust, of whom were commissioning the project, would be interested in my skill set and previous experience of writing literature reviews. Subsequently, an email was written and sent to the divisional management team for cancer care at University College London Hospitals NHS Foundation Trust. Informal discussions with the support and information specialist who had taken the lead on the project took place in order to clarify the consultancy request and assess the level of client expectation. My role as a trainee health psychologist and previous experience of undertaking degrees in psychology were the primary reasons for the consultancy request. Past experiences of conducting research studies may also have been a contributing factor.

During a later meeting with my workplace supervisor, the feasibility of conducting such commissioned work was discussed. I had to assess if I was able to conduct a literature search and write-up the report within an allocated timeframe. As part of the consultancy request, I was also required to provide an oral summary to a multi-disciplinary team of health professionals at a quarterly service board meeting for the trust's cancer care division. I had to consider this aspect of the consultancy carefully and assess how able I felt to present in front of a qualified audience of professionals. After a discussion with my supervisor, I decided that I would accept the consultancy project. Following the meeting with my workplace supervisor, I was advised to draft a document that outlined key information about the consultancy. This included my specific role as a consultant, the aim of the consultancy project, and a consultancy schedule. Consequently, a contract was created (Appendix A) and signed by the client

(see evidence folder). Within the contract, a budget was also included, however this was primarily for practice purposes as the work was carried out on an entirely voluntary basis. The outlined budget was merely a practice exercise, based on accurate figures that would have been requested if I had been a paid employee of the trust.

Consequently, a brief meeting between the deputy divisional manager of cancer care, workplace supervisor and myself was proposed (Appendix B). I found that arranging a suitable time to present the contract and also discuss the feasibility of the consultancy project with the management team at University College London Hospitals NHS Foundation Trust was challenging. This was due to the busy schedule of the deputy divisional manager and her impending maternity leave. Therefore, time restraints and scheduling conflicts often proved to be a barrier. However, despite this a meeting between the client and the consultant was successfully arranged and the contract was signed and dated by the client. This demonstrated that the client was satisfied with the outlined project aims, and preparation for the project was initiated.

Planning the consultancy

In order to effectively assess the consultancy options, I firstly had to consider the theoretical models of consultancy and decide which model was best suited to the project that I was conducting. Due to my lack of experience conducting any previous commissioned work, I wanted to ensure that each stage of the process was completed correctly and to the best of my ability. In order to achieve this, I opted to underpin each stage of the process to *'The Consulting Process in Action Model'*, devised by Lippitt and Lippitt. (1986). Although the model could be deemed out-dated, I believed that the strong theoretical framework was well structured and categorised into key distinct stages, which fitted well with the consultancy project at University College London Hospitals NHS Foundation Trust.

Based on *'The Consulting Process in Action Model'* (Lippitt & Lippitt, 1986), in which eight consultant roles were outlined, my position within the project was established. Upon reflection of the model, my role as a consultant within the online educational project appeared to adopt a *'Fact Finder'* approach to consultancy.

Lippitt and Lippitt (1986) defined a consultant who adopts the *'Fact Finder'* role as a researcher that collects and interprets information about a particular topic of importance to the client. In this case the topic of importance was online education recourses in health care settings. By utilising the *'Fact Finder'* position, the client and the consultant are able to successfully work together in order to overcome a problem, based on the facts that the consultant provides (Lippitt & Lippitt, 1986). This particular theoretical idea underpins the process that was carried out in my own consultancy project. As I worked independently to find facts and detailed information for the final review, I also liaised in parallel with a support and information specialist at the Macmillan Cancer Centre. I also regularly engaged with my line manager in order to successfully complete the project and understand the client's needs.

Firstly, in order to fulfil the client's expectations, I was required to provide a concise justification for the consultancy project and outline any key primary aims. These included:

- To conduct a literature review of the online resources currently available that promote and encourage self-management among people affected by cancer
- Based on review findings, support the development of an online educational and self-management based programme for any person affected by cancer, by presenting the rationale at a quarterly service board meeting.

Secondly, a scheduled timetable was created and outlined within the consultancy contract for the client's attention. Key dates used within the schedule were based on a number of factors: (1) the consultant's schedule in which other commitments had to be considered, (2) the length of the review, and (3) the deadline as set by the client. With these factors taken into account, the schedule was outlined using key stages of the consultancy process:

- Stage 1: Inclusion criteria set and thorough literature search by 18/01/2016
- Stage 2: Findings written in a literature review format by 15/02/2016
- Stage 3: Delivery of review to client and recommendations by 26/02/2016.

However, it should be noted that although the above dates were presented within the contract and agreed between the client and consultant, they were only used as an approximate guide. This was due to a scheduling error that resulted in the service

board meeting being earlier than originally planned. Consequently all of the above dates were moved forward in order for the project to be completed on time. This was an oversight and should have been clarified by the consultant at one of the earlier arranged meetings. However, all stages were still completed in the same systematic order and presented on time at the service board meeting.

Other limitations that emerged during the planning stage of the consultancy included a computer and office shortage within the workplace. Finding a quite space to concentrate and conduct the literature review was sometimes challenging as desk availability was limited and often shared between many other staff members. Due to a slight scheduling error, which had been made earlier in the process, time constraints were noticeably present and at times I felt under pressure to meet the tight deadline. Therefore, having no fixed desk or designated area to work could be stressful at times. I dealt with the problem by preparing printed copies of research papers and spending non-computer time reading and making notes in preparation for when a computer became available. Being organised and prioritising tasks was fundamental and contributed significantly to the eventual outcome of this task. Planning the consultancy was overall a positive process and minor limitations that emerged (e.g. desk space and scheduling misjudgement), were valuable learning experiences that I will consider wisely in future consultancy projects.

Establishing working relationships with the client

Overall this particular consultancy was a small-scale project with clear aims and expectations. My role as a consultant was clearly defined from the start and my task was relatively straightforward. Rather than meet frequently with the client, who had an extremely busy role as the deputy divisional manager for cancer care at University College London Hospitals NHS Foundation Trust, I alternatively worked alongside a colleague (Macmillan Support and Information Specialist) who had taken the lead on the online educational project. Throughout the majority of the project I therefore reported to this colleague if any queries or concerns relating to the consultancy arose. The main method of communication used throughout was email, however informal face-to-face interactions were also a frequent method of communicating that allowed

regular contact with the client. This also ensured that questions were answered promptly and any concerns were dealt with efficiently.

Conducting the consultancy

The key task for the commissioned work was to produce a supplementary report that offered justification and rational for the proposal of a larger scale project. I presented a summary of the review that I had written alongside a colleague who spoke about the proposal. During initial discussions about the consultancy task, it was decided that the literature review would incorporate a combination of research studies and examples of similar projects already being implemented in other worldwide health care settings. Because the aim of the consultancy was to provide evidence and a rationale to support the ongoing project, the client thought that it was important to incorporate examples of previously published literature within the review. It was believed that this would help gain approval for funding from higher tier management at the trust. Incorporating research alongside key examples of similar working practice was additionally important for the client. As UCH MSIS is a leader in the field of supportive cancer care, it was essential to remain up-to-date.

An extensive literature search was then conducted, using a combination of key search terms such as '*self-management*', '*cancer*' (alternates included '*oncology*' and '*haematology*'), '*education*' (alternates included '*knowledge*', '*learning*' and '*information*'), '*support*', '*intervention*', '*programme*' and '*online*' (alternates included '*web-based*', '*digital*' and '*internet*'). Searches were inputted into Google Scholar and City, University of London library search, and databases such as PsycINFO, Embase, Web of science and MEDLINE were utilised. After all relevant and suitable articles had been selected from the search results, they were read and incorporated within the final review. Included articles were selected based on their relevance to the main topic of the consultancy. Due to the fast pace progression of research in the topic area of technology, it was also particularly important for articles and/or research studies to be relatively up-to-date. Therefore, journal articles over approximately five years old, unless it was exceptionally relevant, were excluded from the final review.

In total, the review had a word limit of around two thousand words. This was written and then proof read by a member of the support and information specialist team at MSIS before the final version was completed. Post completion, the '*Wellbeing Workroom*' wish list and literature review were both included within the agenda at the quarterly service board meeting at UCH Macmillan Cancer Centre. The meeting offers an opportunity for healthcare professionals and management team members to propose new opportunities for the cancer centre, as well as discuss any on-going service developments. Members of the service board include the divisional manager of cancer services, clinical leads in supportive cancer care, divisional clinical director for cancer, radiotherapy manager, patient representative, lead cancer nurse and a clinical psychologist. A brief summary of the consultancy report was presented to the meeting attendees and met with enthusiasm and support for the proposed online educational project (Appendix C).

Monitoring and evaluating the process of consultancy

Continuously monitoring and evaluating the consultancy project was essential in ensuring that the task was completed on time and to a high standard. For each meeting an agenda was created in order to stay focused and on point during the limited time available. Minutes were recorded after each meeting had taken place. Included within the minutes was a section that outlined targets and action points. This was beneficial for the overall development and progress of the project.

Furthermore, a Gantt chart was created at the start of the project and was frequently updated as the consultancy progressed (Appendix D). A Gantt chart is a visual tool, which is typically used within project management to display activities or tasks performed against time (Economic Times, 2016). On reflection, I found that this was a helpful technique to interpret and also monitor the progress of the project. As this was a relatively small-scale consultancy project, I followed a basic Gantt chart structure. However, in future projects that may be larger in scale, I would consider employing a more detailed Gantt chart to monitor progress, by perhaps using a software package such as Excel.

Overall, the client was satisfied with the completed review and it achieved the primary aim. After presenting a summary of the report to attendees at the service board meeting, the literature review was positively received and prompted discussion about the future of the online project at University College London Hospitals NHS Foundation Trust. After six months of completing the consultancy project a short follow-up evaluation form was created and offered to the client for completion (Appendix F). The aim of evaluation at six months post-project was to establish the long-term impact of the completed work. Due to the client's demanding role, the follow-up form was intended to be simple and quick to complete. The feedback concluded that the review was helpful and positively contributed to the overall project. However, it was highlighted that due to a lack of funding, the online educational project had been postponed and other initiatives such as the *'Cancer Academy'* and the *'Cancer Vanguard'*, had instead taken priority at the trust.

Word count: 3,009 words

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Appendix A: Consultancy contract

Consultancy Contract

UCH Macmillan Cancer Centre
University College London Hospitals NHS Foundation Trust

Client: ▮▮▮▮▮▮▮ (Deputy Divisional Manager)
Consultant: Emily Robson (Trainee Health Psychologist)

Rationale
At present, UCH Macmillan Cancer Centre offers a supportive on-site wellbeing programme to all people affected by cancer. To reach a wider patient audience and meet the aims outlined by the Independent Cancer Taskforce, Department of Health and National Cancer Survivorship Initiative, the Macmillan Support and Information Service must develop online self-management and educational programmes.

Aims
- To conduct a review of online resources available for self-management and education of people with cancer.
- Based on review findings, help develop an online teaching programme for all people affected by cancer.

Schedule
The proposed work will begin on 4th January 2016, working three days per week, based on the following stages of completion:
Stage 1: Inclusion criteria set and thorough literature search by 18th January 2016
Stage 2: Findings written in a systematic review format by 15th February 2016
Stage 3: Delivery of review to client and recommendations by 26th February.

Reading and reviewing research, meetings with the clients and literature referencing are included within the schedule.

Budget (for practice purposes only)
Daily rate:
Trainee Health Psychologist - £20,000 per year (£55 per day).
Number of days (based on above schedule):
Stage 1: 6 days
Stage 2: 12 days
Stage 3: 6 days
Total = 24 days,

Materials:
Printing, photocopying and computer facilities to be provided by client.
Total Expenditure = 24 days x £55 = £1320.

Client: ▮▮▮▮▮▮▮ (Deputy Divisional Manager)
Sign: Date:

Consultant: Emily Robson (Trainee Health Psychologist)
Sign: Date

Appendix B: Meeting minutes

University College London Hospitals NHS
NHS Foundation Trust

Online education project – consultancy meeting

Minutes of the Meeting held on 15 December 2015, 13:30-13:45pm at 250 Euston Rd.

Present	Job title
▮▮▮▮▮▮▮▮	Clinical Lead for Supportive Cancer Care
▮▮▮▮▮▮▮▮	Deputy Divisional Manager, Cancer Services
Emily Robson (ER)	Trainee Health Psychologist

Item	Matters covered	Action
1.	**Welcome and introduction** -ER provided a brief summary to EC about the planned consultancy project.	
2.	**Feasibility of consultancy** -The project was discussed and the schedule was agreed.	
3.	**Contract review** -The contract was read by EC and discussed with ER and HP. -The budget section of the contract was discussed and clarification was given from ER, which confirmed that the budget was for practice purposes only. -The contract was signed and dated by EC	The literature review can now commence.
4.	**Monitoring the consultancy** -It was decided that no future meeting, between the client (EC – Deputy divisional Manager) and consultant (ER) would be necessary. However regular interaction and discussion about the project would take place between the consultant, HP and a member of the Support and Information Specialist team.	

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University College Hospital
National Hospital for Neurology and Neurosurgery
Eastman Dental Hospital
Royal National Throat, Nose and Ear Hospital
Royal London Hospital for Integrated Medicine

Appendix C: Service board meeting minutes

Macmillan Support and Information Service Programme Board

Minutes of the meeting held on 3 February 2016 at 12:30 - 14:00

Present	Job title
▮▮▮▮▮	Clinical Lead for Supportive Cancer Care
▮▮▮▮▮▮	Clinical Lead for Supportive Cancer Care
▮▮▮▮▮▮	Macmillan Partnership Development Manager
▮▮▮▮	Macmillan Project Lead
▮▮▮▮	Assistant General Manager
▮▮▮▮	Macmillan Support and Information Clinical Nurse Specialist
▮▮▮	Lead Cancer Nurse
▮▮▮▮▮	Red Cell Haematology Clinical Psychologist
▮▮▮▮	Support and Information Assistant/ PA
▮▮▮	Consultant Nurse, Cancer & Supportive Care
▮▮▮▮	Radiotherapy Service Manager
▮▮▮▮	Divisional Clinical Director, Cancer
Emily Robson	Health Psychology Intern
▮▮▮	Support and Information Specialist
▮▮▮▮	Senior Research King's College London
▮▮▮▮	Macmillan LASER
▮▮▮▮	Cancer Information Systems Manager
Apologies	**Job title**
▮▮▮▮	Senior Macmillan Development Manager (N & NE London)

Item	Matters cover
1	**Welcome, introduction and apologies**. Apologies as above. Welcome to new members Jo Annes and Ed Tullis.

3.	**MSIS digital education and support project** Presented by Emily Robson and ▮▮▮▮ The aspiration of the specialist team is to deliver an on-line education and support resource that promotes a self-management approach. It fits in potentially with the Cancer Academy and the vision for Cancer services and the depth and breadth of the project needs further consideration. There was positive endorsement from all those present with the agreed aim of discussing with ▮▮▮▮ and to potentially set up a steering group to take the idea forward.	▮▮ and ▮▮▮▮ (Macmillan Support and Information Specialist) to meet with ▮▮▮▮.

Appendix D: Gantt chart

	November 2015	December 2015	January 2016	February 2016	March 2016	April 2016
1. Consultancy request and initial meeting	▨					
2. Review of literature		▨				
3. Progress meeting			▨			
4. Write up of report			▨			
5. Draft review and amendment				▨		
6. Presentation of review in service board meeting					▨	
7. Client evaluation					▨	

Appendix E: Extract from consultancy review (See evidence folder for full report)

Online/distant learning in a cancer care setting

Rationale

At present, UCH Macmillan Cancer Centre offers a supportive on-site wellbeing programme to people affected by cancer. To reach a wider patient audience and meet the aims outlined by the Independent Cancer Taskforce, Department of Health and National Cancer Survivorship Initiative, the Macmillan Support and Information Service must develop online self-management and educational programmes.

Aims

- To conduct a review of online resources available for self-management and education of people affected by cancer.
- Develop an online teaching programme for people affected by cancer, which falls in line with the aims and objectives set by the National Cancer Survivorship Initiative.

Current guidelines and recommendations for online learning in a healthcare setting

According to the National Cancer Survivorship Initiative, something innovative and far-reaching should be implemented, in order to improve the experience and outcomes for patients of cancer (NHS, 2012). In addition to this, the UCLH Cancer Strategy (2015) highlights the significance of ICT development within the trust, with the aim to improve cancer care for those affected by cancer in the London area.

At present, the Macmillan Support and Information Service offers service users an onsite wellbeing programme that includes a combination of personal wellbeing sessions (e.g. yoga, creative word etc.), self management workshops (managing fatigue, sleep etc.) and support groups (penile cancer support, general oncology support group etc.). Although the service is both well attended and positively reviewed by patients and family members, a replication of this service in a digital form would extend access to a wider patient audience.

Providing easily accessible information to patients with cancer will increase knowledge and prepare individuals for change; developing positive self-efficacy amongst individuals is necessary. It is important for patients to feel empowered and motivated to take control of their health, which can consequently improve physical and mental wellbeing and alter how people use healthcare services in the future (de Silva, 2011). It is understood that cancer patients who receive good information and feel supported with the consequences of their treatment, are more likely to positively assess their overall care experience (Macmillan Cancer Support, 2012).

Self-management in a healthcare setting

The term 'self-management' describes empowering current patients and survivors of cancer to take responsibility for their condition, facilitated by the appropriate clinical assessment, support and treatment (Davies & Batehup, 2010). It is essential to provide access to tailored education, training, and support for the development of self-management skills and strategies, based on personalised assessment and care planning (Davies & Batehup, 2010).

Appendix F: Client evaluation form

Online educational project - consultancy

6-month follow-up evaluation form

How much did the work conducted help with the overall progress of your project? (Please tick)

1. Not at all	2. Not much	3. Not sure	4. A fair amount	5. A great deal

Please rate how well you think the consultant trainee health psychologist conducted each aspect of the consultancy project (online educational review):

	Very poor	Poor	OK	Well	Very well
Initially establishing consultancy needs					
Communication of consultancy progress					
Punctually and efficiency					
Presentation of review					
Overall quality of work					

Do you have any other feedback or comments?

Thank you

Appendix G: Supervisor evaluation report

CITY UNIVERSITY LONDON

Department of Psychology
City University
Northampton Square
London EC1V 0HB
Programme Director –
Email:
Tel:

Professional Doctorate in Health Psychology

Workplace Evaluation Report

Section 1 - To be completed by the trainee:

Trainee's name	Emily Robson
Name of workplace contact	UCH Macmillan Cancer Centre
Nature of work and competence assessed	Consultancy competence – a literature review of online educational resources.

Section 2 - To be given to the workplace supervisor to return directly to above address:
Views on the Trainee's Performance on above piece of work (write comments below or email a separate report). Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

This piece of work was undertaken promptly and efficiently and presented at the our Board Meeting with confidence and clarity. The literature review has been very helpful. J. the sence in the process of developing our on line presence.

Declaration
I verify that the above named trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: Date: 4 June 2016

18

Appendix H: Supervision plan

Supervision Plan - consultancy

Supervisee: ___Emily Robson_____

Supervisor: ___█████████████_____

Consultancy	Area of work (*outside of normal work)	Supporting evidence	Changes
Case study	Setting: University College London Hospitals (UCLH) NHS Foundation Trust (for upper tier management) Description: The aim of consultancy project is to work outside of my normal workplace setting and provide support to upper tier management at UCLH. As requested, a review of literature to support a proposed online educational project is to be conducted. Upon completion of the review, the findings are to be presented at a service board meeting to upper tier management teams at UCLH. The review will be used to support funding applications.	Case study report (3000 words) Workplace evaluation report (signed █████████ ███████) Evaluation form completed by client	

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UNIT 3: BEHAVIOUR CHANGE INTERVENTION

Managing dietary issues: A series of workshops for people living with and beyond cancer

Designing an intervention to change health-related behaviours

Those living with and beyond cancer often experience food, diet and sensory related side effects (Coa et al., 2015). It is well documented that poor diet and frequent unhealthy food choices can lead to obesity (Butland et al., 2007), which could consequently result in a number of other health implications such as diabetes, coronary heart disease, tooth decay and immobility (NICE, 2015). Therefore, it is fundamental for cancer patients to receive appropriate support and advice, at the right tine, regarding diet, lifestyle and general wellbeing. As a result, this could reduce the likelihood of preventable health problems from arising, which could interfere with active cancer treatment or post-treatment recovery. Previous behaviour change interventions that specifically aimed to improve diet among people affected by cancer have reported positive outcomes. In a meta-analysis that reviewed diet related interventions, results found that nutritional intervention programmes were most effective at increasing nutritional intake and improving aspects of QOL among individuals of who were malnourished as a result of cancer treatment (Baldwin, Spiro, Ahern, & Emery, 2011). Similarly, interventions that have focused on improving diet and physical activity levels among people living with and beyond cancer, have also positively reported enhanced QOL and improved body weight, among those who took part (Pekmezi & Demark-Wahnefried, 2011).

The main aim of this professional competency was to conduct a behaviour change intervention for people living with and beyond cancer. Intervention participants must have previously, or currently, received treatment for their cancer diagnosis at UCH Macmillan Cancer Centre. By identifying a need and applying a theoretical framework to the planning process, a permanent behaviour change was expected to occur among those who participated. On completion of the intervention, evaluative

and reflective processes were conducted, in order to assess the effectiveness of the intervention and also elicit best practice in the delivery of future interventions.

Providing advice based on existing evidence and implementing the intervention

A behaviour change intervention is defined as, an attempt to encourage effortful change among a group or specific individual (Ogden, 2012). Interventions aim to alter and change unhealthy behaviours such as smoking, excessive alcohol consumption, poor eating habits and sedentary physical activity. To ensure that an intervention has long-term success, there are a number of theoretical models that outline behaviour change through the application of various methods and beliefs. The *'Transtheoretical Model'* (TTM), otherwise known as the '*stages of change'*, is one key example of a stage theory model. The TTM was devised by Prochaska and DiClemente (1982) and describes behaviour change as a complex process that occurs unsystematically, across five individual stages (Glanz, Rimmer, & Viswanath, 2008; Marks, Murray, Evans, & Willig, 2000). It should be noted that the stages of change element covers only one aspect of the model. Other elements interlink to form what is known as the TTM, these include:

- *'Processes of change'*, which describes the covert and overt actions that people adopt in order to progress through the stages (Glanz et al., 2008)
- *'Stages of change'*, which represents five key steps that people should pass in order to alter their behaviour: (1) pre-contemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance (see Figure 1)
- *'Decisional balance'*, which refers to the consequences that could occur as a result of changing a high-risk behaviour and the individual's perception of the subsequent costs and benefits that could result from changing their behaviour (Horwath, 1999)
- *'Self-efficacy'*, which is the assumption that people can cope with high-risk circumstances without fear of reverting back to their former unhealthy behaviours (Glanz et al., 2008).

The TTM has been described as a circular model that accepts relapse and enables individuals to move through the stages of change with flexibility and fluidity, before an eventual behaviour change can be established (Howe, 2005). Acknowledging and

including relapse as part of the behaviour change process, is a fundamental feature. These are key reasons why the TTM was used within the current health-related behaviour change intervention. It also accounts for the belief that people do make mistakes, particularly when behaviour is embedded and difficult to change. Due to the nature of participants that took part within the intervention (people living with and beyond cancer), the TTM was less restrictive and more flexible than other models, which therefore enabled patients to alter their behaviours successfully in their own time, without pressure or difficulty. Therefore, the TTM was operationised within the development and implementation of the behaviour change intervention at UCH Macmillan Cancer Centre. This was achieved by explaining each stage of the cycle to participants who attended the intervention, during the presentation. The interactive style of each session, enabled discussions to take place and participants were encouraged to reflect on their current stage and think of ways to move forward towards their eventual goal. The pre- and post-evaluation forms also offered space for participants to write down their goals for the sessions. This helped to identify the stage that each participant felt they were at before and after taking part in one of the diet intervention workshops. It was assumed that each individual seeking a diet related behaviour change would move through each stage of the model, highlighted in figure 2, to eventually establish some form of permanent change.

The TTM has previously been applied to other diet related interventions and positive outcomes have been reported. Armitage (2010) found that self-reevaluation, from the processes of change element of the TTM, did predict changes in behaviour and significantly mediated the effect of past behaviour on future behaviour. There has also been evidence that supports the validity of the TTM, when used to describe populations and inform the development of interventions (Spencer, Wharton, Moyle, & Adams, 2007). However, the authors of this paper did note that more work was needed in order to fully understand the effectiveness of TTM-based interventions (Spencer et al., 2007) and evidence that supports the use of TTM in weight loss interventions is understood to be limited, low quality and largely at risk of bias (Mastellos, Gunn, Felix, Car, & Majeed, 2014). However, the most influential criticisms have derived from Robert West (2005), who claimed that the model was outdated and held back advances in the field of health promotion. He suggested that an updated, replacement model should accurately reflect changes in behaviour and be

able to generate useful ideas and predictions, based on how people change suddenly in response to small triggers (West, 2000). Although this critique of the TTM, and the suggestions for a new model are fair, the TTM still proved useful when applied to the health-related intervention at UCH MSIS. The Stages of Change element of the model was useful in providing a clear process for participants to follow and demonstrating how a behaviour change can be a continuous, on-going process that allows for relapses within the process.
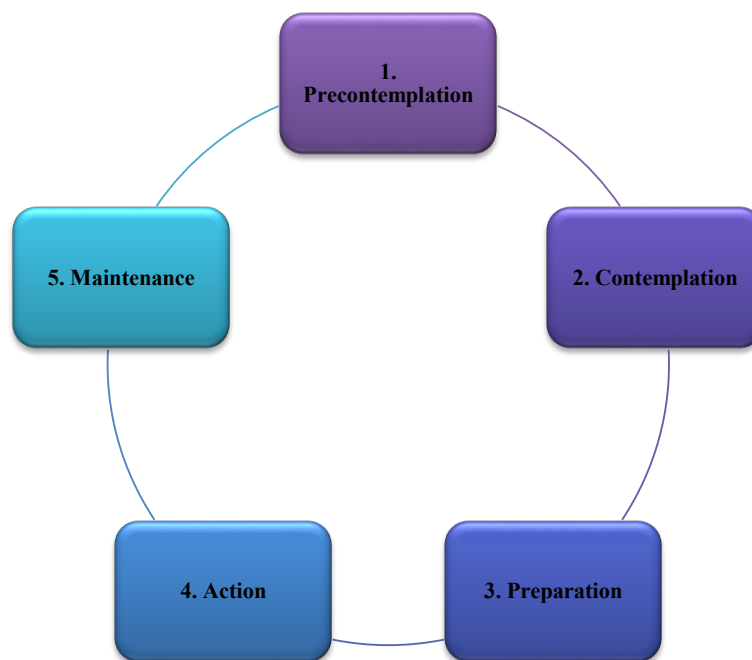

Figure 1. The Transtheoretical Model (Prochaska & DiClemente, 1982)

Assessing the suitability of clients for the intervention

At UCH Macmillan Cancer Centre within the support and information service, four core aspects of health and wellbeing, which were particularly prevalent among people affected by cancer, were offered to service users in the form of group courses, workshops and wellbeing sessions. The four core areas, among others, included diet, physical activity, sleep and fatigue. In general, all group workshops offered to service users were well attended and positively reviewed. However, in previous groups (within the past 12 months), the diet educational talk had failed to maintain consistent attendance rates and was not reaching the ideal group total of six attendees. Working in a patient-facing role, as a trainee health psychologist, I identified a discrepancy between patients' needs and attendance to the 2-hour diet talk. A request for written and verbal information relating to diet was a frequent query and a highly dominant reason for patients' visit to MSIS. Booklets and cancer specific cookbooks, both stocked at the service, were among some of the most popular literature. This highlighted a clear need for some form of diet related health intervention. This then prompted discussions about how the pre-existing diet talk at the service could be developed further and utilised more effectively in order to fulfil patients' needs and benefit a wider audience, for example, people who entered the service to access written information, but not necessarily attend a group workshop or course.

Identifying and negotiating behaviour change goals

During discussions and planning meetings with the UCH cancer specialist dietitian, and through daily interactions with patients who had expressed interest in diet related information, three key target groups were established:

1. Patients who were confused about conflicting dietary advice that had been reported within the media and consequently required general dietary information

2. Patients that had completed treatment and were either struggling to control their weight and/or required additional support on how to manage their weight post-treatment

3. Patients that had lost weight during cancer treatment and needed help with managing their treatment related symptoms (such as taste change, difficulty swallowing and/or nausea).

From these observations, a series of three diet workshops were created and further justification for the development of each topics was researched and is presented below:

Intervention 1 - Dietary information: facts and myths

Confusion and misunderstanding about dietary information reported within the media is a growing concern (Boyle, Boffetta, & Autier, 2008). It is essential that patients remain up-to-date and knowledgeable about basic dietary information and have the ability to distinguish between fact and fiction. Eating the correct food nourishes the body and provides useful sources of energy (NHS, 2015). Eating foods that provide energy and nourishment is particularly important for people undergoing any form of treatment for cancer. It is understood that fatigue and nausea are both common side effects of cancer treatment (Macmillan Cancer Support, 2015a). Therefore, the primary aim of this workshop was to provide clarity on some of the diet myths that were frequently reported within the media. This workshop also aimed to highlight some general dietary information. The workshop allowed time for questions that attendees had during the session.

Intervention 2 - Managing your weight after treatment

In order to successfully support a healthy recovery, it is essential for patients to maintain a healthily physical body weight. Relevant support and information about how to eat a well-balanced, healthy diet post cancer diagnosis, is essential (Beeken, Williams, Wardle, & Croker, 2016). Cancer can have a significant long-term impact on a person's life for many years after receiving treatment (Macmillan Cancer Support, 2013). Therefore, supporting people during their entire cancer care journey, included after treatment has ended, is essential. It is equally important to encourage patients to self-manage their symptoms effectively and learn how to maintain a healthy weight through eating the correct foods and keeping physically active. This may prevent obesity and any subsequent health problems in the future. Therefore, the main aim of this workshop was to advise service users about the benefits of maintaining a healthy diet and lifestyle, after their treatment had finished.

Intervention 3 - Symptom management and building yourself up

A number of challenging symptoms can occur as a result of receiving treatment for cancer (Macmillan Cancer Support, 2015b). These can include sensory alterations, such as changes in taste and smell (Bernhardson, Tishelman, & Rutqvist, 2007; Hutton, Baracos, & Wismer, 2007). Patients also report difficulties related to swallowing, chewing, a lack of appetite and nausea (Coa et al., 2015; Cordella & Poiani, 2014). These physical changes are believed to result in low levels of nutritional intake, reduced enjoyment of food, and an overall impact on their QOL (Hutton et al., 2007). These symptoms can consequently lead to weight loss, which can then lead to a plethora of other health implications. Therefore, practical tips about how to manage symptoms more effectively and details about the '*building up*' diet (consuming extra calories in small quantities) were key elements of this workshop. The key aim of this workshop was to address the needs of people who had experienced some extent of chemosensory alteration through receiving treatment for cancer. The interactive workshop aimed to provide tips and practical advice on how to increase calorie consumption through small quantity meals.

Developing an effective behaviour change plan

After discussions with service users and meetings with colleagues at UCH Macmillan Cancer Centre, three diet workshop topics were finalised and developed: (1) Dietary information: facts and myths, (2) Managing your weight after treatment, and (3) Symptom management and building yourself up (with taster demonstration). Each workshop was scheduled to last for two hours on the first Thursday of each month, starting in May 2016. Patients were encouraged to book a place on the diet workshop of their choice based on the topic(s) most applicable and useful to their needs. Generally, all patients who expressed interest in attending a diet workshop were informed by a professional, either during a clinic appointment with a dietitian or whilst talking to a support and information specialist at UCH MSIS. Generally, service users were recommended to attend the first principle workshop *('Dietary information: facts and myths'*) and then a subsequent workshop that was most

relevant to their needs (either *'Managing your weight after treatment'* or *'Symptom management and building yourself up'*).

Oversee and direct the planned intervention

Through regular face-to-face interaction with service users at the UCH MSIS, it became increasingly apparent that diet related issues affected a broad spectrum of people, not necessarily just the person diagnosed with cancer. Consequently, the series of diet workshops were open to any person affected by cancer including patients, relatives, friends and carers. This opened the workshop to a much wider audience and offered extended support networks (of whom are often under supported) an opportunity to learn about diet and feel part of their loved ones cancer care experience. Adopting an *'open-to-all'* approach for the series of diet workshops was also believed to be beneficial for those patients who perhaps lacked confidence or motivation to attend a group session on their own. In addition to this, being accompanied by a relative, friend or carer also helped some individuals deal with an overwhelming amount of information, by perhaps taking notes or translating information. Ensuring that information was free from complicated medical terminology was an essential priority when planning the intervention. It was also important to consider the needs of patients who might have required additional support, for example those with special educational needs, non-English speaking, or the elderly. Consequently, it was agreed that the workshop would be open for all to attend.

Ensuring technical support for the intervention

Furthermore, it was also important to promote the behaviour change intervention workshops via online avenues, which would reach a different target audience known as the '*e-patient*' (Ennis-O'Connor, 2014). This type of patient is more self-efficient and active with seeking health information specifically relating to their diagnosis and treatment (Ennis-O'Connor, 2014). Although this type of patient is relatively prepared and well researched (Dedding, van Doorn, Winkler, & Reis, 2011; Ennis-O'Connor, 2014), it is still important to reach this patient group and offer them the same level of

support and information. Therefore, information about the diet workshops were featured on the UCLH website (see Appendix C) and across all of the service's social media platforms. This was achieved by contacting and liaising with the communications and ICT department at University College London Hospitals NHS Foundation Trust, to ensure that the information was uploaded onto the website correctly and efficiently.

Monitoring the intervention

It was fundamental that the behaviour change intervention was closely monitored and supported throughout the entire process. This ensured that service users had the most positive and beneficial experience whilst attending one of the diet workshops at UCH MSIS. Consequently, a Gantt chart was produced in order to clearly visualise the key elements of the intervention and the time it had taken to fulfil each aspect (see Appendix A). Promotional materials and methods in which the interventions were communicated to the relevant target audience were vital and played a significant role in the continual monitoring of the intervention. All other workshops and wellbeing group sessions conducted at MSIS were featured within the wellbeing programme and each had their own individual promotional flyer that was displayed within the service for visitors to access. Therefore, it was essential that the material was both informative and eye-catching, which also adhered to the approved guidelines of UCH MSIS (Appendix B).

In addition to this, a booking sheet was created alongside all other booking sheets for groups and workshops at MSIS, to ensure that patient information was stored safely and securely. Booking was encouraged for three main reasons: (1) monitoring the number of attendees booked to attend each workshop, (2) providing those booked to attend with a courtesy reminder call, two days prior to the intervention workshop, and (3) preparation for any printed out materials. However, although booking was required as a general rule, it was also important to reach patients that would not necessarily attend a group and consequently encourage them to attend on the same day. Therefore, on the day of each workshop, details of the intervention was displayed on screens across the hospital (cancer centre and main inpatient hospital) and handwritten on a sign outside the entrance to the service.

Evaluation and communicating the outcomes of the intervention

When planning and developing any type of behaviour change intervention it is essential to include some sort of evaluation process to ensure that the intervention is assessed in terms of its effectiveness and success (Craig et al., 2008). Evaluating an intervention can be carried out through various different approaches and it was decided that the best way to evaluate the diet workshops at UCH MSIS was to provide attendees with a pre- and post-evaluation form (Appendix D). The evaluation form consisted of pre and post outcome measures that assessed patients' perceived motivation and confidence levels in relation to their diet before the intervention took place and after they had attended the workshop. Forms were distributed to attendees at the start of each workshop and instructions on how to complete the form was provided. Completed forms were collected after each workshop and inputted into a computer database. This made it clear if any improvements in confidence or motivation levels had occurred among the participants as a result of attending a diet intervention workshop. A patient feedback summary for the principle workshop, *'Dietary information: facts and myths',* was created in order to highlight the positive outcomes (Appendix E).

The aims of the workshops were to address issues relating to diet, through the delivery of group intervention sessions, rather than in a one-to-one format. This was a more cost effective and beneficial method of delivery for both UCH MSIS and also service users. Attending an intervention in a group setting enabled attendees to engage with others who had perhaps shared similar experiences (Butow et al., 2007). Furthermore, upon completion of a workshop session, if attendees' required additional information about diet related issues, a referral form was completed and sent to the UCH dietetic department, where further information could be tailored to suit the patients' needs and delivered on a one-to-one basis. Overall, attendance rates in the newly developed and improved diet workshops increased and showed visible improvements compared to previous sessions, which followed the out-dated format. In addition to this, reported motivation and confidence levels had both improved, among all participants as a direct result of attending one of the diet workshop interventions at UCH MSIS. Due to these reported positive outcomes, the updated

diet workshops were offered to patients on a continuous basis. However, due to the introduction of a new patient pathway developed to improve patient experience, the diet workshop was later included as part of the regular health and wellbeing events at UCH MSIS. The wellbeing event was primarily for patients who had completed treatment, however those undergoing active cancer treatment and who wanted to attend the diet educational workshop, were welcome and encouraged to participate.
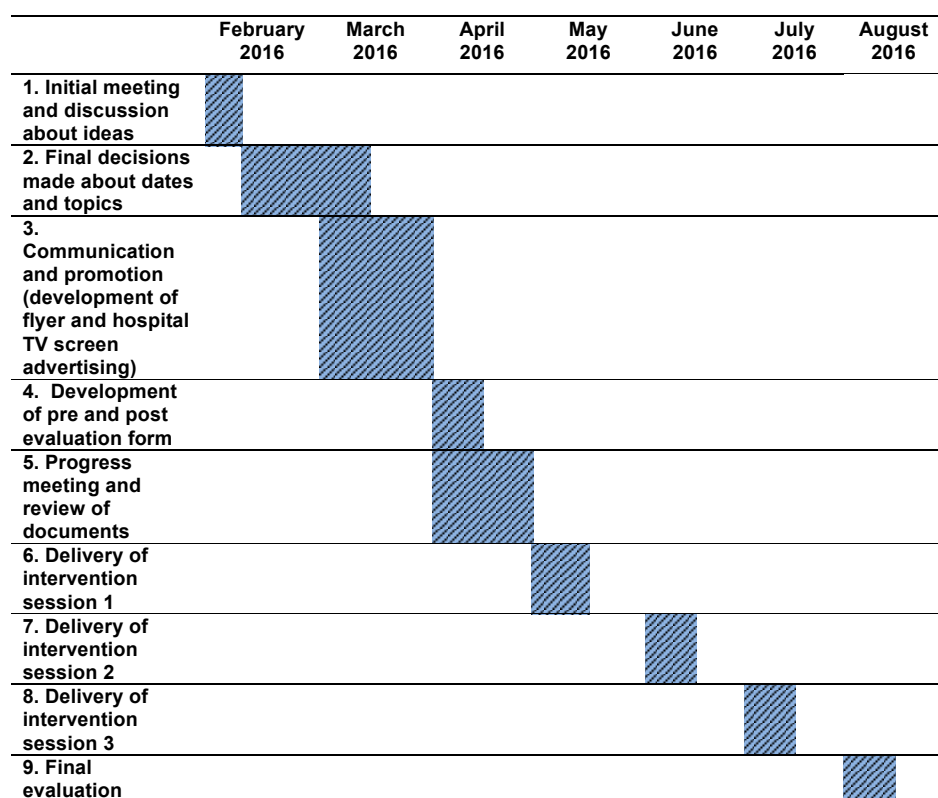
Word count: 3,232 words

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Appendix A: Gantt chart

	February 2016	March 2016	April 2016	May 2016	June 2016	July 2016	August 2016
1. Initial meeting and discussion about ideas	▨						
2. Final decisions made about dates and topics	▨	▨					
3. Communication and promotion (development of flyer and hospital TV screen advertising)		▨	▨				
4. Development of pre and post evaluation form			▨				
5. Progress meeting and review of documents			▨				
6. Delivery of intervention session 1				▨			
7. Delivery of intervention session 2					▨		
8. Delivery of intervention session 3						▨	
9. Final evaluation							▨

Appendix B: Promotional flyer

Appendix C: Online promotional content (UCLH website)

Appendix D: Patient pre and post evaluation form

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CANCER SUPPORT

University College London Hospitals **NHS**
NHS Foundation Trust

Questionnaire: Pre Workshop

Diet Workshop

Date:

1. On a scale of 0-10, how **confident** do you feel about managing your diet?

   0
   (not confident)

   10
   (very confident)

2. On a scale of 0-10, how **motivated** do you feel about managing your diet?

   0
   (not motivated at all)

   10
   (very motivated)

3. What were you hoping to get out of the workshop today? Please list three expectations below (for example to increase knowledge or confidence in the subject, or gain support from others).

   1) _____

   2) _____

   3) _____

Questionnaire: Post Workshop

Diet Workshop – while you are on treatment

Date:
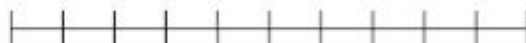
1. Having completed today's workshop on a Scale of 0-10, how **confident** do you now feel to manage your diet?

   0
   (not confident)

   10
   (very confident)

2. Having completed today's workshop, how **motivated** do you now feel to manage your diet?

   0
   (not motivated at all)

   10
   (very motivated)

3. Thinking about the expectations you set at the start of the workshop, were your three expectation met? Please answer yes/no for each one and any comments you would like to make

   1) _____

   2) _____

   3) _____

Appendix E: Evaluation summary

Diet workshop (facts and myths 05/05/2016) - evaluation summary

- 8 pre and post forms completed
- Evaluation scale 0 (not a lot) - 10 (a lot)

1. For the pre-evaluation question that asked, 'On a scale of 0-10, how **confident** do you feel about managing your diet?' The average score across all 8 respondents was **5.75**

On the post-evaluation questionnaire respondents reported that their confidence for managing their diet had increased to 8.62

2. For the pre-evaluation question that asked, 'On a scale of 0-10, how **motivated** do you feel about managing your diet?' The average score across all 7 participants was **7.75**

On the post-evaluation questionnaire respondents reported that their motivation to manage their diet had increased to 9

Graph representing improvements
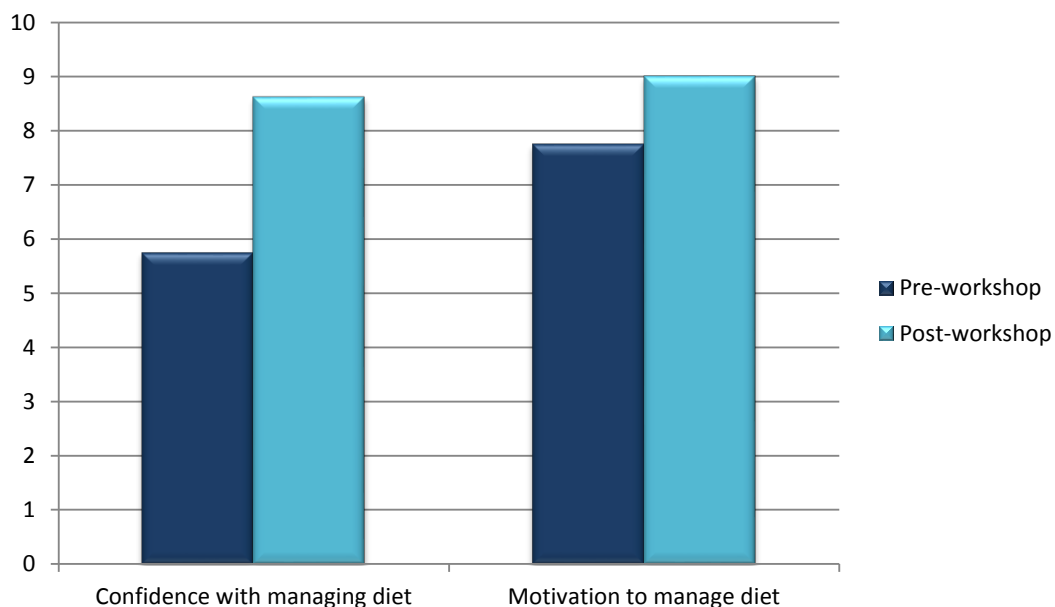
Question number 3 – open-ended question summary

Expectations for the session (recorded by each attendee)	Outcome
1. 'To increase Knowledge' 2. 'To increase motivation'	1. Yes 2. Yes
1. 'Information about sugar and cancer' 2. 'Need motivation' 3. 'Advice about should and should not eat'	1. Yes – 'information about sugar' 2. Yes – 'now motivated and eating carbohydrates' 3. Yes – 'information regarding processed products'
1. 'Increase knowledge' 2. 'Pick up idea on what to eat during treatment' 3. 'Sources of protein for vegetarians during treatment'	1. Yes 2. Yes 3. Yes
1. 'Increase knowledge' 2. 'Understanding nutrition'	1. Yes 2. Yes
1. 'Increase knowledge' 2. 'To ask questions'	1. Yes 2. Yes
1. 'To gain knowledge of what foods to eat' 2. 'To get advice on resources and outside help' 3. 'To learn how to plan my diet in future'	1. Yes 2. Yes 3. Yes
1. 'Ask questions about what fruits and veg work best' 2. 'I like eggs – could I have 1 egg every day?' 3. 'Learn more about nutrition'	1. Yes 2. Yes 3. No comment left
1. 'Increase knowledge'	1. No comment left

Appendix F: Supervisor evaluation report

Appendix 4

CITY UNIVERSITY LONDON

Department of Psychology
City University
Northampton Square
London EC1V 0HB
Programme Director – ███████████
███████
Email: ███████████████████
Tel: ███████████

Professional Doctorate in Health Psychology

Workplace Evaluation Report

Section 1 - To be completed by the trainee:

Trainee's name	Emily Robson
Name of workplace contact	UCH Macmillan Cancer Centre
Nature of work and competence assessed	Behaviour change intervention competence - a series of three diet workshops for people affected by cancer.

Section 2 - To be given to the workplace supervisor to return directly to above address:
Views on the Trainee's Performance on above piece of work (write comments below or email a separate report). Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

Emily has worked alongside a UCH dietician to produce a behaviour change intervention which she has delivered three times to a group of patients with cancer & their carers. This was very well attended and patients appreciated Emily's novel approach. The evaluation form shows improved motivation & confidence. We are delighted with Emily's professional, informed & engaging manner which she has undertaken here.

Declaration
I verify that the above named trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

| Signature: ███████████ | Date: 2.8.16 |

18

Appendix G: Supervision plan

Supervision Plan – intervention

Supervisee: __Emily Robson_____

Supervisor: __█████████_____

Intervention	Area of work (*outside of normal work)	Supporting evidence	Changes
Case study	Setting: UCH Macmillan Support and Information Service (MSIS) Description: After identifying a gap in the wellbeing programme at MSIS, I will work alongside a specialist dietitian to develop a series of diet workshops for people affected by cancer. Three workshops will be created: 1. Dietary information: facts & myths 2. Managing your weight after treatment 3. Symptom management and building yourself up. Promotional materials will be developed and distributed accordingly. Patents will be encouraged to attend whichever workshop(s) suits their needs best. A pre and post evaluation form that measures confidence and motivation levels, will be implemented in order to establish the impact of the intervention. Each workshop will last for two hours.	Case study report (3000 words) Workplace evaluation report █████████ ████) Evaluation forms completed by participants (measuring levels of confidence and motivation before and after the intervention)	

UNIT 4: TEACHING AND TRAINING

Case Study 1: Members of a haematology support group

Planning and designing

As a full-time trainee health psychologist at UCH MSIS, I was invited to speak at a monthly support group for people affected by red cell conditions. The haematology support group was divided into two parts: (1) an initial one hour talk with a guest speaker and (2) an unstructured second hour of discussion between group members. The group's structure shared many similarities with other support groups, with research suggesting that the inclusion of an educational component is a valued and important reason why many people choose to attend support groups (Bell, Lee, Foran, Kwong, & Christopherson, 2010; Marbach & Griffie, 2011; Morse, Gralla, Petersen, & Rosen, 2014). The primary focus of my talk was to discuss my role at UCH MSIS and explain how health psychology can be embedded into routine supportive care. The secondary focus was to share my knowledge about the impact and value of attending a group support session.

Once I had established the requirements of the one-hour teaching session and outlined aims and objectives, I was able to start planning the design of the session. I was required to work independently and use my best judgement to make professional decisions about how the teaching session should be conducted. I was able to prepare for this teaching session with a relative degree of flexibility and I used creativity to plan an interesting and engaging talk. Firstly, I had to consider the target audience, teaching location and available resources. A promotional flyer, which advertised the group and its monthly guest speaker was updated and distributed amongst visitors at the cancer centre (Appendix A). Secondly, I opted for an interactive, semi-structured teaching method that would engage service users on an informal level. From my experience of training at UCH MSIS, I believed that this method would be the most appropriate and effective at fulfilling the needs of the audience. Research has shown that adopting an interactive and collaborative approach to teaching allows the

audience to engage and learn more effectively (Lumpkin, Achen, & Dodd, 2015). Consequently, I created a handout document that incorporated both informative material, visual elements and interactive prompt questions (Appendix B).

Delivering the teaching session

At the start of the teaching session I welcomed group members to the session by introducing myself and explaining my role. I then outlined the aims and structure of the talk:

- Describe the role of health psychology in supportive care services
- Outline the research being conducting at the service
- Understand the value of support groups
- Questions followed by a short break before transitioning into the second hour.

After distributing handouts to all group members (see evidence folder), I read through each sheet timely and clearly, whilst also welcoming any questions and/or comments throughout. It was essential that information was concise and jargon-free. In general, group members varied in age, ethnicity and educational attainment level. Therefore, it was vital that information was comprehensible for every person who attended. Furthermore, I believed that producing the educational material would complement the relaxed nature of the support group and consequently encourage discussion between group members to develop naturally. The handout itself featured some interactive prompt questions that encouraged members to discuss key points. Discussion amongst the group integrated well into the second part of the support group. The informal and intimate nature of this teaching setting meant that I was able to broaden my presenting and teaching experiences. Previous experiences of presenting and teaching to mostly academic audiences in relatively formal settings were a stark contrast to a relaxed support group environment. As a result, I believe that I strengthened my confidence and ability to speak in front of smaller, more interactive groups of people. I am also able to demonstrate flexibility and adjust my teaching style to suit the audiences' needs. This is an important skill that I have acquired which I will take forward with me as I move into a career as a health psychologist.

Evaluation

Due to the sensitive nature of support groups and considering that *'confidentiality'* was highlighted as a fundamental element of the group's *'ground rules'* I decided that it would not be appropriate to ask members to complete a feedback evaluation form at the end of the support group session. Alternatively, I later asked for constructive feedback from the group facilitator; a health care professional who worked within the service as a haematology counsellor. I was thanked for the time and effort I had dedicated to delivering the session. I also received positive feedback for the discussion that had occurred amongst the members in the second half of the support group as a result of the talk I had delivered. An observer report from a member of the support and information specialist team, who also worked as a haematology nurse and was present during the teaching session, was written (Appendix G) and a supervisor's evaluation report was completed (Appendix H). This provides a further level of evaluative feedback. However, in future teaching sessions I would ensure that evaluation forms had been created and distributed to the audience. This would enable those who attended the teaching session to provide honest feedback, which would improve teaching style and content of future teaching sessions. It would also enable me to develop further as a health psychologist and continually improve my teaching style.

Reflection

Overall, I was pleased with how the first teaching session was delivered and received by group members and facilitators. Upon completion of the session, I reflected upon the experience by identifying the challenges, barriers and elements that could be improved for future sessions. As a trainee health psychologist with minimal experience of teaching, I believed it was essential to self-evaluate and critique my work wherever I could, in order to improve and grow as an autonomous professional. As a result, I decided to explore the meaning of reflective practice further to gain a clearer understanding of the value and importance of reflection. Firstly, I identified Gibbs' reflective cycle (1988) as a theoretical guide to reflective practice, which I applied to the teaching session I had conducted at UCH MSIS. As Figure 1 shows, the

somewhat dated, yet still highly relevant theory has six distinct stages: (1) description, (2) feelings, (3) evaluation, (4) situational analysis, (5) conclusion, and (6) action plan (Gibbs, 1988). After I had completed the session I referred to each stage of the model as a guide during the reflective process.

I specifically related to this model due to the circular nature and flexibility to move casually through any of the stages. In addition to this, I also valued the '*feelings*' stage, which enables reflection from an emotional perspective to take place. I also specifically focused on the '*conclusion*' stage of the model. This helped to address the challenges and barriers during the teaching session. In general, the main barrier was the informal and relaxed nature of the group environment, which subsequently led to the inability to gain formal evaluative feedback from group members. In order to avoid similar challenges in future teaching sessions (where the setting is naturally informal), I would perhaps engage with the audience more at the start in order to fully understand their expectations and desired outcomes. This would ensure that realistic aims and objectives are clearly outlined from the start.
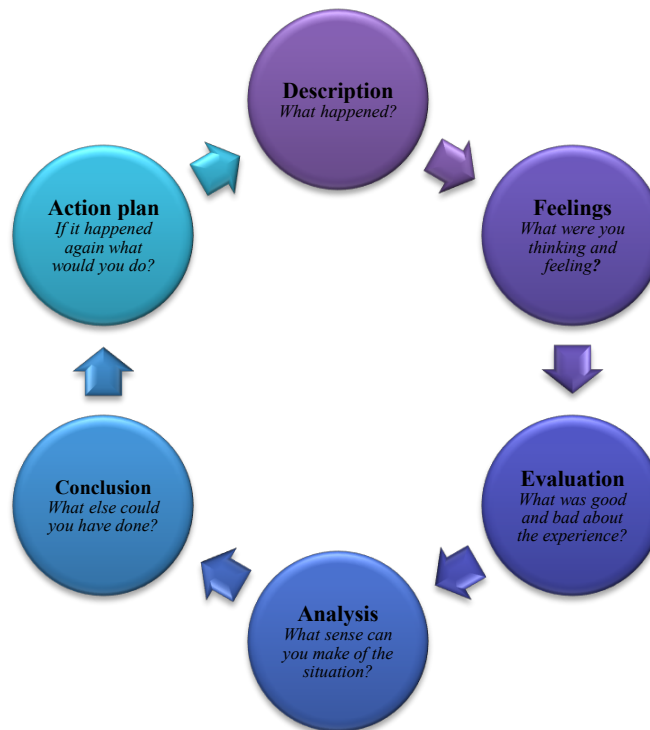
Figure 1. Reflective Cycle (Gibbs, 1988)

Case study 2: Health Psychology MSc students

Planning and designing

I was invited on two separate occasions to teach on the health psychology master's programme at City, University of London. Both sessions followed a similar theme:

1. A three-hour lecture titled *'Impact of cancer screening'* conducted alongside a colleague – a fellow trainee health psychologist - for the *'Behavioural Medicine'* module (November 2016)

2. A short teaching session titled '*Applying health psychology to an oncology setting*' conducted as part of a careers guidance lecture for health psychology students. The session was accompanied by other short talks from health psychologists working in settings such as academia, consultancy and brain injury rehabilitation (February 2017). A detailed observer report was written for this specific teaching session (see evidence folder).

For the purpose of this case study, the longer teaching session (*'Impact of cancer screening'* lecture) will be summarised in detail below. The case study will outline the planning, delivery and evaluation processes that occurred during the first lecture that was conducted, although it should be noted that the shorter session ('*Applying health psychology to an oncology setting*') was also carried out using very similar methods. In addition to this, feedback that was acquired from the students following the '*Impact of cancer screening'* lecture was used constructively to help shape the way the second session was delivered to the same cohort of students.

Firstly, the planning process for the *'Impact of cancer screening'* lecture started by discussing and clarifying lecture aims and objectives, and also highlighting some core reading for the students (Appendix C). Lecture aims included:

- Develop knowledge of available screenings in the UK, with a particular focus on cancer

- Develop awareness of possible factors that influence screening avoidance

- Critically consider interventions as health psychology professionals in order to tackle screening avoidance

- Understand the psychosocial impact of cancer screening and the potential risks associated with outcome.

My colleague and I decided how to divide the presentation based on our individual strengths of the topic area after we had established the teaching aims. As a result of my patient-facing role at UCH MSIS, it seemed appropriate that I should focus on the latter part of the presentation; exploring the psychosocial impact post undergoing a cancer screening test. My colleague therefore focused solely on the first half of the presentation; identifying the available screening programmes and highlighting the advantages of attending a screening test. Once this had been established I was able to begin preparing the PowerPoint slides for the upcoming lecture (Appendix D). As I created the lecture slides I felt that it was important to ensure that a balance between theoretical and practical knowledge was provided to the students. I also wanted the lecture to have a strong interactive element in order to engage with students and encourage natural discussion to occur around the topic area. I had learnt this from my previous experiences of teaching. Interactivity between the student and teacher had previously worked well and received generally positive feedback from students who had enjoyed feeling involved with their learning.

Delivering the teaching session

I arrived promptly and on time before the scheduled lecture, in order to prepare the room and ensure that the lecture started punctually. The presentation was divided into two halves; pre-screening and post-screening. In total, 12 postgraduate students attended the session. Initially, the lecture aims were outlined and an overview of the content was shared with the students. The lecture included a combination of statistical facts, theoretical information, videos, interactive student activities (both individual and in groups), and a presentation of patient case studies. Using a variety of teaching methods added interest to the lecture and retained students' attention throughout. Ensuring that students remained engaged with the content via an interactive element was a fundamental aspect of the lecture. In general, students positively rated this element of the lecture within the evaluation forms. It also allowed me to remain connected to my audience and respond to their reactions (verbal and non-verbal) to

different elements of the lecture. I was able to tailor my teaching style according to their responses and the level of participation within the lecture. This is a key skill that has helped me to develop professionally as a health psychologist throughout this training programme. Finally, the lecture ended with a brief summary of the content covered, key learning points, and a list of recommended further reading. Students were thanked for their attendance and politely asked to complete the evaluation form.

Evaluation

In addition to a supervisor's evaluation report, which was completed after the session, had ended (Appendix I), an evaluation form was also created in the planning and preparation stage prior to the lecture (Appendix E). I made the evaluation form simple and concise for the students to complete. The form asked them to rate their knowledge of the subject area both prior to attending the lecture and also afterwards. Interestingly all students who completed the evaluation form (n=10) highlighted that their knowledge around the topic of cancer screening had improved significantly since attending the lecture. A full summary of all completed student evaluation forms has been created (Appendix F). Students also commented that they found the videos and patient case study examples the most useful aspects of the lecture. This was a frequently emerging comment throughout almost all feedback forms, with some suggesting that they would have liked more of this content. Other positive comments included:

- *"Real life experiences and anecdotes explained very well in both parts"*
- *"The second part was good because sharing experiences and the first part was knowledgeable (liked the videos)"*
- *"It was educational and interesting"*.

Although the majority of evaluation forms were completed with positive comments and reflections, there was also some constructive feedback that will help me to improve as a professional and a potential educator in the future. Comments of this nature included:

- *"More attractive slides"*
- *"Some repetitive information, but nothing else"*

- *"Maybe including some more case studies to bring peoples experiences to life for the group".*

Reflection

After completion of the lecture, I reflected with my colleague on our teaching session. Together we discussed the positive outcomes and also the challenges that we had faced. This provided an additional level of evaluation. We also provided each other with feedback on our teaching style and went through each completed evaluation form to informally analyse the students' responses. Prior to the lecture, I felt apprehensive and worried that I would either present in an unclear manner or be unable to fill the allotted time. However, I had no reason to feel anxious. The students were welcoming and remained completely engaged throughout. Highly positive feedback sought from the evaluative feedback forms increased my confidence and levels of self-efficacy as I move towards a career as a health psychology professional. On the other hand, constructive feedback from the feedback forms provided useful information that will improve and shape teaching sessions that I conduct in the future.

Case Study 3: Training workshop for health professionals

Overview

After gaining two years' experience of working in cancer care, I was asked by a member of the support and information specialist team to help with the planning and delivery of a communication training session. The workshop was specifically aimed at allied healthcare professionals, as part of a two-day communications in cancer care training course. Attendees were all qualified healthcare professionals working and specialising within various divisions of care and many were looking towards a future career in cancer care services. I agreed and subsequently worked with my colleague to prepare the one-hour session. The workshop was titled '*Communication in cancer care: the fundamentals*' and took place in June 2017 at the UCH Cancer Education Centre. The aim of the session was to offer an introductory overview and build upon the audience's existing knowledge and skills. All health care professionals undertake some level of basic communication training during their professional education. This session set out to recap staff members on basic skills, in addition to focusing specifically on the communication differences in cancer care. The following case study will outline the process that took place when I developed and delivered an educational training workshop to health care professionals. It will also summarise the evaluation stage and conclude with a reflective section highlighting how this experience has enhanced my health psychology training experience.

Planning and delivering the training sessions

Firstly, in order to produce an informative yet clear training session it was important to set out well-defined aims and objectives for the session. These included:

- Improve awareness for the importance of good communication in cancer care, among professionals unfamiliar with the cancer division
- Increase healthcare professionals ability to be good communicators through providing practical tips, sharing patient case studies and engaging with interactive activities and videos

- Enhance inter-personal communication skills and confidence to communicate effectively with patients in cancer specific settings.

The session was delivered using presentation slides combining theoretical information, interactive group tasks and videos (Appendix F). In addition to this, presenting patient case studies and professional experiences during open discussion with the audience was also a fundamental aspect of the training delivery. This provided the audience with real insight into how communication in cancer care services may have differed from their own individual experiences.

Many of the professionals present at the training session had experience of working in different departments and/or among varying patient cohorts across the healthcare sector. In total, 27 allied healthcare professionals were present for the training workshop; most were registered nurses. Other professions included physiotherapists, occupational therapists and speech and language therapists. Throughout the session the audience were engaged and responded well to group activities. The presentation prompted positive and relevant discussion throughout and many of the healthcare professionals shared personal experiences, which gave extra depth to the overall learning experience. There was also an opportunity for the healthcare professionals to ask questions relating to the session and also pass around resources that I had offered to the room. These included booklets and informative written information about communicating and talking to others about cancer.

Evaluation

Evaluation is a highly important aspect of any teaching or training session that is conducted. It is vital for self-improvement and reflection that thorough feedback is gained wherever possible. Ideally in this case, a detailed evaluation feedback form would have been developed and distributed at the end of the session to all healthcare professionals that attended the training workshop. This would have provided useful insight into how well the session was delivered and how informative it was for the audience. In addition to this, it would have also provided a space for healthcare professionals who attended the training to offer constructive feedback or suggestions for future improvements via a confidential and anonymous method. This would have

also contributed towards my professional development as a trainee health psychologist. However, as this training session was a small component of a larger and more comprehensive two-day training course, the training organisers therefore sought their own evaluative feedback for the entire training content and duration. Consequently, individual feedback for separate sessions was not possible. However, the training organisers were contacted after the session in regards to the feedback. Unfortunately on it was not possible to establish the effectiveness of the workshop, however a facilitation certificate was provided (see evidence folder) and I was thanked for my time and contribution to the training course. I also received a supervisor's evaluation report (Appendix J), for the training I had delivered.

Together with a colleague (co- facilitator of the training session), we carefully reflected on the experience of co-facilitating a training session to healthcare professionals. Together we discussed both the positive and challenging aspects, and thought of ways in which the session could be improved for the future. Evaluative feedback and draft notes of our thoughts for future improvement were recorded and saved for reference. This process also provided a safe place for me to reflect on my contribution to this training workshop and gain some informal feedback on my teaching style from my colleague whom I trusted.

Reflection

On reflection I am pleased to have been given the opportunity to train healthcare professionals, even though I felt nervous before the session. I was conscious that the audience were all qualified professionals and as a trainee this felt initially overwhelming. However, during the workshop I felt confident in my ability to professionally and skilfully facilitate the session. I particularly liked sharing my own personal experiences with the audience and discussing patient case studies. It was a great opportunity to build on my own presentation and public speaking skills with a professional and qualified audience. However, the session also proved challenging at times, with difficulties regarding the evaluation stage being the most prominent barrier. As discussed previously within this case study, written evaluations were not provided for individual training sessions as feedback was collected on completion of the entire two-day course duration. In future teaching and training sessions I will aim

to collect evaluative feedback wherever possible in order to understand the impact and value to those who attend. As I develop my skills throughout the training programme, I would like to aim future teaching and training sessions at more healthcare professional focused audiences. In addition to this, I would also like to maintain my links with academic institutes and continue to teach students, both on undergraduate and postgraduate programmes.

Word count: 3,351 words

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Appendix A: Support group flyer

WE ARE MACMILLAN. CANCER SUPPORT

University College London Hospitals **NHS**
NHS Foundation Trust

Haematology Support Group

The support group provides a relaxed space where any adult affected by Haematological conditions can meet and share information, ask questions of specialist staff and be supportive to each other at any stage – the group welcomes patients, family and friends.

- The group is jointly facilitated by ▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓ and ▓▓▓▓▓ Patient and Volunteer. A member of the Living Room Information Specialists will usually be in attendance.
- The first hour is usually led by a speaker on an issue or topic of interest to the group.
- The second hour allows for members to update each other and share anything they may wish to with the group or just listen.

Where?   **The Living Room**
Macmillan Support and Information Centre
▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓▓

When?   ▓▓▓▓▓▓▓▓▓▓▓▓▓▓

Our guest speaker on 10 August will be Emily Robson, Trainee Health Psychologist speaking about the value of Support Groups and what takes place in a group based on her research and drawing on the personal experience of group members.

Future dates for 2016:

14 September, 12 October,
9 November, 14 December.

For further information please call ▓▓▓▓▓▓▓▓▓

Appendix B: Extract from support group handout (see evidence folder for full version)

University College London Hospitals **NHS**
NHS Foundation Trust

Wednesday 10th August 2016

Value of support groups and the personal experience of group members based on research at **UCH Macmillan Cancer Centre**

Emily Robson MSc, Trainee Health Psychologist

What is Health Psychology?

Health Psychology differs from other areas of psychology (e.g. clinical, educational), in that it specifically focuses on aspects of health, illness and behaviour. A Health Psychologist deals with the psychological and behavioural processes that contribute to health and wellbeing across the life span. The five main goals of a Health Psychologist are:

1. To prevent illness
2. To promote good health
3. To help with the treatment of illness
4. To investigate the relation between psychological processes and illness
5. To improve the healthcare system and health polices.

Topics that a Health Psychologist might cover include:

- Helping people manage chronic pain
- Sleep problems
- Weight and diet related problems
- Smoking cessation
- Drug and alcohol misuse
- Sedentary behaviour (lack of physical activity).

In order to help people with some of the above, a Health Psychologist might facilitate behaviour change interventions, carry out cognitive behavioural therapy (CBT) sessions, develop health promotion campaigns (to promote healthy behaviours) and/or conduct research to broaden understanding of a particular health related topic.

1

Appendix C: Lecture planning sheet

Module: Behavioural Medicine, HYM003

Module Leader
Dr ▇▇▇▇▇▇▇▇▇▇

Module outline and aims
The rationale of the module is to provide students with the skills to critically evaluate empirical evidence and theoretical models in behavioural medicine. This will include behaviours associated with health outcomes. You will also have exposure to practical administration of some psychometric tests.

The module aims:

1. To develop your awareness of assessment strategies in behavioural medicine.
2. To develop your basic knowledge of interventions within the context of behavioural medicine.
3. To enable you to critically appraise the current knowledge, theory and empirical research in behavioural medicine.

List of Sessions:
1. Introduction to the course and behavioural medicine
2. Health behaviours
3. Smoking cessation
4. Adherence
5. Obesity
6. Neuropsychology and cancer
7. Sexual health & HIV research
8. **Impact of screening**
9. Alcohol and illicit drug use
10. Symptom awareness & illness perceptions in chronic eye disease

Sessions overview
I will like to give students some information about the session you will be giving during the semester. Please give a few learning outcomes (2 to 5) for the session and some key reading references:

Lecturers	▇▇▇▇▇▇▇▇▇▇ & Emily Robson
Name of the session	Impact of screening
Day / Time	24th November / 9am – 12pm
Learning outcomes	- Develop your knowledge of available screenings in the United Kingdom – particularly focusing on cancer - Develop awareness of possible factors that influence screening avoidance - Enable you to critically consider interventions as Health Psychology professionals in order to tackle screening avoidance - Understand the psychosocial impact of cancer screening and

	the potential risks associated with outcome
Reading references	- Brodersen, J., & Siersma, V. D. (2013). Long-term psychosocial consequences of false-positive screening mammography. *Annals Of Family Medicine, 11*(2), 106-115. doi:10.1370/afm.1466 - Cooke R. and French D. P. (2008) How well do the theory of reasoned action and theory of planned behaviour predict intentions and attendance at screening programmes? A meta-analysis, *Psychology & Health, 23:7*, 745-765 - Cordella, M., Poiani, A., & SpringerLink eBook Collection. (2014). *Behavioural oncology: Psychological, communicative, and social dimensions.* New York, NY: Springer New York - Hall, N. J., Rubin, G. P., Dobson, C., Weller, D., Wardle, J., Ritchie, M., & Rees, C. J. (2015). Attitudes and beliefs of non-participants in a population-based screening programme for colorectal cancer. *Health Expectations: An International Journal Of Public Participation In Health Care & Health Policy, 18*(5), 1645-1657. doi:10.1111/hex.12157 - Marlow L. A. V., Wardle J. and Waller J. (2015) Understanding cervical screening non-attendance among ethnic minority women in England, *British Journal of Cancer, 113*, 833-839

Appendix D: Lecture evaluation form

Lecture: Impact of Screening

Module: Behavioural Medicine, HYM003

Date: Thursday 24th November 2016

How clearly were the lecture aims and objectives set out to you? (Please tick)

1. Very clear	2. Fairly clear	3. Not sure	4. Fairly unclear	5. Very unclear

How much did you feel you knew about the subject before the lecture?

1. A great deal	2. A fair amount	3. Not sure	4. Not much	5. Nothing at all

How much do you feel that the lecture improved your knowledge in this area?

1. A great deal	2. A fair amount	3. Not sure	4. Not much	5. Nothing at all

What aspects of the lecture did you find most useful?

_____

_____

_____

_____

What aspects did you find the least useful and/or how do you think the lecture could be improved?

_____

_____

_____

_____

Thank you!

Appendix E: Teaching evaluation summary

Teaching evaluation summary (MSc Lecture – 10 completed forms) – Thursday 24th November 2016

1. When asked, 'How clearly were the lecture aims and objectives set out to you?'

   80% responded with 'very clear'
   20% responded with 'fairly clear'

2. When asked, 'How much did you feel you knew about the subject before the lecture?'

   10% responded 'nothing at all'
   70% responded 'not much'
   20% responded a 'fair amount'

3. When asked, 'How much do you feel the lecture improved your knowledge in this area?

   60% responded 'a great amount'
   40% responded 'a fair amount'

Independent student responses – difference between question 2 and 3
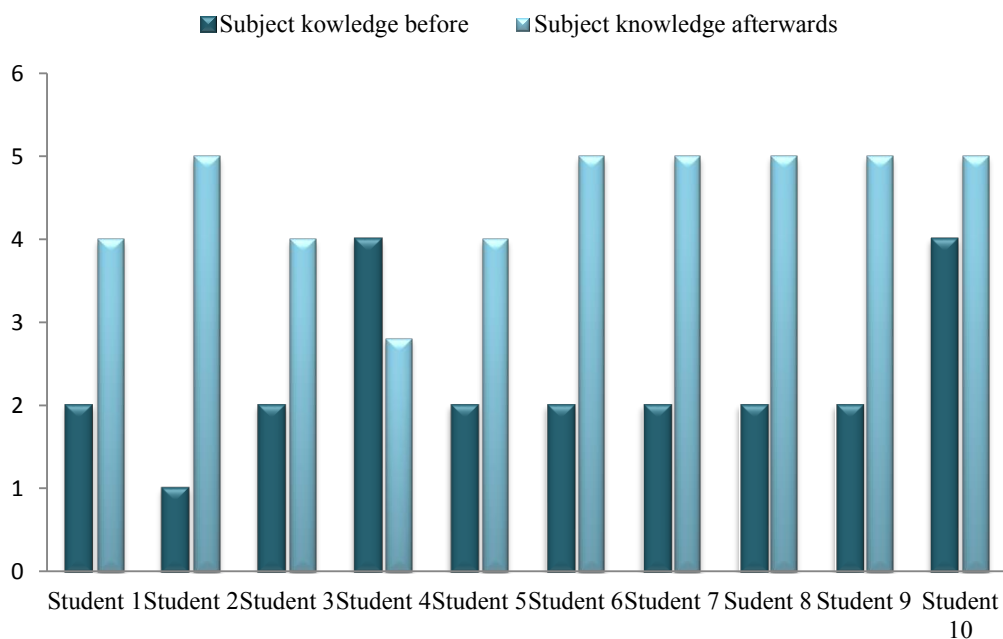
Open-ended answer responses (questions 4 and 5)

	Q4. What aspects of the lecture did you find most useful?	Q5. What aspects did you find the least useful and/or how do you think the lecture could be improved?
Student 1	- 'Understanding how screening process works for the UK'	- 'Maybe including some more case studies to bring peoples experiences to life for the group'
Student 2	- 'Group tasks' - 'Hearing about the issue from a professional experience' - 'The videos' - 'It was educational and interesting'	- 'It was sometimes difficult to hear you both so it would be helpful if you could speak up' - 'Possibly standing when speaking will change the dynamic of the way you both present!' - 'Thanks!'
Student 3	- 'Videos and explanations	- No comment left
Student 4	- 'Psychological aspects of treatment and care'	- 'The epidemiology slides – too small and already covered in previous lectures'
Student 5	- 'The group exercises/updated information about screening treatments/cancer treatments. Also the videos'	- 'More attractive slides'
Student 6	- 'The videos' - 'Real case examples from the lecturers'	- 'Slides a bit repetitive, a few!'
Student 7	- 'Additional links to videos or real life patients'	- No comment left
Student 8	- 'National screening programmes' - 'Highest risk groups, how to communicate to deprived groups' - 'What makes effective communication'	- 'More specific case study focus' - 'Videos were very good'
Student 9	- 'The second part was good because sharing experiences and the first part was knowledgeable (liked the videos)'	- 'Some repetitive information but nothing else'
Student 10	- 'Real life experiences and anecdotes' - 'Explained very well in both parts'	- 'Tasks maybe could be improved'

Appendix F: Training workshop presentation slides

Communication in Cancer Care
Fundamentals of good practice

and Emily Robson
Macmillan Support and Information Specialist and Trainee Health Psychologist

---

What we will cover today

- What is communication?
- Methods of communication
- Communication in cancer care
- How to be a good communicator
- Practical tips and resources

With the person next to you talk about either:

1. Something you did at the weekend
2. Something about yourself

What did you notice?

What is communication?

- The exchange of information between 2 or more people
- Communication is the process of transferring signals/messages between a sender and a receiver through various methods

---

How do we communicate?

- Speaking
- Listening
- Writing
- Remembering
- Non-verbal
- Social media

Research

- Non-verbal communication can override verbal messages

- Doctors' tone of voice and degree of eye contact associated with the doctor seeming interested (Marcinowicz et al, 2010)

- Feeling that the HCP is emotionally engaged through tone of voice and body language/posture, determined if a patient felt 'cared for' or 'ignored' (Timmermann et al, 2017)

7

Barriers to good communication

- Poor body language - not listening

- Heightened emotions – anger, sadness, anxiety

- Handling uncertainty - complex or difficult issues

- Feeling unwell

- Poor environment – noisy, busy

- Language barriers

8

So, how is communication different in cancer care?

- Complex illness
- Influence of media
- "Expert patient"
- Fear – of death, of treatment, of recurrence, of image
- Impact on identity
- Functional adjustments
- Impact on relationships
- Previous experience
- Other medical conditions or special needs

9

Example of poor communication…

Do you have an example?

With the person next to you list the examples of poor communication in the video

https://www.youtube.com/watch?v=oHreolyshYY

10

Good communication skills in a hospital setting

- Sensitivity/awareness/observant
- Kindness
- Time
- Listening
- Body language
- Speaking clearly without jargon
- Ask open questions
- Reflect back

11

…and more…

- Be aware of sensory impairment

- Be aware of language issues

- Be aware of cultural differences

- Be aware of guidelines and legal issues regarding confidential information

- Reporting back

12

What not to do…

- Avoidance…(rushing around, too busy etc)
- Change the subject
- Tell your own story
- Talk too much
- Give advice inappropriately ('what I'd do is…')
- Think you have to have answers

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University College London Hospitals NHS
NHS Foundation Trust

13

Example of good communication…

With the person next to you list the examples
of good communication

https://www.youtube.com/watch?v=wAEEUzcL5P4

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University College London Hospitals NHS
NHS Foundation Trust

14

Helpful Macmillan booklets:

- Talking about cancer
- How are you feeling?: the emotional effects of cancer
- Ask about your cancer treatment
- Talking to children and teenagers when an adult has cancer
- Telling your child you have cancer
- Talking with someone who has cancer
- Coping when someone close to you has cancer

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NHS Foundation Trust

15

…and finally….

LISTEN….

https://www.youtube.com/watch?v=1pw8m_NTJ_0

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16

Any questions?

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NHS Foundation Trust

17

Appendix G: Observer report (case study 1)

WE ARE MACMILLAN.
CANCER SUPPORT

University College London Hospitals **NHS**
NHS Foundation Trust

Observer report for Emily Robson - Haematology Support Group guest speaker

Date: Wednesday 10th August 2016
Topic: Role of Health Psychology and overview of research about groups
Duration: 1 hour
Number of attendees: 8 patients + 3 facilitators (2 health professionals & 1 volunteer)

Emily delivered a one hour guest teaching session to members of the monthly haematology support group at the Macmillan Support and Information Service, in August 2016. Emily talked about the role of Health Psychology in clinical settings and gave an overview of her research about groups. The topic was of particular interest to the group and prompted much discussion amongst the members which continued through to the second half of the support group.

Emily introduced herself well at the start of the talk and continued to speak confidently and clearly throughout. An informative and detailed handout was a useful addition, which patients could take home with them if they wished. Emily answered questions and comments with clarity and detail. Overall, the talk was presented well to the audience and created a relaxed informal feel which added to the nature of the support group.

Reviewer: ▮▮▮▮▮▮   **Signature:**   **Date**: 17/08/2016
(Support and Information Specialist)

261

Appendix H: Supervisor evaluation report (case study 1)

Professional Doctorate in Health Psychology

Workplace Evaluation Report

Section 1 - To be completed by the Trainee:

Trainee's name	Emily Robson
Name of workplace contact	UCH Macmillan support and Information service
Nature of work and competence assessed	Guest talk at a monthly haematology support group

Section 2 – to be completed by the Workplace Supervisor:
Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

10ᵃ August 2016 Emily successfully completed a guest talk requested by co Haematology Support group – attended by patients with Haematological malignancies and red cell disease. The talk was about Emily's research into groups and was well received with much enthusiasm.

Declaration
I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: ██████████ Date: 8.6.17

School of Health Sciences
City University
Northampton Square
London EC1V 0HB
Programme Director – ██████████
Email: ██████████
Tel: ██████████

Appendix I: Observer's report (case study 2)

School of Health Sciences

Observer's Report

Name of Reviewee:		Department/School:		
Emily Robson		Health Services Research		
Date of Review 31.03.17	**Session/activity to be reviewed:** Careers Presentation	**Module:** HYM007	**Level:** MSc	**Number of students:** 14

Areas you would like feedback on
This might include (e.g.) the style of communication with students, your management of a situation etc (please see guidance notes)
• The quality of the content of the presentation • Communicating ideas to students • Time-keeping skills • Level of engagement and interactions with the students

Feedback on the identified area
There was a clear outline and structure to Emily's presentation, which included a nice balance of slides and videos to describe the work she is involved with as a Trainee Health Psychologist on placement. The presentation had a clear aim and message, i.e. the role of a Health Psychologist in a cancer support setting. Up-to-date and relevant information was presented. Emily has a nice presentation style, explaining ideas clearly and in an engaging manner. Emily timed her presentation well, allowing time for questions from the students to ensure understanding. Emily had a good level of interaction with the audience and was openly welcome to ideas from the students. When asked a question Emily went straight to the point and was clear in her answers.

Additional Comments
Emily had met the students in a previous session so had not necessarily needed to introduce herself in great detail, but should be aware to introduce herself in every teaching session to enable students to feel at ease. Another consideration for future sessions would also be to include contact details either on the first or last slide and signpost students to contact details in case they would like to get in touch after the session.

Reviewer Name: ▉▉▉▉▉▉▉ **Signature:** ▉▉▉▉▉▉ **Date:** 11/04/17

Appendix J: Supervisor evaluation report (case study 3)

Professional Doctorate in Health Psychology

Workplace Evaluation Report

Section 1 - To be completed by the Trainee:

Trainee's name	Emily Robson
Name of workplace contact	UCH Macmillan Support and Information Service
Nature of work and competence assessed	Communication in cancer care training session with health care professionals.

Section 2 – to be completed by the Workplace Supervisor:

Views on the Trainee's Performance on above piece of work. Please also comment on any reason for delays in the completion of this piece of work and report any periods of prolonged absence.

5ᵗ June 2017. Emily conducted a training session for 27 Nurses and Allied Health Professionals currently working in the Trust and wanting to gain experience and understanding of 'Communication in Cancer Care: the fundamentals'. Session very well received.

Declaration

I verify that the above named Trainee has undertaken the above mentioned piece of work. I am of the opinion that it has been completed to a satisfactory professional standard.

Signature: ▮▮▮▮▮▮ .   Date: 8·6·17

CITY
UNIVERSITY OF LONDON
— EST 1894 —

School of Health Sciences
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Email: ▮▮▮▮▮▮
Tel: ▮▮▮▮▮▮

Appendix K: Supervision plan

Supervision Plan – teaching and training

Supervisee: ___Emily Robson_____

Supervisor: __████████████_____

Teaching and training	Area of work (*outside of normal work)	Supporting evidence	Changes
Case study 1 (Teaching 1)	Setting: UCH Macmillan Cancer Centre Audience: Patients Description: Invited as a guest speaker to a monthly haematology support group for people affected by a red cell condition. Teaching session lasted for one hour. Aim of the talk is to describe my role and explain how health psychology can be integrated into supportive cancer care.	Case study report (1000 words), Observers report Workplace evaluation report ████████████	
Case study 2 (Teaching 2)	Setting: City, University of London. Audience: Postgraduate students Description: An MSc Health Psychology lecture to students as part of the Behavioural Medicine module. The lecture will focus on cancer screening and risk perception and will use presentation slides to deliver a combination of theoretical knowledge, facts/statistics, videos, interactive activities and real-life patient case studies. The lecture will last for 3 hours. Evaluation forms will be distributed upon completion of lecture in order to gain constructive feedback.	Case study report (1000 words) Evaluation forms completed by students Observer report	
Case 3 (Training)	Setting: University College London Hospitals NHS Foundation Trust Audience: Healthcare professionals Description: Training workshop to be delivered as part of a larger 2-day training course. The workshop will focus on communication skills within cancer services. The training workshop will employ activities, practical skills and tips and real-life patient case studies.	Case study report (1000) Facilitation certificate	

SECTION E: SYSTEMATIC REVIEW

The effectiveness of mindfulness techniques for adults with recurring chronic headaches and migraines: A systematic review

Abstract

Introduction: Chronic headaches and migraines are amongst the top three common causes of disability worldwide. Symptoms can cause debilitating pain that interfere with everyday tasks and QOL. Typically, single analgesics and prescription drugs are used to manage pain, however unpleasant side-effects have led to increased uptake in alternative therapies (e.g. mindfulness). Engaging in mindfulness has shown positive outcomes when applied to health conditions including schizophrenia. Mindfulness has also been associated with improved mental health and reduced stress.

Aim: Identify and assess the effectiveness of mindfulness techniques for adults managing recurring chronic headaches and/or migraines.

Method: A search of English, peer-reviewed literature published between 2007-2017 was conducted within 11 databases. Key words included '*mindfulness*', '*headache*' and '*adult*'. Inclusion criteria consisted of adults aged over 18 years, diagnosis of headache and/or migraine, randomised control trial (RCT), and use of an intervention that applied mindfulness-based techniques. A quality assessment tool was also applied.

Results: After initial searching, 369 studies were retrieved. Following screening and eligibility checks, 7 RCT studies remained. Interventions that applied mindfulness-based stress reduction techniques (including relaxation and breathing exercises) occurred most frequently. Results reported favourably for the effectiveness of mindfulness-based interventions. Frequency and duration of headaches decreased and wellbeing and QOL improved.

Discussion and conclusion: It is fundamental that alternative treatments such as mindfulness are offered as part of pain management interventions more frequently. Future reviews should focus on mindfulness for children and/or adolescents with headache, and also qualitative study-designs exploring patient experience of participating in mindfulness interventions, should be included. Whilst this review presents preliminary findings, more rigorous RCTs should be conducted in the future in order to explore the research question further.

Introduction

Chronic headaches and migraine prevalence

A headache is defined as being '*painful and disabling*' and is typically diagnosed as migraine, tension-type or cluster headache (Ahmed, 2012; World Health Organization (WHO, 2016). Recurrent headache disorders, including migraines, are among the most common disorders to occur within the nervous system (WHO, 2016). Chronic headaches and migraines both rank in the top three most common causes of disability, for men and women, worldwide (Steiner et al., 2015; Steiner, Stovner, & Birbeck, 2013). Research has shown that headaches and migraines are among the most recurring medical complaints that general practitioners (GP) receive each day (Starling & Dodick, 2015). Although chronic headache and migraines can affect any age, including children and adolescents (Lipton et al., 2011), interestingly it is most common among adults under the age of 50 years (Steiner, Stovner, & Vos, 2016). In addition to this, migraine affects three-times as many women as men with hormone related factors believed to be the most likely reason (WHO, 2011). As a result, middle-aged females aged between 45-54 years, of whom consult a healthcare professional with symptoms relating to headache or migraine pain, are most likely than males to receive a repeat medication prescription than any other age category (Latinovic, Gulliford, & Ridsdale, 2006). Reports have shown that in primary care settings alone, 44 consultations per 1,000 will be complaints relating to headache or migraine pain (Latinovic at al., 2006). These figures have a costly impact on society as chronic headache and migraine is estimated to cost the NHS £150 million and £250 million respectively per year (House of Commons, 2010). It is believed that this substantial annual sum is mostly comprised of prescription drugs and patient visits to GP services (House of Commons, 2010).

Psychosocial impact

Recurring chronic headache and migraines have shown to have a lasting impact on many aspects of a person's social and psychological health (Lanteri-Minet, Duru, Mudge, & Cottrell, 2011). Physically, headaches and migraines can cause debilitating

268

and throbbing pain that can reach moderate to severe intensity for up to 72 hours if left untreated (Headache Classification Committee of the International Headache Society, 2013). Repeated pain from headaches and migraines can interfere significantly with normal everyday activities and negatively affect QOL (Lanteri-Minet et al., 2011; Leiper, Elliott, & Hannaford, 2006). Research suggests that in the UK around 25 million days of work or school are lost each year as a consequence of chronic headache and migraine attacks (Steiner et al., 2003). For employed adults this could mean potential loss of earnings and for school-aged children and adolescents it could result in missed periods of education. Therefore, both may cause long-term implications for the person affected (McCrone et al., 2011). Links have also been established which suggest that depression and headaches are closely related to one another (Wynd, Martin, Gilson, & Meadows, 2015). In a cross-sectional study that used a relatively large sample of participants recruited from 10 European counties, findings concluded that migraine is comorbid with both depression and anxiety (Lampl et al., 2016). Similarly, a small-scale qualitative study also found that headaches had caused negative feelings such as depression, aggression and worry to occur among the participants (Leiper et al., 2006). However, it should be noted that the size of this study does not necessarily attribute reliable levels of causation between negative feelings and migraine. In addition to this, health-related QOL is also reported to be lower as migraine attack frequency increases among those who suffer from the disorder (Lanteri-Minet et al., 2011; Terwindt, Ferrari, & Launer, 2003).

Previous research has already suggested that recurring headaches can elicit a host of distressing feelings including depressed mood, helplessness and social withdrawal (Andrasik, 2001). To add to this, further qualitative research has provided insights into some of the difficulties that people with chronic headache disorders have to contend with each day (Rutberg & Öhrling, 2012). Findings from the study reported that the '*invisibility*' of headache pain to others and living with '*uncertainty*', were among two of the main concerns that people with neurological disorders may experience (Rutberg & Öhrling, 2012).

Treatment and management

At the stage in which a headache becomes a medical complaint, it is the healthcare professionals role to identify if the headache is primary (headache is the disorder) or secondary (headache is the symptom) (Marcus & Ready, 2016). This will allow the healthcare professional to assess and appropriately deliver a suitable treatment plan to the patient. For those who suffer from a neurological disorder (e.g. headache), it is common to also experience other migraine related comorbidities, such as nausea (Headache Classification Committee of the International Headache Society, 2013) and/or photophobia (light sensitivity) (Wang, Chen, & Fuh, 2010). Furthermore, if left untreated chronic headaches and migraines can also increase the risk of developing much more serious medical complications in the future such as stroke, cardiovascular disease and epilepsy (Sacco & Kurth, 2014; Wang et al., 2010).

A large variety of treatment options are currently available for acute migraine and headache. Ideally, treatment should relieve the pain and associated symptoms of headaches both quickly and efficiently without causing side effects (Friedman & Grosberg, 2009). The most commonly prescribed medications used to treat chronic headaches and migraines include over the counter medication such as single analgesics and prescription only medication such as ergots, opioids and triptans (Thorlund et al., 2016). However, research has found that those who take analgesics and opioids to relieve symptoms of chronic headache and migraine are at an increased risk of developing medication-overuse headache as a result (Thorlund et al., 2016). Therefore, a significant proportion of patients are growing increasingly reluctant to take medication as a result of unpleasant side-effects that prescription drugs can cause (Mauskop, 2007). As a result, those who suffer from headache and migraines have developed awareness for non-traditional forms of treatment, including behavioural therapy (e.g. relaxation therapy, CBT, and biofeedback therapy), acupuncture, and nutritional therapies (e.g. herbal remedies) (Mauskop, 2007). Research has positively supported the use of alternative therapies for the treatment of chronic headache and migraines (Posadzki at al., 2015). A qualitative study revealed that patients preferred to adopt migraine-inhibiting strategies such as relaxation, acupuncture and CBT, in an attempt to avoid headaches and migraines from occurring (Varkey, Linde, & Henoch, 2013). The study also added that by embracing alternative therapies, participants (of

whom all experienced frequent migraines) felt more inclined to accept and attempt to control their headache related pain (Varkey et al., 2013).

Applying mindfulness principles to health

Mindfulness has gained heightened public awareness in recent years and has shown beneficial outcomes when applied to a range of minor and acute medical conditions (Lancaster, Klein, & Knightly, 2016). The term mindfulness has amassed a number of definitions and meanings, however the essence of mindfulness has generally been defined as, *"moment-to-moment, non-judgmental awareness"* (Kabat-Zinn, 2015). The Oxford English Dictionary (2017) definition of the word adds that it is *"a mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique"*. Mindfulness installs calmness into busy and hectic lives and includes partaking in behaviours such as relaxation, meditation and concentration (Hölzel et al., 2011).

Previous reviews within this research area have typically been dominated by studies conducted in the United States, and have also failed to include meditation and relaxation training techniques. There has also been a lack of reviews that have focused specifically on migraines and/or chronic headaches; previous papers have typically generalised their searches to effectiveness of mindfulness techniques for chronic pain (Chiesa & Serretti, 2011; Hilton et al., 2016). This therefore provided a rationale for a new systematic review to be conducted. However, there have been numerous behaviour change interventions that have aimed to improve health and general wellbeing, which have been based around the general concept of mindfulness. In a study that explored methods of reducing social anxiety among young adults, positive outcomes, including enhanced levels of self-compassion and self-esteem, were established when mindfulness-based techniques were applied to a stress reduction programme (Hjeltnes et al., 2017). In addition to this, a systematic review and meta-analysis that included 47 trials within the review, also found that mindfulness meditation programmes showed small to moderate evidence of improved anxiety, depression and pain (Goyal et al., 2014). Therefore, in light of such positive

findings that support the use of mindfulness-based techniques for managing health related problems, it is clear that the use of mindfulness for the management of chronic headaches and migraines should be considered.

Review aim and rationale

The aim is to identify and assess the effectiveness of mindfulness techniques for adults managing chronic headaches and/or migraines. The review will aim to provide preliminary findings that will allow the reader to evaluate the weight of evidence presented throughout. It will also aim to include only the most recent literature that solely focuses on migraines and/or chronic headaches. Highlighting preliminary findings for the effectiveness of mindfulness will hopefully encourage more rigorous interventions, ideally in the form of RCTs, to be developed in the future.

Method

Search Strategy

A search of English language peer-reviewed literature has been conducted using both keyword and subject searches within core databases. Literature within the review included papers published within a 10-year duration (2007-2017). This specific date range was primarily chosen to ensure that the most recent data was incorporated into the review. Advances in research, particularly focusing on mindfulness interventions, have increased in popularity in recent years, therefore the researcher believed that studies over the age of ten years would not be representative of current mindfulness interventions conducted in current healthcare settings.

During the searching stage of the process ECSCOhost and Ovid Online platforms were used to complete searches in relevant healthcare databases. Keywords were identified from the research question (mindfulness, adults and headaches) and alternative words with the same meanings were identified and also included within all searches.

Specific key words that were entered into the search included; Mindfulness –
("*Mindful*" OR "*Meditation*" OR "*RelaxationTechniques*"); Adults – ("*Adult*" OR
"*MiddleAge*" OR "*YoungAdult*" OR "*Aged, 80 and Over*"; and Headaches –
("*Headache*" OR "*Headache,Primary*" OR "*Headache, Secondary*" OR "*Migraine*"
OR "*TensionHeadache*" OR "*Cephalgia*" OR "*VascularHeadache*").

Searches took place using 11 key healthcare databases: Cinahl PLUS full text,
Medline Complete, Cochrane Controlled Trials, Embase, PsycINFO,
PsycARTICLES, PubMed, Science Direct, Web of Science and Scopus. A full search
strategy was created in a table on Microsoft Word, which recorded details of each
individual search conducted (Appendix A). In addition to this, a database specifically
identifying unpublished *'grey'* literature was also utilised (opengrey.eu) and hand
searching throughout individual reference lists took place. In depth searching was
essential in ensuring that suitable research was included in the review. The entire
process, from initial database searching through to screening and quality assessment,
was carefully documented and recorded in a flow chart diagram (Figure 1). The
diagram is based on The Preferred Reporting Items for Systematic Reviews and Meta-
Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, & Altman, 2009).

Selection Criteria

The PRISMA statement (Moher et al., 2009), which consists of a 27-item checklist,
was used whilst conducting the review. This was to ensure that all important aspects
of the review were included. In regards to the review's methodology, the PICOS
acronym (Centre for Reviews and Dissemination 2008) was utilised. It is outlined
within Table 1 to present the review's inclusion criteria.

Table 1

Inclusion criteria based on the PICOS acronym (Centre for Reviews and Dissemination, 2008)

		Inclusion criteria
P	Participant	- Participants aged 18 years and over - Participants who have been diagnosed with recurring migraine and/or chronic headaches. This may also include chronic tension headaches
I	Intervention	- Any intervention that uses mindfulness based techniques, including relaxation training techniques, breathing exercises and/or meditation, in order to help adults effectively manage a diagnosis of either recurring chronic headaches and/or migraines - The intervention should last for a minimum duration of two weeks
C	Comparator	- Headache and/or migraine frequency and pain level outside of the intervention, either a control group or participants pre-intervention (base level)
O	Outcome	- Any objective measure that highlights a bio-psycho-social change in the frequency and/or pain of recurring migraines and/or headaches as a result of employing mindfulness-based techniques (such as, relaxation training techniques, breathing exercises and/or meditation) for the management of chronic headaches or migraines
S	Study design	- Randomised controlled trials - Published within the last 10 years, between 2007 and 2017 - Published in English - Considered a '*strong*' or '*moderate*' quality study according to the chosen quality assessment tool.

Exclusion Criteria

Any study in which the sample used children and/or adolescents was excluded. In addition to this, any study that recruited participants with a diagnosed neurological disorder such as multiple sclerosis, and who experienced secondary headache disorder as a result, were also excluded from the review

Quality Assessment

To assess the validity of each study, the Effective Public Health Practice Project (EPHPP), Quality Assessment Tool for Quantitative Studies (EPHPP, 2009) was applied. This took place after abstracts had been screened and duplicates removed; the remaining full text papers where then read and the quality was assessed. The quality assessment tool required the assessor(s) to rate eight components of each study as weak, moderate or strong. Components include: (a) selection bias, (b) study design, (c) confounders, (d) blinding, (e) data collection methods, (f) withdrawals and drop-outs, (g) intervention integrity, and (h) analyses. The lead researcher took primary responsibility for this task. If uncertainty arose, the supervisor was consulted and both researchers discussed the outcome. Studies considered '*weak*' according to the EPHPP quality assessment tool were automatically excluded from the final review. This ensured that all studies featured within the review were high quality and offer reliable findings (Table 2).

Data Extraction and Synthesis

Interventions used within the final nine studies all differ significantly in terms of the methods and mindfulness-based techniques that they featured. Consequently this caused a level of heterogeneity to occur. Therefore, narrative synthesis was conducted on the data obtained throughout the studies. Narrative synthesis uses text to primarily summarise findings and generate new insights and recommendations from multiple studies (Snilstveit, Oliver, & Vojtkova, 2012). A data extraction table (Table 2) documents all relevant information and results from the studies.

Results

Study Selection

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┌─────────────────────────────┐      ┌─────────────────────────────┐
│ Records identified through  │      │ Additional records          │
│ database searching          │      │ identified through other    │
│ (n = 367)                   │      │ sources (n = 2)             │
└─────────────────────────────┘      └─────────────────────────────┘
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Records identified through database searching (n = 367)

Additional records identified through other sources (n = 2)

Records screened (title only) (n= 369)

Records excluded (n = 298)

Records screens (abstract only) (n = 71)

Duplicates removed (n=37)

Full text articles assessed for eligibility according to quality assessment tool (n=34)

Full text articles excluded, with reasons (n=27)

- Inappropriate design (e.g. not RCT) (n= 25)

- Inappropriate sample (headache and/or migraine was not the primary reason for recruitment to intervention) (n= 2)

Final studies in review (n = 7)

Figure 1. Flow chart detailing the search process

After initial searching was conducted in 11 separate databases, a total number of 367 results were retrieved. Additionally, 2 further studies were identified through hand searching individual reference lists. A search for unpublished *'grey'* literature was also conducted; however this retrieved no suitable studies. Subsequently, all identified research titles and abstracts, respectively, were reviewed in order to exclude inappropriate studies. Duplicate results were also removed. Consequently, 34 full-text studies were then reviewed and quality assessment checks conducted. Following this

276

stage, a further 27 studies were excluded: 25 had an inappropriate study design (not RCTs - other designs included articles, clinical reviews, mixed-methods/qualitative studies, case studies, pilot studies and comparative studies), and 2 had inappropriate samples (headache and/or migraine was not the primary reason for recruitment to intervention). Upon completion of all reviews and eligibility checks, a total number of 7 studies (all RCTs) remained and therefore included in the final review. One pilot RCT study was included in the sample (Wells et al., 2014). This was deemed appropriate for inclusion because of the conclusions found. Detailed characteristics of each study have been recorded and presented in Table 3.

Table 2

Quality assessment scores

	Study	Overall EPHPP quality assessment rating	Individual EPHPP scores (Selection bias, Study design, Confounders, Blinding, Data collection methods, Withdrawals)
1	Bakhshani, Amirani, Amirifard, & Shahrakipoor. (2015)	1	1, 1, 2, 2, 1, 1
2	Feuille & Pargament (2015)	2	3, 1, 2, 1, 1, 2
3	Omidi & Zargar. (2014)	1	1, 1, 2, 2, 1, 1
4	Wells, Burch, Paulsen, Wayne, Houle, & Loder. (2014)	1	1, 1, 2, 1, 1, 2
5	Bhombal, Usman, & Ghufran. (2014)	2	1, 1, 2, 2, 2, 2
6	Cathcart, Galatis, Immink, Proeve, & Petkov. (2014)	1	1, 1, 2, 1, 1, 1
7	D'Souza, Lumley, Kraft, & Dooley. (2008)	2	3, 1, 2, 2, 1, 2

Note. 1 = *strong,* 2 = *moderate,* 3 = *weak*

Table 3

Data extraction highlighting studies aims, sample, intervention measures, control, follow-up and outcomes.

	Study	Aims	Participants (diagnosis/ sample size/number of participants in each arm of trial)	Intervention measures	Control/ comparator	Follow-up (duration)	Outcomes
1	Bakhshani, Amirani, Amirifard and Shahrakippor. (2015)	To determine the effectiveness of mindfulness-based stress reduction (MBSR) on perceived pain intensity and QOL in patients with chronic headache	Patients diagnosed by a neurologist or psychiatrist Chronic headache (primary chronic migraine and tension-type headache) (N = 40) M, 13 F, 27 Intervention group (N = 20), Control group (N = 20)	Pain QOL questionnaire, MBSR intervention programme (2 hours) and daily homework (90 minutes) for 8 weeks. Headache log perceived intensity in 3-parts: (1) 10-point likert scale ratings, (2) number of hours of pain per day, and (3) pain frequency during the month. A short-form 36 questionnaire was also completed	Continual use of pharmacotherapy (including specific and nonspecific drugs), prescribed by their neurologist	Long-term follow up has not been reported and was stated as a limitation in the study's discussion	The main effect of MBSR was statistically significant (p=0.001) indicating that pain intensity was lower in the MBSR intervention (Mean = 53.89) compared to the control group (Mean = 71.94) The covariate (pre-test pain) was also significant (p=0.001) indicating that there was a positive relationship in pain scores between pre-test and post-test Significant improvements in QOL was also evident
2	Feuille and Pargament. (2015)	To test whether mindfulness is effective in improving pain-related outcomes in participants with migraine	Predominately college students recruited through a university campus and local community Migraine (N=74)	Participants screened using the ID-Migraine screener The headache Impact Test (6 item version) was used to assess severity. Religious beliefs were recorded. 5-point likert scale was used to assess level of connection to assigned technique. The	Comparison between condition groups and dependent measure–cold-pressor task	14–17 days after pre-test (15minutes)	Standardised mindfulness led to statistically significant (p = 0.032) reduction in stress levels (Mean = 1.2) compared to the relaxation group (Mean = 1.8). The effect of the condition (cold-pressor stress task) varied

			M, 13 F, 59 Not recorded, 2 Standardized mindfulness group (N = 27), Spiritual mindfulness group (N = 31), Relaxation group (N = 29)	Toronto Mindfulness Scale was also used Daily diaries (12–14weeks) Participants assigned and trained in one of three conditions: standardized mindfulness, spiritual mindfulness and relaxation (20 minutes practice, per day for 2 weeks)			significantly by condition, as did state mindfulness Results did report that participants found the technique moderately to quite helpful and post- hoc tests reported that the spirituality condition had a significantly greater connection to self-reported mindfulness awareness (p=0.038)
3	Omidi and Zargar. (2014)	To evaluate the efficacy of MBSR on pain severity, perceived stress, general mental health and mindfulness skills	Patients referred by psychiatrist and neurologists Tension type Headache (N = 60) M, 12 F, 48 Control group (N=30), Experiment group (N=30)	MBSR intervention sessions that included breathing and relaxation exercises (150 minutes per session, each week, for 8 weeks) International Headache Classification Subcommittee Diary Scale for Headache and Mindful Attention Awareness Scale were both used	Treatment as Usual (antidepressant medication and clinical management)	Immediately after and at 3 months questionnaires were completed	Statistically significant reductions in pain severity (Mean pre-intervention = 7.36, Mean post follow-up = 6.07) (p<0.001) MBSR group showed higher scores in mindfulness awareness in comparison to the control group at follow-up sessions. This result was also statistically significant (p<0.001)

| 4 | Wells, Burch, Paulsen, Wayne, Houle and Loder. (2014) | To assess the safety, feasibility, and effect of MBSR in migraineurs vs. usual care | Patients recruited via flyers, referrals and medical records at a headache clinic located within a hospital

Migraine

(N = 19)
M, 2
F, 17

Intervention group (N = 10), Control group (N = 9) | 2-hour weekly mindfulness sessions for 8 weeks. Plus one 'mindfulness retreat day' (6 hours), led by a trained mindfulness instructor

Additional daily headache logs

- Headache Impact Test.
- Migraine Disability Assessment
- Migraine Specific Quality of Life
- Questionnaire (version 2.1).
- PRIME-MD Patient Health
- Questionnaire depression module.
- The State Anxiety Inventory.
- The Perceived Stress Scale-10
- Five Facet Mindfulness questionnaire
- Headache Management Self-Efficacy Scale. | Usual care (control group was offered intervention on conclusion of study) | 1 month | MBSR was safe with 0% dropout and excellent adherence. MBSR participants had 1.4 fewer migraines per month (MBSR: 3.5 to 1.0 vs. control: 1.2 to 0 migraines per month)

Headaches were recorded less severe and shorter, compared to the control group. Self-efficacy and mindfulness improved in MBSR vs. control

No statistically significant changes were reported in the findings of this study |
| 5 | Bhombal, Usman and Ghufran. (2014) | To assess the Effectiveness of behavioural management in the treatment of migraine among adult patients | Patients from 5 outpatient sites

Migraine

(N=90)
M, 18
F, 72

Intervention group (N = 45), Control group (N= 45) | Structured behavioural management (includes breathing and relaxation exercises) and pharmacological treatment (1 year) | Pharmacological treatment only | 2 weeks and 4 weeks | A significant reduction in the average frequency of migraine attacks was observed from baseline up to 4 weeks (p<0.001)

In the average score of severity of pain, significant reduction was observed for time (p<0.001)

A statistically significant difference was reported for how extreme QOL was affected (p<0.001). (42% at baseline compared to 2.2% at 4 weeks) |

| 6 | Cathcart, Galatis, Immink, Proeve and Petkov. (2014) | To conduct a pilot study into the efficacy of brief mindfulness based therapy for chronic tension type headache | Recruited from general population via advertisements in local print, radio and television

Chronic tension type headache

(N=42)
M and F figures Unreported

Intervention group (N= 23), Wait list control group (N = 19) | 6 x 2 hour sessions, for 3 weeks (2 sessions per week). Based on MBSR and mindfulness-based cognitive therapy

Self-report questionnaires and headache diaries

Five Facet Mindfulness Questionnaire and Depression Anxiety Stress Scales were also both used | Wait-list control group – no contact | Immediately after the treatment. No long-term follow up assessment | Treatment group showed a statistically significant decrease in headache frequency (pre-treatment mean to post-treatment mean: 7.99 hours to 7.73 hours)

A statistically significant increase in the observe element of the mindfulness questionnaire, from baseline to post-treatment was identified in the treatment group |
| 7 | D'Souza, Lumley, Kraft and Dooley. (2008) | To conduct the first test of Written Emotional Disclosure (WED) vs. control writing in both tension and migraine headache sufferers | Undergraduate Students

Tension type headache or migraine

(N = 141)
M, 19
F, 122

Relaxation training group (N = 45), WED group (N = 48), Control group (N = 48) | Two intervention groups: relaxation training and WED

4 x 20 minute sessions over 2 weeks

Headache diaries

Abbreviated version of the Positive and Negative Affect Schedule-Expanded Version. Migraine Disability Assessment Scale. Physical symptoms rated on the 12-item Symptom Checklist-90-R | Neutral writing control group | 1 month and 3 months | Headache frequency decreased for the relaxation group (Mean at baseline = 11.82 to follow-up = 6.82 hours), compared to WED and control group

WED led to a statistically significant increase in negative mood (p< 0.001) and both headache and migraine severity improved for participants in the relaxation group |

281

Study Characteristics

From the 7 RCTs included, the countries in which they were conducted include: United States (n=3), Canada (n=1), Iran (n=1), Australia (n=1), and Pakistan (n=1). In accordance with the outlined inclusion criteria, all included studies were written in English and published between the years 2007 and 2017 (inclusive). There was a combined total sample size of 466 participants. Each study also only included participants over the age of 18 years who had received a diagnosis of either migraine (n=3), headache (n=2) or both (n=2). In addition to this, each study was also rated as either '*strong*' (n=4) or '*moderate*' (n=3), according to the EPHPP quality assessment tool (Table 2).

Generally, studies that applied mindfulness-based stress reduction (MBSR) techniques within the interventions were among the most popular (n=4). Furthermore, relaxation training (n=4) and breathing techniques (n=2) were two aspects that featured notably within the studied interventions. Other features that were used alongside the main interventions included diary/log completion (n=3) and regular set homework and/or independent practice (n=2). All interventions lasted for a minimum of two weeks. Typically, most participant samples were recruited via clinical settings such as health care professional (e.g. psychiatrist and neurologists) referrals (n=3) or hospital adverts and/or flyers (n=1). Other participants included university students (predominately psychology undergraduates) (n=2) and local community of whom frequently experienced headache and/or migraine pain (n=1). Furthermore, the total number of participants across all studies (of which accurately reported demographic information, n=6) highlighted a significantly higher number of female participants (n=345) than males (n=77). Participant samples used throughout the 7 studies also had a mean age of 33.7 years.

The aim of the review was to identify and assess the effectiveness of mindfulness techniques for adults that experience recurring chronic headaches and/or migraines. Through identifying the aims and outcome measures of nine RCT studies (outlined in Table 3), it is evident that the burdening experience of headaches and/or migraine disorders consists of three core elements: (1) pain severity, (2) frequency and duration, and (3) wellbeing and QOL. Below outlines preliminary study findings on how mindfulness-based techniques can potentially be used for managing the key aspects associated with headaches and migraine disorders.

Pain severity

Pain severity was a key outcome identified in 5 of the 7 studies; a total sample of 302 participants. Types of interventions for this outcome included an emotional disclosure and relaxation training intervention (D'Souza et al., 2008), mindfulness-based pilot intervention that included stress reduction and cognitive therapies (Cathart et al., 2014), and mindfulness-based stress reduction interventions that used control groups to compare effects, including one pilot study (Bakhshani et al., 2015; Omidi & Zagar, 2014; Wells et al., 2014). In terms of the overall quality of studies included in this outcome, the mean quality assessment score was 1.2 (SD = 0.44).

Results from a MBSR intervention reported that there was a significant difference (p=0.001) in headache pain intensity levels after taking part in the mindfulness-based intervention compared to the control group (MBSR group mean = 53.89 vs. control group mean = 71.94) (Bakhshani et al., 2015). Similarly, in a study that also applied MBSR, results reported statistically significant reductions in pain severity (mean pre-intervention = 7.36 vs. mean post follow-up = 6.07) (Omidi & Zargar, 2014) as rated by The International Headache Classification Subcommittee Diary Scale for Headache (Omidi & Zargar, 2014).

Wells et al. (2014) also reported that headaches in the mindfulness intervention group were less severe than those in the control group, however this finding was not statistically significant (p=0.53). Similarly, Cathcart et al. (2014) also reported non-significant differences for headache intensity, even though some level of slight improvement (pre-treatment mean to post-treatment mean: 2.26 to 2.16) was identified. In addition to this, D'Souza et al. (2008) found that migraine participants within the relaxation group experienced lower levels of pain severity than those in the Written Emotional Disclosure (WED) and the control groups (relaxation group: baseline mean = 6.57 to follow-up mean = 4.68; WED group: baseline mean = 6.39 to follow-up = 5.23; control group: baseline mean = 6.35 to follow-up mean = 5.55). Similar findings were also present for headache only participants included within this RCT (D'Souza et al., 2008).

Frequency and duration

The frequency and duration of headaches or migraines, was another key outcome that was identified within 4 of the 7 studies; a total sample of 292 participants. Interventions evident in this outcome included an emotional disclosure and relaxation training intervention (D'Souza et al., 2008), mindfulness-based pilot intervention that included stress reduction and cognitive therapies (Cathart et al., 2014), mindfulness-based stress reduction pilot intervention that used control groups to compare effects (Wells et al., 2014), and a mindfulness-based therapy, which included breathing and relaxation exercises (Bhombal et al., 2014). In terms of the overall quality of studies included in this outcome, the mean quality assessment score was 1.5 (SD = 0.57).

Reported findings from a pilot RCT study stated that headache frequency, as well as headache duration, was less compared to the control group (Wells et al., 2014). Participants in the MBSR group had a total of 1.4 fewer migraine episodes per month compared to the control group (MBSR: 3.5 to 1.0 vs. control: 1.2 to 0 migraines per month), and reported them shorter in duration (-2.9 hours/headache, P = .043) compared to the control group. However, neither of these effects reached statistical significance (p=.38), which means that firm conclusions can not be drawn from this data. However, in a further paper migraine attack frequency did show statistically significantly reductions in migraine attacks, as a result of taking part in a structured behavioural management intervention for a period of one year (Bhombal et al., 2014). Findings revealed that at the 4-week follow-up stage, only 6.7% of participants (n=3) in the trial group reported migraine attack frequency that lasted between 12-24 hours, in comparison to the baseline score of 40% (n=18). The control group showed less change in migraine attack frequency, with 22.2% of control group participants (n=10) reporting the same attack duration at 4-weeks follow-up compared to 28.9% (n=13) at baseline (Bhombal et al., 2014). However, despite these improvements from baseline to the 4-week follow up stage, there was no statistical difference in mean migraine attacks between the intervention and control groups (p<0.945)

Furthermore, Cathcart et al. (2014) also reported that headache duration in the MBSR group had significantly decreased (Chi = 6.16, df = 1, p = .01) in terms of days per fortnight (pre-treatment mean to post-treatment mean: 11.04 days to 9.37 days), compared to the control

group (pre-treatment mean to post-treatment mean: 9.82 days to 9.65 days). However, the study did report that group effects were not significant (Chi = .50, df = 1, p = .60). Likewise, in the RCT conducted by D'Souza et al. (2008), findings reported that participants in the relaxation training group showed significantly greater improvement in headache frequency (F(1, 31)=16.34, p<0.001), compared to those in the written emotional disclosure and control groups (mean at baseline = 11.82 days/month versus mean at follow-up = 6.82 days/month).

Wellbeing and quality of life

The final outcome, wellbeing and QOL, was reported in a total of 5 of the 7 studies; a combined sample size of 364 participants. Types of interventions included, mindfulness-based stress reduction interventions, including one pilot RCT, which included wellbeing or QOL measures (Bakhshani et al., 2015; Wells et al, 2014), an intervention that focused on standard mindfulness, spiritual mindfulness and relaxation techniques (Feuille & Pargament, 2015), the emotional disclosure and relaxation training intervention (D'Souza et al., 2008), and a mindfulness-based therapy intervention that included breathing and relaxation exercises (Bhombal et al., 2014). In terms of the overall quality of studies included in this outcome, the mean quality assessment score was 1.6 (SD = 0.54).

From the five studies that included wellbeing or QOL measures within the design of their intervention, only two studies reported statistically significant outcomes that related specifically to QOL (Bhombal et al., 2014; D'Souza et al., 2008). The intervention conducted by Bhombal et al. 2014. reported significantly better QOL in trial participants compared to the control group, whereas D'Souza et al. (2008) reported that participants in the relaxation group of their study experienced significantly reduced negative mood compared to those allocated to the control group. Unfortunately, due to incomplete reporting of statistical data and heterogeneity that was present in the outcome measures that were used in the papers, it was not possible to calculate the effect sizes or combine the findings in order to present firm conclusions for this review. Measures for the remaining studies reported on outcomes related more generally to wellbeing, including stress and self-efficacy (Bakhshani et al., 2015; Feuille & Pargament, 2015; Wells et al., 2014).

In the RCT by Bakhshani et al. (2015), covariance analysis (MANCOVA) revealed that subscales of QOL did report statistically significant differences in aspects such as bodily pain (p=0.002), mental health (p=0.002), and energy and vitality (p=0.002). However, interestingly other dimensions of QOL such as physical functioning (p=0.314) and social functioning (p=0.138), did not report significant differences (Bakhshani et al., 2015). The RCT study by Feuille and Pargament (2015) reported that participants in the standard mindfulness group of their intervention showed significantly reduced pain-related stress in comparison to the intervention's simple relaxation group. Authors of the paper added that participants allocated to the spiritual mindfulness group, also showed a significantly greater connection to self-reported mindful awareness (p = 0.038), compared to the other groups. As a result, it was suggested within the paper that participants in this arm of the trial might have experienced better overall health and general wellbeing as a result of enhanced levels of self-reported mindful awareness (Feuille & Pargament, 2015).

According to the *'Headache Management Self-Efficacy Scale'* that was employed in the study conducted by Wells et al. (2014), self-efficacy improved among those who participated in the MBSR group, compared to the control arm (difference in change score from baseline to final follow-up = 13.9, p = .060). The RCT study also reported an improvement in QOL, which was scored according to the Migraine-Specific Quality of Life questionnaire (difference in change score from baseline to final follow-up = -7.5, p = .35) (Wells et al., 2014). However, both of these findings did not reach statistical significance, so although the findings are interesting, it is not possible to identify a firm change based on the data.

Discussion

Summary of findings

It is evident from these findings that mindfulness-based techniques can provide some level of relief to adults who live with a chronic headache or migraine disorder. Three key aspects that highlighted some change as a result of the mindfulness-based techniques used within the interventions included: (1) pain severity, (2) frequency and duration, and (3) wellbeing and QOL. However, statistical significance was notably absent in many of the studies included within the review. In the 5 studies that measured pain severity, only 2 reported statistically

significant improvements in pain (Bakhshani et al., 2015; Omidi & Zargar, 2014), whereas the remaining 3 studies failed to indicate any firm changes (Cathcart et al., 2014; D'Souza et al., 2008; Wells et al., 2014). Therefore, these findings do not provide strong enough evidence to support the effectiveness of mindfulness on headache pain severity; more research is needed to establish this. In the 4 studies that measured frequency and duration of headache or migraine attacks, only 3 studies reported statistically significant improvement (Bhombal et al., 2014; Cathcart et al., 2014; D'Souza et al., 2008). However, these results only indicated significant time by effect; they did not report statistically significant group effects. In the remaining study (Wells et al., 2014), no statistically significant changes were reported. Therefore, based on these findings, it is also not possible to establish any firm conclusions on the effect of mindfulness on frequency and duration of migraine attacks. Finally, in the 5 studies that measured wellbeing and QOL, 4 of the studies reported statistically significant changes in some of the outcome measures used (Bakhshani et al., 2015; Bhombal et al., 2014; D'Souza et al., 2008; Feuille & Pargament, 2015). It was reported that stress significantly decreased, whilst levels of mindful awareness increased (Feuille & Pargament, 2015), QOL statistically improved (Bhombal et al., 2014; D'Souza et al., 2008), and outcomes such as energy and vitality, and mental health, reported significantly positive changes (Bakshani et al., 2015). The pilot RCT (Wells et al., 2014), failed to report any statistically significant changes in wellbeing or QOL outcomes; only non-significant improvements were evident among participants in the intervention group.

In general, the application of mindfulness-based techniques, as a therapeutic tool for managing chronic headache or migraine disorders, was generally mixed. Although some of the findings showed statistically significant changes, which is encouraging for the future of pain management interventions, many of the studies failed to indicate any firm conclusions based on statistical analysis of the data. It is important to point out that limitations were present throughout and there was a clear level of disparity in findings that used qualitative self-report data versus statistical analyses. There was also incomplete reporting of some of the data, in some of the studies, which caused a high level of heterogeneity. This prevented data synthesis from taking place. As a result, strong conclusions were unable to be established within the review.

Findings in relation to previous evidence

Generally throughout the sample it emerged that mindfulness-based stress reduction, specifically applying relaxation training and breathing techniques, was a popular choice for migraine and/or chronic headache interventions. Other elements that were recurrent among the seven interventions included homework and the use of headache diaries. These elements relied heavily on participants self-reporting their symptoms and independently self-managing their condition. This feature aligns with NICE guidelines (2012), which supports the use of headache diaries and logs for managing headaches in those aged over 12 years. In addition to this, an abundance of research has been developed which supports the notion of self-management in a variety of health areas. Positive outcomes have been displayed in areas around medication adherence (Chapman & Bogle, 2014), symptom management for long-term conditions (Allen, Vassilev, Kennedy, & Rogers, 2016; Whitehead & Seaton, 2016) and supporting people live well beyond a diagnosis of disease (Polley et al., 2016). Health reports have also suggested that self-management is a forward-thinking approach to patient care, which will help people effectively manage pain alongside appropriate clinical treatment (de Silva, 2011). It is also known through research that patients who actively self-manage, show increased levels of self-esteem (Bromberg et al., 2012; McCorkle et al., 2011), develop stronger coping mechanisms (Blixen, Levin, Cassidy, Perzynski, & Sajatovic, 2016), and feel more involved with their treatment decisions (Hibbard, 2017).

According to Leonardi (2015), alternative therapeutic approaches for the management of headache and migraine disorders should be considered, in order to start effectively dealing with the large-scale issue of headache and migraine pain (Leonardi, 2015). In a systematic review that explored the effectiveness of psychological interventions for migraine, a total of 15 studies (out of 18 studies that measured effects of psychological interventions on headache-related outcomes), reported statistically significant improvements (Sullivan, Cousins, & Ridsdale, 2014). The review also reported significant improvements in psychological outcomes, among the participants who were allocated to intervention groups (Sullivan et al., 2014). These conclusions were stronger than those presented in the present study, as the quality of research was better and more rigorously conducted. A total of 17 out of 24 papers were rated 'high quality', whereas the present review mostly included papers that were rated 'moderate' according to the quality assessment tool. Therefore, this suggests that findings were more reliable and conclusive in the previously published review, and more

work should be conducted which expands upon this. Further research would also help raise awareness and start to normalise therapeutic treatments, such as mindfulness, for the management of headache and/or migraine related pain. It has been reported that complementary and alternative therapies such as mindfulness, still go largely unrecognised by many health care professionals (Bjerså, Stener Victorin, & Fagevik Olsén, 2012; Frass et al., 2012), and so therefore it is vital to engage with health care professionals about the importance of alternate therapeutic approaches and holistic support for patients managing long-term chronic pain. This would provide patients with a wider range of holistic options that go beyond pharmacological drugs. It could also help reduce the prevalence of drug related side effects, provide patients with an updated range of evidence-based treatment options and minimise the financial pressures on the NHS (House of Commons, 2010).

Limitations

There were some notable limitations throughout this review. Firstly, studies in the sample lacked quality in key aspects of the intervention, design and sample. These were studies were consequently rated as '*moderate*' on the quality assessment tool. The mean overall age of participants across the 7 studies was 33.7 years, which was lower than the typical average age of headache and migraine patients according to research (Steiner et al., 2016). It is possible that this limitation is due to the inclusion of university students (predominately undergraduate) from 2 of the 7 of the studies, which could have lowered the overall mean age. This in itself also highlights a limitation as it suggests that the sample is non-representative of a wider population. From the two student-sample studies, one reported that the participants received credits for study contribution (Feuille & Pargament, 2015). This could have led to potential participation bias. Research has found that performance-based incentives can elicit better performance and performance can improve as task difficulty increases (Brase, 2009). This could suggest that participants' increased effort was due to a perceived belief that this would elicit desired responses and subsequently higher incentives.

Secondly, the outcome measures of the sample studies were fairly heterogeneous due to the varying nature of the interventions that were used. Each intervention applied various measurement tools and adopted different mindfulness-based techniques. This therefore prevented any synthesis or comparisons regarding the effectiveness of mindfulness-based interventions from being established. This form of limitation has also been reported in a

previous systematic review that explored the efficacy of psychological interventions for migraine disorders (Sullivan et al., 2014). The review focused on the use of biofeedback, relaxation training and cognitive behavioural therapy for the treatment of migraines between the years 1999 and 2014. They too found that heterogeneity occurred within the sample and listed this as a limitation (Sullivan et al., 2014).

In addition to this, one study within the review sample was pilot RCT study. This limits the conclusions that could be obtained from the review as the authors did not necessarily report all findings accurately. Wells et al. (2014), focused particularly on feasibility and dropout rates, which was then used to aid the development of interventions in the future. Although this information was useful to some degree, and the pilot RCT did show report some interesting findings in regards to the efficacy of mindfulness interventions, in general the study could not fulfil all of the review's aims and therefore is a weakness.

Recommendations

Firstly, there was a clear lack of long-term follow-up among all 7 of the review's included studies. Some of the studies noted that follow-up occurred immediately after participants had completed the intervention, and in some cases there was no evidence to suggest that any form of follow-up was completed at all. This is a weakness. Therefore, forthcoming RCT studies that apply mindfulness-based techniques to help manage pain, should consider incorporating longer-term follow-up methods within the study design. This would subsequently offer more detailed and in-depth data around the long-term efficacy of interventions. Secondly, the findings drawn from this review offers an opportunity to bridge the gap between routine clinical practice and alternative therapeutic treatments. Although studies supporting the use of CAM among healthcare settings have risen in popularity, there is still some level of uncertainty over the suitability and credibility of the approach (Bjerså et al., 2012; Frass et al., 2012). Therefore, it is important that reviews are disseminated to appropriate audiences, such as health care professionals, policy makers and members of the public, in order to raise awareness for therapeutic approaches. Finally, it is clear from the review's findings that further research needs to be conducted in order to explore the research question further and establish the effectiveness of mindfulness-based techniques for adults managing headache and migraine disorders. Ideally, research should include rigorous RCT studies, with long-term follow up durations and greater participant samples. This present review, which has

reported mixed results and been unable to indicate any firm conclusions, offers a basis for future research to follow.

Conclusion

This review concluded mostly mixed results for the effectiveness of mindfulness-based interventions in adults managing migraine and headache disorders. However, it did identify some significant improvements in pain severity, frequency and duration, and wellbeing and QOL. Although some of the results were encouraging, a lack of reported significant findings between intervention and control groups means that firm conclusions about the efficacy of mindfulness-based interventions cannot be established. Therefore, more rigorous research is needed and should be conducted in order to explore the research question further. Stronger evidence in this area would help to narrow the gaps between: (1) ever expanding research in the field of CAM that reports positive findings; (2) health care professionals' perspectives and understanding of CAM, and (3) the integration of mindfulness-based interventions for people experiencing chronic pain, into routine clinical practice. This would offer patients more treatment options, improve wellbeing and QOL, and raise awareness of therapeutic treatments for pain among multi-disciplinary health professionals.

Word count: 6,184 words

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Review study references

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Appendix A: Search strategy

Date of search	Database	Dates included in search	Search terms	Number of results retrieved
January 9, 2017	Cinahl PLUS full text	2007-2017	"Mindfulness" OR "Mindful*" OR "Meditation" OR "Relaxation Techniques" **AND** "Adults" OR "Adult*" OR "Middle Age" OR "Young Adult" OR "Aged, 80 and Over" **AND** "Headaches" OR "Headache*" OR "Headache, Primary" OR "Headache, Secondary" OR "Migraine" OR "Tension Headache" OR "Cephalgia" OR "Vascular Headache"	197
January 9, 2017	Medline Complete	2007-2017	Same as above	14
January 10, 2017	Cochrane Controlled Trials	2007-2017	Same as above	12
January 10, 2017	Embase	2007-2017	Same as above	96
January 10, 2017	PsycINFO	2007-2017	Same as above	44
January 10, 2017	PsycARTICLES	2007-2017	Same as above	0
January 12, 2017	PubMed	2007-2017	Same as above	4
January 12, 2017	Science Direct	2007-2017	Same as above	0
January 12, 2017	Web of Science	2007-2017	Same as above	0
January 12, 2017	Scopus	2007-2017	Same as above	0
			Total (databases)	**367**
January 14 – 15, 2017	Other sources (hand searching and grey unpublished literature)	2007-2017	Relevant key words in title (e.g. mindfulness intervention, headache/migraine, adults)	**2**
			Total (other sources)	**369**