

# **Malnutrition remains unrecognised and untreated: examples from dietetic practice and implications for action.**

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This thesis is submitted as partial fulfilment of the requirements of Liverpool John Moores University for the degree of Doctor of Philosophy by published work. This original work is my own and has been carried out at Liverpool John Moores University, in conjunction with Liverpool Women's Hospital, and has not been submitted for any other degree award.

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## **Abstract**

### **Background**

It is well documented that malnutrition has been and still is a widespread problem in NHS hospitals, yet it not considered a priority. Sub-optimal nutrition in pregnancy can adversely affect the health of both mother and foetus. Poor dietary intakes following pelvic radiotherapy can impact on health and recovery of cancer sufferers. In UK hospitals, numerous policies and campaigns have attempted to increase awareness and improve clinical management of malnutrition in recent decades, with limited success. The researcher is also a dietitian at the study hospital and so has an obligation to increase awareness and management of malnutrition.

### **Aims**

To identify the prevalence of some nutrition related problems in an NHS hospital; to explore which areas of the community contribute malnourished women to the hospital; to investigate the role of nutrition and its promotion within 'holistic care' and to review recent guidelines and policies aimed at tackling malnutrition in NHS hospitals.

### **Methods**

Data were collected from a hospital database 'Meditech' regarding BMI, age, parity and postcode for all pregnant women booking-in for ante-natal care. The data were used to determine prevalence of underweight and obesity and geographical distribution of these problems by plotting postcodes on maps. Qualitative and quantitative data were collected from women who had received pelvic radiotherapy; via interviews and 'open' questions added to a questionnaire and via a validated questionnaire used to detect bowel problems respectively. These data were explored to provide insight into the experiences of women suffering symptoms of CRE and to determine the prevalence of these symptoms. MUST screening data from the hospital was combined with data from published literature to critically examine the issues related to malnutrition in hospitals.

### **Findings**

All methods identified a high prevalence of malnutrition at the study hospital, with 27% and 17% of pregnant women overweight and obese in early pregnancy, and 4% underweight. Furthermore, almost 50% of women who had been treated with pelvic radiotherapy experienced symptoms of CRE. However, malnutrition appeared to be unrecognised and untreated as no care pathways were in place and referrals to the dietitian were low and inconsistent. Hence it is concluded that nutrition was not a priority. These health problems are associated with negative impacts on physical, social and psychological quality of life. Nutritional intervention could be very beneficial to these women, promoting optimal weight gain (associated with successful pregnancy outcome), ensuring a balanced nutritional intake and preventing CRE symptoms. This seems to reflect a deeper problem, common to the NHS, of a lack of holistic care

Conclusion.

A holistic approach would consider the physical, social and psychological aspects of women's health, rather than a narrow focus on the 'pregnancy' or the 'cancer' and might better address the problems identified. As nutrition is a basic need, health professionals need to ensure that nutritional needs are met before attempting any further intervention. A holistic approach would also promote health literacy, empowering women to make informed choices about their health.

## 1.0 Introduction

This thesis consists of six peer-reviewed published articles for the consideration of PhD by published work. All of the papers relate to identifying and/or managing nutrition-related health problems in women. All papers are joint-authored but each study was designed, conducted and analysed by Julie Abayomi and in each case she was the main researcher and author. All six papers were peer-reviewed and accepted for publication in professional health journals prior to submission.

## 2.0 Refereed papers (see Appendix 1 for full text)

- Abayomi, J; Watkinson, H; Topping, J and Hackett, A (2007). Obesity and underweight among first trimester pregnant women. *British Journal of Midwifery*. **15** (3) 143-147.
  - Abayomi, J; Watkinson, H; Topping, J and Hackett, A (2009) Identification of Hot spots of obesity and underweight in early pregnancy in Liverpool. *Journal of Human Nutrition & Dietetics* **22**:246-254.
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- 15.0 Abayomi J, Judd S & Hackett A (2009) Malnutrition in hospitals: Still unrecognised and ignored. *Journal of Healthcare Management* **15**(10):488-494.

### **3.0 Structure of the research proposal**

The organisation of the research programme is as follows: The overall aims are presented first, followed by the rationale (based on current literature published in the area of the role of the dietitian in dealing with nutrition-related problems and holistic care). This leads into an interpretation of the published papers that focuses on their aims, findings and conclusions. Next is a summary and critical review of the papers and finally conclusions are drawn and recommendations for further study made.

### **4.0 Aims of the research programme**

1. To identify the prevalence of some nutrition related problems in an NHS hospital.
2. To explore which areas of the community contribute malnourished women (both under and over weight) to the hospital, in order to direct preventative resources to where they are needed most.
3. To investigate the role of nutrition and its promotion within 'holistic care'.
4. To review recent guidelines and policies aimed at tackling malnutrition in NHS hospitals; identifying causes of malnutrition, barriers to treating and preventing it and ways to overcome it.

As a science, nutrition research traditionally took a positivist approach which aims to predict and control natural phenomena (Guba 1990). This was often via well-controlled laboratory experiments (Gibney *et al* 2009). However, dietetic research involves working with patients and aspiring to use a patient-centred approach often contradicts a positivist approach as it would be difficult and unacceptable to attempt to control the participants being investigated. Therefore a post-positivist approach to this research programme was adopted, as this acknowledges the need for varied sources of data, theories and methods (Guba 1990). A post-positivist approach recognises external influences and acknowledges that it is impossible for the researcher to step outside humanness whilst conducting the research

(Guba 1990). This is particularly relevant to this research programme where the researcher also had a clinical role in caring for the participants.

In order to realise these aims, the research used a combination of quantitative and qualitative methods in an attempt to collect the most useful data from both biological science and social science approaches required for patient-centred research. Quantitative methods involved the collection, compilation and analysis of routine data recorded at ante-natal clinic, from the hospital database (Meditech). Identifying hotspots in the community involved entering BMI and postcode data into a mapping software package (Edina). A validated questionnaire (Bugg *et al* 2001) was also used to collect data regarding bowel problems and their effect on quality of life. One-to one, tape-recorded interviews were used to collect qualitative data, allowing women to describe problems in their own words and the impact this had on their quality of life. Reviewing policies and guidelines regarding malnutrition involved a detailed literature search and in-depth discussions with relevant National Health Service (NHS) colleagues.

## **5.0 Rationale for the research programme**

Malnutrition literally means 'bad' nutrition and so can refer to over nutrition as well as under nutrition. The Malnutrition Advisory group (MAG) defines malnutrition as follows:

“A state of nutrition in which a deficiency, excess or imbalance of energy, protein, and other nutrients causes measurable adverse effects on tissue (shape, size, composition), function and clinical outcome”. (BAPEN 2003)

Hence, it is possible to be over nourished in terms of energy intake, whilst deficient in nutrients such as vitamins and minerals at the same time.

Between 10-60% of hospital patients are malnourished (Elia *et al* 2005). These figures have changed little over the past 40 years (Hill *et al* 1977), suggesting that nutrition is still not taken seriously in hospitals. Thorensen *et al* (2008) found that doctors and nurses with

greater access to dietitians (dietitians visited their wards frequently), had an increased focus on clinical nutrition, were more likely to identify under nutrition and have a better insight regarding the importance of good nutrition. Thorensen's (2008) study also highlighted a common problem in multi-disciplinary teams (MDT) of not all team members acknowledging the dietetic expertise available to them, with few doctors and nurses admitting to shortages in dietetic resources on their wards, despite a high prevalence of malnutrition.

Dietitians are best placed to identify and treat nutrition-related health problems and have a range of approaches available to provide interventions appropriate for an individual patient (Thompson *et al* 2003). Clinical dietitians are the only health professionals focussing solely on nutrition and should work in partnership with other health professionals to optimise nutrition support of patients (Thorensen *et al* 2008). However, most dietitians working in NHS hospitals rely on referrals from other health professionals, particularly doctors and nurses, who usually have limited nutritional knowledge (Jackson 2001; Summerbell 1996; Brett *et al* 1986). The National Institute for Health and Clinical Excellence (NICE) state that all patients at risk of under nutrition should have access to a clinical dietitian, but as most hospitals employ only a small number of dietitians, they suggest that some roles be delegated to other health care professionals (NICE 2006). However, they admit that lack of nutritional awareness amongst other health care professionals has led to poor referral rates to dietetic services.

Doctors and nurses often fail to identify nutritional problems in patients as they do not look for them (Allison 2003, McWhirter and Pennington 1994). The British Association for Parenteral and Enteral Nutrition (BAPEN) has recommend screening for all hospital patients to identify those at risk of malnutrition (Elia 2000). They state clearly that malnutrition is under-recognised and under-treated and that nutritional interventions produce significant clinical benefits, once patients are identified. (Elia *et al* 2005). Other studies show that

identifying malnourished patients by using clinical judgement alone is both unreliable and inadequate (Abayomi & Hackett 2004).

BAPEN is a national body of multidisciplinary healthcare professionals which aims to promote the recognition and management of malnutrition. In recent years it has championed screening for malnutrition and has promoted integrated and patient-centred policies relating to nutritional care (BAPEN 2005). These initiatives have a well-researched, clinical approach but have not always been implemented or embedded into clinical practice (see below). However in 2010 BAPEN published 'The Toolkit for Commissioners and Providers in England: Malnutrition Matters: Meeting Quality Standards in Nutritional Care in 2010'. For the first time this recognises the role management has to play and aims to help Commissioners, health trusts and care providers implement optimal nutritional care. BAPEN's (2010) four key steps to implementing nutritional care are:

1. Identify malnutrition through screening (use of 'MUST') and assessment
2. Implement appropriate care pathways for all identified or at risk of malnutrition
3. Train all front line staff in the importance of nutritional care
4. Ensure management structures are in place to support best nutritional practice.

Other recent initiatives include the NHS 'Institute for Innovation and Improvement' which asked nurses and midwives to identify actions that would improve the quality of patient care and reduce costs. From this eight areas referred to 'high impact actions' have been prioritised; one such action is providing adequate nutrition to hospital patients. The next stages are to work with 'demonstrator sites' to identify areas of good practice and then to implement this good practice across the NHS. This initiative differs in that the priorities have been decided by nurses and midwives themselves and the responsibility for communication and implementation also lies within these professions, recognising that nurses and midwives are best placed to influence other nurses and midwives (NHS 2006).

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Following Lord Darzi's 'High Quality Care for All' (DH 2008), the Care Quality Commission (CQC) has introduced the Quality, Innovation, Productivity and Prevention Programme (QIPP 2009). QIPP is a priority for NHS management, following the recognition that the NHS is likely to have fewer resources in the future and so must become more efficient in order to maintain services (Tribal 2010). It is argued that such initiatives have helped integrate care by uniting clinicians and managers around quality and by focussing efforts to use innovation to improve the quality of patient care (whilst saving money). It can also be argued that this programme is novel as it aims to change the mindset of the NHS, engaging with health professionals to create a culture of change, ensuring that change is more likely to happen (Tribal 2010). One area identified by CQC is meeting the nutritional needs of patients (Outcome 5). Health and social care providers now have to provide *evidence* that they support clients to achieve adequate nutrition and hydration ([www.cqc.org.uk](http://www.cqc.org.uk)). Previous attempts at addressing malnutrition have failed to integrate care and to encourage a culture of change (Better hospital food, for example); however, it could be argued that such approaches are only now being implemented for financial reasons.

At the study hospital there is one full time equivalent (FTE) dietitian divided into 2 posts: 0.6 FTE for gynaecological oncology and 0.4 FTE for ante-natal and maternity. This is despite the hospital being a tertiary referral centre for a number of specialist services, including gynaecological oncology, pregnancy support, reproductive medicine and medical disorders of pregnancy. The hospital is very busy: delivering approximately 8,000 babies per year, and conducting 11,500 gynaecological procedures (Liverpool Women's Hospital 2008). Screening for malnutrition is conducted only for oncology patients using the Malnutrition Universal Screening Tool (MUST) (BAPEN 2006). However, for other nutritional problems and malnutrition among other patient groups the dietitians rely on referrals from other health professionals.

Once dietitians are involved with patients, numerous studies show positive benefits: Thompson *et al* (2003) found that patients advised about lipid lowering by dietitians experienced a greater decrease in blood cholesterol than those advised by doctors. Wolff *et al* (2008) determined that dietetic counselling resulted in less weight gain and improved insulin metabolism in obese pregnant women. Isenring *et al* (2004) found that nutritional intervention by dietitians in oncology patients resulted in less weight loss and less deterioration in nutritional status.

Collins (2005) found that unlike doctors, other health professionals communicate differently with patients; nurses (and dietitians) have more opportunity to develop closeness and connectedness with patients and the tone is usually more conversational. This encourages patients to say more and disclose issues which they would otherwise not mention to a doctor, either for fear of wasting the doctor's time or because they believe it may be irrelevant (Collins 2005). Furthermore, patients may fail to mention certain problems to doctors, or even try to conceal them, if they are of an embarrassing or personal nature (Faithful and Wells 2003).

The dietitians at the study hospital were aware of a number of otherwise unrecognised health-related issues being raised by patients during dietetic consultations. These problems appeared to be receiving little attention from the MDT. Firstly, problems related to obesity in pregnancy were receiving a lot of media attention (CEMACH 2004; CEMACH 2007), but the prevalence of the problem among this patient population was unknown and no guidelines for its management existed. The issues related to under nutrition in pregnancy were never mentioned and appeared not to be a concern at all. Secondly, many women who had been treated with pelvic radiotherapy for gynaecological cancer were having problems with diarrhoea and/or faecal incontinence. Although, oncology doctors were aware that this was a potential problem there was a lack of understanding regarding the prevalence and implications of these symptoms, reflecting much of the current literature: Gami *et al* (2003)

argues that such problems are 'unimportant' if quality of life is unaffected; Yeoh and Horowitz (1987) estimate that only 5-15% of patients experience such symptoms.

Finally, poor nutritional management of in-patients was regarded as common-place at the hospital, with patients not receiving adequate diet or supplements, despite dietetic intervention. The researcher, who is also one of the dietitians at the study hospital, decided all the above issues warranted further investigation.

## 6.0 Holistic approach to care

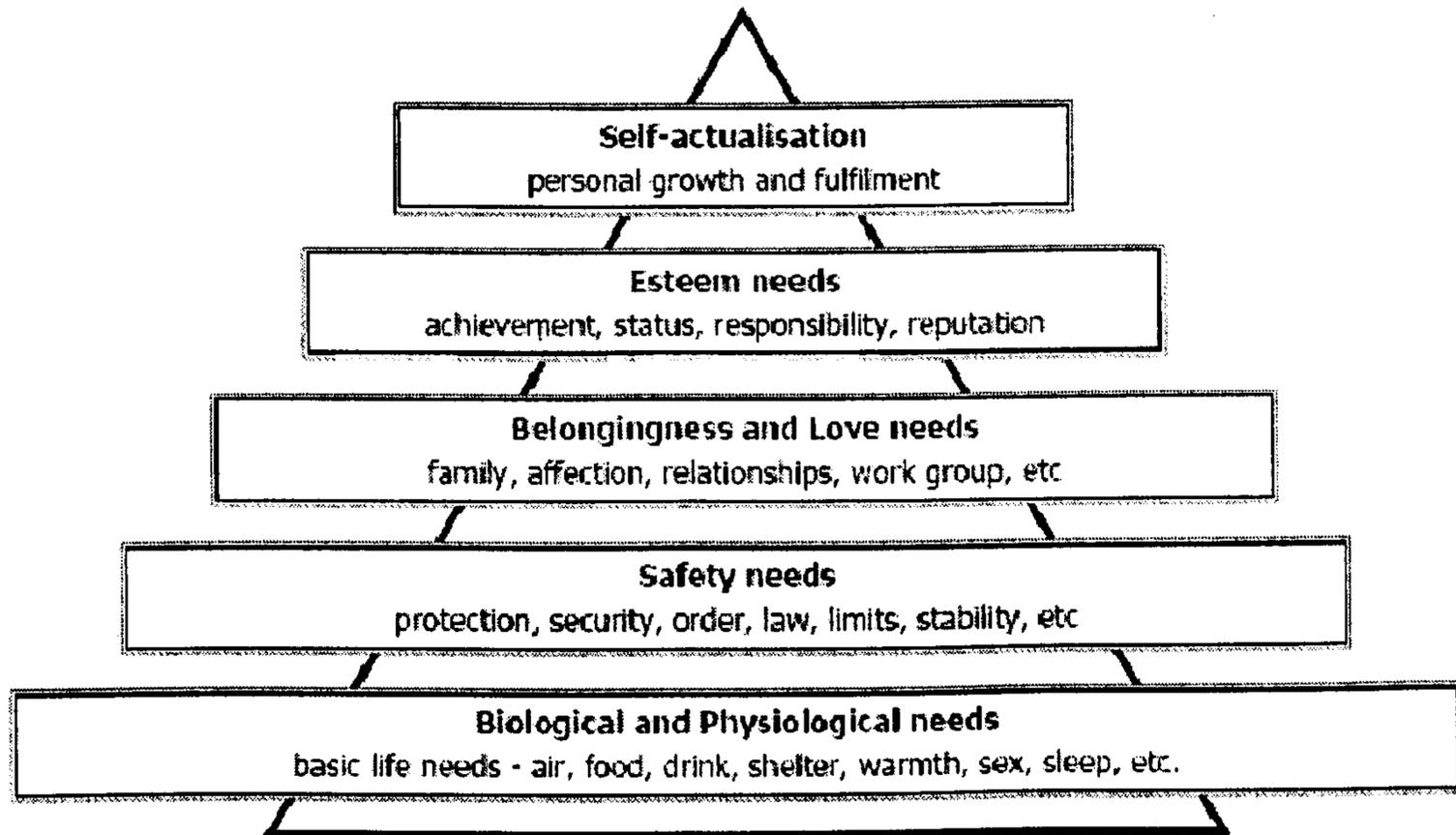
Within the healthcare system there is often a tension between the 'medical model' of care, which focuses on the pathophysiological view of care, underpinned by biological science and medicine and the social model, which focuses on the behavioural and intuitive aspects of care (Akinsanya 1989). Currently in the NHS there is an emphasis on scientific underpinning, with the promotion of 'Evidence-based practice' (DH 2007) and NICE guidelines only refer to published scientific evidence ([www.NICE.org.uk](http://www.NICE.org.uk)). Although health professionals would agree that evidence should be an integral part of clinical decision making, this approach often fails to consider the individual person receiving the care (McKenna *et al* 1999). Guidelines are appropriate in healthcare as people are similar and often have similar symptoms, but people also have individual differences (Akinsanya 1989).

A holistic approach to care is often viewed as the ideal model of care as it embraces both the medical and social models of care. Often referred to as 'patient centred care' (Stewart 2001), it focuses on the whole patient. The holistic approach to healthcare is defined as:

*"A system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; his or her response to illness; and the effect of the illness on the ability to meet self-care needs."* (Anderson 2002).

Many healthcare professions, such as nursing (and dietetics), endorse individualised care for patients; this derives from a desire to meet each person's unique requirement (Akinsanya 1989). It also stems from a caring approach to individual patients, where healthcare professionals want what is best for their patients because they are concerned about them. However, Johns (2000) recognises that external factors often influence caring and that within organisations where the medical model of health is the dominant belief culture, caring often becomes a sub-culture and is not valued in the same way. Johns (2000) also warns of the dangers of a culture of managerialism, where organisations become "lean and driven to meet medically determined outcomes for minimal cost" (such as Government targets) as it may be difficult to assert caring in such an environment. Other explorations of the concept of holistic care found that healthcare professionals endeavoured to balance the biomedical and holistic approach and described being 'masters of walking on a tightrope' (Berg *et al* 2005). Stewart (2001) found that doctors varied, but most provided *partial* patient centred care. She also found positive outcomes of using patient centred approaches with improved patient satisfaction, compliance and better health outcomes.

Maslow (1971) promoted a holistic view of health. He stated that 'good human beings' need a 'good society' in which to thrive. He also recognised that nutrition had a part to play in this, using the example that children in India often suffered poor brain development due to protein deficiency and that political, economic and cultural circumstances lead to this deficiency. Maslow (1971) believed that 'self-actualisation' was when a person reaches their full potential. In order to reach this point a various layers of needs must be met (below):



**Maslow's Hierarchy of Needs.**

From: [www.gp-training.net](http://www.gp-training.net) (accessed 23/06/2010).

This theory is a further example of the tension between biomedical and social models of care. It illustrates that people have basic and complex needs, all of which can be influenced by external factors. The above diagram suggests that meeting these needs is a hierarchical process; that is only after the basic needs are met (food, drink for example), can higher needs be addressed (well-being and ultimately self actualisation).

The science of nutrition is often described as interdisciplinary, and reflects similar tensions between the biomedical and social models of care:

“To understand, study, research and practice nutrition, a holistic integrated approach from molecular to societal level is needed” (Gibney *et al* 2009).

Nutrition and dietetics needs to be underpinned by biological science and medicine, but also must acknowledge behavioural, social and psychological aspects of care, particularly when addressing lifestyle changes. A holistic approach to nutrition recognises that good nutrition influences not only the physical health of an individual but also psychological health (brain development, cognitive function); social health (ability to work or attend school and

contribute to society) and emotional health (mood, satiety) (Albon and Mukherji 2008). Furthermore, optimal balanced nutrition is a chief determinant of health; it can be used not only to promote health but also to prevent and treat ill-health (Gibney *et al* 2009).

## 7.0 Synthesis of Submitted papers

### 7.1 Paper 1

Abayomi, J; Watkinson, H; Topping, J and Hackett, A (2007). Obesity and underweight among first trimester pregnant women. *British Journal of Midwifery*. 15 (3) 143-147.

***Aim: To determine the prevalence of obesity and underweight among women booking-in for antenatal care at a Liverpool hospital and to estimate the dietetic resources needed to deal with the problem.***

Over weight and underweight in pregnancy can cause health problems for mother and baby. Predominantly the risks associated with overweight are: Caesarean delivery, hypertensive disorders and gestational diabetes (Galtier-Dereure *et al.* 2000); and the risks associated with underweight are: Low birth weight (LBW) (Johnson and Yancey 1996), inter-uterine growth retardation (IUGR) and premature labour (ADA 2002; Ehrenberg *et al.* 2003). Nationally there is an increased awareness of the risks of obesity in pregnancy with the publication of the last two Confidential Enquiries into Maternal Death (CEMACH 2004 & 2007). These reports highlighted that obesity was implicated in 35% and 50% of all deaths respectively. At the time of data collection, the hospital's strategy for dealing with the problem was to suggest that all women with a BMI > 30 kg/m<sup>2</sup> at booking-in should be referred to the dietitian – job done. However, they had no idea how many women this would involve, nor if they had the resources to deal with it.

This study involved analysing data routinely collected at the booking-in appointment to identify how many women were classified as overweight (BMI > 25 kg/m<sup>2</sup>); obese (BMI > 30 kg/m<sup>2</sup>) and underweight (BMI < 20 kg/m<sup>2</sup>) (WHO 2000). Although height and weight should be measured and recorded by midwives at the booking-in appointment, BMI for over 1000 women (13.4%) could not be calculated as height or weight had not been measured or

recorded accurately. This suggests that the midwives did not appreciate the importance of recording this data.

The data showed a high prevalence of overweight (27%) and obesity (17%), with 44% of women having a BMI > 25 kg/m<sup>2</sup>. There was also a considerable number of women underweight and possibly malnourished (BMI < 20 kg/m<sup>2</sup>) or probably malnourished (BMI < 18.5 kg/m<sup>2</sup>), 10.7% and 3.8% respectively; a total of 14.5% underweight. Increasing age and parity were both positively associated with increasing BMI ( $p < 0.001$ ). It is possible that more women were at risk but not identified, because their height or weight is absent (not recorded).

If all women with a BMI > 30 kg/m<sup>2</sup> or < 18.5 kg/m<sup>2</sup> were referred to the dietitian, as the hospital proposed; an extra 1,456 patients would need to be seen each year. If all obese and underweight patients were offered an initial and a follow-up appointment, an additional 42 hours of work would be generated per week. As there is only currently 0.4 WTE dietitian for all ante-natal and maternity, a further 1.2 WTE dietitian is needed, equivalent to a 300% increase in staffing and related resources.

The study highlights a disregard for the nutritional needs of overweight and underweight pregnant women: At the time of data collection, **none** of these women were referred to the dietitian for nutritional advice, despite BMI's of 14 kg/m<sup>2</sup> and 65 kg/m<sup>2</sup> being recorded, revealing extremes of both under and over nutrition. This suggests that midwives either ignored the problem or did not regard it as an important risk in pregnancy. Although hospital management acknowledged that obesity was a risk and wanted to implement a policy that addressed this risk; resources to deal with the problem were inadequate. To date a policy regarding the management of obesity in pregnancy has been written, but there is no mention of diet and there is no dietetic input to the antenatal obesity clinic.

## 7.2 Paper 2

Abayomi, J; Watkinson, H; Topping, J and Hackett, A (2008) Identification of Hot spots of obesity and underweight in early pregnancy in Liverpool. *Journal of Human Nutrition & Dietetics* 22:246-254.

**Aim: To identify neighbourhoods with high density or 'hot spots' for underweight and obesity in first trimester pregnant women in Liverpool and surrounding area.**

As identified earlier (Paper 1), numerous health risks are associated with both underweight and obesity in pregnancy. Also, the study hospital has a high prevalence of underweight and overweight women attending for antenatal care. Obesity is thought to be linked to deprivation (Acheson 1998; House of Commons Health Committee 2004; Department of Health 2006) and Liverpool is known to be the most deprived local authority in England (ODPM 2006). This study involved the BMI data (collected in paper 1) and the residential postcodes of the women to plot point maps, showing the geographical distribution of the women across Liverpool. Separate maps were constructed using all pregnancies, obese pregnancies and underweight pregnancies.

The maps illustrated that both obesity and underweight were found across all areas of Merseyside. However, the kernel-smoothing approach allows concentrations not related to population density (or 'hotspots') to be identified. Six neighbourhoods were identified as hotspots of obesity. More interestingly, a number of areas were found to be hotspots for **both** obesity and underweight, namely parts of:

- (1) Picton, Granby, Smithdown and Arundel
- (2) Dovecot and Broadgreen
- (3) Breckfield and Anfield.

In many respects, the obesity map resembled the general map, suggesting that obesity is a widespread problem. However, the underweight map was less predictable, with no apparent

explanation for the underweight hotspots. Other lifestyle factors such as smoking, drug/alcohol consumption may be implicated but were not explored in this study.

The data implies an inequality issue as all hotspots were located in deprived wards, with 5 out of 8 of the wards identified, listed in the top 100 deprived wards in the UK (ODPM 2006). However, Speke is the most deprived ward in Liverpool but did not feature as a hotspot for either underweight or obesity. At the time of the data collection, Speke was often described as a 'food desert' with little access to food shops and 'takeaway' outlets for local people. This raises the possibility that environmental factors may contribute to malnutrition need further investigation.

The real concern that emerges from this paper is that high levels of malnutrition, with extremes of underweight and overweight, live side-by-side in this city. The obesity probably masks underlying under nutrition in terms of micronutrients too. Obesity in pregnancy has received a lot of attention in recent years but the problem of underweight is largely overlooked. Poverty and deprivation are well-known causes of under nutrition and have been linked to poor pregnancy outcome and low birth weight (LBW) (Doyle *et al* 1992; Acheson 1998; Burchett & Seeley 2003). The UK has the highest incidence of LBW in Northern Europe, at 7.0% (UNICEF 2001) but critics argue that it is a neglected public health issue; it has never featured as a key objective in health policy (Ashdown-Lambert 2005) and no supplementary food schemes (such as those found in USA and Canada) exist (Higgins *et al* 1989; Beuscher *et al* 1993).

Once again, it appears that nutritional needs are not a priority. The areas of the city found to be 'hotspots' for both underweight **and** obesity should be targeted as a priority for intervention. Nutritional intervention should improve pregnancy outcome for both underweight and overweight women, preventing nutritional problems being transmitted from one generation to the next.

### 7.3 Paper 3

**Abayomi, J; Kirwan, J; Hackett, A & Bagnall, G (2005) A study to investigate women's experiences of radiation enteritis following radiotherapy for cervical cancer. *Journal of Human Nutrition & Dietetics* 18: 353-363.**

***Aim: To describe experiences of chronic radiation enteritis (CRE) patients specifically in relation to effects on diet and nutrition, which affect quality of life.***

Symptoms of CRE can be distressing and include tenesmus, diarrhoea and faecal leakage (Butler-Manuel *et al* 1999). Published literature suggests the prevalence of CRE is about 5-15% following pelvic radiotherapy (Yeoh and Horowitz 1987). Preliminary investigations at the study hospital suggested the prevalence to be much higher than this and that it considerably affects quality of life (Israel, unpublished data). Despite the side-effects of pelvic radiotherapy being well-known to the oncology team, the impact of these symptoms on quality of life appeared to be underestimated. No screening was used at the hospital to identify potential sufferers and no care pathway regarding management of symptoms was employed. Once identified, sufferers can be offered regular medication, such as Loperamide (Groenwald, 1993) and /or dietary advice, such as low residue diets (Liu *et al* 1997) or elemental diets (Bounous 1983; Craighead & Young 1998) to help manage symptoms. However the nature of these diets is restrictive and needs dietetic supervision to ensure a balanced nutritional intake (Sekhon 2000; Shaw 2000).

Much of the previous research into CRE has been quantitative, but using qualitative methods explored how the women themselves perceived and interpreted their experiences of CRE and its impact on their daily lives. Ten women who had completed radiotherapy for cervical cancer were interviewed on a one-to-one basis, using an interview-guided approach. Topics covered included: Experiences of diagnosis, experiences of treatment, problems experienced during/after treatment, impact of symptoms on quality of life, attempts to control symptoms and any professional help sought/received in dealing with these symptoms.

Most women experienced symptoms during/immediately after treatment but found that this resolved quickly. Symptoms that continued or appeared later had a much greater impact on quality of life. The most distressing symptom seemed to be diarrhoea, which often involved urgency and sometimes resulted in incontinence. The fear of this habitually led to social withdrawal, with some women describing feeling imprisoned in their own home. Women also expressed a withdrawal from normal roles of housewife or mother when symptoms were severe. Unexpectedly, women complained of weight gain; this seemed to be due to reduced physical activity and/or comfort eating- both associated with social withdrawal. Dietary changes described included eating less food (especially before going out) and avoiding fruit and vegetables. Unnecessarily limited diets may compromise recovery and lead to further health problems (Sekhon 2000).

Few women reported receiving professional help in dealing with CRE but were unwilling to disclose problems, either due to embarrassment or a reluctance to 'complain'. Women were reluctant to discuss symptoms at a busy, impersonal clinic appointment. Other women believed that health professionals were not interested in CRE and that there was an expectation to 'just get on with it', or it was never mentioned.

This study confirmed that symptoms CRE are distressing and that they compromise quality of life. Despite this, there appeared to be little probing by health professionals to identify, prevent or manage these problems. Nutrition intervention may help with symptoms and promote a balanced diet but this is rarely considered by the MDT, another example of nutrition as a low priority. The main concern seems to be the elimination of the cancer, rather than the overall wellbeing of the patient; contrary to holistic care. If health professionals are to identify and care for women affected by CRE they need to be more pro-active, routinely questioning and observing women at follow-up appointments, as sufferers may be reluctant to seek help themselves.

#### 7.4 Paper 4

Abayomi, J; Kirwan, J & Hackett, A (2009). Coping mechanisms used by women in an attempt to avoid symptoms of Chronic Radiation Enteritis. *Journal of Human Nutrition & Dietetics* 22(4):310-316.

***Aim: To explore medication use and/or changes made to diet by women treated with pelvic radiotherapy, in order to manage symptoms of CRE.***

As identified in paper 3, CRE is associated with a range of distressing symptoms affecting quality of life. In the absence of appropriate professional advice, women in this study described a number of self-prescribed measures they were taking in order to avoid and/or cope with symptoms. This forth paper attempts to describe such measures in more detail and indicates the number of women resorting to these measures in an attempt to manage their symptoms.

The study used a validated questionnaire previously used to identify bowel problems such as diarrhoea and faecal incontinence (Bugg *et al* 2001). A number of additional questions were added at the end of the questionnaire asking about medication use, advice received and any changes to diet (identified from women's comments in paper 3) These additional questions were not included in calculating the score to maintain the validity of the questionnaire.

About half the women achieved scores indicative of CRE (47%), although there was a wide variation in severity of symptoms (score range was 20-85, with 0 = no symptoms). Some women were using anti-diarrhoea medication, 13% weekly and 13% more than once per week. However the majority (74%) never used medication, despite this being an effective way of managing diarrhoea without dietary manipulation (McGough 2007). Patients who had received advice from a dietitian were more likely to be taking regular medication ( $p < 0.05$ ) and those who were using medication stated that it helped most/all of the time ( $p < 0.001$ ).

This illustrates a clear benefit from dietetic intervention regarding management of symptoms, not necessarily related to diet.

Only 45% of women had received advice from a dietitian and there was no relationship between score and receiving advice ( $p > 0.05$ ), indicating that women with the most severe symptoms were not necessarily the ones referred. It is not clear why some were referred and others were not, but this warrants further investigation. It suggests that referring to the dietitian was little more than a random process. Furthermore, 45% had changed their diet, but there was no relationship between dietary change and receiving advice either ( $p > 0.05$ ), so many women had made changes without professional advice. However, there was a positive association between score and changing diet ( $p < 0.001$ ), suggesting that women with more severe symptoms were more likely to manipulate their diet in an attempt to avoid symptoms. Changes to diet were very restrictive and included: avoiding fruit (24%), vegetables (18%) or wholemeal cereals (23%). These changes may result in an unbalanced diet being consumed, which is deficient in fibre and micronutrients such as antioxidants, especially vitamin C. As CRE symptoms are unlikely to resolve, such dietary restrictions would be long-term, potentially resulting in long-term health problems.

This study is further evidence that nutritional considerations are not a significant component of existing care. The MDT seems unaware of the prevalence and severity of dietary restrictions and their potential impact on long term health. The study also suggests that all women should be screened routinely following radiotherapy to identify those with symptoms of CRE. Following identification, there should be a clear care pathway that indicates those who may need referral for further investigation or support by incontinence specialist nurses, a specialist gastroenterologist, or dietitian, to help them manage their symptoms safely but effectively. The current system seems to have no indication of who should be referred to whom, or why. Improved access to dietitians may raise the profile of nutrition at the hospital and improve the nutritional awareness and knowledge of the MDT.

## 7.5 Paper 5

Abayomi, J; Kirwan, J & Hackett, A (2009). The prevalence of Chronic Radiation Enteritis following radiotherapy for cervical or endometrial cancer and its impact on quality of life. *European Journal of Oncology Nursing* 13 (4): 262-267.

***Aim: To identify how many women experience symptoms of CRE following radiotherapy for cervical or endometrial cancer and to investigate whether women who have higher doses of radiotherapy or more advanced stage of cancer are more at risk.***

CRE is associated with a range of distressing symptoms affecting quality of life (paper 3); yet health care professionals appear to be unaware of the prevalence or the impact of CRE symptoms. This problem is unlikely to be unique to the study hospital. Putta and Andreyev (2005) found that many clinicians deny that faecal incontinence is a common problem following pelvic radiotherapy. This fifth paper aims to identify the number of women likely to be affected by CRE and also which women were at increased risk of developing CRE.

A validated questionnaire (Bugg *et al* 2001), previously used to identify bowel problems was used to collect data regarding type and severity of symptoms. The responses were scored and compared to the scores for known faecal incontinence (Bugg *et al* 2001). Using a score of '0' to indicate no symptoms, 47% of women gained a wide range of scores indicative of CRE, ranging from 20-85 (mean 34). So, about half of women treated with pelvic radiotherapy have symptoms of CRE and yet no process for identification of sufferers or management of symptoms was in place.

Further statistical analysis revealed that some domains scored higher than Bugg *et al*'s group (2001), namely 'General health'; 'Sleep and energy' and 'Severity measures'. It is deduced that women score higher in the 'severity measures' domain as they get fewer warning signs or triggers and so experience more 'accidents' (as reported in qualitative

data). Scores for 'Social function' and 'Personal function' indicate that women in this study have similar quality of life to women with known faecal incontinence in terms of personal relationships and socialising. However, scrutiny of the actual responses and the additional comments made gives further insight regarding the impact of symptoms on the lives of sufferers. Many comments reflect the findings of paper 3, with 27% of women reporting depression and 32% reporting anxiety about their bowel problem. Moreover, 42% stated that their bowel problem made them rush to the toilet; 39% had to watch what they eat; 23% wear pads to keep clean and 32% frequently change underclothes.

No association was found between symptoms of CRE and treatment dose, cancer type or stage, or length of time since treatment. This indicates that all patients treated with pelvic radiotherapy are potentially at risk. Although this paper has less focus on diet and nutrition, its findings are similar to the earlier papers in that the problems described are largely preventable and yet mainly overlooked by the MDT. The priority seems to be the treatment of cancer rather than improving the quality of life of the patient, hardly a holistic approach. Simple advice regarding regular medication and appropriate changes to diet may help prevent some of these distressing symptoms. This in turn would have a significant impact on the physical, psychological and social well-being of sufferers, possibly allowing a return to normal roles.

A more pro-active, holistic approach is required, particularly as it is difficult to predict who is likely to suffer CRE and sufferers are often reluctant to mention symptoms. Patients should be screened for CRE at regular intervals and a clear care pathway is needed to identify those who would benefit from further intervention to enhance their quality of life. Furthermore, as CRE is a long-term condition, enhancing the knowledge of patients to aid understand their symptoms and offer mutual support to fellow sufferers, via an 'expert patient' programme for example, may empower patients to manage symptoms effectively.

## 7.6 Paper 6

**Abayomi J, Judd S & Hackett A (2009) Malnutrition in hospitals: Still unrecognised and ignored. *Journal of Healthcare Management* 15(10):488-494.**

***Aim: To review recent guidelines and policies aimed at tackling malnutrition in NHS hospitals to identify causes of malnutrition, barriers to treating and preventing it and ways to overcome it.***

This final paper draws together a common theme that runs through the five previous papers: Nutrition is not a priority in NHS hospitals. It identifies that malnutrition amongst hospital patients remains prevalent and is a costly barrier to effective treatment and recovery; even in Florence Nightingale's day it was acknowledged that malnourished patients recovered less well. A plethora of papers have been published demonstrating how malnutrition is associated with increased morbidity and mortality and NHS costs (Lennard-Jones 1992; McWhirter and Pennington 1994; Allison 2003; Elia *et al* 2005).

For decades the NHS has tried to tackle the problem of malnutrition via numerous campaigns and policies, with little success. The focus of these campaigns has been the improvement of hospital food, bringing in celebrity chefs for example. However, it has been well documented that problems acquiring and eating the right food are multifactoral and not always related to food *quality* (Allison 2003). The 5 previous papers are all examples of where patient care and quality of life could be greatly improved if nutrition were given a higher priority: Identifying overweight and underweight women in pregnancy and offering appropriate care could reduce maternal and foetal health risks; Identifying women suffering from CRE and referring them for appropriate management of symptoms may allow a more balanced dietary intake and a return to normal social roles. However, in all cases, very little is put in place to identify such problems and referrals for appropriate interventions were low and inconsistent.

The culture of the NHS does not allow nutrition to be seen as a priority: budgets for food provision are held within 'hotel services' rather than clinical services, contrary to the portrayal of nutrition as an essential part of patient care. In comparison to other countries, the NHS has less money to spend on food provision (Allison 2003). Other initiatives to promote ward food consumption, such as PMT and red trays, are not enforced, and so are ineffective. With shorter hospital stays, the window of opportunity for identifying and treating malnutrition is reducing. NICE and BAPEN both recommend screening all patients on admission to hospital to identify those at risk. However, without adequate resources to tackle the problem, screening becomes a pointless exercise. The study hospital has been reluctant to introduce screening for patients (other than oncology patients) as a substantial investment in dietetic resources (costing about £100,000) would be required to provide appropriate intervention.

However, the responsibility for identifying and treating malnutrition lies with the whole MDT. Health professionals appear reluctant to take responsibility for food provision, possibly because it is viewed as a menial task. Health professionals such as doctors and nurses need greater emphasis regarding the importance of nutrition support in their undergraduate and post graduate training. Previous studies show that their knowledge is poor in this area (Jackson 2001; Summerbell 1996; Brett *et al* 1986) and that malnutrition is undetected because it is not even considered (McWhirter and Pennington 1994; Kelly *et al* 2000; Abayomi & Hackett 2004). This is also true of primary care health care professionals. BAPEN now recommend screening of community patients and the responsibility for identifying and treating malnutrition may shift into the community rather than the acute setting as a result of this.

There are still many unanswered questions as to why nutrition is given such a low priority but dietitians are best placed to inform and motivate health care professionals, raising the profile of nutrition. However, dietitians have had little impact so far as they remain a significant

minority in most hospitals, with little power. Changing the culture of the NHS will require clear leadership from those who decide NHS priorities: management and government.

## **8.0 Data analysis**

**8.1 Quantitative data** were analysed using a variety of statistical tests via SPSS (Chicago, IL, USA). The advice of a medical statistician (Dr Anna Hart) was sought for each paper.

### **Non-parametric data**

Data in papers 1, 2, 4 & 5 violated the assumptions for parametric statistical analysis so the appropriate non-parametric statistical tests were used (Hinton 2004).

### **Chi<sup>2</sup> test**

This test uses independent categories and determines if there is a significant relationship or pattern between the two variables (and that this relationship has not happened by chance).  $P < 0.05$  was considered significant in all cases.

### **Binary logistic regression**

In paper 1, logistic regression was used to determine whether age or parity was the most significant influence for increasing BMI. Both variants were found to be highly significant when analysed separately using chi<sup>2</sup> ( $p < 0.001$ ), but increasing parity also depends on increasing age. Logistic regression helps the researcher to determine if there is an underlying relationship between the variables and to predict what that relationship might be (Hinton 2004). The findings were that both variables (age and parity) were highly significant, but age gave a slightly better model for predicting obesity than parity. This indicates that age is slightly more influential than parity regarding increasing BMI.

### **ZM test**

This statistical test is used to compare the mean of a group, with a known mean (using mean and standard deviation). It was used to compare the scores for each domain (from paper 5) with the known scores from the Bugg *et al.* (2001) study. It is possible to use other tests, such as an independent T-test, but raw data is required. The ZM test was

used as the author did not have access to the raw data from the Bugg *et al* (2001) study, only the mean and standard deviation.

## **8.2 Qualitative data**

Qualitative data were collected via in-depth interviews (paper 3) and via additional comments added to the questionnaire (paper 4). In both papers analysis involved examining the text and highlighting potential categories, (paper 3 used NUDIST; paper 4 used colour coding). Highlighted data were sorted into categories of common themes and then connections and/or differences in themes were explored.

## **9.0 Summary and critical review**

The six peer-reviewed publications form a coherent programme of research into one facet of my professional role as a dietitian: the recognition of and response to malnourished hospital patients. Each article addresses nutrition-related health problems experienced by women attending the study hospital. Furthermore identifying and managing these problems seemed to be low on the hospital's list of priorities, despite considerable impacts on quality of life. Although my research focuses on 2 examples related to my work and relate to one hospital at one time, it is unlikely that they are isolated cases (as reflected in literature below). It can be presumed therefore that many more nutrition-related problems exist in NHS hospitals throughout the UK.

In 2008, BAPEN published the results of a national screening survey which revealed significant levels of malnutrition in hospitals, care homes and mental health units (BAPEN 2008). In each case the majority of patients at risk were identified as 'high risk' by MUST screening, with 28% of hospital admissions, 30% of care home admissions and 19% of mental health admissions found to be at some risk. These figures are considerably higher than those found at the study hospital (14.5% of pregnant women at risk, with 3.8% at high

risk). However, BAPEN's (2008) report also acknowledged that malnutrition was common on all types of wards and diagnostic categories, with oncology (43%), gastrointestinal (43%) and neurological patients (33%) having noticeably more malnutrition than other groups. In agreement with papers 1 & 2, BAPEN (2008) found low levels of weighing, with less than half of patients weighed, despite most hospital reporting adhering to a screening policy (89%). They accept that much malnutrition continues to be under-recognised and under-treated as a result.

The papers raise very fundamental issues concerning the nature of medicine, expectations of patients, professionalism (including training and CPD) and management. The low priority given to nutrition, identified in all 6 papers, seems to reflect a deeper problem common to NHS health professionals, of a lack of 'holistic' care.

The papers suggest that health professionals focus on dealing with the medical aspects of the women involved, the pregnancy or the cancer for example, rather than comprehensive needs of the patient. In fact, health care professionals often refer to patients by their condition, "ca ovary"; "ca cervix"; "primigravida" for example. Johns (2000) suggests that a culture of efficiency often adversely affects holistic care. If health professionals are focused on meeting medically determined outcomes for minimum cost, they are less focused on the individual needs of the patient. The nutrition-related problems identified, that is being malnourished; overweight or underweight in pregnancy and CRE, are shown to be associated with significant impact on the physical, emotional, psychological and social needs of patients. Little attention was given to these issues by the MDT, with women describing an expectation of having to "just get on with it". In terms of hospital malnutrition, doctors and nurses still do not regard nutrition as a priority, despite the impacts on health and recovery being well documented (Lennard-Jones 1992; McWhirter and Pennington 1994; Allison 2003; Elia *et al* 2005). Furthermore, there was little leadership from management as no care pathways were put in place, nor sufficient funding for resources.

Addressing the nutritional needs of patients can be viewed as part of a holistic approach. Maslow's hierarchy of needs (1971) identifies that for the complex needs of a person to be met, such as cognitive and aesthetic needs, the basic needs must first be attended to. One of the basic needs referred to by Maslow, is the need for food and fluids. If the nutritional requirements of patients are not met, then any other attempts to intervene in health problems will be ineffective. Health professionals seem to be unaware of this theory, often searching for high impact interventions to treat specific problems. Examples I have encountered include: investigating patients for cancer following marked weight loss (in fact due to poor nutritional intake); investigating for renal failure following abnormal blood results, (when patients are in fact dehydrated); and suggesting bowel surgery/colostomies to manage CRE, (before considering antibiotics or dietary intervention). Maslow (1971) also identified that meeting basic needs, such as nutritional adequacy is often a complex process; influenced by external factors such as economics and politics. At the study hospital this also appears to be the case, with basic needs of patients being affected by insufficient resources and the constraints of Government targets.

Furthermore, the approach is very reactive; there was very little evidence of attention to health promotion, or the proactive prevention of health problems in the papers. Good nutrition and optimal maternal weight prior to conception would give the best pregnancy outcome, reducing maternal and foetal mortality and prevent LBW (Allen & Burke 1999; Johnson & Yancey 1996). These women were already pregnant, and so potentially any harm has already taken place. Birth defects and LBW are the two major causes of infant mortality and increased hospitalisation in the Western world (Bendich & Deckelbaum 1997). Improving the nutritional status of women, *prior to* conception could reduce infant morbidity and mortality. Recent examples include folic acid supplementation, which can reduce neural tube defects by 50% (Bendich & Deckelbaum 1997) and food supplementation to underweight pregnant women to reduce the incidence of LBW (Scholl *et al* 1997). At the

study hospital, there appeared to be little attention to prevention: Obesity was only receiving attention because of the increased risk of maternal death, whilst underweight in pregnancy was never even mentioned. Moreover, there was no pre-conception care or opportunities for pre-pregnancy counselling.

Simple instructions regarding regular anti-diarrhoeal medication and the importance of achieving a balanced diet could help prevent some CRE symptoms and protect women against long-term health problems associated with poor diet and sub-optimal BMI (via over or under eating). Taking regular Loperamide prior to eating can be very beneficial in preventing diarrhoea (McGough 2007), yet very few women (13%) were taking regular medication. Women could be given this advice prior to treatment, to empower them to tackle problems as soon as they appear, rather than waiting for them to develop problems. Another feature of holistic care is the empowerment of patients, allowing them to determine their own needs (Ellis 1999). Specialist intervention by a gastroenterologist would help to identify the cause of unresponsive diarrhoea, resulting in appropriate management via simple treatments such as antibiotics or bile-salt sequestrants (Andreyev 2007), yet no referral pathway to gastroenterology has been put in place.

The Wanless report (2002) found that years of underinvestment in preventative care in the NHS had led to shortfalls, resulting in poorer quality care than was found in other European countries. The report went on to recommend that large gains could be made by shifting the focus to promoting good health & preventing illness. This report was the first of its kind in assessing the resources required to provide high quality health care for the future. It also warned of the consequences of not investing in preventative medicine: insufficient resources to deal with the demand. The health problems discussed in papers 1-6 are all situations where preventative medicine could not only improve quality of life, but also make economic sense as preventing these problems is far more cost-effective than treating them. In 1998 the average cost for major large bowel surgery (without complications) at an NHS hospital

was £2,606 per patient. A caesarean delivery (needed more for obese women) costs the NHS on average £1,577, whereas a normal delivery costs £720. Admission to the neonatal unit (needed more for LBW babies, born to underweight women) costs an average of £1,179 (DH 1998). The savings made by preventing further health problems in later life are immeasurable. Elia (2005) suggests that £7.3 billion per year is spent on treating malnutrition and Lennard-Jones (1992) estimated that the NHS could save £266 million annually in reduced hospital-stay alone, by treating malnutrition. Perhaps new initiatives such as QIPP and High Impact Factors will have more success as they focus on improving quality not just to improve care but also to save money?

Part of holistic care is protecting the autonomy of patients: providing sufficient information to allow them to make informed decisions about their treatment (Kinnair 2009). Many patients in papers 1-5 appear ill-informed regarding their nutrition related health problems: Women report a lack of awareness regarding symptoms of CRE; sometimes failing to connect their problem to the treatment received, or were unaware that any help was available to manage their symptoms. None of the overweight or underweight pregnant women were referred to the dietitian for intervention, despite BMIs of 14 and 65 being recorded. Perhaps if they had been made aware of the risks to their/their baby's health, they would have requested a referral?

The UK has one of the worst adult literacy rates in Europe, with one in 5 adults (7 million people) struggling with basic numeracy and literacy (Basic Skills Agency 1999). In order for people to interpret complex information to be able to make informed choices about their health, they require a high level of skill. This is often referred to as 'health literacy':

*"Health literacy aims to help individuals in the community to take control of the management of their own health and health problems, and of getting the best from the services they need."* (DH 2009).

The UK Government recognises that low health literacy is associated with poor health outcomes and usually affects those in more deprived communities. There is now a campaign to improve health literacy as a way of tackling health inequalities: 'Skilled for Health' (DH 2009). The aim of this programme is to engage with disadvantaged communities, improving their basic skills to enable them to make informed decisions regarding their health. As Liverpool is described as the most deprived local authority in England (ODPM 2006), improving health literacy among the hospital population could empower patients to request more support when it is required, rather than wait for it to be offered. Women who are either very overweight or underweight in pregnancy or suffering symptoms of CRE would be more likely to demand help and actively want to address their health problems rather than wait for a health professional to suggest it. Expert patient programmes may help empower patients to fully understand their situation and offer mutual support for each other, recognising that they are not in isolation with their problems (NHS undated).

Therefore, in promoting good nutrition in the context of holistic health care, dietitians should be at the fore-front of raising awareness and increasing knowledge. Dietitians have a range of approaches to use, including advanced communication skills, such as motivational interviewing. Dietitians tend to have more of a holistic view, as advising people about food and eating requires an awareness of the client's social, economic, physical and psychological circumstances. Greater access to dietitians increases the nutritional knowledge of the MDT, enhancing awareness and raising the profile of nutrition (Thorensen *et al* 2008). However, most hospitals employ a small number of dietitians; they tend to be a powerless minority. For example, at the study hospital there are only 2 part-time dietitians (1.0 WTE), resulting in no regular access to dietitians on the wards/at clinics. The hospital has invested in other professions: the number of oncology consultants and Macmillan nurses has doubled in recent years, whereas dietetic resources have remained the same. It appears that undervaluing the role of the dietitian is part of NHS culture too.

## **10.0 Satisfying the aims**

The first research aim was to establish the prevalence of nutrition-related health problems affecting women attending the study hospital. Papers 3, 4 & 5 describe CRE and estimate that about half of women experience symptoms. Although the dietitians were aware that women were encountering problems, no screening was in place to identify women with CRE and no care-pathway or policy regarding management of symptoms had been written. Papers 1 & 2 identify the prevalence of underweight (10.7%), overweight (27%) and obesity (17%) in women booking-in for antenatal care at the hospital. Although women's BMI was calculated and recorded at their booking-in appointment, no care-pathway or policy existed regarding their management during pregnancy. Furthermore, there were no guidelines regarding referring any of these women for dietetic intervention and no monitoring of the prevalence of these problems was in place.

The second aim was to explore areas of the city with greater prevalence of underweight and overweight in pregnancy, in order to direct resources in dealing with the problem to where they are needed most. Paper 2 used mapping to identify areas of the city with 'hotspots' of underweight and/or obesity. Overall, this study revealed that overweight and obesity were widespread throughout the city. Hotspots of underweight cannot be easily explained, but three areas, located in deprived wards, were hotspots for both; indicating two extremes of malnutrition co-existing. These areas should be targeted for intervention as a priority as they are likely to have the poorest diets overall and suggest an inequalities situation.

The third aim was to investigate the role of nutrition within holistic care. Papers 3, 4 & 5 describe how symptoms of CRE affect the physical, social and psychological well-being of sufferers. Papers 1 and 2 highlight how underweight and overweight in pregnancy can impact on the health of the mother and the foetus. All of these papers describe a lack of holistic care, with health care professionals focussing on the 'cancer' or the 'pregnancy' rather than the person and her 'well-being'. A holistic approach would recognise that

satisfying basic needs for diet and fluids must be considered first, so that more complex interventions (such as surgery, radiotherapy, caesarean section) are more likely to be successful. Nutrition intervention could help prevent and possibly treat some of the CRE side-effects experienced and could help encourage optimal weight gain/ weight maintenance in pregnancy, yet referrals to the dietitian were low and inconsistent. Furthermore, there appeared to be a culture of focusing on biomedical models of health, which may be driven by political and economic factors, such as Government targets, the drive for 'efficiency' and insufficient resources.

The fourth aim was to review NHS policy regarding tackling malnutrition and to identify barriers to identifying and treating malnutrition. Paper 6 determines that malnutrition largely exists in the NHS as it not regarded as a priority (Allison 2003) and may be viewed as a menial task. Doctors and nurses have poor nutritional knowledge and NHS managers see food provision as a 'hotel service' rather than part of clinical care (Maryon Davis & Bristow 1999). However papers 1-5 also imply that the nutritional problems identified are associated with poor nutritional awareness and could be improved if nutrition was regarded as a higher priority.

## 11.0 Original contribution

The main findings from this body of research are:

Malnutrition in its broadest definition of 'bad' nutrition, in more than one form, is still not comprehensively recognised within the NHS and is therefore often untreated. Organisations such as BAPEN have made great strides in increasing awareness of *under* nutrition by campaigning for screening and by promoting integrated and patient-centred policies relating to nutritional care (BAPEN 2005). However, these policies do not consider that patients maybe malnourished and NOT underweight. NICE guidelines state that only *under* nourished patients should have access to a dietitian (NICE 2006). Paper 6 describes how limited screening has been introduced at the hospital, due to limited resources; however

papers 1 and 2 suggest that overweight women would not be identified as malnourished even if MUST screening were to be introduced at antenatal clinic. In papers 3, 4 and 5 some women with CRE were following extremely restricted diets, unlikely to be meeting their nutritional requirements, yet MUST screening would not identify them as malnourished either, particularly as many also reported weight gain.

A key finding is that malnutrition impacts greatly on the quality of the lives of patients. Papers 1 and 2 describe how malnutrition in pregnancy (both under and over weight) can significantly increase health risks for both the mother and foetus. Although much of the literature describes risks to physical health, poor pregnancy outcome will also affect psychological and emotional health. The social factors involved in the prevalence of malnutrition in pregnancy also cannot be ignored. Paper 2 found that certain neighbourhoods in the city were identified as hotspots for underweight and overweight. Most interestingly three neighbourhoods were identified as hotspots for both, suggesting both extremes of malnutrition living side-by-side. Although these three areas are deprived parts of the city, it is unclear what social or other factors have led to this situation and this warrants further investigation.

Papers 3, 4 and 5 describe clearly how CRE can impact on the lives of women, using the patient's own words. CRE affected the nutritional intake of some of these women and also their ability to digest and absorb food. Problems which result from poor intake or poor digestion/absorption of food considerably influence quality of life. These problems can have far-reaching effects; such as limiting socialising and challenging personal relationships; affecting social roles such as 'wife' or 'mother' and may cause psychological and emotional problems such as anxiety and depression.

The above findings highlight the role nutrition has to play in the holistic promotion of health and the prevention/treatment of ill-health (Gibney *et al* 2009). Optimum, balanced nutrition

enhances not only the physical health of individuals, but allows for good psychological, social and emotional well-being (Albon and Mukherji 2008). Conversely, without optimum nutrition, individuals may be disadvantaged in terms of physical, psychological and social health. Patients have individual requirements, which need to be addressed via holistic patient-centred approaches (Akinsanya 1989). General nutritional advice would be ineffective any of these women; health professionals need to assess them holistically, considering individual problems and the impact this has on their quality of life. This can be time consuming and hence expensive (needs more resources). Holistic approaches might also empower some patients to determine their own needs and ask for help when required (Ellis 1999). Optimum nutrition fulfils a basic human need; without this more complex needs cannot be met (Maslow 1971). Health professionals should ensure that the basic needs of patients are met (such as food, fluids, hygiene) before attempting more complex interventions (such as surgery or radiotherapy). These interventions are likely to be ineffective without meeting basic requirements first.

## **12.0 Future Work and recommendations for further study**

- Firstly, the most important recommendation is that nutrition should be considered a priority, as important as any other treatment, within the NHS. Improving the undergraduate and post-graduate training of health professionals will help with this, but there also needs to be a substantial mind-shift by the MDT, managers and politicians.
- A more holistic, proactive approach to treating patients is required. Preventative measures need to be valued as much as reactive measures, even if they are less exciting and involve less technology. The focus should be on the long term well-being of the patient, rather than finding a 'cure', however this approach could be contrary to some Government targets. Once again improved education and a considerable mind-shift by the MDT, managers and politicians would be required.

- A general improvement in the awareness of good nutrition amongst the population at large would help prevent a number of nutrition related problems from occurring in the first place. The public are often faced with misleading and confusing information in the media, for example from bogus and unqualified celebrity “nutritionists”. Accurate information given alongside improved health literacy would empower people to make informed choices regarding their health.
- Health professionals need to recognise their own limitations and value the expertise of other members of the MDT. If they find themselves faced with an unexpected problem or do not know how to manage it, they should refer to someone who does. Team building and CPD may help inform the MDT about the expertise of other colleagues and how they are able to help.
- The NHS should invest in more dietitians. The literature shows that dietitians can be very successful in their interventions; they use advanced communication skills and tend to have a more holistic approach. Currently most hospitals are under-resourced and dietitians appear to be a powerless minority, unlikely to influence much change. Improved access to dietitians would help raise the profile of nutrition and increase awareness/knowledge of the MDT.

*As a result of this research, dietetic referral rates have dramatically increased at the study hospital. As a consequence, 1.0 FTE community dietitian has now been employed working with women of child-bearing age in deprived areas of the city. The MacMillan organisation has also agreed to increase the funding for the oncology dietitian from 0.5 to 1.0 WTE. A team of researchers and professionals at the hospital were awarded £250,000 from ‘Mersey Beat’ to further investigate obesity in pregnancy and decide guidelines for best practice. This research has been empowering for the researcher involved: prior to publication attempts at improving nutrition in the hospital were considered personal opinion; since publication efforts are taken more seriously.*

- Further research is required:
- To aid the understanding of why nutrition is not considered a priority. Many of the recommendations above will not be met until this question can be answered. The arguments for prioritising nutrition are ethical, medical, economic and common sense, yet it is still ignored.
- To determine the optimal management and prevention of CRE. At present there is a lack of consensus regarding those most at risk and the most appropriate way of managing symptoms.
- To determine the optimal management and prevention of overweight and underweight in pregnancy. The current literature appears to 'sit on the fence' in terms of guidelines for managing obesity in pregnancy: no one has yet recommended safe weight loss in the context of a healthy diet, yet further weight gain can only be detrimental to health.

## 13.0

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## Appendix 2: Supporting Publications

1. Berridge, K; Hackett, A; Abayomi, J and Maxwell, SM (2001). An investigation into the relative costs of breast and bottle feeding in Liverpool infants, up to the age of four months. *Proceedings of the Nutrition Society*, **60**:212.
2. Abayomi, J and Hackett, A (2004) Assessment of malnutrition in mental health clients: nurses' judgement vs. a nutrition risk tool. *Journal of Advanced Nursing* **45** (4): 430-437.
3. Berridge, K; Hackett, A; Abayomi, J and Maxwell, SM (2004). The cost of infant feeding in Liverpool, England. *Public Health Nutrition*, **7**: 1039-1046.
4. Berridge, K & Abayomi, J (2004). Why don't women breast-feed for longer? *Proceedings of the Nutrition Society*, **63** (1):22.
5. Berridge, K; McFadden, K and Abayomi, J (2004). Supporting women to breast-feed for longer. *Proceedings of the Nutrition Society*, **63** (1):23.
6. Abayomi, J; Kirwan, J; Hackett, A and Bagnall, G (2004). Experiences of Women with chronic radiation enteritis indicate the need for dietary advice. *Proceedings of the Nutrition Society*, **63** (1):28
7. Berridge, K; McFadden, K; Abayomi, J and Topping, J (2005) Views of breastfeeding difficulties among drop-in-clinic attendees. *Maternal and Child Nutrition* **1**(4): 250-262.
8. Abayomi, J (2005) Infant formula- Evaluating the safety of new ingredients *Journal of Human Nutrition and Dietetics* **18**: 226.
9. Abayomi, J; Morrison, G; McFadden, K; Wood, L & Purewal, TS (2005) Can Continuous Subcutaneous Insulin Infusion assist women with type 1 diabetes in breastfeeding? *Journal of Diabetes Nursing* **9** (9) 346-351.
10. Abayomi, J; Morrison, G; McFadden, K; Purewal, TS and Hackett, A (2006) An illustration of post-partum hypoglycaemia in respect to breastfeeding for women with type 1 diabetes. *Proceedings of the Nutrition Society*, **65**: 45.

11. Abayomi, J; Watkinson, H; Topping, J and Hackett, A (2007).The prevalence of underweight and probable under nutrition in first-trimester pregnant women. *Proceedings of the Nutrition Society*, **66**: 63.
12. Abayomi, J; Kirwan, J; Hackett, A (2008). The impact of chronic radiation enteritis on quality of life, following radiotherapy for cervical or endometrial cancer. *Journal of Human Nutrition & Dietetics* **21** (4): 373-374.
13. Abayomi, J; Kirwan, J; Hackett, A (2008). Coping mechanisms initiated by women in an attempt to avoid symptoms of chronic radiation enteritis. *Proceedings of the Nutrition Society*, **67**(8): 417.
14. Abayomi J, Judd S, Hill L & Hackett A (2009) Malnutrition in hospitals: The cost of implementing MUST screening. *Proceedings of the Nutrition Society* **68**: 111.