**Safe in the bubble, out into the unknown: returning home
following allogeneic stem cell transplantation.**

A phenomenological study

by

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Abstract

Aim. This paper reports a study exploring the lived experience of fifteen men and women treated with allogeneic stem cell transplant (SCT) for haematological malignancy.

Background. Evidence suggests that treatment of haematological malignancy including allogeneic stem cell transplant has a significant impact on the quality of life (QoL) of recipients and quantitative studies have measured dimensions such as physical function and psycho-social and spiritual domains. Fewer studies have considered individual's lived experience of allogeneic SCT and their subsequent recovery.

Methods. The study followed an interpretive phenomenological methodology using semi-structured interviews. Fifteen participants aged between 22-68 years were purposively recruited from two specialist treatment centres and were interviewed within three months to one year post SCT between April and September 2013. Data were then analysed using interpretive phenomenological methodology to gain insights into their lived experience including their personal and social experience of the world following treatment.

Findings. Two overarching concepts emerged from the data: *The Immediacy of Illness and Existential Crisis* and *The Recovery Journey*. *The Immediacy of Illness and Existential Crisis* illustrate the participant's experiences of critical events in relation to disease onset, diagnosis and treatment and the enduring uncertainty which continues into recovery including facing their own mortality. Participants suffer major disruption to their lives physically, psychosocially and emotionally as a result of illness without a sense of when they may resume the normality of their former life.

Conclusion. Ambiguity and uncertainty characterise the illness and recovery journey for those with haematological malignancy. Whilst participants have access to specialist teams, there are opportunities for health and social care professionals to provide more support for individual's returning home after prolonged hospitalisation and in the months that follow.

What is already known about this topic

- Stem cell transplantation is increasingly considered the treatment of choice for patients with haematological malignancy.
- Haematological malignancy and its treatment including allogeneic stem cell transplant poses risks to patient's mortality and has a significant impact on survivor's quality of life.
- Patient's undergoing allogeneic stem cell transplantation can develop acute and chronic forms of graft versus host disease resulting in complications such as organ damage and gastro-intestinal symptoms in addition to serious risks of infection.

What this paper adds

- This study illustrates the severe disruption caused to patient's lives and the enduring uncertainty associated with haematological malignancy and its treatments.
- Patients and their care givers feel overwhelmed with the responsibility for self-monitoring and interpretation of symptoms.
- Survivors have a need to understand more about their recovery; how long it will take and what to expect in terms of returning to their previous sense of normal.

Implications for practice and/or policy

- An intervention such as an educational programme organised in a quality of life framework, that is: physical, psychological and social domains including spiritual and survivorship aspects would be of assistance to both patients and care givers pre and post SCT.
- Employment of an advanced level practitioner to support patients in their transition home following allogeneic SCT and on-going management of acute and chronic symptoms could provide significant reassurance to patients and their families.
- Administration of intravenous antibiotics at home could be considered in some cases reducing the need for readmission to hospital though this maybe judged too high a risk for some patients.

Introduction

Haematopoietic stem cell transplant is increasingly considered the treatment of choice for patients with a range of malignant haematological diseases including leukaemia, non-Hodgkin lymphoma, Hodgkin lymphoma and myeloma (Rizzo et al 2006). Globally, 10 000 patients are treated annually (Gratwohl et al 2008). For those with malignant disease, SCT follows challenging and intensive courses of chemotherapy and radiotherapy including total body irradiation in some cases. Significant morbidity and mortality are associated with the underlying diseases and their treatments including transplantation and extend well into the post transplant recovery phase (Andrykowski 2005, Lee et al 2001). In addition to the severe physical challenges posed to patients, there are distinct psychosocial and emotional manifestations to be faced (Cooke et al 2009, Sherman et al 2005, Hacker & Ferrans 2003, Hacker et al 2002, Hendricks & Schouten 2002, Fife et al 2000).

Background

Patients' need for support in their cancer journey is highlighted in current policy (Macmillan 2013, NCSI 2013). Specific to haemato-oncology the government paper, Improving Outcomes in Haematological Cancers (NICE 2003) called for particular attention to be given to helping patients to adjust back to daily life, and to the management and monitoring of long-term side effects. As patients' survival rates following allogeneic SCT continue to improve researchers have begun to consider the wider context of the psychosocial and emotional impact of treatment for haematological malignancy including SCT.

Considerable attention has been dedicated to the assessment of quality of life (QoL) for patients undergoing SCT and is important in order to compliment research relating to new chemotherapeutic and immuno-suppressant agents, novel treatments and survival outcomes. Conceptualising QoL, however, is not straightforward since definitions vary (Ferrans 2000) and researchers strive to identify and develop the most appropriate instrument to reflect their own conceptualisation. In the thirty-two studies included in an integrative review (Hacker 2003) investigating QoL in adult patients undergoing bone marrow

transplant or peripheral blood SCT over a decade, only five stipulated a definition of QoL. Liptrott (2007) acknowledges the difficulties of applying QoL assessment to clinical practice in view of the wide variation of measures used and the relative importance attached to their specific domains. Hacker & Ferrans 2003 found that patients experienced diminished functional ability, increased symptoms and poorer quality of life immediately after conditioning therapy.¹ In a review of QoL literature between 2002-2007, Mosher et al (2009) found that although physical, psychological and social aspects of QoL improve over the years following HSCT, survivors experience persistent anxiety and depressive symptoms, fatigue, sexual dysfunction and fertility concerns. Pidala et al 2009 reviewed 37 studies examining QoL after SCT and whilst some studies suggest greater impairments to QoL in allogeneic SCT compared with autologous SCT and chemotherapy others do not. However acute and chronic GVHD were found to pose threats to QoL (Pidala 2009) corroborating Lee et al's (2006) findings in patients after 6 months post transplantation. Over recent years studies of patient experience have begun to highlight the challenges faced (Stephens 2005, Jones & Chapman 2000, Coolbrandt & Grypdonck 2010), not least to try to make sense of the traumatic events leading up to and during treatment. Less attention has focussed specifically on patient's experiences of returning home following allogeneic SCT.

Aim

The aim of this study was to explore the patients' experience of returning home in the first year following allogeneic SCT.

Design

The study followed an interpretive phenomenological methodology (Smith et al 2009) to gain insights into participants lived experience following allogeneic SCT. Smith et al (2009) advocate the study of a homogenous sample so that convergence and divergence of

¹ Conditioning therapy refers to the chemotherapy or irradiation given immediately prior to SCT the purpose of which is to eradicate the patient's disease and suppress immune reactions to the donors stem cells

experiences can be examined in some detail. The participants in this study formed a homogenous sample by virtue of their treatment with allogeneic SCT whilst their experiences, personal characteristics and contexts were unique.

Setting and sample

A purposive sample of 15 participants aged between 22-68 years were recruited from two specialist treatment centres in the UK. Participants were approached by the researcher in the out-patient departments when they attended their follow up appointments post SCT. The purpose of the study was outlined, an information sheet supplied and an arrangement made to contact the potential participants to elicit their willingness to take part. Nine men and six women agreed to participate and information about the participants is shown in table 1.

Data collection

Participants were interviewed on one occasion only between 3 months and 1 year post SCT in their home or at the treatment centre between April and September 2013. Since the essence of phenomenological enquiry is to understand the experience through participants accounts (Smith & Osborne 2007) the interview was non directive other than the opening question "Can you tell me about your experience of being treated with allogeneic SCT and what has it been like returning home?" This was then supported by probes and affirmations of understanding (Kvale 1996). The narrative style of interview enabled the participants to tell their story and to talk about experiences which were important to them in relation to the overall purpose of the study. The validity of such data may be called into question, since participants have a choice what to disclose or not as the case may be and their accounts change over time. It is argued by Frank (1995 p22) however, that there is no such thing as a false account. In accordance with this view, Charmaz (1997 p219) conceives that the telling and retelling of stories by those suffering illness serves to solidify and reify their stance on the event, themselves and their future selves.

Ethical considerations

A favourable opinion was granted by the National Research Ethics service for England, the University of Surrey ethics committee and the Research and Development Departments at the two study sites. The primary ethical issue concerned the possibility of causing distress to a vulnerable group of people. The most important strategy put in place was being prepared to discontinue the interview in such circumstances. The participant's specialist teams and general practitioners were informed about the study and the participant information sheet stated that the researcher could make referrals for professional support should this be required.

Data analysis

Interviews were recorded and transcribed by the primary researcher. Thematic analysis of the interview transcriptions was conducted using the procedural steps outlined by Colaizzi (1978) and Smith et al (2009) as a guide. This process ensured a standard approach was taken with each interview transcript with reading and re reading the transcript and line by line coding. Then identifying common themes which clustered together and highlighting any exceptions across the data sets. Interpretive phenomenological methodology recognises and accepts that a researcher's previous knowledge and experience are included as part of the analysis (Colaizzi 1978, Crist & Tanner 2003, Smith 2009). This was gained commencing work in the field of haemato-oncology at the inception of the study.

Rigour

Establishing rigour in both methodological congruence and in the interview process is one of the principle tenets of phenomenological inquiry (Wimpenny & Gass 2000). Kvale & Brinkmann (2009) promote the concept of interviewing as a craft whereby the interviewer becomes skilled with practice and is able to apply educated judgements to inform the data collection process and its subsequent analysis. The researcher is a nurse, experienced in eliciting patient's stories and a pilot interview served as valuable practice in narrative interview technique. The first author of this paper conducted the primary data analysis and the second two authors provided commentary on raw data and the emergent themes. Reading relevant literature and maintaining a research log and field notes contributed to the overall rigour of the study. The researcher was not involved in providing clinical care for the participants.

Findings

Although two overarching concepts emerged from the data : *The Immediacy of Illness and Existential Crisis* and *The Recovery Journey*, this paper will focus on the first of these: *The Immediacy of Illness and Existential Crisis*. The sudden or insidious onset of haematological malignancy throws the participant's lives into an existential crisis in both an immediate and enduring sense. Challenges include their literal fight for survival through intensive conditioning chemotherapy and radiotherapy treatments with stem cell transplantation as the only remaining option available to them to treat aggressive or relapsing disease. The participant's experiences have resonance with Bury's (1982) suggestion that illness, both acute and especially chronic illness is the kind of experience where structures of everyday life and the forms of knowledge that underpin them are disrupted' and involve 'a recognition of the worlds of pain and suffering, possibly even of death which are normally only seen as distant possibilities or the plight of others' (Bury 1982 p169). The immediacy of illness resulted in an existential crisis for participants including critical events during the illness journey which was experienced throughout by high levels of uncertainty.

Critical events

The participant's illness journey is characterised by critical events resulting from being near to death at diagnosis, having to be in protective isolation due to impaired immunity, receiving intensive conditioning chemotherapy and the possibility of eventual stem cell rejection. Systemic infections and in some cases reaction to trial chemotherapeutic agents pose life threatening risks with the pre-transplant conditioning therapy being one of the most physically and mentally challenging. The life and death nature of the illness is described by a patient's wife:

"they actually told my husband when he was brought into the hospital he had a fortnight, it was that close. I mean we just about got him out of the car into the hospital before he collapsed, it was that bad." (P16W)

In this data extract the patient's wife is describing how close to death her husband was before he was admitted to hospital where he was confirmed to have acute myeloid leukaemia. She goes on to describe:

"It was like being thrown into a cement mixer and wondering what was going to come out at the other end (it was just a haze really, yea, so much going on P16)." (P16W)

The 'cement mixer' analogy portrays a sense of the complete disruption that was occurring with little conception of what was going to happen at the other end of treatment. The immediacy of the life and death situation and the complete uncertainty was an overwhelming experience.

Furthermore describing treatment experiences of chemotherapy and radiotherapy leading up to SCT, participants liken the time spent in a protective isolation facility as feeling like a 'caged animal' (P15) or 'serving a prison sentence' (P11 and P15). Participant fifteen found these times particularly frustrating, 'when you're feeling mentally ok, it just drags' and kept a calendar to cross out the days until he was able to come out of isolation. The temporal aspects to which this gentleman refers accord with the 'treatment calendar' as portrayed by

Schou & Hewison (1999 p49) over which he has little control and which conflicts with his personal and life calendar enforcing a sudden disruption to his day to day plans.

‘It’s going to be like nothing you’ve had before’

A number of the participants describe the conditioning phase of the transplant experience as being particularly distressing and the inherent risk to survival is also evident. Participant nine, a sixty eight year old lady, eleven months post SCT for acute myeloid leukaemia recalls:

*“And I landed up with one platelet! God knows how I survived. They’re now a hundred and sixty-six, woopeeee! Put the flags out! I mean ok, I laugh about it but it was... I’m going to say this, you probably won’t put it in but I was knocking on death’s door...the professor said to me it’s going to be like nothing you’ve had before. I know you’ve had three lots of chemo, and in different stages it’s got stronger and stronger, but this one is the ultimate. He said you can never have **any more**. He said if this comes back I’m afraid it’s curtains.”* (P9)

Whilst this lady appears to speak fairly light-heartedly about her experience, it was obviously one which carried very real and potentially life threatening consequences illustrated by her reference to ‘*knocking on death’s door*’. Furthermore, the professor’s sobering advice that if the ‘*ultimate*’ treatment failed it would be ‘*curtains*’. The fact that she feels able to laugh about it now suggests her relief to have survived or perhaps the use of humour was a deliberate strategy to underplay the seriousness of the situation. According to Fox (1979) humour is a key strategy to mask the stress that uncertainty brings. It is also sobering that for this woman this would be her final treatment as she is not able to receive any more chemotherapy so it is her last chance.

Participant eleven’s powerful description of his experience of conditioning therapy and SCT is articulated in the following data extract:

*"you've had the **core** of your body **killed** and brought back to life again and you can't just shrug that off and bounce back."* (P11)

This gentleman's description of '*the **core** of your body being **killed***' and being '*brought back to life again*' correlates with findings in Potrata et al's (2010) study aimed at understanding distress and distressing experiences in patients living with multiple myeloma. Potrata et al (2010 p127) found that the conditioning phase of allogeneic SCT was particularly stressful and considered a 'violation to the body', where several participants associated conditioning chemotherapy with the beginning of death. This temporary state of 'death' ceased when the stem cells were infused and there was evidence of successful engraftment. Though not specifically referring to any one part of the SCT process another participant in the current study affirmed '*you've had a huge bang to your body*' and '*you've been stripped down from your whole*'.

Infection, GVHD and rare complications

Some of the participants experienced critical events associated with infection and GVHD. Three of the participant's (5, 8 and 9) spent several weeks on life support in an intensive care facility as a result of severe systemic infection and two of them describe flashbacks suggestive of the negative recall associated with associated with post traumatic stress disorder (PTSD). The husband of participant eight was told on numerous occasions that his wife may not survive and therefore it is understandable that he continues to worry on her return home. In the following data excerpt he expresses his concern about how quickly an infection can take hold and become life threatening:

*"I make sure she's done the temperature and if she gets up in the night, I'm awake, I can hear her, I'm alert for her all the time, you know, because they say that it can come on so quickly. Your temperature can go from normal to forty within such a short time and that's at **danger** point and they said be alert, because people that **aren't alert** don't wake up in the morning."* (P8H)

The emotional burden felt by participant eight's husband is evident. Because he has been warned how quickly an infection can develop he is constantly '*alert for her*' which undoubtedly interrupts his sleep and results in a high level of anxiety. As he describes below:

*"I can never **relax**, I can never feel good about things, even if there's good news, I don't feel like it **is** good news. The doctors say oh, everything's going well, but as far as I'm concerned it's only going well **today**, up to this point, tomorrow it could change, and so I'm just on my guard all the time."* (P8H)

These words illustrate his reasoning that he is only able to live for today and takes no comfort in good news as everything can change tomorrow. Participant fifteen similarly faced a critical event related to an extremely rare complication. Despite being treated aggressively with both chemotherapy and radiotherapy, he developed a tumour on his optic nerve:

"I was on chemotherapy and I developed really bad headaches...and then I woke up one day and I couldn't see anything" (P15)

This participant was newly married in the same year that his illness became apparent. He had two small children and had recently set up his own business. Coming to terms with his underlying diagnosis and subsequently facing possible loss of his sight was clearly an event of inordinate magnitude. He explained that when he was seen by a specialist ophthalmologist, she acknowledged that in her many years in the speciality, she had never seen nor treated a case such as his. Threatened with the loss of sight in both eyes, his stunned reaction is evident in the following narrative extract:

"but I've got two young children and I can't see anything, I can't see and I could just hear her talking and she said I think you'll never be able see again and I was sat with a nurse 'cos the nurse had to walk me to my ward because I couldn't see where I was going and I was just thinking, I just couldn't get my head round it." (P15)

Whilst the shock of this news and all its implications was difficult to absorb, his immediate thoughts involved not being able to see his children. Not only was this a critical event in this gentleman's treatment phase but held devastating consequences for his future. As he explained however, after several scans he started targeted radiotherapy to the optic nerve the following day which resulted in his sight being restored.

Uncertainty

Participants experience acute uncertainty at the time of diagnosis, in the immediate post transplant period and for others in a more enduring way. The sense of uncertainty was particularly acute when patients were ready to go home where they felt psychologically unprepared for going home.

The majority of participants described how it felt to leave hospital and return home, as one lady (P4) expressed it, '*I was safe in this bubble*'. The following extract from participant one's narrative illustrates his feelings of anxiety and uncertainty about making this transition:

*"when they tell you to go, that you're ready to go home you need that psychological support, as soon as they said that your counts have gone up and they tell you that you're ready to go you get that almost overwhelming feeling inside that you can't wait to leave the hospital and you almost wonder whether it's staying in one place all the time that makes you feel weak or if it's still the treatment that's kicking in, you're still not sure, as soon as they tell you you can go home where do I start from there? That's, a **huge, huge** thing and being by yourself and being told that, sometimes you can take those things for granted that you're being given a key that unlocks certain doors back to your normal life but not fully understanding the consequences of being left to stand on your own two feet after such a ... journey."* (P1)

This gentleman's '*overwhelming*' sense of anticipation about going home coupled with feeling weak and not knowing 'where to start' psychologically make the transition difficult to contemplate. When he says he was told by clinicians that '*your counts have gone up*' and

that he is 'ready to go' it is the physiological parameters of his blood test results informing this decision to which he refers. The disparity between the physiological and psychological reality is tangible and powerfully expressed. Whilst acknowledging metaphorically that he is being given a '*key that unlocks certain doors back to your normal life*' he nonetheless conveys the uncertainty and insecurity he feels. Frank (1995 p18) testifies to the importance of people telling stories of illness in order to give voice to an experience that medicine cannot. For Frank, (1995) reading the professional literature after having cancer himself compounded his belief that the language used failed to describe the immediacy of the embodied suffering he had recently experienced. This notion has a significant resonance with the experience articulated by participant one where the simplicity of the declaration that he is ready to go home, particularly as he was alone when this occurred, totally underestimates the enormity of its implications for him '*after such a journey*'. These findings concord with Jones & Chapman (2000) where a participant similarly described her emotional turmoil on being discharged home.

In the immediate post transplant phase after returning home all of the participants revealed their anxiety about complications and in particular infection which they had been warned could be fatal in their immune-compromised state. Participant sixteen comments on the weight of responsibility he felt when he returned home and his uncertainty as to whether he was following instructions correctly:

"I suppose a mental aspect of it was slight paranoia to start with. I just thought, is that an infection, in goes the thermometer. Have I done that right have I done this right. When I'd left hospital it was then my responsibility to follow all the instructions that they gave me when I left and of course you tend to take things by the letter" (P16)

The use of the word '*paranoia*' suggests the strain this gentleman felt regarding self monitoring his condition and the interpretation of symptoms and how diligent he was in following the instructions he was given to the letter.

Progress isn't linear, waiting for it to come back

Once the participants return home, challenges associated with a more chronic state become evident with the threat of acute events ever present. As stated by participant six:

*"I've been warned by lots of people that progress isn't linear with this and it's **not**, so going through, you think everything's well not ok because there's something wrong, but that you're going in the right direction and then you have a setback, you get a bit lower, then it picks up again, so you pop up and down the change curve several times." (P6)*

Similarly, other participants in this study report fluctuating physical and psychological effects throughout their illness, treatment and post treatment phases which are not necessarily related to the disease itself. Eight of the fifteen participants had graft versus host disease (GVHD) ² causing mild skin rashes in some cases and more disruptive gastro-intestinal symptoms for others. Though temporarily reassured by acceptable blood test results, doubts prevail that this situation may be short-lived due to the possibility of stem cell rejection, disease relapse or other complications. As participant twelve who experienced a brain seizure after his diagnosis of lymphoma explained:

*"I imagine it's the same as when you've had a heart attack, I don't have the **luxury** to have twinges or aches and pains..if I feel something in my head I think ooh is it coming*

² GVHD occurs when particular white blood cells (T cells) in the tissue (the graft) recognize the recipient (the host) as "foreign". The transplanted immune cells then attack the host's body cells

back in my head...if I feel a twinge in my stomach I don't just think I might have had a dodgy prawn sandwich or something you think ooh is this lymphoma' (P12)

Participant twelve's experiences demonstrate his heightened awareness of bodily symptoms that could indicate that all is not well in his body. His continued concerns are that these must be related to the original lymphoma disease. He does however acknowledge that these worries are lessened by the passage of time post SCT.

Left to fight and fend and work it out for yourself: financial issues

Forced to take early retirement on ill health grounds due to the uncertainty of her prognosis, participant four articulates the seriousness of her financial position:

"I think I may lose the house. I've written to the mortgage company again, I've used all my savings now to keep paying the mortgage, but of course, my son with his situation, because he is depressed, he doesn't work and if anything happens to me he's going to be homeless, so that's a huge issue for me and you know I just think people don't realise the impact, not just on your health, that leukaemia has such an effect on those around you, you know?" (P4)

Concerns for her son and also her mother with dementia are paramount for this lady. Since her disease relapsed following her first transplant and success of the second one is not guaranteed she has to cope with the fact that she has reached the limit of available treatments and that her future is therefore uncertain. Later in her narrative she states how lucky she is to be in remission and the fact that she has been given extra time to make provisions for her family.

Participant fifteen, a self employed estate agent, just one year into starting his own business highlighted the considerable strain caused by sustained interruption to his work situation. It appears that this young man and his wife did not receive the information they required to understand what if any benefits they were entitled to and were left to '*fight and fend*' to work it out for themselves. This, at a time when he felt as his most vulnerable and unsure about his prognosis took valuable time and added to their anxiety and uncertainty. As he stated '*I was more stressed about the finances than I was about the treatment*'. Supporting this view, his wife pointed to the irony of the advice they received:

"that's the one thing they say, stay as relaxed and calm as possible, no stress and then you've got other stuff like this to deal with." (P15W)

The anxiety experienced by this young man and his wife is similar to that of participant four and suggests a significant lack of attention to these important social and financial aspects of illness. This finding concurs with evidence from an explorative study of financial concerns, advice, support and coping in people diagnosed with cancer and their carers (Wilson et al 2011) and the findings of Meehan et al (2006) and Hamilton et al (2013). Whilst Macmillan grants are available, (Macmillan 2012) and health care professionals eligible to apply on behalf of patients, it is possible that the participants in the current study were either not eligible or that this aspect of support was overlooked.

Summary of findings

The findings illustrate the severe disruption caused to the participants both in terms of their physical, psychosocial and emotional being and their everyday lives. Critical events concerning diagnosis, systemic infections and the conditioning therapy remain at the forefront of their minds, and all of the participants describe significant aspects of their illness journey which relate to uncertainty. Uncertainty is evident at the time of becoming ill and at diagnosis and on-going insecurities experienced on their return home. Anxieties concern the

responsibility for self monitoring, the fear of disease relapse, the strain felt by care givers and social aspects such as employment and financial issues.

Discussion

Disease onset, the urgent requirement for medical help and subsequent treatment poses an existential crisis to the participants in this study. For the two participants who describe 'flashbacks' to their experience in intensive care an inability to interpret their situation adequately engendered fear and confusion. Similarly, in Parker's (in Clandinin & Connelly 1999) study of patients' recollections of their intensive care experience distress was found to be associated with disorientation and being unable to move through paralysis and the constraint of tubes and life supporting equipment. Accordingly, Rattray et al (2008) found that being in intensive care can result in on-going significant emotional and psychological problems, particularly for patients who were less aware of their surroundings or who had frightening experiences.

All of the participants in the current study continue to experience uncertainty in the post treatment phase associated with on-going threats to survival through infection, acute and chronic GVHD and the risk of disease relapse or secondary malignancy (Potter & Kerridge 2004). Whilst Bury's (1982) conceptualisation of illness as a major disruptive experience was based on empirical evidence of those with chronic disease it is relevant to the experience of participants in the current study. Not only do some of the participants experience a major disruption and life and death situation at the inception of disease but this continues post SCT as survival now extends beyond one year (Hahn et al 2013). No one participant could be sure what recovery was going to mean in terms of resuming their former life state, giving credence to Mukherjee's (2011) observation that those surviving cancer must define and live with a 'new normal'. What was evident was that they would need to maintain a high level of vigilance regarding symptoms indicating infection or other complications. It can be argued that what the participant describe as their 'paranoia' is actually an act of self-preservation

supporting Ehrenreich's view (2009) that uncertainty and vigilance are important survival mechanisms.

The prevailing fear of disease recurrence and associated vigilance for self monitoring has a detrimental effect on the participant's emotional and social well-being and has resonance with Bredon's (1997 p978) finding that the women in her study described a survival process that includes viewing 'the body as a house of suspicion'. As suggested by Penrod (2010), uncertainty accentuates threats to confidence and controlling current situations. A number of authors propose storytelling as an effective intervention for patients who have been critically ill because it allows for positive reappraisal and regaining a sense of control (Sakalys 2003, Pennebaker 2000). Accordingly, Adelstein et al (2014) recommend the development of a structured narrative intervention designed to promote meaning-making amongst survivors of SCT. Findings in the current study concur with this recommendation since participants have little opportunity to share experiences with other patients due to being in protective isolation. Whilst support groups are available, the participants found it difficult to attend due to fatigue, distance to travel and the requirement to attend many follow up appointments. Reluctance to share their fears with loved ones is based on their reluctance to over burden. However, Bartley et al (2013 p1) found that 'holding back' or withholding of discussing disease-related thoughts and emotions were significantly related to lower levels of social well-being.

In addition to the physical manifestations of their illness, participants described the major disruption to their psychosocial and emotional well-being. Their ability to fulfil their former roles within the family and participate in social activities including sport were significantly compromised due to infection avoidance, fatigue (all participants) and in some cases a loss of confidence (P2 and P5). These findings accord with what Little et al (1998 p1485) refer to as 'boundedness' whereby the individual's social world contracts through an awareness of limits to space, available time and empowerment as a result of cancer. There were also wider concerns regarding financial issues and the ability to resume former education and employment.

Conclusion

In the first year of returning home, participants face considerable uncertainty about their future in terms of survival and resuming a sense of normality. Exploration of patient's experiences from a medical sociological perspective suggests that are opportunities for health and social care professionals to provide increased support to patients and their families on discharge from hospital and in the longer term. The second paper in the series will present the subsequent overarching theme of 'the recovery journey' as experienced by the participants and told through their stories.

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Conflict of interest

No conflict of interest has been declared by the authors

Author contributions

LD and AA were responsible for the study conception. LD performed the data collection. LD, AA and AG performed the data analysis. LD drafted the manuscript and revisions were made following critical appraisal by AA and AG.

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Advanced Research Methods

by

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Aim: To understand the challenges in researching into end of life issues within England.

Research Questions:

- How can we define end of life and 'a good death'?
- What are patients and their carers' views on research into 'a good death'?
- What are the perceptions of researchers when studying 'a good death'?
- Are there any particular challenges (practical, ethical, methodological, emotional) when researching into 'a good death' with a vulnerable patient group?
- To what extent do vulnerable patients and carers wish to be involved in researching into 'a good death'?

The aim of this study is to understand the challenges in researching into end of life issues within England. It was noted by (Clarke 2003) that there is a dearth of cross cultural research addressing the changing needs of patients and their families throughout their end of life trajectory. Subsequently, a systematic literature review was conducted (Kendall 2007) confirming a scarcity of literature related to the practicalities of end of life research. Currently, there is a wide range of terminology and definitions within existing literature relating to 'end of life', 'quality of death', 'quality of life at the end of life' and a number of recent studies internationally which aim to define what factors contribute to or constitute a good death (Vig et al 2002, Goldsteen et al 2006, Kehl 2006, Mitsunori 2008, Steinhauser et al 2009). The consistent message is that factors contributing to a good death differ by role, individual and are dependent on diverse perceptions of quality. The paucity of evidence particularly from patients and their carer's perspective affirms the requirement for further research and to investigate the challenges of carrying this out.

Research Design

An explorative and inductive investigation (Morse and Field 1996) is deemed as an appropriate research design in order to answer the questions posed. Where there is little evidence about a phenomena the utilisation and development of grounded theory (Glaser and Strauss 1967, Strauss and Corbin 1998) could serve as the basis for future quantitative studies. An initial literature search is contraindicated by those espousing a purist approach to theory generation (Glaser and Strauss 1967) though for others this serves as a broad orientation and overview phase to a subject of study. I favour the viewpoint that one's professional background, knowledge and interest justifies and drives the desire for further exploration whilst 'the trick is to use it without letting it stifle your creativity or strangle your theory' (Charmaz 2008:166). Arguably, bias may be eliminated since theories are grounded in the actual data collected, demonstrated by the author's transparency and reflexivity.

Box 1: Literature Review

MEDLINE, CINHAL AND PSYCHLIT augmented by hand searching current journals and sourcing secondary references

Key words: end of life care, good death, dying well, peaceful death, dignified death
patient choice and death, quality of death, quality of life at the end of life will be used

Religious, sociological, psychological, cultural and health perspectives will be sought

Policies including the Cancer Reform Strategy, End of Life Care strategy, Commission on Assisted Dying will be reviewed

Grounded theory

A Straussian (1987) approach is a constructivist' grounded theory based on an 'emic' position where the researchers create the theory of a social process through their own understanding of the social realities. Strauss and Corbin (1998) note that almost inevitably researchers trained in grounded theory method become completely absorbed in their work and that the sense of absorption in and dedication to the work in progress

provides a sense of enhanced integrity. The highly systematic and rigorous analysis characterised by grounded theory gives credibility to this method.

Box 2: Characteristics of a grounded theorist (Strauss and Corbin 1998)

1. The ability to step back and critically analyses situations2. The ability to recognise the tendency towards bias3. The ability to think abstractly4. The ability to be flexible and open to helpful criticism5. Sensitivity to the words and actions of respondents6. A sense of absorption and devotion to the work process

The theoretical model emerging from the proposed study has the potential to contribute to an evidence base of end of life care thereby enhancing patient experience and educating health and social professionals.

Data Collection Methods

Data gathering methods will include semi-structured interviews with researchers, patients and if indicated professional and non-professional carers. Priority in the research timetable will be given to patients and their non-professional careers with maximum flexibility regarding their choice of time and place. Patients will be asked to identify their prime professional carer and arrangements will be made to conduct a subsequent interview. Researchers will be identified through the literature search and contacted by e-mail or telephone depending on contact details supplied in their literary papers and further potential participants identified by researchers within their community of practice. Depending on their geographic location, arrangements will be made to interview them in person or on the telephone. The specific research questions presented in Box 2 will form the basis of the semi-structured interview schedule and questioning around the topics as open as possible to allow participants to express themselves as unique individuals.

Box 3: Interview questions

- How would you define end of life and 'a good death'?
- What are your views on research into 'a good death'?
- What are your perceptions as a researcher of studies investigating 'a good death'?
- Are there any particular challenges (practical, ethical, methodological, emotional) when researching into 'a good death' with a vulnerable patient group?

To avoid preconceived bias or ideas about participants' responses the interview questions will be focussed using open stimuli such as:

Researchers

'Could you tell me about your experiences of researching 'a good death'?'

Patients and carers

'Tell me how you feel about researchers asking you about your illness?'

Box 4: Timetable for data gathering

Contact researchers January 2011

Semi-structured interviews of researchers (round 1) January-June 2011

Semi-structured interviews of patients and non-professional carers together or separately January-March 2011

Researcher field notes January-June 2011

Semi-structured interviews of professional carers January-May 2011

Since data gathering and analysis are interwoven processes within grounded theory methodology, changes may be made to this provisional plan if analysis indicates the need to adopt a different sequence or source of data.

All participants in the study will be encouraged to reflect on their interview and to contact the researcher with additional thoughts by telephone, e-mail, fax or face to face, including how they felt about participating. Field notes made by the researcher will be kept to mark significant non-verbal or environmental factors and to record discourse after the interview

has finished and the tape recorder switched off. The researcher will remain cognisant at all times of how patients may be feeling physically, psychologically and emotionally and progress accordingly.

Sample inclusion/exclusion

A purposive sample of researchers will be identified through a systematic review of current literature. Kendall et al (2007) utilised this method successfully interviewing thirty-two researchers with published works concerning views of people affected by cancer about end of life issues between 1980-2004. For this study, a systematic review of papers from 2003-2009 will be used including studies awaiting publication at the time of Kendall's review and those published since. The principle of selection in purposive sampling relies on the researcher's judgement as to 'where to start'. Since analysis begins after the first interview, categories that develop guide the researcher to extend their sample based on emerging theory referred to as theoretical sampling. Not surprisingly, researchers have experienced issues of gaining access to vulnerable patients for inclusion in a study. Professional 'gatekeepers' (Lincoln and Guba 1985, p.253) may deny access on the grounds of protecting sick families and their families from distress or from the acknowledgement of their own mortality or an unknown diagnosis/prognosis. Fetterman (1989) suggests that the best way of gaining entry to a community is by personal introduction.

Given the recommendations in a recent Help the Aged project 'Dying in Older Age' (Owen 2005) it would seem pertinent to seek participants who would be keen to contribute to 'good death' discussion and to have their voices heard. For this reason a purposive sample (Patton 1990) of elderly participants will be sought through hospital physicians at a teaching hospital in South England. Wright and Flemons (2002) found that without exception the deciding factor for patients' agreement to participate in their investigation into the lived experience of terminal illness was one of the author's

association with their Doctor and his signed letter of introduction and support for the study. Participants will be asked to identify the most significant professional and non-professional person involved in their care. Following explanation and consent, interviews will be conducted in person, by telephone or e-mail depending on practical, logistical and geographical considerations.

Ethical Issues and Practical Considerations

Practical, ethical, methodological and emotional challenges will emanate from the researcher's own experiences within this study though mitigated as far as possible by adhering to the following general considerations:

Box 5

- Research and development and ethical approval will be obtained and the principles of GCP adhered to.
- An information sheet will be provided to all participants explaining the aims and rationale for the study i.e. that the research will contribute to a knowledge base to inform professional care givers about patients and their families needs regarding end of life care.
- Verbal and written consent from all participants at the initial point of contact and prior to all interviews.
- There will be no coercion to participate and assurance given to all participants that they can withdraw from the study at any time with no adverse effect on their care.
- Re-scheduling of interviews due to fatigue, deterioration in physical, psychological or emotional well-being or any other reason will be respected.
- Confidentiality and anonymity will be maintained.
- A high quality tape recorder will be used in particular to record participants whose voice may be weak.
- Interview tapes will be stored securely and destroyed after the study's completion.
- Interview transcripts will be shared with participants for verification/clarification purposes.
- All participants will be supplied with contact details of the researcher.
- Provision for referral for counselling will be made due to the sensitive nature of the research.
- A research group including a lay representative will oversee the study and identified members provide 'inter rater' during analysis.
- Interview training will be undertaken by the researcher and a series of pilot interviews conducted.
- Budgetary, people and time resources will be addressed early in the planning of the study.

The researcher will carefully consider the multiple factors affecting study accrual and retention and also the eventuality of participant death when planning the study. Although a relatively small number of patient participants is anticipated, a back up plan to recruit further subjects may be necessary.

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A comparison of hospital and telephone follow-up after treatment for breast cancer.

Aim: to compare traditional out-patient hospital follow up in one district general hospital in the UK with telephone follow up by specialist nurses from that hospital after treatment for breast cancer.

Research Questions:

1. What is the extent of knowledge on nurse-led follow-up after treatment for breast cancer?
2. Do the anxiety levels of patients differ between traditional and telephone follow-up?
3. Is there a difference in patient satisfaction between traditional and telephone follow-up?
4. Are there differences in the level and range of clinical investigations ordered between traditional and telephone follow-up?
5. Is there a difference in time to detection of recurrent disease between traditional and telephone follow-up?

The following paper will critically analyse and justify a research design, data collection methods, sampling (including exclusion/inclusion criteria) and ethical issues to address the research questions above. Set headings will be used to structure the plan of investigation highlighting where the specific research questions are addressed.

Literature Search

In order to answer this question a comprehensive literature search and review will be performed. Breast cancer is a global health issue and one of five main tumour types contributing to overall cancer mortality each year (WHO 2009). For this reason the literature review would initially include any studies concerned with follow-up after treatment for breast cancer available on a global scale. Depending on time and resources exclusions may be required, for example, studies not available in the English language. Maguire (1978) and Maguire (1983) identified the specific emotional and psychological needs of women diagnosed with breast cancer and this work led to the development of the Breast Care Nurse role in the United Kingdom. Other countries including North America, Australia and

Scandinavia have also established and developed this role over the past 20 years (Cruickshank 2008). Therefore any studies where Breast Care nurses contribute an active role in patient follow-up would provide relevant information in order to situate the study in the context of current knowledge. Where available literature is extensive, previous literature reviews on the topic are invaluable in addition to limiting the review to within a specific time frame such as the past 15 years. Box 1 outlines the search strategies to be used including the phrases.

Box 1: Search Methods

AMED

British Nursing Index

Cochrane Central Register of Controlled Trials (CENTRAL)

Cochrane Database of Systematic Reviews

CINHAL

Database of Abstracts of Reviews of Effects (DARE)

MEDLINE

National Research Register

NHS Evidence

Pubmed

Embase

Cancerlit

Psychlit

Theses

System for Information on Grey Literature (SIGLE)

Conference proceedings

Box 2: Key words and phrases

Nurse- led follow-up

Breast cancer follow-up

Telephone follow-up and breast cancer

Follow-up for breast cancer

Breast cancer surgery follow-up

Follow-up following treatment for cancer

Traditional follow-up after treatment for breast cancer

Hospital follow-up after treatment for breast cancer

GP follow-up after breast cancer

Physician-led follow-up following breast cancer treatment

Oncologist follow-up after treatment for breast cancer

Surgical follow-up following treatment for breast cancer

Out-patient hospital follow-up for cancer patients

Research Design

A quantitative research approach is proposed to compare traditional out-patient hospital follow-up in one general district hospital in the UK with telephone follow-up by specialist nurses from that hospital after treatment for breast cancer. The chosen design is a longitudinal randomised control trial to examine the differences in patient's anxiety, satisfaction, level and range of clinical investigations ordered and the difference in time to detection of recurrent disease in the two groups. Randomisation guarantees that all participants have an equal chance of assignment to a control or intervention group (Polit & Hungler 1985, Smith & Ryan 2008), thereby in this study ensuring a robust comparison of patients receiving traditional (control group) or nurse-led (intervention group) follow-up reducing any bias and maintaining representativeness. Any differences in the outcomes between the groups can be attributed to the intervention and not to differences in other factors such as age or social class. A longitudinal study is designed to collect data at more

than one point in time and therefore appropriate to measure patient satisfaction and anxiety at strategic points throughout the follow-up period. Randomised control trials are considered to be the gold standard of research design and therefore if a large enough study is conducted with favourable outcomes for telephone follow-up there is the potential to influence future policy and implementation of research findings. Criticisms of randomised control trials include high cost and resource issues in addition to the numbers of participants required to produce meaningful data. The choice of design may be defended, however since the results could lead to an improvement in quality and convenience for patients. There is also the potential to reduce costs of traditional follow-up within acute care services though a well conducted economic analysis of telephone versus traditional methods would be required. The Plan of Investigation is shown in Figure 1, the Procedure of Recruitment, Intervention and Evaluation in Figure 2 and the rationale outlined below.

Methodology

Site Selection

A general district hospital where traditional follow-up is provided for women following treatment for breast cancer and where breast care nurses are available to provide telephone follow-up will be chosen. The author of this research has access to information and communities of practice within the South East Cancer Network and this would help identify an ideal site to conduct the study. The volume of patients fitting the criteria outlined in the section on sample below is vital information in relation to design as a larger population size will increase generalisability of the findings. A statistician will be consulted to advise on the sample size required to attribute adequate statistical power to any interventional effects which may be realised.

Sample

Review of relevant previous studies (Beaver & Luker 2005, Beaver et al 2009, Koinberg et al 2004) helps to inform the rationale for inclusion and exclusion criteria. This is particularly

important in relation to the detection of any recurrent disease when new follow-up arrangements are considered. Participants in this study will be in the category of low to moderate risk of disease recurrence based on a number of factors including grade and size of tumour, completion of primary treatment, evidence of disease recurrence and lymph node involvement. A written protocol for determination of patients' risk category will be agreed between the consultant surgeons and oncologists. Exclusion criteria will apply to patients with a tumour size > 50mm and inflammatory carcinoma and sarco-carcinomas and those already involved in a trial requiring a specific follow-up programme. Practical considerations include the requirement for participants to have a telephone, be English speaking and possess no cognitive or auditory impairment.

Randomisation

An external computerised randomisation tool will be employed to avoid potential bias from clinical and research staff involved in the trial.

Data Collection Methods

The Hospital Anxiety and Depression scale (Zigmond & Snaith 1983) will be used to measure patients anxiety at baseline and subsequently at bi-annual intervals throughout the five year trial period. This screening tool has proven reliability and validity for identifying and measuring these two most common forms of psychological distress. A questionnaire based on a reliable and valid tool will be used to measure patient satisfaction following each traditional or telephone follow-up appointment. If an existing tool is considered unsuitable a questionnaire will be designed by the steering group with patient/lay representatives and be piloted for applicability and efficacy. Both questionnaires will be sent to patients homes with prepaid return envelopes to the independent research team. This is to ensure patients are assured of confidentiality and that their responses do not affect their treatment. Timely

provision and completion of the questionnaires will enhance memory recall though reminders will be sent to increase the response rate. Data regarding the level and range of tests ordered including indicators of recurrence will be collected prospectively in both groups. The key index dates pertaining to time to detection of recurrent disease suggested by Beaver et al (2009) will be replicated in this study.

Ethical Considerations

All staff will adhere to the Good Clinical Practice guidance. Research and Development approval will be sought and funding streams identified. The ethical responsibilities towards study participants as portrayed by De Vaus (2002) including voluntary participation, informed consent, no harm, maintaining confidentiality, anonymity and privacy will be maintained along with a participants right to withdraw at any stage during the study. The identity of the organisation, staff and participants involved in the study will not be revealed.

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Appendix 1

Jan-March 2010	Literature review
March-May 2010	Research proposal and research protocol
May-July 2010	Seek trial approval and funding
May 2010	Identify computerised randomisation tool
July-August 2010	Application for sponsorship
July- August 2010	Commence staff training*
August 2010	Contact statistition
July 2010	Set up trial management and reporting steering group**
August 2010	Clinical supervision and organisation of debriefing sessions
August 2010	Organise support for patients and develop strategy to address any serious clinical or safety concerns
September 2010	Commence trial
September 2015	End of trial - complete data collection

Staff Training

*A specially designed training programme for the Breast Care nurses involved in the study will be undertaken including familiarisation with a scripted follow up tool to ensure all patients receive a comparable experience. Clinical supervision and regular de-briefing opportunities will be available as support for the staff.

**A trial steering group will be set up to design and manage the study and discuss any issues arising and this will include a lay representative. The group will address concerns relating to patient safety and well-being with clear management guidance.

Appendix 2: Procedure of recruitment and intervention (adapted from Cox et al 2008)

The use of a remote monitoring system at home for patients with Chronic Obstructive Pulmonary Disease (COPD).

Aim: to test the acceptability and useability by COPD patients and their healthcare team in Surrey of the symptom assessment tool housed on a piece of medical technology and also to explore the extent to which quality of life has altered for patients and their carers.

Research Questions:

1. What is the current evidence on telecare use within COPD?
2. To what extent is the medical technology in the study both accepted and used by patients, carers and health professionals?
3. What are the perceptions of patients and carers on the assistance provided by this technology?
4. How have the relationships changed between patient, carer and the healthcare team with the use of this technology?
5. To what extent have patients' and carers' quality of life altered by using the technology?
6. What are the challenges to the healthcare team in adopting the technology?

Slide 1: Title Page

Slide 2: Research Question

Current evidence on telecare use by individuals with chronic obstructive pulmonary disease and their healthcare team will be researched using the strategies and keywords on Slide 2.

A plethora of terms exist relating to technology supported health and social care in the home setting and are often used interchangeably, hence the inclusion of a comprehensive range. Scrutiny of a recent systematic review will inform the researcher of the current evidence and any gaps that exist and studies that consider the acceptability and useability of telecare in relation to monitoring other chronic diseases will also be included to identify any significant and comparable themes.

The chosen design is a case study approach where the process of 'getting to know your case in context' (Gillham 2000) should be considered in parallel with relevant literature. This enables the researcher to 'follow up' leads gained in the inquiry and to apply theory to the emerging themes.

Slide 3: Literature Review

Slide 4: Research Design

An instrumental case study design (Stake 2000) has been chosen as a research approach appropriate to the questions posed. This case study is instrumental in nature as the cases (i.e. the individuals with chronic obstructive pulmonary disease, their carers and their healthcare team) will be studied to understand the phenomena (i.e. the acceptability and useability of medical technology as a symptom assessment tool). In their systematic review of home tele-monitoring for respiratory conditions Jaana et al (2009) recommend future randomised controlled trials with larger samples and longer observation periods to better evaluate and generalise the effects of telemonitoring. However, justification for the case study design here is based on the advantage of a multi-method approach (Yin 2003, Morse et al 2005) in order to 'get to grips' with the breadth and depth of factors affecting the use of

technology and its effects on quality of life. The flexible but nonetheless systematic approach upholds the notion of refining and incorporating data collection methods as opportunities arise throughout the study (Gillham 2000) so that all relevant material contributes to the 'wholeness' of the picture. This is supported by a 'chain of evidence' (Yin 1989) where triangulation affirms interpretations and preserves rigour. Limitations of this approach includes small sample size, lack of a control group and the inability to generalise findings but is defended in favour of the richness and depth of complex factors likely to be elucidated. Yin (1989) maintains that general applicability results from the methodological qualities of the case.

Slide 5: Data Collection Methods

The data collection methods proposed for this study and justification for their choice are shown in Table 1. However, the researcher should be open to changes in design and methods as their understanding of the field grows (Simons 2009).

Slide 6: Sampling

A purposeful sample of six-eight participants using telecare as a validated symptom assessment tool to manage their COPD will be studied. Stake (1995) recommends the selection of cases based on an opportunity to maximise what can be learned within given time constraints. Identification of subjects will be sought through a key person within the healthcare team in Surrey. Contact with this person will be established initially by telephone followed by an appointment in person to discuss the study, gain access to those who may be willing to participate and to establish a working relationship with them and subsequently the healthcare team. As described by Payne et al (2007) identification of a principle liaison person to supply information about the service, its users and the staff will be invaluable in facilitating access and shared learning.

Slide 7:Ethical Considerations

Box 1

- Ethical approval for the study will involve timely submission of NRES and application to the ethics committee of the hospital or community organisation to proceed.
- Study protocols will be devised and available for all participants
- Purpose of the study will be explained and informed consent gained from all participants.
- Permission will be sought from patients' General Practitioners or hospital consultant to ensure they are not approached if contra-indicated.
- Anonymity and confidentiality will be assured.
- Assurance will be given that all data is secure and only available to the researcher/s.
- Particular consideration must be given to persons not agreeing to participant observation when the researcher is 'in the field'.
- Patient participants may withdraw from the study at any time without affecting their subsequent care.
- The researcher will be sensitive towards carer, patient and healthcare team relationships.
- Resources and funding will be identified and will inform the study time

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Slides

Literature Review

- Policy, Legislation, Guidelines, Journals, Books re Research Methods
- Definition of Telecare, Telehealth, Telemedicine
 - Telecare is 'a high tech system that can detect if someone has fallen and needs help, if a pan has boiled over on the stove, or if there is a gas leak, fire or flooding' (DH 2007)
 - Telehealth/Telemedicine 'refers to the remote monitoring of vital signs to enable chronic conditions to be effectively managed' (Kohler 2008)
- Quality of Life measurement tools e.g. SF36, St Georges Respiratory Questionnaire (SGRQ), Chronic respiratory Disease Questionnaire (CRD)
- Case Study Research Methods

Research Design

"Case study is a strategy for doing research which involves an empirical investigation of a particular contemporary phenomenon within its real-life context using multiple sources of evidence."
(Yin 2003)

"The central defining characteristic is concentration on a particular case (or small set of cases) studied in its own right."
(Robson 2003)

The term 'site' might be preferable "because it reminds us that a 'case' always occurs in a specified social and physical *setting*: we cannot study individual cases devoid of their context in a way that a quantitative researcher often does."
(Miles and Huberman 1994)

Data collection methods

- Interviews including patients, carers, healthcare team, call centre staff
- Review of patient's medical records
- Direct observation
- Participant observation
- Documents including criteria for inclusion of patients receiving telecare
- Observation charts
- Telecare records
- Physical artifacts e.g. photograph of telecare monitoring system in the home and in the call centre, video-recording of patient using the equipment, other technology, environmental factors
- Patient Diary
- Field notes

Sampling (inclusion/exclusion criteria)

- How many patients currently using telecare in Surrey?
- Long term monitoring/acute episodes
- Purposeful sample
- 'Willing and able to share experience'
- Healthcare team in agreement and act as guide to 'suitable' patient choice for study

Ethical issues

Pre-research ethical considerations including: burden, costs, smoking, compelled to 'welcome' technology, stigma, age, cognition and dexterity, 'imprisonment', assumptions re capability, reliability of equipment, patient confidentiality, patient safety, intrusive and unsightly equipment, incompatible technology particularly across boundaries

Healthcare team/patients and carers

- Anonymity/confidentiality/participant observation
- Researcher bias 'going native'
- Sensitivities regarding carer/patient/healthcare team relationships
- Reliability of technology
- Medico-legal considerations
- Understanding of study purpose and informed consent
- Withdrawal from study
- Storage of data

Power Politics and Policy

A policy review essay

The Cancer Reform Strategy

(Department of Health 2007)

by

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PART TWO

Faculty of Health and Medical Sciences

Division of Health and Social Care

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Introduction

This policy analysis reviews the development and impact of the Cancer Reform Strategy [CRS], (Department of Health [DH] 2007a). The policy built on the progress achieved since the introduction of the Cancer Plan (DH 2000a) which aimed to link prevention of disease, screening, diagnosis, treatment and research into one comprehensive programme of action supported by improved staffing, equipment, drugs, treatments and information systems. The broad areas of focus were:

- To save more lives
- To ensure people with cancer get the right professional support and care as well as the best treatments
- To tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals
- To build for the future through investment in the cancer workforce through strong research and through preparation for the genetics revolution so that the NHS never falls behind in cancer care again.

(DH 2000a)

Whilst the Cancer Plan (DH 2000a) concentrated on timely access to specialists with the necessary expertise, the CRS (DH 2007a) encompasses the whole patient pathway from investigation through diagnosis to full assessment and treatment planning including support following treatment completion, management of recurrence and late effects and end of life care.

Due to the range of issues incorporated in the CRS (2007a) a selected number specifically relevant to the author's scope of practice will be explored including disease prevention, implications for the nursing workforce alongside generic themes of world class commissioning, evidence based practice, professional education, patient choice and quality

of care. Key stakeholders will be identified and the drivers and barriers to policy implementation will be explored throughout the text.

What is Health Policy?

For the purpose of this analysis it is useful to consider what constitutes health policy within the wider context of public policy in the United Kingdom today and the key factors which legitimise its existence and attention. Universally, there are an eclectic range of definitions and interpretations of what policy is and the precise meaning of the word. In many parts of Europe the words politics and policy are interchangeable thereby causing confusion (Craig and Smith 2008).

One interpretation is that public policies are a reflection of the government's ideology and aspirations in significant areas of public concern including the economy, education, social deprivation and health. In terms of health policy in particular, the commitment to redress the balance of under-investment in the National Health Service was encapsulated in the NHS Plan (DH 2000b). This does appear to reflect the vision and modernisation strategy advocated by Tony Blair, Prime Minister at this time, intended to create a health service fit for the 21st century. However, this can be viewed as an over simplistic representation given the dynamic nature and complexities of the 'policy processes'. It should be noted that policy making is an opportunistic and iterative process and often policies are simply adopted by successive governments until they are prioritised for review.

In the mid twentieth century Easton (1953) argued that political activity is concerned with 'the authoritative allocation of values within society' pertaining to the distribution of resources and sanctions by those in authority. He acknowledges the multi-factorial nature of decision-making, the incremental adjustments that occur as a result of a change in context or as a result of implementation issues. Where some authors describe a policy as a purposive

course of action, Dye (2001) postulates that public policy is as much concerned with lack of action as formal action by the government in power. Others highlight inertia, the focus on policy maintenance (Ham 2004) and symbolic policy making (Endelman 1971) as barriers to addressing areas of greatest need or those requiring fundamental reform.

According to Solesbury (1976 p 382), the acid test for issues to survive the policy making process is that they must command attention, claim legitimacy and invoke action. Whilst health reforms in general were high on the political agenda in the late 1990's, cancer care in particular gained significant attention. The NHS Cancer Plan (DH 2000) is recognised as the first comprehensive strategy to prevent, diagnose and treat cancer and to tackle the major inequalities in service provision and survival rates compared to the rest of Europe and the United States of America. Subsequently, The Cancer Reform Strategy (DH 2007a) was published with the aim to build on progress made and to set a clear Direction for world class cancer services in England. There can be no doubt that successful implementation of health policy is dependent on a number of factors including correct interpretation, adequate resourcing and most importantly the will to change.

The Cancer Reform Strategy

Whilst acknowledging the improvements made in cancer services, the CRS notes a failure to close the gap in survival rates between England and the best performing European countries. Also identified was the rising incidence of cancer, alongside increasing numbers of survivors and associated cost and capacity challenges. The following six actions to improve outcomes and four actions to drive delivery were set out:

Table 1

Six areas of action to improve outcomes:

1. Preventing cancer
2. Diagnosing cancer earlier
3. Ensuring better treatment
4. Living with and beyond cancer
5. Reducing cancer inequalities
6. Delivering care in the most appropriate setting

Four areas of action to ensure delivery:

1. Using information to improve quality and choice
2. Stronger commissioning
3. Funding world class cancer care
4. Building for the future

Background

In 1997, the newly elected Labour Government pledged a radical modernisation of the National Health Service alongside significant investment to achieve this ambition. The plans were captured in 'The New NHS: modern dependable published in the same year outlining key strategies such as National Service Frameworks (NSF's), clinical governance, the National Institute for Clinical Excellence (NICE) – now the National Institute for Clinical and Health Excellence and the formation of a regulatory body – the Health Care Commission since superseded by the Care Quality Commission (CQC). Underpinning this strategy was an emphasis on the systematic use of evidence in parallel with the development of more effective monitoring processes and outcomes through clinical audit. Driving up quality and reducing waiting times were important drivers for change.

The Calman-Hine policy framework (DH, Welsh Office 1995) provided a platform on which to build the National Cancer Plan (DH 2000a) and publication of the White Paper Saving Lives: our healthier nation (1999) set national standards for a number of diseases presenting a significant health burden including mental health, cancer and coronary heart disease.

Over one in three people develop cancer during their lifetime in England with the incidence increasing significantly with age and although much attention has focussed on the most prevalent solid tumours, policy is concerned with all cancers including those affecting blood.

The author of this paper works in an acute hospital trust within the Haematology and Oncology specialty. The proposed area of enquiry for the Doctoral thesis is the patients' experience undergoing stem cell transplantation for the treatment of haemato-oncological disease and therefore consideration of the CRS (DH 2007a) is highly relevant.

Policy Analysis tool – rationale for choice

The framework for policy analysis used here is the health policy triangle as described by Buse, Mays & Walt (2005). Originally attributed to the work of Walt & Gilson (1994) this analytical approach examines the 'context' within which policy is formulated, the 'actors' associated with the policy making and the 'processes' which take place throughout development and implementation (or not). Importantly, the interactions between these three elements is considered. Universally applicable, the framework is considered to be an appropriate tool to analyse the CRS (DH 2007a) in the UK within the wider context of global health.

Whilst appreciating that policies can be developed by organisations other than government to establish rules and standards, Walt (1994) sees health policy as synonymous with politics. From an economic point of view, this is understandable when the UK spend on health rose from 6.8% of the gross domestic product (GDP) in 1997 to over 9% in 2007-8 (Stevens

2004). Clearly, policies supporting a healthy population are integral, amongst other factors, in sustaining the economy of the country.

Actors

Consideration of the actors involved and their ability to influence the strategic direction of cancer care will now be discussed. In the broadest sense of the word, 'actors' within policy making include a wide variety of individuals, groups and organisations outside of the formal government structure. These may take the form of special interest or pressure groups seeking to exert influence on those with formal power on a particular issue.

Within government itself the actors involved in health policy span parliament, the Department of Health, standing advisory groups, the cabinet office, civil servants and policy units amongst others.

See figure 1 overleaf.

The relative power of these varies according to the way in which the elected political party is structured and organised and by the same token the ability of these groups to influence decision-making and the political agenda. In addition to those assigned specifically to policy-making, key individuals attain high positions of power and influence such as the Chancellor of the Exchequer and those nominated to spearhead an inquiry into a major area of concern (Ham 2008).

It is pertinent here to examine the actors engaged in developing the CRS (DH 2007a). As discussed earlier, health reform was rife in the late 1990's with commensurate investment to modernise the NHS, its estates and practice. Political, clinical and patient groups joined forces under the leadership of a highly respected and influential figure, Professor Mike Richards, National Cancer Director. Often referred to as 'policy elites', high ranking individuals or groups within an organisation are noted for their ability to exert influence through connections with others in similar positions of power (Buse 2005).

Critical to the success of the Cancer Plan (DH 2000a), the CRS (DH 2007a) and associated policies relating to cancer care has been the strong position of the General Medical Council [GMC] and the British Medical Association [BMA] in forming an effective alliance with government.

As previously mentioned the findings of the expert advisory group [EAG] culminating in the Calman- Hine report (1995) set the wheels in motion for a concerted effort to raise standards of cancer care in England and Wales. The EAG consisted of fourteen members including the two Chief Medical Officers of England and Wales in collaboration with eminent Doctors, Professors and Directors within primary, secondary, tertiary care and academic institutes. The report was prepared 'following extensive consultation with professional bodies, the National Health Service, related charities, Community Health Councils in England and Wales and other organisations' (Calman-Hine 1995). The authority and influence afforded by this prestigious group undoubtedly set the agenda for major changes in the commissioning and delivery of cancer services.

With regard to the CRS (DH 2007), membership of the working groups was extensive and expert contributing to six major workstreams: Awareness and early detection; Patient Experience; Clinical outcomes; Provider development/service models and Commissioning and levers for change. Whilst patients were included it is difficult to assess the influence they were able to exert on the policy content. From the list incorporated in the membership document (DH 2007b) a total of four patients and three nurses were included across four of these. Amongst the senior experts involved there appears to be uneven representation of nurses and patients potentially resulting in a marginal impact of their views and opinions. Also, there appears to be a lack of professions allied to medicine such as physical and psychological therapists.

Though not within the scope of this essay, comprehensive analysis of the CRS (2007a) should include interviews of the members as this would elucidate their views. Perceptions of their power and influence within the group and to 'have their voice heard' would be of interest, particularly in relation to the minority of representatives. Quennell (2003) examines the involvement of patients' organisations in the technology appraisal process of the National Institute of Clinical Excellence (NICE). NICE guidance, based on clinical and cost-effectiveness is intended to be robust and reliable, underpinned by evidence-based medicine and legitimated by a range of stakeholders. However, Quennell (2003) highlights some disparities between what patients consider to be significant evidence and the emphasis afforded to randomised controlled trials [RCT's]. Their arguments centred on the fact that clinical trials often fail to take account of patient-defined outcomes and that contrary to the opinions of some, user views can help to fill the scientific gaps as opposed to being dismissed as anecdotal and insubstantial. She sites a powerful example of how a randomised controlled trial researching a new treatment for Alzheimer's disease reported significant improvement in memory rather than the true quality of life benefits such as enhanced social skills and confidence. It is worth focussing on the parallel here, whereby prevention, treatment outcomes and survival form the prime aims of the CP (2000a) and the CRS (2007a), the themes that emanate from patients stories, surveys e.g. The National Cancer Patient Experience Survey programme (DH 2010) and qualitative studies of patient experience place at least equivalent emphasis on dignity, effective and compassionate communication, co-ordination of care and consistent information i.e. quality as well as quantity of life. The importance of this type of evidence is echoed by Wilcock et al (2003) who describe the use of 'discovery interviews' to inspire patient-centred quality improvement. Critical to the desired changes outlined within the CRS (DH 2007a) has been the involvement of a number of organisations, charities and collaborations and alliances. Not only are substantial funds made available to support the policy but initiatives emanating from it such as the End of Life Care Strategy (DH 2008c) is championed through the Marie Curie

Patient Choice programme working in collaboration with commissioners, providers and patients.

Promotion of the programme through National conferences, website information and educational tool kits helps to drive the implementation and sustainability of local projects to support patients and their families in choosing end of life care at home. Similarly, the Department of Health and MacMillan Cancer Support partnership is instrumental in driving the National Cancer Survivorship Initiative.

Given the substantial financial contribution to direct patient care, research and specialist expertise afforded by charities such as Marie Curie and MacMillan it is not surprising that their function as patient interest groups and advisory bodies to government is commensurately strong (Peterson 1999).

The National Cancer Plan identified Networks as the organisational framework through which its targets would be achieved. Bringing together 'health service commissioners and providers, the voluntary sector, and local authorities, cancer networks will provide all the services needed for prevention, screening, diagnosis, treatment and care of cancers (except for some rare cancers which are best managed on a regional or supra-regional basis)' (DH 2000). Throughout the years following the Cancer Plan and the Cancer Reform Strategy, published annual reviews of progress, the development of Cancer Networks and the monitoring of standards through peer review have ensured the continued drive for success.

Pluralist theory upholds the notion that power is widely dispersed throughout society and that 'health policy emerges as the result of conflict and bargaining among large numbers of groups organised to protect the special interests of their members' ((Buse, Mayes & Walt pp27 2005). It could be argued that the CRS represents the culmination of views of a wide range of stakeholders therefore demonstrating a degree of pluralism. On the other hand, is it really the pure economic viability of organisations such as the pharmaceutical industry and

wealthy charitable organisations which enables them to court our political leaders more in keeping with elitist or public choice theorists. Indeed, the alliances between pharmaceutical companies and charities with the medical profession, already a powerful group in their own right, will only serve to increase their sphere of influence and bargaining power.

Context

Firstly, it is worthwhile considering the wider context of health policy development under Tony Blair and Gordon Brown. A move away from the internal market structure introduced by Margaret Thatcher's government and the advocacy of centralised planning by previous Labour governments was conceptualised by the so called 'third way' of reform. A criticism of Blair's government (Ham 2009) was the six month delay in publishing the White Paper proposals for The New NHS (DH 2007). He argues that this lack of investment in time and money in developing clear policy strategies prior to their election is an inherent weakness of political parties in 'Opposition'. The resulting inertia can account for a slowing down of the pace of change and reform in favour of the 'business as usual' approach. Indeed, despite the initial allocation of extra resources to the NHS pending the comprehensive spending review (CRS) culminating in 1998, significant reduction in waiting times targets and other improvements were not realised for some time. However, other confounding factors including pressures on hospital beds and influenza outbreaks undoubtedly hinder the implementation of improvement initiatives.

Specific to cancer waiting time targets, progress had been slow since the inception of the Cancer Plan (DH 2000a) though significant and sustained improvements occurred following the establishment of the National Cancer Waits Project, demonstrating the benefits of clear targets and renewed pressure. Recognition of these achievements (Rosen et al 2006) led to a recommendation by the National Audit Office (2005) that the success of government policies should be built upon and hence the Cancer Reform Strategy was developed. The International and national political, economic and social climate can have a significant

bearing on health policy. Leichter (1979) categorised these systemic elements under four headings of situational, structural, cultural and International or exogenous factors.

In terms of the CRS, the situational factor or focusing event can be tracked historically to a recognition of poor outcomes for patients with cancer. An incremental set of changes instigated by the health reforms of Blair's government have been evident through subsequent cancer specific policies including those addressing chemotherapy, radiotherapy and general care and survivorship issues (DH 2000b, DH 2003a, DH 2003b, DH 2004b, DH 2008a, DH 2008b). The ability to measure and compare cancer mortality rates globally triggered a concerted effort to tackle health inequalities. Despite progress, it should be noted that improvements in Europe and beyond mean that England is still lagging behind 'best performance' globally. Also, persistent geographical inequalities exist within England and Wales with the highest mortality rates occurring in the same geographical areas over the past century (Wells & Gordon 2008).

From a structural point of view the approach to health policy under New Labour's rule was to place a greater emphasis on evidence based practice. The creation of a Policy Directorate combining the expertise of civil servants with members of the Policy Unit aimed at bringing sources of advice and effective decision-making closer to the Prime Minister.

The processes of policy making

The stages heuristic as described by Sabatier and Jenkins-Smith (1993) is a useful theoretical model representing a series of steps undertaken as part of the policy making process. These are not dissimilar to the pattern of ideas and points considered by other authors (Patton & Sawicki 1993, Pollard and Court 2005) for both the development of policy and analysis *for* policy.

As already discussed the government commitment to health reforms, the burden of cancer and the concerted support of cancer charities make for a mutual acceptability that cancer should be firmly on the policy agenda.

In terms of legitimacy, feasibility and support as described in Hall et al (1975) model of agenda setting the CRS (DH 2007) presents a programme of actions which firmly tick these three boxes. It would be hard to argue with the principles of this policy though there may be similar concerns for other aspects of health perceived as being neglected in terms of comparative investment. Also, as will be discussed later, the legitimacy of a policy is dependent on successful implementation.

Kingdon's (1984) three stream model of agenda setting describes the 'ideal environment' for action to occur:

- The problem stream
- The policy stream
- The politics stream

He proposes that 'policy windows' occur when all three streams converge and that this is when issues move onto the government's formal agenda. It could be argued that annual reviews of progress keep the CRS (DH 2007) on the political agenda though renewed impetus and campaigning may be necessary to maintain momentum and to address the areas of sub-optimal progress. For example radiotherapy treatment has been highlighted as a problem area with severe delays and out-dated technology (Sikora 2007).

Implementation

Over the past ten year trajectory of cancer reform, not all areas incorporated within the strategy have reached their anticipated potential (Sikora 2006, Mayor 2006, Leatherman and Sutherland 2008). Raising public awareness of risk factors and the promotion of cancer prevention strategies such as healthy diet and exercise and smoking avoidance is of prime importance. However, a recent survey undertaken by Cancer Research UK's Reduce the Risk campaign revealed a deficit in the general population's knowledge base. In essence, only five percent could identify four of the six lifestyle factors linked to cancer and seventy five percent were only able to name two (Wardle, Waller, Brunswick and Jarvis 2001). For many years ASH and associated interest and pressure groups lobbied hard for the ban on advertising tobacco and smoking in certain public places with only piecemeal success despite smoking being the largest preventable cause of death from cancer. For economic and political reasons the government did not choose to introduce smoke free law until 2007 and then it was largely due to the backing of the British Medical Association and the Royal College of Physicians as powerful 'producer' groups (Buse, Mays and Walt 2005).

Previous attempts to tackle the problem through the Health Action Zone [HAZ] smoking cessation programmes have been criticised (Woods, Lake & Springett 2003) who postulate that contrary to addressing health inequalities these have only served to further disadvantage those in greatest need. Militating against health inequalities and reaching deprived groups is a constant theme throughout the decade of health reforms under New Labour.

It is interesting to note the role of the media in awareness of ill health prevention and recognition of symptoms as well as effecting health policy. An example of the former was the publicity afforded to a competitor in the popular reality show 'Big Brother', which was considered to raise awareness and increase the uptake of cervical screening and vaccination. The latter can be illustrated by the medias ability to 'get issues into the public arena' such as vCJD and demonstrates how relatively low risk problems take precedence over widespread higher risk issues.

Raising the plight of individual cases such as Mavis Skeet (Ham 2009 p58) whose scheduled operation was cancelled on a number of occasions resulting in surgery no longer being viable alongside unequal access to expensive new therapies such as herceptin have seized public attention. Events such as these can have a far wider impact on raising public awareness than other more formal education strategies.

Patient information campaigns have raised awareness of self-management strategies such as breast examination and more recently focussed on the male population in relation to prostate and testicular cancer. However, reaching vulnerable groups remains a challenge in relation to prevention, screening, access to treatment and for many the reporting and management of the side effects of chemotherapy and radiotherapy.

Prevention of cancer

Over half of all cancers could be prevented if people adopted healthy lifestyles such as:

- **Stopping smoking.**
Over half of all cancers are potentially preventable, with smoking being the single largest preventable cause of death,
- **Avoiding obesity.**
Obesity is now the most important preventable risk factor for cancer in non-smokers,
- **Eating a healthy diet,**
- **Undertaking a moderate level of physical activity,**
- **Avoiding too much alcohol, and**
- **Excessive exposure to sunlight -**
The government will increase funding to raise awareness of the dangers of overexposure to sunlight and is considering the need for regulating the sun-bed industry.

Achievements since the Cancer Plan:

Better prevention - action on tobacco and the smoking ban have led to a fall in smoking rates (from 28% of the population in 1998 to 24% in 2005), amounting to 1.6 million fewer smokers.

More cancers detected through screening - national cancer screening programmes exist for breast, bowel and cervical cancers. New screening programmes will be introduced as and when they are proven to be both clinically and cost effective.

Faster diagnosis and treatment - waiting times for cancer care have reduced dramatically. Improved access to better treatments - there has been a major increase in the use of drugs approved by the National Institute for Health and Clinical Excellence (NICE), to treat cancer with less variation between cancer networks.

Free prescription charges for people with cancer - since April 1 2009, patients undergoing treatment for cancer, including the effects of past cancer treatment, have been able to apply for a medical exemption certificate. It is expected that the new scheme will benefit up to 150,000 people already diagnosed with cancer, who might pay £100 or more each year in prescription charges.

(CRS 2007a)

Commissioning

Effective commissioning is dependent on a high level of technical, political, financial and managerial ability (DH 2007; Ham 2008; Olsen 1998) with the quality and range of information being crucial factors in the implementation of strategic purchasing power.

Although systems for data collection and submissions have been introduced since the inception of the Cancer Plan (2000), it is widely acknowledged that suboptimal reporting and delay in publication severely limits its usefulness. Halvorson (2007) argues that 'effective buying' in the commercial sector relies on a high level of specification in relation to the quality of goods and that the lack of these standards results in weaknesses within the healthcare market. Specific to the Cancer Reform Strategy (2007), examples include the availability of equipment and expertise to perform new techniques such as keyhole surgery for bowel cancer, the availability of novel therapies, advances in radiotherapy technology and clinical trial activity.

It will be interesting to observe the development of the new General Practitioner Consortia and the measures taken to gain the necessary expertise required for world class commissioning (DH 2007c) and the achievement of value for money. This latest political move in health reform may well have at its heart the aim to integrate delivery systems to drive up quality and efficiency whilst reducing cost.

Nurses are often best placed to reflect the views and requirements of their patients but miss opportunities to influence policy in a meaningful way (Hewison 2007). An example here would be the ability of nurses to contribute to the development of end of life care strategies by conducting research and helping to highlight inequities of service provision. The Next Stage Review (2008) promotes radical reconfiguration of clinical services focussed on supporting patients closer to home and delivery of specialised care in designated centres. Delivery of chemotherapy and supportive care in the community is an opportunity for nurses

to enhance the quality of patient care (Carballo 2008; Richardson 2004; Trevatt, Petit & Leary 2008), diminish gaps between acute and community providers and to engage in analysis 'for' future policy.

Diagnosing cancer earlier

Much as achieving targets have required new processes and a focus on increasing uptake of screening and treatment pathways, perhaps one of the most challenging aspects of the change process is moving towards an ambulatory model of cancer care. Not only will success be dependent on clinical safety and patient outcomes but importantly the cultural changes, blurring of professional boundaries, competition and the alteration of historical power bases (DH 2008) associated with its delivery. As asserted by Hartlapp and Hemmeling (2008) 'the institutional embeddedness of actors co-determines their behaviours' and consequently affects policy implementation. The CRS (DH 2007) calls for effective service models to be developed at all points in the care pathway. The effectiveness of ambulatory care is dependent on the creation of roles that support continuity and co-ordination of all aspects of the patient's journey, as highlighted by the patients themselves (Richardson 2004). Similarly, the D'Arzi review (2008) advocates the radical re-configuration of clinical services focussed on supporting patients closer to home and delivering specialised care in highly specialised centres. However, provision of chemotherapy and supportive care in polyclinics and in patients' homes presents a challenge to healthcare professionals in secondary care settings to 'let go' of previously accepted treatment delivery systems. Instead, to embrace opportunities for improved dialogue and diminished gaps between acute and community providers. Trevatt et al (2008) charge clinical nurse specialists to secure ownership of this important role and to define caseloads which will uphold equity of care provision.

Evidence Based Practice

Proponents of evidence based practice [EBP] (Sackett, Straus, Richardson, Rosenberg & Haynes 2000) define it as the integration of clinically relevant, patient-centred research evidence with clinical expertise and patient values to deliver optimal care. Conversely, critics argue that evidence based medicine [EBM] undermines other forms of knowledge and risks replacing professional acumen and decision-making with 'formulaic' practice (Trinder cited in Trinder & Reynolds 2000).

Both advocates and critics recognise the lack of empirical evaluation of the effectiveness of EBP itself (Rosenberg & Donald 1995) and bring attention to the deluge of research of variable quality in certain specialist areas compared with a relative paucity in others along with associated problems of its value and application.

Pioneering the use of systematic reviews and meta-analyses, Cochrane (1972) had a profound influence in the UK National Health Service. The Cochrane Collaboration reflects the adoption of his principles concerned with the preparation and dissemination of systematic reviews of health care research. Continued support of this research and development strategy are evident in the White Paper, *Health of the Nation* (DH 1992) stipulating the requirement for the health service to focus on an increased knowledge base around cost and clinical effectiveness. Subsequent White Papers, *Realising Our Potential* (1993) and the New NHS: *modern, dependable* emphasised the importance of translational research and the latter, the establishment of the National Institute of Clinical Excellence. In terms of improving care for cancer patients Mullins, Montgomery & Tunis (2010) acknowledge the important contribution of RCT's but argue that comparative effectiveness evaluation allowing consideration of two new treatments is of greater benefit. A further caution relates to the inclusion and exclusion criteria of the RCT study design which limits generalisability to broad patient populations displaying a high incidence of co-morbidities and complications. It must be acknowledged that the National Cancer Research Network (including the NHS, other government agencies and the large cancer charities) have made a substantial contribution to

the volume of clinical trials putting the United Kingdom as one of the fastest growing areas of clinical research globally (Sinha G. 2000).

Health inequity

Despite significant increase in funding for cancer care over the past decade, there have been a number of competing priorities within the National Health Service. Competitive demands on resources such as 'balancing the books' in order to achieve Foundation Trust status and the concerted efforts to reduced hospital and community acquired infection through the Saving Lives campaign contribute to these. It could be argued that the Quality and Outcomes Framework (QOF) introduced to incentivise General Practitioners in four key domains have worked in favour of long term conditions such as coronary heart disease and diabetes. For example, in 2009/10 the 'clinical care domain' awarded 697 points for coronary heart disease, heart failure and hypertension compared to less than 50 points in total for the 'additional services' domain including cervical screening, child health surveillance, maternity and contraceptive services.

Similarly, equity of resource distribution within the cancer specialty itself can be called into question. Despite the aspirations of the Cancer Plan (DH 2000a) and the Cancer Reform Strategy (DH 2007a) for all patients to have access to a Clinical Nurse Specialist, the English Cancer Network Census of Cancer Specialist Nurses, commissioned by the National Cancer Action Team (NCAT 2010) found inconsistencies. Despite increases in this specialist workforce from 2007-2010 it appears to be insufficient in relation to cancer prevalence and an uneven distribution between tumour groups and haematological conditions. This reflects similar findings from a mapping exercise carried out by Trevatt, Petit & Leary (2008).

Conclusion

The Cancer Reform Strategy (DH 2007a) has continued to make significant inroads into waiting times (for GP, diagnostic tests and subsequent specialist review), improved screening, treatment and longer term survival for patients living with and beyond a diagnosis of cancer. Though challenges remain regarding the accuracy and timeliness of available data used to measure improvements, health informatics systems continue to be invested in and developed. There is no doubt that the relatively new coalition government's radical reforms and the current economic climate are set to challenge the providers of healthcare in the public and private sectors. Extension of screening programmes, access to diagnostic testing and new medical and surgical treatments are to be funded largely by a further reduction in hospital bed days and emergency admissions. Improvements in survival rates will continue to be tackled by improved health promotion strategies, patient information and stronger commissioning (IOSC 2011). The new commissioning consortia (Health and Social Care Bill) will need to be 'active leaders of change, pursuing a vision for how healthcare should progress' (Nicholson 2011). A focus on integration and multiple styles of communication and persuasion will be required (Reardon, Reardon & Rowe 1998) by the strategic leaders and implementers of new healthcare delivery systems and processes. The funding of cancer networks is not guaranteed though evaluation of their influence, success and expertise could secure their future in the transition phase from Primary Care Trust commissioners to General Practitioner consortia.

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**Service Evaluation: change, risk and development
Leadership in healthcare organisations**

by

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Service Evaluation and Leadership Essay

Introduction

Research indicates that patients who have been treated with peripheral blood stem cell transplantation (SCT) or high dose chemotherapy for malignant haematological conditions experience difficulty overcoming the transition from hospital to home. Reasons cited include fatigue, resuming their former role, returning to work, worry regarding disease recurrence or of a secondary cancer and other psychosocial issues (Bird et al 2009, Hacker & Ferrans 2003, Hacker et al 2002, Hendricks & Schouten 2002, Sherman et al 2005). Sanson-Fisher (2000) highlights patients' need for support in their cancer journey corroborated by Cardy (2006) in a large scale study of the emotional impact of cancer, sponsored by Macmillan Cancer Support, where a quarter of the participants reported feeling 'abandoned' and unsupported during their rehabilitation phase. Physiological treatment complications include infections related to neutropenia, in addition to nausea, vomiting, taste changes and mucositis (Larsen et al 2004), some of which continue in the post treatment phase.

Background

In The South London Trust where the author works as a Matron in Haematology, patients receive their stem cell transplant and associated treatments as in-patients over a mean length of stay of four weeks. Subsequently, they are discharged home and attend out-patient clinics and a Haematology Day Unit setting for review, approximately two to three times weekly. In the immediate post transplant phase, a patient is more susceptible to infections due to a low white cell count, anaemia due to a low red cell count (Hb) and possible bleeding as a consequence of a low platelet count. Therefore blood tests are carried out to monitor the levels and if indicated interventions such as a blood or platelet transfusion may be given. Antibiotic therapy is commonly required to treat infections.

In the light of key recommendations emanating from the model of care for cancer services (NHS Commissioning Support for London 2010) two London Foundation Trusts are combining their SCT programmes within the recently formed Academic Health Science Centre. The rationale for this change is based upon economies of scale benefits associated with greater centralisation, particularly in high cost, high risk and complex services requiring specialist facilities, expertise and experimental research capacity. As work on the service reconfiguration continues at this present time it is evident that the nominated centre lacks out-patient and day care capacity to provide adequate post transplant care.

Service evaluation

The proposed service evaluation will focus on the development of a nurse led telephone follow-up for SCT patients with blood tests performed in the community only necessitating a hospital day care attendance if blood product transfusion is required. One of the aims of this new service is to empower patients to self manage certain aspects of their care in partnership with a dedicated clinical nurse specialist, the wider health care team both in hospital and in the community and their informal care givers where appropriate. Service user involvement confirms that this key worker figure is central to the experience of care that they receive (NICE 2004) reinforced in the Cancer Reform Strategy (DH 2007) identifying clinical nurse specialists as the essential purveyors of technical, informational, emotional and co-ordination functions for both patients and importantly their families and carers.

Aim: To compare traditional hospital and nurse led telephone follow-up for patients treated with autologous stem cell transplantation for a haematological malignancy in the first three months following discharge from hospital.

Objectives:

1. To investigate the extent of knowledge of patient experience following discharge from hospital after autologous stem cell transplant for haematological malignancy.
 2. To investigate if the anxiety levels of patients differ between traditional hospital and nurse led telephone follow-up.
 3. To investigate if there is a difference in patient satisfaction between traditional hospital and nurse led telephone follow-up.
 4. To investigate if there are differences in re-admission rates between traditional hospital and nurse led telephone follow-up.
 5. To investigate if there is a difference in the need for medical consultations, treatments and infections reported between traditional hospital and nurse led telephone follow-up.
-

Underpinning framework

Evaluation is key in developing health services in order that any changes made are proven to be of benefit to patients and that resources are utilised optimally. Evidence based policy therefore requires prerequisite knowledge which is valid and reliable. The underpinning theoretical framework selected for this proposed service evaluation is the MRC (2000). Its structured and linear approach could be viewed as a limitation but is congruent with the randomised controlled trial in this inquiry. Although the realist evaluation model advocated by Pawson and Tilley (1997) allows for plurality of methodology feeding into the cycle of theoretical development it does not resonate as effectively with the RCT design.

Literature review

A literature search using the Cochrane Library, CINAHL, British Nursing Index and PSYCHLIT was conducted between September 2000-2011. Reasons for this timescale are threefold. Firstly, policies relating to cancer survivorship are current and support on-going care for cancer survivors (DoH 2010, DoH 2007). Secondly, nurse-led follow-up arrangements are evolving (Beaver 2005, Cox et al 2008, Cox & Wilson 2003) and thirdly technological advances have resulted in telecare being adopted, thereby empowering patients to self manage chronic disease at home (Jaana & Sicotte 2009). The following key words were used: autologous stem cell transplant, bone marrow transplant (BMT – refers to

the method of stem cell collection but often used as a generic term for stem cell transplant), follow up, consultations, out-patient appointments, post discharge care, home care and hospital at home. The search revealed limited publications relating directly to follow up after autologous stem cell transplantation. An evaluation of this service development is therefore deemed useful to address this gap in knowledge.

Methodology

A quantitative research approach is proposed to compare traditional out-patient hospital follow-up with telephone follow-up by specialist nurses and a community based phlebotomy service to allow close monitoring of blood test results. The chosen design is a longitudinal randomised control trial to examine the differences in patient's anxiety, satisfaction, re-admission rates, medical consultations required and infections in the two groups. Randomisation guarantees that all participants have an equal chance of assignment to a control or intervention group (Polit & Hungler 1985, Smith & Ryan 2008), thereby in this study ensuring a robust comparison of patients receiving traditional (control group) or nurse-led (intervention group) follow-up reducing any bias and maintaining representativeness (see appendix 2). Any differences in the outcomes between the groups can be attributed to the intervention and not to differences in other factors such as age or social class. A longitudinal study is designed to collect data at more than one point in time and therefore appropriate to measure patient satisfaction and anxiety at strategic points throughout the follow-up period. Randomised control trials are considered to be the gold standard of research design and therefore if a large enough study is conducted with favourable outcomes for telephone follow-up there is the potential to influence future policy and implementation of research findings. Criticisms of randomised control trials include high cost and resource issues in addition to the numbers of participants required to produce meaningful data. The choice of design may be defended, however since the results could lead to an improvement in quality and convenience for patients whilst reducing demand on acute hospital services with limited capacity. Although a qualitative approach has the potential to elucidate rich in depth

information relating to patient experience (Carter & Henderson 2005, Lavery 2003, Holloway & Wheeler 2002, Polit & Hungler), its limitations include the relatively small number of participants interviewed in most naturalistic studies and therefore lacks generalisation of findings. In this study it would not allow for the comparison of a control and experimental group.

Methods

An application will be made to Macmillan to support the project in order to employ a clinical nurse specialist who will be dedicated to telephone follow-up and monitoring of all patients in the study. If successful, an external evaluation will be required to justify the funding for this post and has the advantage of combining resources to accomplish this whilst securing additional expertise and objectivity (Institute for Innovation and Improvement :Evaluating improvement, 2007). An external computerised randomisation tool will be employed to allocate patients to the two arms of the study and avoid potential bias from clinical and research staff involved in the trial. Patients will be supplied with a thermometer, blood pressure monitor and a hand held electronic device on which to record their results. The nurse will telephone the patient weekly on an agreed day to discuss blood results and to offer any advice relating to physical or psychosocial issues. Both the satisfaction and anxiety scale questionnaires will be sent to patients homes with prepaid return envelopes to the independent research team. All information will be stored as an electronic patient record accessible by the clinician and the project nurse. Clinical information, instructions and the escalation process will be entered for each individual patient using a web browser and internet connection and any abnormality such as a low platelet count or an elevated temperature will result in an automatic alert to the project nurse or designated person covering the service.

A steering group will be set up to design and manage the service development including lay representatives recruited through the established patient support group. Issues relating to the methods of evaluation, modifications and patient safety and well-being will be addressed and

included in the analysis of the service evaluation. Involvement of the wider multidisciplinary team during project planning, implementation and evaluation stages will be arranged through the regular departmental operational, quality management, audit and educational meetings.

Data collection

Table 1

The following data collection methods will be used in the evaluation.

Data parameters	Data source or method
Patient demographic details	Patients' medical record
Patient satisfaction	Patient satisfaction tool (reliable and valid)
Patient anxiety	Hospital Anxiety and Depression scale (Zigmond & Snaith 1983)
Re-admissions	Patients' medical record
Infections	Patients' medical record
Out-patient consultations	Patients' medical record
Treatment interventions e.g. antibiotics, platelet & blood transfusion	Patients' medical record

Box 1

Sampling inclusion/exclusion criteria

It is estimated that the number of patients in the combined stem cell transplant programmes of the two acute hospitals will constitute approximately one hundred and fifty per year and a statistician will be consulted to advise on the sample size required to attribute adequate statistical power to any interventional effects which may be realised. A written protocol will be agreed with the haematologist and project steering group to determine patients' inclusion in the study and to identify any risk factors (see box 1). Performance status ≤ 2

Platelets $\geq 20 \times 10^9/l$

Neutrophils $\geq 0.5 \times 10^9/l$

No active infection

No evidence of recurrent disease

Support at home

Mental capacity

Patient has a telephone

Ethical considerations

Box 2 provides a summary of ethical considerations.

- Research and development and ethical approval will be obtained and the principles of GCP adhered to (De Vaus 2002).
- An information sheet will be provided to all patients explaining the aims and rationale for the study.
- There will be strict adherence to the standard operating procedure guidance regarding blood tests required (see appendix 1)
- Verbal and written consent from all participants at the initial point of contact, prior to treatment and on discharge from hospital.
- There will be no coercion to participate and assurance given to all participants that they can withdraw from the study at any time with no adverse effect on their care.
- Confidentiality and anonymity will be maintained.
- All data will be stored securely and destroyed after the study's completion.
- Interview transcripts will be shared with participants for verification/clarification purposes.
- All participants will be supplied with contact details of the researcher and the out of hours specialist registrar.
- A research steering group including lay representatives and an ethicist will oversee the study.

Table 2 Potential risks associated with this service evaluation

Risk	Implication
Patient preference for traditional medical follow up	Patient declines to enter the study and may affect significance of findings Action: factor this into patient retention strategy and statistical significance
Unplanned medical consultations required	Clinics may over run causing delays for patients and stretch clinic resources Action: plan 'emergency slots' into clinic bookings
Quality of patients' medical assessment	Cost of training and requirement for consultant support Action: utilise existing expert nurse and provide protocols and training
Impact on other parts of the haematology service	May require movement of resources to sustain implementation Action: robust business planning
Electronic failure e.g. alerts to nurse specialist regarding blood results	Paper copies maintained and telephone access to nurse specialist and clinical team

Economic evaluation

An economic evaluation will be undertaken to analyse cost consequences of traditional and nurse led telephone follow up as recommended by Drummond et al (2005). The two options will be contrasted clearly and explicitly for all the relevant costs and outcomes, though the complexity of this task should not be underestimated nor 'hidden' costs overlooked (Rizzo et al 1999). Decision makers can subsequently impute their own values on the basis of the costs and consequences identified though this may not always be the most efficient choice. The cost of the evaluation itself will be taken into consideration.

Table 3 illustrates a range of costs and outcomes which will be considered.

	Traditional follow up	Nurse led telephone follow up
Cost of consultation	£	£
Patient/carer travel costs	£	£
Hospital admissions	£	£
Patient satisfaction	Significant difference in satisfaction score	Significant difference in satisfaction score
Patient anxiety	Significant difference in anxiety level	Significant difference in anxiety level

Leadership

The next part of this paper will reflect on and analytically discuss the importance of patient and public involvement within the project steering group and my role as its leader.

Patient and Public Involvement

Varying degrees of success in harnessing patient and public opinion and participation have been demonstrated in health care. Tineke and Broerse (2009) argue that patient involvement and empowerment can enhance the practical relevance and quality of medical knowledge. Furthermore, that their engagement in research increases its legitimacy and rationality of decision-making, in addition to enhancing the value and applicability of its outcomes.

Evidence of effective inter-professional collaboration with service users in the development of cancer services (Sitzia, Cotterell & Richardson 2006) supports this view. Their evaluation suggests that the Cancer Partnership Project made significant contributions to local service development, whilst they acknowledge the cultural changes required to achieve this alliance. Conversely, Buckland and Gorin (2001) highlight limited consumer involvement in NHS research programmes and Gilbert (2003) subsequently identifies the lack of voice mechanisms for the public in any NHS organisation studied. Despite specific roles being created such as non-executive directors, experience demonstrates that they have limited ability to influence agendas or decisions and can be viewed as merely 'rubber-stamping' the decisions of the board (Pickard & Smith 2001). This evidence is corroborated by Pickard (in Hann 2008) who contends that public engagement strategies are particularly poor in primary care trusts and the National Health Service in general.

These examples suggest that concerted effort is required to actively engage patients and the public in service and research development. Ferlie and Pettigrew (1996) assert that key networking attributes are critical to the success of a modern day leader with commensurate

interpersonal and listening skills associated with the ability to construct long term relationships. This view is supported by Goodwin (2006) who advocates a facilitative leadership style based on the multi-organisational and cultural nature of today's health care. I feel that these abilities are important for the project steering group leader in order to engage with the steering group members whilst remaining cognisant of political and organisational strategic objectives.

The quest for hard evidence based objective data in judging health care systems and clinical medicine is ever present and valid though Mannion and Goddard (2004) caution against the rejection of the softer, qualitative information which they argue compliment it. Patient experience is an important factor in the assessment of hospital services (Mannion & Goddard 2004) and hence ensuring the voices of the lay representatives as service users is key in developing consumer led choices and preferences.

Voice

Voice is described as an agency by which a particular point of view is expressed or represented (Oxford English Dictionary 1998). As an individual's expressive capacity, voice is both a form of identity authentication and an interactive link to others (Smith, Kotthoff-Burrell & Farber 2002). The authors argue that nothing else so profoundly diminishes and isolates an individual as the loss of voice.

I understand this to include the metaphorical loss of voice in addition to mechanical failure due to illness. The inability to listen effectively misses the opportunity to elicit patient values, health beliefs and preferences and as such has equivalent negative connotations to prejudices such as ageism, negative stereotyping and cultural ignorance. As stated by Smith, Kotthoff-Burrell & Farber (2002) health care professionals have an ethical obligation to respect patients' autonomy and to promote beneficence.

The increasing global nature and pluralism of our society can conspire against effective communication due to language differences and a myriad of different health beliefs. Additionally, informed choice may be compromised when inadequate written information is supplied, although as Fotaki et al (2005) asserts, little evidence suggests that patients want this. Instead, they argue that issues such as waiting times and dignity take precedence. Conversely, since the uncontested cultural prestige afforded to conventional medicine in the 1960's (Clow 2001) suggests that experience and expectation rather than fear and ignorance shape health care choices of both cancer sufferers and the public. In his seminal work on public choice and loyalty, Hirschman (1970) asserts the importance of voice as a lever for negotiation as opposed to the adoption of an exit strategy. Fostering responsiveness through voice is an essential requirement of today's healthcare.

I will now critically appraise two leadership theories which merit attention in the context of my role as leader of the project steering group consisting of lay representatives and health care professionals. Through this process I will focus on the potential of these to achieve inclusion, diversity and voice for all participants. As mentioned earlier, it can be argued that patient and lay involvement has not been as effective as it could be in health care but the perceived potential threat to health care professionals' roles and authority (Fletcher & Bradburn 2001) must also be recognised.

Situational leadership

Leadership theories have developed over past centuries focussing on traits, behavioural styles (Blake and Mouton 1964) and more recently the emergence of situational leadership (Stogdill 1948, Hersey & Blanchard 1977, 1982). This latter theory is dependent on the leader's ability to employ a range of styles in response to the situation or context they are in. Despite its relative modernity, a situational element to leadership was postulated by Machiavelli, (Machiavelli 2001 [1531], p. 472) better known for his somewhat immoral and unscrupulous attitudes towards power and its attainment. Pertaining to the needs of

societies' inhabitants, he alludes to their quest to secure a strong and brave leader for survival purposes but once achieved, their preference was for a leader demonstrating qualities of prudence and justness. Despite acknowledging the advantages of behavioural flexibility, he refutes the idea that leaders are able to change their innate style nor willing to try.

The modern day interpretation of situational leadership focuses on task and relationships, dependent on the skill of the leader to adapt appropriately to the degree of support or direction required of a group whilst recognising their individual competence, commitment and maturity (Hersey & Blanchard 1982). Whilst these theories pertained to organisational leadership, I feel that the approach has potential for harnessing the knowledge skills and experiences of professionals and lay representatives.

Critics, however, (Bass 1990, Yukl 2002) question the validity of situational leadership in terms of limited evidence. Furthermore, Yukl (2002) highlights the potential limitations of supporting less experienced group members at the cost of devaluing others' expertise within the four levels of maturity identified by Hersey & Blanchard (1987). It could be argued, however, that a skilled and experienced leader could achieve an effective balance between support, delegation and shared learning within the group.

Distributed leadership

It is suggested that distributed leadership developed in direct response to the limitations of hierarchical structures and the single leader to achieve organisational growth and transformation (Harris 2008). Gronn (2009 in Harris 2009 p. 200) describes a trajectory of 'distributed phenomena' including distributed knowledge and cognition, distributed work, distributed learning and distributed decision-making. He attests that the genealogy of distributed leadership is broad and extensive but its' subsequent development halted by the dominance of individualism and organisational theory. Critics of distributed leadership view it

as a re-birth of managerialism (Fitzgerald & Gunter 2006) whereas others argue that it provides a convincing theoretical framing of leadership practice (Spillane 2006, Harris 2009).

Similarly, the constructionist view espoused by Ospina and Sorenson (2006) presumes that an understanding of leadership is socially constructed over time as individuals interact with each other rather than something embodied or possessed by them.

“A constructionist lens suggests that leadership happens when a community develops and uses over time, shared agreements to create results that have a collective value.” (Ospina & Sorenson 2006:188).

Leadership constructs which transcend individual leader's qualities or traits have developed into consideration of a more group oriented perspective and within education, it is acknowledged that shared leadership and positive student outcomes can be achieved through the advancement of professional networks (Hargreaves & Fink 2009 in Harris 2009) and communities of practice (Louis & Marks 1998). Critics however, argue that distributed leadership is a subtle ruse to ensure delivery of key government reforms and performance targets. Whilst leadership is devolved to willing actors, the overall strategy is pre-destined (Hartley 2007). Based on Wenger's (1998) notion of communities of practice, where knowledge is viewed as a social enterprise integral to its' members interactions, McDonald & Viehbeck (2009) attest their import in developing research-based practices and policies through the engagement of users and producers of research. Characteristics of these social and intellectual networks include mutual negotiation, reciprocity, trust and cohesion.

Conclusion

In considering situational leadership and distributed leadership theory in relation to the project steering group I have found merits in both approaches. I believe that creating an environment where the contributions of all participants are recognised for their individual and

collective value is initially dependent on the project lead. It can be argued that their style and response to the situation, task and relationships within the group set the scene from the outset. The situational leader allows members to share responsibilities according to their confidence and abilities and establishing the levels of these within the group would be important. Arguably, however, the tenets of distributed leadership best support the aims of inclusivity and collaboration within the steering group. The transformation of educational institutes through distributed leadership and the associated motivation for shared learning resonates well with the ambitions its members. Furthermore, the success of networks and communities of practice have helped to de-construct organisational boundaries and encourage engagement of researchers and practitioners. Adopting the philosophy of distributed leadership will ensure that voices will be heard and that the project will be steered utilising the knowledge, skills and experiences of all participants.

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Appendix 1: Laboratory Tests

All patients:

Test	Frequency	Comments
Full blood count, differential	Each visit	
Liver function tests Alk Phosphatase, ALT, AST, LDH, Tot Bilirubin	Each visit	*Patients on immunesuppression/hepatotoxic drugs should have LFTs measure more frequently, if abnormal
Renal Function Tests Serum Creatinine, Urea, magnesium	Each visit	

Day +100 assessment / Annual assessments

Detailed follow-up examination and investigations are carried out at specified times post transplant, i.e. 3, 6, 12 and 24 months and yearly thereafter.

Tests	
Blood Tests	Full blood count Biochemistry profile incl. renal and liver function tests Ferritin, Serum Fe, transferrin and %transferrin saturation Immunoglobulins and lymphocyte subsets Peripheral blood for PCR for molecular markers Thyroid function tests FSH, LH, oestradiol (women) or testosterone (men) Chimerism

Appendix 2: Procedure of recruitment and intervention (adapted from Cox et al 2008)

Appendix 3: Steering Group Meetings

Adapted from Schiola (2001)

Dimension	Aim	Characteristics
Planning	Purpose of steering group clear Commitment of participants clear Efficient use of resources	Invitations and maps sent in advance Information regarding purpose of the steering group and project proposal explicit and supplied in advance Realistic budget availability
Leadership strategy	To acknowledge views, skills and knowledge of group	Distributive
Environment	Comfortable, accessible and conducive to meeting purpose	Comfortable seating Wheelchair access Room temperature adequate Natural light if possible Materials available for group work e.g. flip charts and comment cards
Introductions	Individual expectations and feelings identified	Inclusive and diverse
Ground rules	All able to articulate own views and respect those of others	Safe, honest and open culture
Group work	All opinions heard and respected	Activities varied to suit variety of styles
Decision strategies	Decision making is informed	Process and actions clear Group consensus
Time management	Efficient use of resources	Clarity re time commitment and flexibility/willingness to detour if situation demands it
Deep listening	Complete understanding of person's view	Paying attention Questioning Reflecting back Checking for meaning Recognising what is not said Sensing discomfort
Resources	Ensure efficient use of time, people and budget	