

BRITISH PSYCHOSOCIAL ONCOLOGY

Newsletter Issue 2 2012

SOCIETY

Letter from the Chair



Dear BPOS members,

The six months since our last Annual Conference have continued to be busy for the BPOS Executive Committee.

We have successfully launched our online membership renewal system and we are currently working with an external design company on the new BPOS website.

Preparations for the 2013 Annual Conference are starting to come together and I'm incredibly grateful for the hard work that Claire Foster and her team at the University of Southampton are putting into planning what I'm sure will be an excellent 30th Anniversary celebration for BPOS. I'm delighted to be able to confirm our four keynote speakers: Amanda-Jane Ramirez (King's College London), Neil Aaronson (University of Amsterdam), Eilis McCaughan (University of Ulster), and Jessica Corner (University of Southampton). Abstract submission is now open and online registration will be opening later this month. On behalf of all involved in planning the conference, we are very much looking forward to welcoming many of you to the Southampton

DeVere Grand Harbour Hotel on the 17th and 18th January 2013.

As usual, our Annual General Meeting will be held in conjunction with the conference, and one of our most important items of business will be to elect new members of the Executive Committee. From January 2013, the following positions will be available for nomination: Chair Elect, Psychiatry, Palliative Care and one Open position. If you would like more information about these committee roles, please do get in touch and I'd be happy to discuss this with you and provide you with a nomination form. Nominations should reach me by 30th November.

We are continuing to strengthen our links with IPOS and, in doing so, to contribute to the international development of psycho-oncology. As a society, we have recently endorsed the IPOS Standard of Quality Cancer Care. You can read more about this initiative at www.ipos-society.org/about/news/standards_news.aspx. The Executive Committee were also asked to provide consultation feedback on new Guidelines for Best Practice in Oncoplastic Breast Reconstruction; following integration of our feedback we were happy to also provide endorsement for this important document.

Finally, I'm very pleased to be able to inform you about the continued success of Psycho-Oncology, our official society journal. The 2011 Impact Factor has been released at 3.339 (an increase from 2.874 in 2010) which makes the journal 3/37 in the Social Science Biomedical Journal Category, 15/75 for Psychology, and 64/194 for Oncology. A huge achievement I'm sure you'll agree, and I'd like to encourage all BPOS members to consider Psycho-Oncology when disseminating your work.

With my very best wishes

Nick Hulbert-Williams
BPOS Chair

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British Psychosocial Oncology Society

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Welcome to the 2012 summer issue of the BPOS newsletter.

This issue contains a special feature on the book *The Other Side* by Dr Kate Granger, an Elderly Medicine Registrar in Yorkshire. *The Other Side* tells the story of Kate's journey as a patient coming to terms with a terminal cancer diagnosis. This newsletter contains three reviews of Kate's book (by a medical student, an SpR in palliative medicine and a senior lecturer in cancer and palliative care) and a Questions-&-Answers feature with Kate, as well as two short excerpts from Kate's new forthcoming book *The Bright Side*.

This issue also sees the beginning of a new regular feature: 'PhD student spotlight'. In this issue's spotlight, Dawn Doran from the University of Central Lancashire tells us about her PhD research into the experiences of gay men with prostate cancer. We also have student reviews of the recent 'Surviving the Psychosocial Oncology PhD' event at the University of Chester. Thank you to all our newsletter contributors.

You will have noticed that this issue of the newsletter has arrived in your e-mail inbox rather than through your letter box. At the last BPOS executive committee meeting in June, for financial and environmental reasons, a decision was made to move to an electronic only newsletter. However, please do let us know your thoughts and feedback on this decision, as it will be reviewed before production of the next issue.

If you would like to contribute an article to the newsletter, please do get in touch. Articles might be reports of studies in progress, reports of preliminary research findings, brief literature reviews, explorations of relevant methodological or ethical issues, conference reviews or book reviews. If you have something that you'd like to contribute, please contact me to discuss your ideas. The deadline for content for the next edition will be 31st January 2013.

I hope you enjoy this issue.

Laura Ashley

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The Other Side by Dr Kate Granger

In the words of author Dr Kate Granger, *The Other Side* is "a true story of one doctor's journey as a patient coming to terms with a terminal cancer diagnosis".

The hope is that healthcare professionals will read it, in particular young doctors and medical students, and understand exactly what being a patient is really like and how their behaviours, no matter how small can impact massively on their patients. It is also a story of personal battles with control and learning how and when to relinquish it.

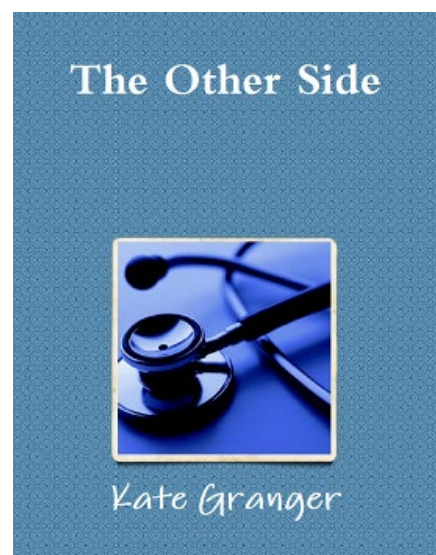
This issue of the newsletter features three reviews of Kate's book: from James Gupta, a first year medical student, from Jennifer Klimiuk, an SpR in Palliative Medicine, and from Anne Arber, a Senior Lecturer in Cancer and Palliative Care. There is also a Questions-&-Answers feature with Kate, as well as excerpts from Kate's new forthcoming book *The Bright Side*.

Review of *The Other Side* by James Gupta, medical student

There is no shortage of books on cancer. Amazon even gives it its own category boasting over 11, 000 different books. In spite of this, '*The Other Side*' stands out as one that is remarkably honest, personal and especially to healthcare professionals – important.

Whilst it discusses themes that are certainly of interest to the wider public, it is definitely aimed towards a more professional audience. However, it should be pointed out that it is not by any standards 'difficult reading' – the many themes and potentially practice-changing messages of the book are woven seamlessly into an almost diary style narrative of Dr. Granger's (Kate's) experiences.

One recurrent theme in the book that illustrates this is ordering tests that may not be absolutely necessary. An elderly medicine registrar, Kate describes herself as a 'conservative physician' which I strongly believe is something to aspire to, especially in a time when more and more procedures, tests and scans are being driven by physician, rather than patient



demand. Below is an excerpt from the book where Kate describes her first experience of an MRI scanner:

"I am feeling really petrified now and shut my eyes tight. I decide I will not be opening them again until the scan is completed. I grip the buzzer and try to concentrate on my breathing which has become uncontrollably rapid and erratic"

And even after the scan is completed:

"I am a total wreck and daren't open my eyes... ...I keep telling myself it's over but the internal scared feeling stays with me all day"

The take-home message here is clear to any healthcare professional who has ordered a test. Modern technology and the changing roles in healthcare means that for doctors, ordering a test is often a matter of signing a form or clicking a button, waiting for a bit and then receiving the results. This process, whilst efficient and beneficial in many ways, comes with the huge drawback that we do not experience the 'middle bit' between ordering the test and receiving the result: it blinds us to the often disrupting and potentially traumatising effects that tests can have on patients. I personally believe »

that this is one of the major sources of communication breakdown between doctors and patients.

As a first year medical student studying at Leeds, where the medical curriculum has been radically updated with a strong emphasis on patient safety, ethics, communication skills, the so-called 'humanitarian' side of medicine, I was able to relate a lot of what was being said to what I have learnt this year, and I strongly believe that this book should be incorporated into the curriculum as a way to highlight the topics we are being taught.

In summary, *The Other Side* touches on a number of issues such as attitudes to death, DNARs and palliative care that healthcare professionals will find interesting. Whilst Kate confidently offers her opinion on these topics, they are not the main focus of the book.

The main focus of the book, and in my opinion the reason why you should read it is that by experiencing the hospital setting as a patient rather than a professional, Kate has a unique and valuable insight that she has been able to use to make a number of simple but significant changes to her practice that allow her to better relate to and communicate with her patients.

It is fortunate that the majority of us will never be put into this position, though by reading her book we can still benefit from this unique insight and become better clinicians.

James Gupta

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Review of *The Other Side* by Jennifer Klimiuk, SpR Palliative Medicine

'*The Other Side*' by Kate Granger is a surprising and incredibly insightful piece of work. It is a graphic and truthful account of the author's personal experience as a patient with a terminal disease. The author, a Specialist Registrar in Elderly Medicine, was diagnosed with a rare type of malignancy at only 29 and this book offers her unique, intimate and emotional insight of this experience through the eyes of a doctor.

The author writes articulately and candidly about her journey from diagnosis, to treatment and beyond. She describes the often unpleasant daily experiences of life as a patient which, as doctors, we often dismiss as routine; what this book illustrates is they often have profound and distressing impacts on patients and their experience at the hands of medical professionals.

One could argue after reading this book that it is worse to be a patient as a doctor, owing to the 'burden of knowledge'. The opposite can also be argued, at least we as doctors have understanding of the basic processes behind what happens- simple questions like 'why am I seeing a different doctor every day?', 'what happens next?', 'what is this next scan for?' are easy to discern for clinicians but others do not have that same insight. What was also evident from this story is how utterly gruelling, unyielding and bewildering cancer treatment can become for some patients and what relief can often come, physically and emotionally, from focusing on palliation and moving towards this ultimate purpose.

This account highlights to a startling degree how communication skills amongst professionals can vary and what an impact this ultimately has on the emotional and psychological state of a patient. A small, indifferent gesture can have a huge impression upon a patient in a vulnerable state and clinicians are often blissfully unaware of the inner turmoil patients are suffering. It is evident, especially

from this book, that if communication were better, the overall experience of patients would ultimately be better. Communication does not eradicate pain, nor does it change the need for surgery or remove the upset of a terminal diagnosis. It does however eliminate the anxiety and uncertainty associated with many of these, anxiety that is driven by a multitude of factors, not least a lack of understanding or a simple feeling of facing things alone. Many medical professionals feel uncomfortable that they cannot 'change' what is happening for patients and this causes distress for them. Ultimately, patients don't expect that from us, they want someone who will be honest and clear about what is happening, someone who will discuss the uncertainties with them, someone who will listen to their concerns even if they can't change them – someone just human.

Communication skills are a much greater focus in Medical Undergraduate and Postgraduate teaching today but there are still many misconceptions about how to approach patients, especially those with a terminal diagnosis. This book should be an absolute must read for every medical student and doctor. It highlights the small things that we take for granted that can be a source of immense anxiety for our patients when they don't understand what is happening and it shows that good communication doesn't always have to be an hour long conversation about prognosis and expectations, it can simply be a reassuring smile, a short explanation or a bit of honesty when things are uncertain.

I hope this book gives confidence to those who read it and they see that it is in the small day to day things where we can often have the greatest impact for patients. Ultimately, we need to see that we are not Doctors administering to patients or professionals looking after the public; we are human beings caring for other human beings, it is never wrong to remember this.

Dr Jennifer Klimiuk

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Review of *The Other Side* by Anne Arber, Senior Lecturer in Cancer and Palliative Care

Kate Granger, a highly experienced doctor (Elderly Care Registrar) suddenly becomes seriously ill with an advanced cancer while holidaying in California. She was in the midst of a fantastic family holiday when she had to be taken to the Urgent Care Centre and her journey to becoming a patient with advanced cancer starts. *'The Other Side'* is her story of being a patient through a doctor's eyes. She hopes that health care professionals will read her story and get an understanding of 'what being a patient is really like'. Once I started reading the book it was hard to put it down; it is so vivid, sometimes funny but also disturbing. What stands out to me are all the examples of poor communication from the health care professionals, regarding breaking significant news, managing the treatment pathway, preparation for and reporting the results of invasive tests. Kate works hard to keep her dignity, through invasive investigations and intimate physical examinations.

Kate returns to the UK health care system where she finds her GP practice has a good system with a named GP allocated to her. She is admitted quickly to the hospital admissions unit and this is where it becomes frightening for her. She picks

up from the white board on the ward that she is to have an MRI scan – nobody has discussed this with her. She can hear every word of the nurse's handover, including the reference to her as bed 27. Things do not get any better, a registrar whom she has not met before breezes into her room without knocking and asks Kate why she is upset. When Kate replies that she is 29 and has cancer the registrar's reply is: 'you are too young, it will be something benign'. This is just so crass Kate asks her to leave. Later on, a gynaecology Senior House Officer whom she has never met, enters the room looking nervous, sits down and out of the blue announces 'your MRI shows evidence of spread'. She is astounded by the lack of skill in delivering bad news, there is no warning shot. He goes on with some false reassurance: 'they think it's a germ cell tumour, which should be very treatable'. In fact this turns out to be far from the situation Kate finds herself in. In the future I can use these examples when teaching how not to break bad news. The problematic communication continues with the clinical nurse specialist using lay type language to explain chemotherapy, which Kate finds patronising. Sadly many of the staff's communication skills do not live up to Kate's expectations and I found this distressing. When she is moved to the specialist cancer centre the quality of the medical and nursing care including communication is significantly improved.

The oncology nurses are 'brilliant at multi-tasking' know how to manage her pain, have excellent aseptic technique and the consultant is described as 'a lovely oncologist', he has a gentle manner, listens well and shows great empathy.

This is a great book, which is a really helpful resource for teaching medical, nursing and allied health professionals. This book should be required reading for all medical and nursing students. Kate's story raises many questions about dignity in care. The Royal College of Nursing has put 'dignity at the heart of everything we do' and the General Medical Council is using patient and colleague feedback for capturing evidence about whether doctors are delivering dignified care. We need to do more; some staff are seriously out of their depth without the tools, strategies and skills to deliver dignified care especially in the area of communication and information giving. More 'on the job' training with junior medical staff regarding breaking significant news and information giving such as Advanced Communication Skills training is a priority for this group.

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Questions-&-Answers with Dr Kate Granger



You started to feel unwell last summer while on holiday in California; briefly tell us about your cancer diagnosis and treatment experience from that point...

A few days into our trip I began to feel unwell with some back pain and nausea. My symptoms rapidly worsened necessitating admission to an American hospital where I was diagnosed with acute renal failure caused by both my ureters being obstructed by multiple soft tissue masses within my abdomen and pelvis. They patched me up in the US and we came home to pursue further investigations and treatment in the UK. The diagnostic process was not straightforward and I needed several biopsies and scans to work out that I had a Desmoplastic Small Round Cell Tumour (DSRCT) which is a very rare and aggressive type of sarcoma. The cancer had metastasised to my liver and bones. Unfortunately whilst the diagnosis was being made I became very unwell again with renal failure and sepsis, which necessitated me undergoing multiple painful invasive procedures. Eventually I was well enough to undergo chemotherapy, which was really the only therapeutic option for me. The chemo was given every three weeks as an in-patient for four to five days, with a few days break at home before being readmitted after every cycle with febrile neutropaenia. After five cycles on New Year's Eve I made the difficult decision to stop chemotherapy

and get on with living my life. I am very lucky to have a chemo-sensitive tumour, but the burdens of treatment had definitely begun to outweigh the benefits at which point I always said I would withdraw from treatment, knowing full well from the outset of my illness that the Oncologists were never going to cure my cancer.

How do you think being a doctor has affected your experience as a patient?

I think being a doctor patient has its advantages but also has its downsides. In some respects it makes life easier. I understand what is going on, I know what questions to ask, I feel confident to advocate for myself and question my doctors about their management plans to make sure any actions are best for me and to ask for things that I think would help me. Having contacts within the profession for advice is also useful; I have some good colleagues in Haematology and Interventional Radiology who have definitely influenced my decision making along the way. Sometimes though I wish I did not have as much knowledge and experience, for example knowing what is in store for you with regards to a procedure is not necessarily a good thing. Coming into contact with people I knew through my professional life when I was a patient was also very uncomfortable for me.

In *The Other Side*, although you recount that you received some excellent patient care, you also note that you experienced episodes of poor doctor-patient communication; tell us about the features of these episodes and how they made you feel as a patient...

It is easy to criticise poor communication but I do recognise how difficult it can be to have these conversations. I think remembering the simple things when communicating with patients is so important. For example I was told I had metastatic disease without any clarification of what I already understood, with no warning shot, with no opportunity to have anybody with me and the nurses were not told that I had just received such devastating news. The doctor could not leave the room quickly enough after

delivering this news and I never saw him again. Receiving news like that is never going to be a nice experience but I'm sure it would have been easier to hear if I had been supported by my husband and the conventional communication structure had been adhered to. I think it is also important to think about the environment and setting when communicating with patients.

I remember being seen on a ward round once with eight people staring at me. I felt like a circus act and there was absolutely no need for all those people to be present.

From your perspectives as both doctor and patient, why do you think it is that doctors sometimes get it wrong when it comes to patient communication?

I think we as doctors are all incredibly pressurised in our jobs and sometimes 'breaking bad news' can just be seen as another task in a busy day. It is all too easy to forget that for the individual patient that this is their one and only opportunity to receive this news and doing it badly can cause immense and irreparable psychological harm. I think some doctors are extremely good at relating to their patients and showing true empathy, but that some others struggle with this and much of it is simply down to personality. On occasion I think doctors forget that being a patient can be very frightening and even something that seems simple and straightforward to us such as an MRI scan can be hugely scary to a patient.

You have returned to work three days a week; do you think your experiences as a cancer patient have altered your own clinical practice?

Definitely. I am much more patient-centred and empathic now. I understand how scary it is to be sat in a hospital bed so I try to take more time to explain investigations, procedures and treatments properly to my patients and allow them time to discuss their questions and concerns. I also have a better understanding of the vulnerability, indignity and embarrassment of being a patient these days and remember this especially when I am examining patients. I am probably a stronger advocate now and will push harder for what I believe is right for the people I look after than »



I did before my own illness. One of my main focuses at work is providing good quality Palliative Care in the acute hospital setting and I invest a lot more time and emotional energy into looking after my patients in the final days of their lives and making sure their families are well informed during this difficult time.

What messages from *The Other Side* do you hope that doctors and health care professionals will take away and implement?

One of the aims of the book is that healthcare professionals will recognise the importance of the 'little things' such as holding a patient's hand when they are upset, sitting down next to them on the same physical level rather than standing over them and recognising the impact of illness on the individual rather than thinking of patients just as their disease entities. These behaviours are small and easy to achieve but have a huge impact on making patients feel at ease with the people looking after them and their ability to relate to and trust these people. I was very lucky to be able to advocate for myself effectively throughout my illness but I hope the book emphasises the need to be doctor to but also advocate for your patients. I also hope that by reading the book doctors may take just a little more time to properly listen to and respond to their patients' needs. ■

After *The Other Side*, *The Bright Side*...

Next month, Kate will launch a long awaited sequel to *The Other Side*, titled *The Bright Side*, in which she writes about getting back to work and how her experiences as a patient have changed her practice as a doctor. *The Bright Side* also looks at living with a terminal diagnosis and the struggle to maintain positivity.

Excerpts from the forthcoming *The Bright Side*...

I'm not sure what the etiquette is for living life with a terminal cancer diagnosis hanging over you. I guess there is no rule book for a situation like this and I am very much of the opinion that I can only do my very best to plough on with things and try to be as normal and active as possible for as long as possible, bearing in mind that I might feel rubbish and that things may start to get on top of me both physically and psychologically at times. I am therefore packing as many activities into my life as is humanly possible. I have quite high expectations of what I can achieve in my remaining time; some might feel these expectations are set too high. I have always been an ambitious individual though and this aspect of my character is not going to change just because I am dying.

Why as a cancer patient are you seen as 'heroic' and a 'fighter' if you accept all the burdensome, in the most part futile treatment for incurable cancer? Does this mean that if you refuse these interventions that you are somehow foolish or weak? I have been thinking about this a great deal recently. There is a tendency for media surrounding cancer to use highly emotive language. For example the Cancer Research charity slogan is 'together we will beat cancer'. No we won't. It is a result of being a living organism that cell division and repair will sometimes go awry and the result of this will be cancer.



We may become increasingly capable of counteracting the pathology, but I cannot imagine there will ever be a human society without cancer. I do not mean to say that people who choose to go through lots of treatment are doing anything wrong if this is truly what they want to do, but I think all too often patients feel under external pressures to battle on when deep down inside they just want to enjoy their remaining time without so many medical interventions. Death and dying are such taboo subjects in our Westernised society and I have never understood why, after all it is the one thing that we all have in common, we are all going to die one day. There are campaigns and organisations out there such as 'Dying Matters' tackling these issues but it is going to take such a monumental effort to change societal attitudes. Acceptance is a hugely difficult thing.

All profits from the sale of *The Other Side* are being donated to the Yorkshire Cancer Centre which is the fundraising arm of St James's Institute of Oncology, where Kate is being treated. To buy a copy of Kate's book (£10), please visit www.theothersidestory.co.uk

Dawn Doran, University of Central Lancashire

Dawn explains why she has chosen to research the experiences of gay men with prostate cancer, and briefly outlines some of her study plans.



Introduction

Despite Government calls to reduce health inequalities in the lesbian, gay, bisexual and transgender (LGBT) population and to ensure that diversity is reflected in age related issues, health research within this community has predominantly focused on matters relating to sexual or mental health and HIV. Research aimed at uncovering the unique challenges faced by the LGBT community following major and chronic diseases, such as cancer, has been slower to emerge. However, whilst some studies have begun to identify the unique challenges experienced by lesbian women in relation to breast and cervical cancer, there is still a distinct lack of research outlining the challenges that confront gay men. My PhD study aims to address this gap by exploring how gay men experience one of the biggest threats to male health – prostate cancer (PC). I will outline the need for research in this area, before briefly discussing some aspects of my study including potential challenges and its wider implications.

A hidden problem

Sexual orientation is not routinely monitored within the NHS, so it is not possible to know how many gay men are

affected by PC. Nonetheless, given the number of new diagnoses of PC each year, in relation to the LGBT population in the UK, it is feasible to assume that a significant number of gay men will experience PC at some point during their lives. Moreover, whilst Stonewall, one of the UK's leading LGBT charitable organisations is currently attempting to identify effective ways of monitoring sexual orientation within health settings, it is debatable whether statistical data would accurately reflect the scale of the problem. A recent survey by Stonewall (2012) found that a third of gay men had not disclosed their sexuality to their own GP's, while a briefing prepared for NHS social and healthcare staff reported that only 14% of older LGB people are open about their sexuality with healthcare providers (DOH, 2007). The most common reasons cited for non-disclosure include fear of discrimination, heteronormative or homophobic attitudes and concerns surrounding confidentiality (DOH, 2007; Fenge & Hicks, 2011).

Gay men and PC – key issues

Psychosocial research has played a vital role over the past two decades in highlighting the impact of PC on men.

In turn, this has led to a greater understanding of how men renegotiate their identity, masculinity and sexuality following treatment. However, as the majority of studies have been conducted with heterosexual men, it is questionable whether key findings from previous studies can be generalised to non-heterosexual men. Furthermore, whilst both gay and heterosexual men will undoubtedly share similar concerns relating to PC, the findings from two separate studies also highlight some differences. Both studies (Susman, 2011; Motofei et al, 2011) compared the effects of PC treatment on gay and heterosexual men on their daily functioning. However, significant reductions across all levels of physical, sexual and psychological functioning were reported by gay men compared to those of heterosexual men. Whilst reasons for this variance are still unclear, researchers such as Blank (2005) stress that the process of renegotiating masculinity, identity and sexuality after PC treatment will, in part, be greatly influenced by the social and cultural structures inherent within each group. Hence, not all aspects of intimate relationships, support networks and patterns of sexual behaviour are directly comparable. »

The impact of ageing on PC

As the risk for developing PC increases as men continue to age, the additional challenges faced by the ageing LGBT population may also impact on men's experiences. The concern is, knowing whether gay men are likely to require increased support following PC treatment. Findings from studies conducted with the ageing LGBT population report high levels of isolation and exclusion amongst the older LGBT community and the overriding need for gay friendly services (The Gay and Grey in Dorset project, 2006). Moreover, older LGBT people are twice as likely to live alone and four times less likely to have children (DOH, 2007). In contrast, wives and extended family members are frequently cited within psychosocial research as being pillars of strength and support for men throughout their cancer journey (Arrington et al, 2005) as are community support groups (Lepore & Helgeson, 1999). Contrary to assumptions, the Gay and Grey in Dorset Project (2006) also reported that older gay men are still very sexually active. However, given that so few LGB people are willing to openly discuss their sexuality with health providers (DOH, 2007) older gay men with PC may be even less willing to initiate discussions about the negative impact of treatment on their sex lives.

Addressing needs

Whilst there is still, undoubtedly, much to learn about the psychosocial experiences of men with PC, regardless of their sexuality, there is clearly a paucity of research dedicated to understanding and addressing the challenges which are unique to gay men, in particular, the interplay between PC and issues specific to LGBT ageing. My study aims to focus on the experiences of gay men with PC, and in doing so, consider how their psychosocial and support needs might differ from those of heterosexual men and how they can be addressed. By adopting a qualitative approach and utilising a hermeneutic framework, my study intends to uncover meanings, provoke thought amongst health professionals and inform psychosocial PC literature about their experiences.

Potential challenges

Like most other PhD students, I do anticipate that some aspects of this project may be more challenging than others.

For example, due to the difficulties of monitoring sexual orientation within the NHS, multiple sampling strategies may have to be employed to ensure that the population I wish to recruit can be reached. Yet equally, the use of alternative sampling strategies could also be viewed as a unique opportunity on which to build strong connections with local and national LGBT groups and charities. Seeking advice from members of the gay community will ensure that recruitment/promotional materials used within the study are culturally sensitive. I am also aware that my status as a perceived 'outsider' could impact on the extent to which some individuals choose to disclose and share information with me. However, I intend to make use of the advice and guidance of researchers in this field by ensuring that my study is also embedded in the wider context of LGBT research aimed at tackling social and health injustices.

Wider implications

Finally, in addition to informing and contributing to the current PC knowledge base, I am hopeful that my study will have wider implications with regard to conducting research. By sharing good practice and methodological challenges met along the way, my study may have the potential to offer further practical advice and guidance to other novice researchers; particularly those who also share an interest in conducting psychosocial research with minority groups or individuals who are often perceived as being 'hard to reach.'

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Surviving the Psychosocial Oncology PhD

A review of the BPOS student learning event 27th June at the University of Chester

On the 27th June 2012 BPOS hosted a one-day event for PhD/doctorate students at the University of Chester. Fifteen students attended the day and 14 completed an evaluation form – 10 first year students, 2 second year, 1 third year and 1 fourth year. The aim of the event was to provide an opportunity for students to meet and share experiences with other fellow PhD students undertaking research in psychosocial oncology.

The individual sessions on stress/emotional impact of psychosocial oncology research (7 = excellent, 7 = very good) and relationships with supervisors (9 = excellent, 5 = very good) were rated highly, and the students valued the opportunity to present their research and engage in group discussions. Overall the day was a great success – 8 students rated the day as excellent, and 6 as very good, and most (Yes = 13, Maybe = 1) indicated that they would consider returning to a future PhD event. Additionally all of the students indicated that they had made contacts at the event that might be useful for the future.

Here, three students share their experiences of the event.

Chantal Smeekens, University of Cambridge

Fifteen PhD students from various universities, working in psychosocial oncology and cancer care attended the very first PhD student event of the British Psychosocial Oncology Society; "Surviving the Psychosocial Oncology PhD". The event took place at the University of Chester, a compact campus not far from the beautiful historical city centre. After we all arrived, Professor Dr Eila Watson from Oxford Brookes University welcomed all PhD students and introduced us to the organizers: Dr Nick Hulbert-Williams, Dr Fiona Kennedy and Sam Williams.

PhD students' research projects

The day started with all students presenting their own research. It was inspiring to learn about the other PhD students' studies. There was a surprisingly large variety within these topics. Examples are: Patients' and their partners' experiences of recurrence of colorectal cancer (Marta Wanat), psychosocial interventions to support breast cancer patients affected by hair loss (Melissa Pilkington) and the experience of gay men with prostate cancer (Dawn Doran). (Lucy Bryning will tell you more about the PhD projects in her review.) Despite of the variety in topics, all PhDs were related to psychological and/or social issues, cancer and patients. I am working in a medical department (the Primary Care Unit in Cambridge) on a study (on the role of emotion in patients' time to presentation with symptoms possibly indicative of cancer) that also touches on other disciplines. Therefore it was stimulating to meet other students with similar interests in the interdisciplinary field of psychosocial oncology. »

Emotional impact of psychosocial oncology research

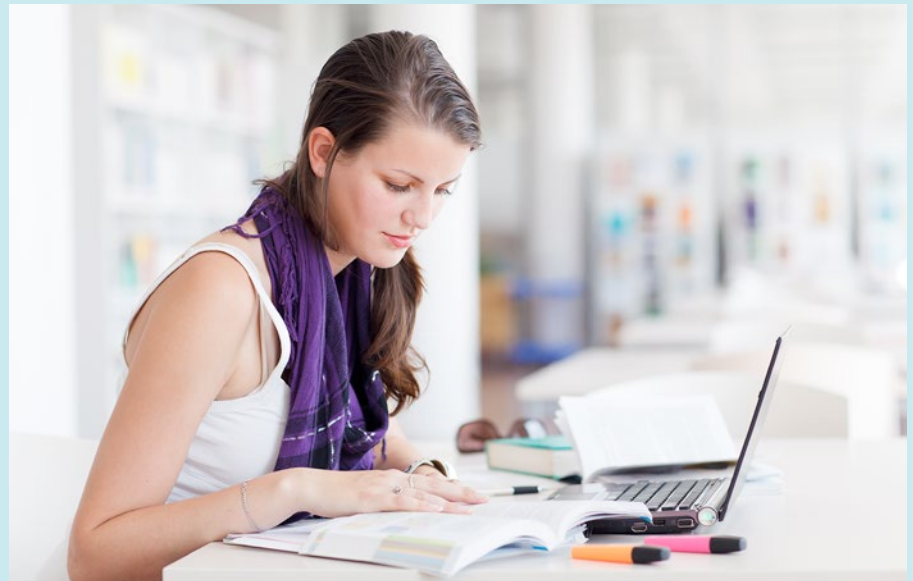
Then, Dr Nick Hulbert-Williams gave an insightful presentation on the stress that may be related to working in oncology; clearly a relevant topic given the sensitive character of many of the studies carried out by us PhD students. His presentation was an interesting mix of theory on stress, appraisal and coping, and applied use of coping strategies to deal with the stress in the oncology working environment. Then, Dr Fiona Kennedy highlighted specific difficulties that may arise in (qualitative) research among cancer patients. How to deal with the death or worsening health of a patient who you interviewed several times? How to keep professional boundaries? Interviewing patients with cancer is not easy for any of us. Therefore, I think that talking about it with fellow researchers or students is one of the best strategies offered in the presentation. Cathy Shneerson discusses this session in more detail.

Relationships with supervisors

After the break there was a session "Relationships with Supervisors", led by Dr Mandy Yilmaz. Mandy led an interactive session and shared her own experiences as a student as well as a supervisor. The relationship with your supervisor(s) is an important one and vital for a successful PhD trajectory. She gave advice on how to have productive meetings. Also, she gave examples of situations when the relationship between student and supervisor affected PhD work, negatively as well as positively. There was opportunity to share experiences in working with our supervisors. We were able to give each other advice on how to deal with certain situations; for example, when you have two or more supervisors from different disciplines whose opinions are contradicting, or practical tips on how to get the most out of your meetings. Mandy engaged everyone with her down-to-earth and amusing way of leading the session.

Group discussion

The last session was led by Dr Nick Hulbert-Williams and was a group discussion on several issues related to the psychosocial oncology PhD. Topics were: What is (not) expected from a PhD student, what do examiners want to see



in a PhD dissertation, and how long should it be (a good point of advice from Nick was that the possibility of 4 publications indicates that you have enough data). Finally we talked about how we see the future of the BPOS PhD student network. Personally, I hope that after this productive day a PhD student network will remain active to support each other and exchange knowledge and advice. Making these contacts with other students was one of the most valuable aspects of the day for me. I hope that there are many other PhD student events to come, preferably in other parts of the country to reach more students and establish a broader network across the country.

I would like to conclude with thanking the organisers and presenters for this interesting and useful day, and the wonderful presentations on relevant topics for us PhD students.

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Cathy Shneerson, University of Birmingham

The first session of the morning was co-presented by Nick Hubert-Williams and Fiona Kennedy who covered some of the issues relating to stress and emotions amongst cancer workers and those involved in cancer research. The prevalence of stress amongst cancer workers such as doctors and nurses, has been well documented (1), with many reporting emotional exhaustion, depersonalisation of self and low personal accomplishment, with a third of cancer

workers considering a career change. Reasons for this increased stress may appear obvious with cancer workers having increased exposure to death and dying, experiencing feelings such as helplessness and guilt. This is coupled with the need to provide emotional and practical support to cancer patients and their families and friends (2). This may leave cancer workers more vulnerable to stress. When combined with other factors such as decreased job satisfaction, lack of peer support, time constraints, and a highly pressurised hospital environment (3), it is easy to see why so many cancer workers fall prey to the hazards of stress.

As researchers directly removed from the clinical oncology environment in terms of caring for these patients, it is easy to assume that we will not be exposed to these stressors, and will be protected from the consequences of stress. However, although researchers are not caring for cancer patients in the physical sense, relationships can still be formed on an emotional level. This is especially true in qualitative research where researchers are often recipients of personal, highly charged, sensitive information, which may not have been divulged to anybody else previously. This is a privileged position to encounter, as the researcher is permitted access to aspects of the cancer patient's life from their own perspective. From this a rich and detailed picture of the patient's individual experiences, thoughts and feelings may emerge. However, alongside this privilege lies the challenge of trying »

to engage and connect with the patient and their experiences whilst maintaining a certain level of professionalism and keeping boundaries in place. This can be difficult, especially if the research participant evokes sensitive and emotional responses in the researcher. Fiona Kennedy provided an example of this, recounting how one research participant was of a similar age and came from a similar background to herself. She described the difficulties of 'staying professional' rather than stepping into a 'friend' role to provide emotional support to the participant who felt she had no one to turn to. This example illustrates the conflicting emotions that the researcher may be faced with, as the natural instinct to empathise and assist has to be counterbalanced with the need to remain impartial, so as not to influence the interview's flow.

Feelings of emotion can be compounded when, in certain situations, the researcher becomes the confidante for the research participant, as they reveal personal feelings or experiences which they have not felt comfortable telling anyone else before. In these situations it may be very difficult to maintain a professional distance as most one-to-one human interactions have a reciprocal feel to them, with people sharing information with one another to build trusting, balanced relationships. Here again the need to remain 'at a distance' may seem unnatural and forced.

The session closed with Fiona talking about some of the strategies for dealing with these conflicting emotions and pressures, in order to minimise the stress that they can invoke. These included the need for adequate research training for researchers in interview technique and communication skills training, maintaining an open-door policy with supervisors so that any problems or difficulties that arise can be discussed and resolved, speaking with peers and sharing experiences, and undertaking regular stress management activities be it in the form of exercise, socialising or holidays!

The presentation raised some interesting points and served to remind BPOS PhD members of the inherent pressures involved in carrying out research with members of the public. Whilst the benefits of forming

researcher/participant relationships remains high, the session served to highlight the importance of taking steps to ensure that the psychological and emotional stresses that these interactions may incur can be dealt with by the facilitation of a supportive research environment.

1. Grunfield E, Whelan T, Zitzelsburger L, Willan A, Montesanto B, Evans W. Cancer Care Workers in Ontario: Prevalence of Burnout, Job Stress and Job Satisfaction. *JAMC*. 2000;163(2):166-9.

2. Rousseau P, Kukulka D. Nurses and Caring. *Am J Hosp Palliat Care*. 2003;20(1).

3. Parrish M, Quinn P. Laughing Your Way to Peace of Mind: How A little Humour Helps Caregivers Survive. *Clinical Social Work Journal*. 1999;27(2):203-11.

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Lucy Bryning, Bangor University

As a PhD student in my first year I was unsure what to expect from the BPOS event 'Surviving the psychosocial oncology PhD' on the 27th of June 2012. One of the most striking things was the broad scope of the research exhibited during the day. The presentations given by the students covered diverse topics and research approaches, and it was a fantastic opportunity to hear about the specifics of all the projects. Innovative uses of new and existing technologies were showcased, targeting a wide range of unmet need in psychosocial cancer care. Individuals with a wide spectrum of cancer experiences were represented throughout the research including haematological, breast, prostate, testicular, colorectal, brain cancers and cancer as a broad category. In addition, research topics also included ethnicity, sexuality, disability, economics and role of the family and carer, largely under-researched areas. I came away impressed by the amount of work people were fitting into their PhD programmes, and reassured that I will manage the task ahead.

Coming together as a group always serves to remind me that however unique my experience feels to me, there are others facing similar challenges. A PhD in any field is a serious undertaking, and we have

the added complication of working in what is commonly an emotion provoking area. This event helped to emphasise that individual resilience is not always enough to get us through this kind of work, and the support of our peers, supervisors, and a wider network is crucial.

A key message, although not specific to PhDs in this area alone, was how to make the most of our supervisors. Effective supervision is different for each individual, and it was good to hear of all the different approaches and how effective each was. The importance of managing our own supervision is clearly apparent, while not always an easy task.

During the event other students raised a number of questions, most notably 'what will you do once you've got your PhD?' This is not something I have given a great deal of thought to so far, so it was great to discuss these things with people at different stages. I gleaned an insight into what might be around the corner as we shared our top tips for 'survival' throughout the day.

A resonating theme throughout the room was that it really is just a PhD and not a Nobel Prize, something we all find very easy to forget when immersed in our own work.

While the research being undertaken under the banner of a psychosocial oncology PhD is diverse and often multi-disciplinary, the overlaps between the projects became apparent in the discussions. The event served to show where potential collaboration may be possible, and has provided us with a useful network that I'm sure will aid us both professionally and socially. Since the event we've even had the first few emails making use of our new contacts list instigated by one of the other students who attended the event.

It would be great to see more events aimed at students hosted by the BPOS as I thoroughly enjoyed the event. I'm definitely looking forward to attending the BPOS annual conference in 2013, hopefully to have another opportunity to hear more about the interesting high impact research being undertaken by psychosocial oncology students and researchers.

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Forthcoming events

2013 BPOS Annual Conference

The 2013 conference, 'Celebrating 30 years of BPOS', will take place on 17th and 18th January at the DeVere Grand Harbour Hotel in Southampton, UK.

Abstract deadline: **12th October 2012**

2014 BPOS Annual Conference

We are currently looking for a venue for the 2014 BPOS annual conference. If you have any ideas for locations, or are interested in hosting the conference, please contact Dr Nick Hulbert-Williams, BPOS Chair.

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BPOS on Twitter

BPOS now has a Twitter feed. If you or your organisation is also on twitter, you can follow us **@BPOSUK**. We are keen to use our twitter feed to inform people about general news, conferences, and funding information etc that is relevant to UK psychosocial oncology. If you have anything you'd like us to share with our members through twitter, please contact Laura Ashley (**l.j.ashley@leeds.ac.uk**)

BPOS e-newsletter

To ensure you receive our new quarterly e-newsletter, please make sure that you let the BPOS secretary have your up-to-date email address

(Samantha.Williams@wlv.ac.uk)

If there is something you would like us to include in the next e-newsletter, please email Laura Ashley

(l.j.ashley@leeds.ac.uk)



Advertising in the newsletter

Advertisements will be included at the discretion of the Executive, at a rate of £3.00 per column inch (3 columns per page) for BPOS members or £5.00 per column inch for non-members (£50 per half page). Please contact the Editor in the first instance.