

Forthcoming events

17 March 2009, Birmingham
Joint BPOS/SIGOPAC Symposium on Cancer Survivorship
<http://www.bpos.org/events.html>

7 – 10 May 2009, Vienna
11th Congress of the European Association for Palliative Care
<http://www.eapcnet.org/vienna2009/>

21 – 25 June 2009, Vienna
IPOS 11th World Congress of Psycho-Oncology, Vienna
<http://www.ipos-society.org/ipos2009/>

23 – 26 September 2009, Torino
20th World Congress of Psychosomatic Medicine
<http://www.icpm2009.com/site/index.asp>

December 2009,
date and venue tbc
BPOS Annual Conference
<http://www.bpos.org/events.html>

How to Join BPOS

Membership forms are available from
<http://www.bpos.org/membership.html>

Full membership £85

Associate membership £25

Students receive a £5 discount on either type of membership by sending proof of student status to the secretary on application of membership

Full membership includes subscription to Psycho-Oncology journal, voting rights, reduced entry cost to meetings and newsletter.

Associate membership includes the newsletter, notification of meetings, and reduced entry cost to meetings.

Contacting BPOS

Full details of the BPOS executive committee are listed on our website at <http://www.bpos.org/executive.html>. Any general enquiries can be directed to bpos@mvh-ljmc.org.

Nick Hulbert-Williams, the newsletter Editor, can be contacted by email at n.hulbert-williams@wlv.ac.uk, or by telephone on 01902 321329.

Website Updates

If you were at our 2008 conference, you'll be aware that the BPOS website (www.bpos.org) has undergone a make-over. Make sure you take a look at the changes we've made, including:

- ◆ New design
- ◆ New 'events' page
- ◆ New 'current projects' page
- ◆ Minutes from previous AGMs and Executive Committee Meetings
- ◆ Back editions of the newsletter
- ◆ Updated 'links' page
- ◆ ...and much more!



SIG Special Interest Group in Oncology & Palliative Care (SIGOPAC)



BPOS and SIGOPAC (The British Psychological Society Special Interest Group in Oncology and Palliative Care) would like to invite you to attend a one day symposium on:

Cancer Survivorship

Tuesday 17th March 2009
Queen Elizabeth Hospital, Birmingham

Keynote Speakers:

- Dr Sue Gessler,
University College London
- Prof Clare Wilkinson
Cardiff University, School of Medicine
- Dr Penny Wright & Dr Jane Haworth
St James's Institute of Oncology, Leeds

Registration fee: £15

Booking forms can be downloaded from the BPOS website.
Deadline for registration, Wednesday 4th March.

For more details, please contact Nick Hulbert-Williams at n.hulbert-williams@wlv.ac.uk.

Call for Articles

If you would like to contribute an article to the BPOS newsletter, please contact the Editor, Nick Hulbert-Williams. We welcome articles on research, service development, conference reports, or any other issues that will be of interest to those working in the field of psychosocial oncology.

Rates

Advertisements will be printed 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.

BRITISH PSYCHOSOCIAL ONCOLOGY SOCIETY

Newsletter Issue 1 2009

Dear BPOS Members

I welcome you to the latest edition of our newsletter, which closely follows the BPOS annual conference in December 2008 in Leeds. I am sure that those of you who came to the conference would agree that we had an exciting and stimulating time. Over the two days of the conference 91 delegates attended, despite the challenge of the bad weather, the snowstorms, icy roads and the long taxi queues in Leeds. However, once inside the hotel it offered us a warm and cosy atmosphere, with excellent organisation and tasty meals.

At the conference we launched the new BPOS website (www.bpos.org). It is newly designed by Justine Kilkerr from the Brighton Psychosocial Oncology Group. It contains updated information about our society. The executive committee is determined to make the website a useful resource for all society members. It already has available a large number of the posters presented at the BPOS conference. Please check the website regularly for updates on ongoing and future events.

It was a real pity that Leeds airport was closed and our first keynote speaker for the Peter Maguire lecture, Harry Burns, could not come from Scotland. However, we were all impressed by the forward planning of our main conference organiser, Penny Wright from Leeds, who, having heard the weather forecast the night before, had quickly put together slides from a talk she had given in Inverness a few weeks before, just to have something at hand in case things do not go according to plan. I am extremely grateful to Penny for saving the day and starting an invigorating two days of discussions and debates. Our next keynote speaker, David Cameron, Director of the National Cancer Research Network (NCRN), outlined the importance of psychosocial research within the NCRN portfolio and discussed ways forward for future successful collaborative work within the NCRN. Our keynote speaker on Friday, Barbara Monroe, challenged our approaches to studying social and deprivation issues in cancer, with stimulating examples and suggestions for a greater focus on simple individual interventions that will make a difference.

During the conference, we had an excellent set of oral presentations by predominantly young researchers, which indicates that our field is moving forward attracting new and enthusiastic researchers.

We all enjoyed a typical Yorkshire dinner, with a huge Yorkshire pudding, tasty meat and lovely desert. The energetic ceilidh dancing turned out to be a challenge for many of the delegates and we only managed about an hour of hopping and skipping!

It should be said that our successful and lively conference happened during a difficult time for psychosocial research in UK. At the end of November 2008, Cancer Research UK announced its new five-year strategic plan, which focuses the resources of the biggest cancer charity on prevention, early diagnosis and curative treatment of cancer. The charity has made the decision to discontinue funding of psychosocial oncology, quality of life research and research into doctor-patient communication. This unilateral decision will have a major impact on the field, as it will mean an end to a number of large programme grants, a large number of projects and discontinuation of funding for fellowships for young researchers. Several months later, there is still no unified strategy as to how the gap left by Cancer Research UK will be filled. It is likely that in the near future, the National Cancer Research Institute will perform a major review of the direction of travel within psychosocial oncology and patient-centred research and hopefully will identify alternative sources of financial support. On the positive side, since the announcement, many health care professionals and service users have passionately expressed their support for research in psychosocial oncology and patient-centred research, emphasising the important achievements of this research, which has changed the face of British oncology in the past 10 years. As a research community we should work together and try to turn this difficulty into an opportunity to look back at our achievements, build on our strengths and develop exciting ideas for the future.



We should work more actively with other societies and professional organisations to expand our research agenda. In March 2009, BPOS has organised a joint meeting in Birmingham with the British Psychological Society Special Interest Group in Oncology and Palliative Care (SIGOPAC), to discuss issues in cancer survivorship research. Please visit our new-look website for more information and registration details. Please come along to the Birmingham meeting, we look forward to seeing you there.

Galina Velikova
Chair of BPOS

In this issue



- 1 Introduction
Galina Velikova
- 2 BPOS 2009 Conference Reports
Teresa Young
Tony Duffy
Helen Aslett & Fiona Zinovieff
- 6 Special Report -The social impact of cancer on people of south Asian origin: Staff and patient interview study
Naheed Hanif
- 7 Special Report - A longitudinal study of the psychosocial impact of DCIS
Fiona Kennedy
- 8 Notices and forthcoming events



British Psychosocial Oncology Society

Registered Charity 29430

Conference Report: BPOS 2008

Despite a 5am start from the snowy depths of North Wales, a windscreen wiper malfunction on our train at Chester station (!) and the world's longest taxi queue at Leeds station (thank you Liz, Christine and Alisdair for rescuing us), we just managed to arrive at our first BPOS conference on time.

Irene Tuffrey-Wijne presented first on an ethnographic study into the extent to which people with learning disabilities are able to understand their cancer diagnosis and its implications. Huge knowledge gaps in relation to their understanding of cancer and its consequences were revealed, which highlighted the need for new models of open communication and better training in how bad news might best be conveyed to such individuals.

This was followed by Michelle Winslow speaking about mammography screening preferences in the over 70s. Analysis showed that most of the sample felt it important they were given a reminder about the availability of screening but that they should be given the autonomy (and necessary information) to decide whether or not to attend. There was a striking lack of awareness that currently those over 70 could have a mammogram on request.

The final presentation before lunch was by Naheed Hanif who conveyed with great enthusiasm her research with the Leeds Group into how the Social Difficulties Inventory (SDI) might be translated and used with Urdu, Punjabi and Hindi speaking cancer patients (see special report); let's hope that these tools can now be incorporated in models of good practice.

Lunch then beckoned, past the roaring log fire into the resplendent restaurant of the Thorpe Park Hotel where we dined on salmon and pasta (or in Fiona's case some "interesting" quorn!).



Simon Rogers gave an impassioned presentation on the development and use of the Patient Concerns Inventory (PCI) in his head and neck clinics. This touch screen computer based inventory allows patients to specify problems or concerns that they may currently be experiencing and is then electronically fed to consultants so that consultations can be tailored accordingly. Simon reported how he felt it had improved the quality of his consultations without a significant increase in consultation time and that patients felt that their consultations were more personalised. It will be interesting to see if this can be extended to other specialities.

Hannah Gilbert then presented some concerning findings on the implicit biases on clinician referral to sperm-banking. Hannah's research goes some way in explaining the low uptake in sperm banking. This is despite clear NICE guidelines that all men and adolescent boys about to undergo treatment should be offered such opportunities. Clinicians clearly need to receive appropriate training in how to broach this often difficult subject.

Elena Takeuchi then presented ongoing work on cancer specialists' reactions to using symptom assessment and psychosocial tools and their willingness to discuss such issues with patients. Whilst clinicians were keen for psychosocial assessment to be part of routine clinical practice, uneasiness was expressed by oncologists in their ability to deal with such issues as this was outside their 'comfort zone'.

Our afternoon tea break was swiftly followed by Fiona Kennedy and her engaging presentation on how DCIS diagnosis impacts on quality of life (see special report). DCIS is not life-threatening, but patients receive surgery similar to those with more serious forms of breast cancer. Fiona's research demonstrates how patient perception of a DCIS diagnosis could ultimately affect their long-term psychological outcome. An intervention clearly beckons!

The information needs of those close to a person receiving a cancer diagnosis is something of key interest to us in Bangor and so Eike Adams talk was keenly anticipated; she did not disappoint with her presentation of a systematic review of familial information needs. There is also a clear need for information that meets the needs of longer term cancer survivors but a dearth of research for cancers other than breast or prostate – something which we are addressing at Bangor.



Our final speaker on Thursday was Ziv Amir who presented results of a survey conducted with Occupational Health practitioners (OHPs) in relation to helping cancer survivors return to the work place post-treatment. Compared to other illnesses and conditions that may lead to protracted periods of time off work, there were often delays in cancer survivors being referred by their managers to OHPs.

Further research is required to identify the information and confidentiality issues surrounding return to work and to improve understanding and communication between health professionals involved in this process.

Having danced every dance in the ceilidh (where were you Fiona?) and getting to bed far too late after trying, but failing, to stay up longer than certain members of the exec committee (you know who you are!!!), we were amazed at how awake we felt on the Friday morning and glad we were too as we were treated to four great talks as well as a wholly inspiring key note speech from Barbara Monroe.

Christine Campbell started with her lively prize winning talk on barriers to colorectal screening in South Asian communities and low SES populations. This focus group study found that barriers to uptake included cultural taboos (familial shame surrounding a diagnosis, embarrassment, and disgust at the nature of the test) and the ability to read and understand the test information. Christine's talk made us all appreciate the importance of demystifying screening tests and making them accessible to all.

Emma Blows, recipient of the new researcher presentation award, followed with a research presentation into the extent to which Asian and Afro-Caribbean women access cancer support services and the extent to which they feel that their information and support needs are met. Again, using focus groups, results identified a strong feeling amongst the groups that publication imagery was primarily targeting Caucasian

patients suggesting that the services themselves could be isolating certain groups who are also in need of contact with others.

The penultimate presentation of the early morning session came from Sally Sheppard and the tricky issue of discussing sexual functioning in outpatient consultations. Using items from the FACT-G on 4 occasions, Sally identified that more than half of the sample at both time 1 and time 4 reported some level of dissatisfaction with their sex lives. Shockingly, these were not discussed in any of the consultations. Whilst health care professionals acknowledged the importance of this issue, they did not feel equipped to discuss them in consultations and felt particularly constrained by time. Action is needed to break down reluctance to broach this subject.

Rounding off BPOS 2008 was Robert Whistance's presentation focusing on the validity and reliability of a Body Image scale in relation to colorectal cancer patients (previously this has only been validated for breast cancer patients).

Although the sample size was relatively small (n=89), it was found that the body image scale was applicable to colorectal patients, and that BI scores were significantly worse for the stoma group. Robert further suggested that the scale should be reduced to a nine-item scale with the final item being a stand alone question to address feelings about the surgical scar.

The overall standard of presentations was high throughout the conference and topic coverage provided us with a great insight into hard to reach populations.

Greater time for discussion would have been welcomed, but time was limited due to such a full and informative programme. Nevertheless we headed back to North Wales feeling very inspired from what we had heard and keen to return next year!

Helen Aslett & Fiona Zinovieff
Bangor University



BPOS 2008:

A report on the keynote speeches



Heavy snow resulted in the first keynote speaker, Dr Harry Burns, being stranded in Glasgow. Fortunately, Dr Penny Wright was able to present on Psychosocial Oncology Research and Clinical Application. Penny used the Lauria et al. (2001) framework to highlight how people may respond psychologically and socially to a diagnosis of cancer. She then presented information regarding the development of touch-screen technology in cancer clinics which is hoped to improve the detection of distress that the traditional clinical interview has been demonstrated to frequently miss. Another new development Penny presented was the creation of the Social Difficulties Inventory which is intended to be another tool in the armoury of those attempting to identify psychological and social distress in people attending cancer clinics so to aid clinical outcomes.



The second keynote lecture was delivered by Professor David Cameron. As Director of the National Cancer Research Network (NCRN), his talk focused upon where psychological and quality of life research fits into the activities of the NCRN. After briefly describing the purpose of the NCRN, David emphasised that recently the portfolio has widened to include more non- and pre-cancer studies looking at all aspects of the cancer patient's experience. Psychosocial studies are now included in the NCRN database (currently there are 15 studies of which six are randomised control trials). Although the funding of such studies may be affected by the withdrawal of CRUK funding, David reminded delegates that there are still many other, admittedly smaller, organisations continuing to fund psychosocial oncology research. It appears as though the faster rather than the larger research studies appear more attractive to funding bodies at the moment. Cross-speciality studies that include non-cancer diseases may make "speedy" research proposals even more attractive.



The final keynote lecturer was Mrs Barbara Monroe, Chief Executive of St Christopher's Hospice. Directly addressing the theme of this conference, Barbara highlighted how end of life care is still inadequately delivered in many areas of Britain, especially if the dying person comes from one of the sub-groups that form those 'hard to reach' such as those in minority ethnic groups or those with mental health problems. After voicing concern that there appears to be a growing trend to draw back from delivering psychosocial services in favour of services that reflect a biomedical model of care, Barbara voiced her belief that limited resources need to be shared more freely and more wisely. Focusing upon communication skills training as an example, she stated that many professional care staff should receive brief training in the basic skills rather than only a few senior staff attending lengthy and expensive training advanced skills courses, the impact of which is questionable. In a time of recession, Barbara warned that we should not expect to see an expansion of services so maybe this is the time to focus upon providing greater support, including financial, to the many unpaid, informal carers who deliver so much care to the dying in Britain.

Tony Duffy
Swansea University

BPOS 2008:

A report on the poster presentations

With 41 posters submitted to BPOS it was a difficult and challenging task to view them all in the short time available. A lesson we have taken on board when planning next year's conference is to ensure posters can be viewed on both days. It is also not possible for me to comment on them all so I shall concentrate on those that interested me most. As someone whose office is 20 metres from the chemotherapy outpatients suite and 100m from the radiotherapy machines, and whose path through the hospital is through a myriad of waiting rooms packed with patients, my interest lies in those projects where someone has introduced a new service or intervention that directly impacts on patients rather than those who have done literature reviews or in depth qualitative interviews with patients about a particular concern. Such work is of course very necessary and without it others would not have the inspiration for their new projects or be able to plan or evaluate them effectively.



One such poster that caught my eye was the Development of a Sexual Rehabilitation Service for Cancer Patients introduced in the Birmingham area. The poster clearly described the need for the service with the majority of staff admitting they did not feel comfortable raising the topic and yet 30-50% of patients suffer some degree of sexual dysfunction, many being long term survivors. Only 30% of the referrals needed complex and time intensive interventions, the remaining 70% were helped with brief interventions. The authors recommended the adoption of a four tier model for providing sexual rehabilitation similar to that used for psychosocial support. Another poster from Nottingham described an RCT looking

at biopsychosocial rehabilitation programmes for patients following stem cell transplant. However it would appear that the maxim 'one size fits all' does not apply in this situation as patients expressed reservations about the standardised nature of the programme.



Researchers in Sheffield looked at providing an educational programme to help breast cancer patients prepare for discharge from routine annual follow up. The four sessions addressed issues around living with having cancer, the threat of recurrence and moving on from follow up. Patients are encouraged to view the transition as a positive experience giving them hope and confidence for the future. Changes in follow-up practice form an important part of the NHS Survivorship agenda and ways of facilitating these transitions will become more important. A poster from the SE London Cancer Network described the issues around setting up multiple support groups for a range of diagnosis across a whole network, including training and supervision of facilitators. So far eight new groups have been established and evaluation is just beginning. Salisbury District Hospital introduced a group programme to help patients as they finish their adjuvant treatment – a time when patients are known to feel particularly vulnerable as their contact with health professionals is reduced and anxieties about recurrence start to arise and they have to deal with 'picking up the pieces' of their life. The course has educational and therapeutic elements and led to a significant reduction in levels of depression when compared to patients who declined and invitation to the group.

However for many patients travel to attend a support group is not an option and yet they may still benefit from psychological support. A study from the Royal Marsden looked at delivering psychological support via the telephone (ProFITT®). The system is based on cognitive behavioural and problem-focussed therapy adapted to the needs of cancer patients and results from the study suggest a high patient satisfaction. Another poster of interest described the preparatory work for new web-based patient Decision Support Technology for women diagnosed with breast cancer who are offered surgical treatment options. Reactions to the system were mixed with many expressing concerns that the system might replace some face-to-face consultations and could provide information inconsistent with that provided by the breast care team. It will be interesting to see if and how the system is implemented and how much change was required from the original vision – definitely an area to watch as we all become more computer savvy and turn to computers for information.

The poster which won the overall prize came from Leeds and described work undertaken in a Head and Neck Cancer clinic where patients were invited to complete a number of similar quality of life questionnaires and were then asked which they preferred. They were also asked which areas they felt should be covered in their consultation and how this was reflected in practice. Patients reported that symptoms and side effects were often or always discussed (61%) and yet their priority 'disease specific limitations' was only discussed in 33% of consultations. Another patient priority was 'emotional aspects' and again there was a discrepancy between the patients wishes (63%) and actual practice (26%). Identifying acceptable questionnaires and ascertaining patient priorities will all contribute to patient care.

All the abstracts will be published in the April issue of Psycho-Oncology.

Teresa Young
Lynda Jackson Macmillan Centre

Special Report:

The social impact of cancer on people of south Asian origin: Staff and patient interview study

Health and social care professionals who work with oncology patients have a responsibility to provide access to information and services, and to offer support to all patients who attend cancer clinics and wards.

We planned a program of work to investigate the social impact of cancer on patients of south Asian origin living in Yorkshire with the vision of expanding routine patient centred assessment to include this patient group. This is a collaboration between the NHS Health Institute for Research at Bradford Royal Infirmary, Cancer Research UK Psychosocial and Clinical Practice Research Group in Leeds and the Department of Health Sciences, University of York.

The first part of the study involved translating the Social Difficulties Inventory (SDI), a 21 item inventory exploring social difficulties, into three prevalent south Asian languages, Hindi, Urdu and Punjabi (Figure 1). As the SDI was developed in main from a white British population we wanted to test the translation of the SDI in terms of cultural relevance, equivalence, effectiveness and understanding. Additionally, we wanted to find out patients experience of support, and what they would like and expect if routine patient centred assessment was introduced.

Recruitment took place between November 2007 and September 2008, from a variety of Oncology and Haematology clinics across three sites; Bradford Royal Infirmary, St James' University Hospital and Airedale General Hospital. Eligible patients were those of south Asian origin with Hindi, Urdu or Punjabi as their primary language and who were physically and mentally capable of taking part in an interview. Patients were excluded from the study if they were already participating in a psychosocial oncology research project, if they had taken part in an earlier phase of the development of the SDI, or if they had been diagnosed with cancer less than three months ago.

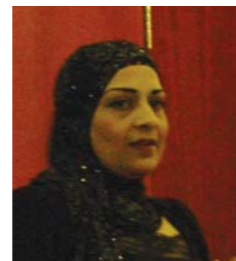
Fifty-five patients agreed to take part (65% participation rate). Participating patients were diverse in diagnostic site, treatment intent, age (18-80 years), socio-demographics, levels of education, primary language and migration history. There was a good balance between the numbers of male (N= 25) and female (N= 30) patients accrued.

Patients were asked to complete the SDI in the language of their choice and then interviewed around the reasons for patient response choices, expected outcomes on each of the SDI items and the feasibility of introducing routine patient centred assessment for cancer patients of south Asian origin in terms of patient acceptance and relevance. Framework analysis was applied to analyse the interviews. Preliminary patient interview analysis has revealed some recurring themes including:

- ◆ South Asian cancer patients' acceptance of SDI as culturally relevant and useful screening tool.
- ◆ Willingness of patients to discuss social difficulties with healthcare professionals.
- ◆ Patients dealing with social difficulties themselves (such difficulties are generally seen as their own responsibility).
- ◆ Acknowledgement that when there is a lack of personal support or a worsening of difficulties, outside support is wanted and accepted.
- ◆ Language barriers as hindering communication between patients and healthcare professionals and limiting understanding of accessing support.
- ◆ Similar social difficulties to the general population participating in previous studies.

The second part of the study involved interviewing 10 members of staff to investigate how oncology and haematology outpatient nurses and doctors interpret the SDI item responses provided by south Asian patients and to investigate what reasons they had for choosing to act, or not to act, on the SDI response (no action, discussion with patient, referral etc.) We also wanted to explore what training they would find useful in using the SDI with this patient group in clinical practice. Analysis of staff interviews is ongoing.

The study is providing information on the experiences of cancer patients from minority populations, their knowledge of and access to services, attitudes to being included in patient centred assessment and expectations of health and social care professionals. Comparisons will also be made with similar work undertaken on the mainly white British cancer patient population. This will help develop and evaluate supportive care guidance for patients and staff, provide a more equitable health and social care environment for 'all-comers' in oncology, and should result in improved patient well-being and staff confidence.



Naheed Hanif
Psychosocial and Clinical Practice Research Group, Leeds.

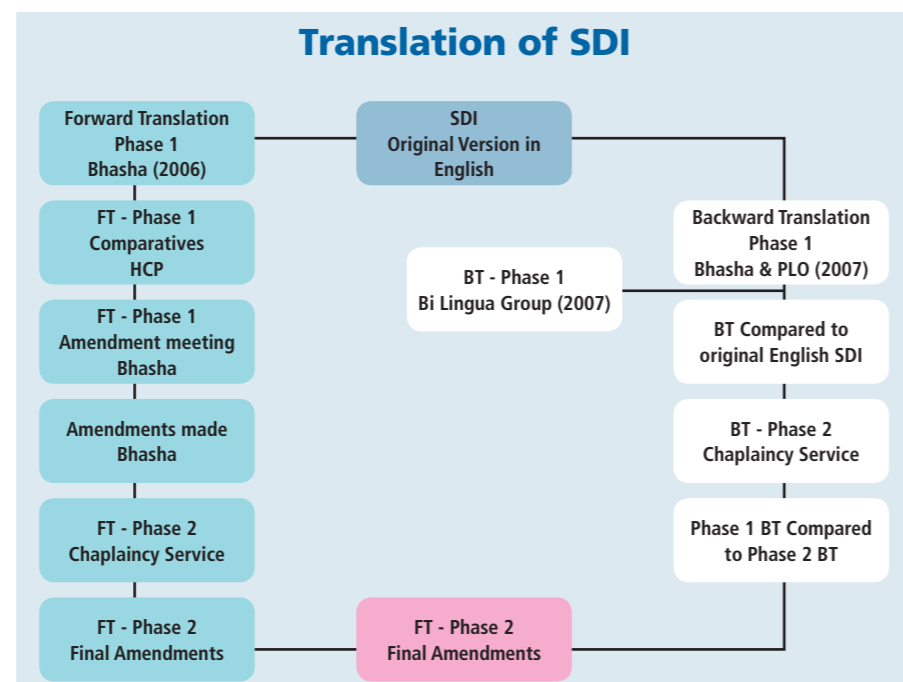


Figure 1: Flowchart showing process for translating the SDI into three south Asian languages

Special Report:

A longitudinal study of the psychosocial impact of DCIS

Diagnoses of ductal carcinoma in situ (DCIS) have risen dramatically since the National Health Service Breast Screening Programme (NHSBSP) was established and now represents 20% of screen-detected breast cancers in the UK (NHSBSP, 2006). DCIS is a non-invasive condition, where cancer cells are detected but confined to the ducts of the breast (Leonard & Swain, 2004) and currently do not have the ability to spread. It is important to distinguish DCIS from invasive breast cancer (IBC); in particular that, whilst the cells are contained within the ducts, the condition is not life-threatening and most patients have an excellent prognosis post-treatment (Ernster et al, 2000). Despite this positive outlook, women with DCIS may still experience a range of psychosocial issues, which may be 'different' to those reported amongst IBC patients (Wellisch, 1997), due to its asymptomatic nature, lack of prior awareness, uncertainty (e.g. it may or may not progress into IBC) and the treatment paradox (women typically undergo extensive treatment, including mastectomy, to treat this non-invasive/early disease). Yet, to date, there has been a paucity of studies investigating DCIS patients' experiences, especially prospective work in the UK (Carrera & Payne, 1999).

Research at the University of the West of England (Bristol) has been exploring the psychosocial impact of DCIS. Early work with women previously diagnosed with DCIS indicated that it was a challenging and confusing diagnosis, and that women held diverse perceptions about the condition (ranging from "a type of breast cancer", to "pre-cancer"), which impacted on their experiences of treatment, support and adjustment (Kennedy, Harcourt & Rumsey, 2008).

More recently a mixed methodology prospective study was conducted to explore the psychosocial impact during the first year following diagnosis. Following multi-site ethical approval, a pragmatic method recruited women newly diagnosed with DCIS (< 3 months post-diagnosis) from 9 breast clinics in the UK. The approach was flexible to ensure that women were not overburdened during this early, sensitive period. Within the quantitative phase (which was presented at the BPOS conference in Leeds, December 2008), women completed questionnaires at baseline, 6 and 9 months, including the HADS, Hopwood Body Image Scale, Global Quality of Life (QOL) and the Illness Perception Questionnaire (IPQ-R). Forty-two women with pure DCIS completed all assessments. Nineteen women had a mastectomy (including one bilateral), of which 9 underwent immediate reconstruction.

Firstly, in terms of anxiety case levels (HADS > 11) there was a considerable level of anxiety in all surgical groups at baseline (see Figure 1), which was expected given

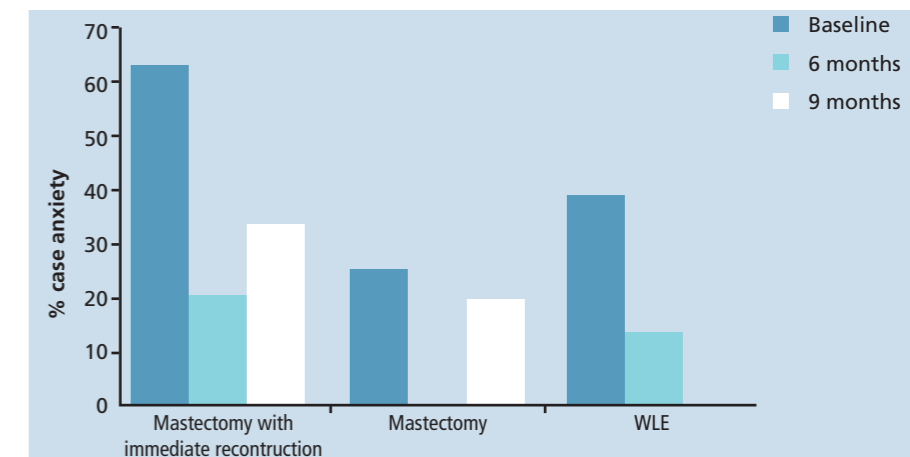


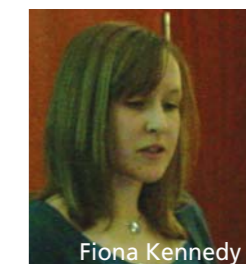
Figure 1 - Percentage of HADS 'case' anxiety according to surgery (N.B. represents surgery received/receiving at baseline, and final surgery at 6 and 9 months)

the proximity to diagnosis, but it was particularly apparent among immediate reconstruction patients. Anxiety dropped considerably at 6 months but at 9 months post-diagnosis, 20-30% of the mastectomy and immediate reconstruction groups reported case levels (whereas there were no case levels in WLE patients). Repeated measures ANOVAs found that anxiety and depression decreased significantly from baseline to 6 and 9 months. There was also a significant surgery effect, whereby patients who underwent immediate reconstruction had higher depression and body image distress (compared to WLE patients). However, it is important to highlight that there were only small numbers of participants in each surgical group.

Subsequent multiple regression analyses revealed that perceiving higher consequences of DCIS (a subscale on the IPQ-R that explores the individual's perceptions of the seriousness and impact of the condition) was a strong predictor of higher anxiety, depression, body image distress, and lower QOL at 9 months. Having an immediate reconstruction also predicted higher body image distress and lower QOL, although interestingly having a mastectomy alone was associated with higher QOL.

This study observed significant improvements in anxiety and depression overtime. However, women who opted for an immediate reconstruction appeared to endure longer term difficulties (e.g. body image distress/depression) and therefore these women may require more help and support adjusting to the diagnosis and treatment. There also appears to be an important role in how women perceive the consequences of DCIS, which needs further investigation but may relate to our earlier work that highlighted the diversity of DCIS perceptions (Kennedy et al. 2008). There are obvious caveats in this study, especially the small sample which limits the interpretations that can be drawn.

Overall, this study was exploratory and highlights the need for further in-depth research of newly diagnosed patients experiences and their perceptions of DCIS. The qualitative data that was also collected as part of this study (at baseline and 9 months) is revealing interesting, in-depth findings which will add to the growing literature on the psychosocial impact of DCIS.



Fiona Kennedy, Diana Harcourt, Nichola Rumsey
Centre for Appearance Research, Faculty of Health & Life Sciences, University of the West of England

Contact Details: fiona2.kennedy@uwe.ac.uk

Key references

- Carrera C, Payne S (1999). Ductal carcinoma in situ (DCIS) of the breast: The need for psychosocial research. *Psycho-oncology* 8(6): 538-545.
- Ernster V.L, Barclay J, Kerlikowske K, Wilkie H, Ballard-Barbash R (2000). Mortality among women with ductal carcinoma in situ of the breast in the population-based surveillance, epidemiology and end results program. *Archives of Internal Medicine* 160(7): 953-958.
- Kennedy F, Harcourt D, Rumsey N. (2008). The challenge of being diagnosed and treated for ductal carcinoma in situ (DCIS). *European Journal of Oncology Nursing* 12: 103-111.
- Leonard G.D, Swain S.M (2004). Ductal carcinoma in situ, complexities and challenges. *Journal of the National Cancer Institute* 96(12): 906-920.
- National Health Service Breast Screening Programme (2006). Screening for breast cancer in England: past and future. NHS Cancer Screening Programmes, Sheffield.
- Wellisch D.K (1997). Commentary to Chapter 28: Psychological impact of non-invasive breast cancer. In: Silverstein M.J (ed) *Ductal Carcinoma In Situ*. Williams and Wilkins, Baltimore, pp 311-312.