Identification of Support and Information needs along the care pathway for patients with non-small cell lung cancer (NSCLC) receiving Treatment with curative intent chemo-radiotherapy: Emerging findings from the INSIGHT study

Jackie Fenemore Lung Cancer Nurse Clinician, The Christie Hospital, Project team; Grant Punnett, Research Associate
Christie Patient Centred Research (CPCR), Janelle Yorke, Professor of Research
Fiona Blackhall, Professor of Medical Oncology
What we know already

- Concurrent chemo-radiotherapy
- It’s not an easy treatment!
- Complex pathway
- Toxic/difficult side effects of treatment
- Prolonged side effects and recovery time
- Uncertain prognosis
- Curative pathway/ no choice?
- Recent compassionate use approval for Durvalumab (immunotherapy) to add to the mix post concurrent chemo-radiotherapy
Nursing Research

- Fantastic opportunity at The Christie due to Professor Janelle Yorke’s team and the CPCR team (Christie Patient Centred Research) Group
- NLCFN small grant award
- Steep learning curve to navigate around the research process
- Setting up even this small scale trial 1-2 years
- Recruitment over 6 months July-Dec 2017
Background

- Greater Manchester has a high incidence of lung cancer.
- Approx. 80-85% of lung cancers in the UK are NSCLC
- (Adenocarcinoma, Squamous Cell Carcinoma)
- Only approx 20% of all NSCLC pt’s are Stage 3 (non metastatic) at diagnosis
- Treatment with curative intent when surgery is not possible is concurrent chemo-radiotherapy.
- In 2017, The Christie were referred 43 patients for concurrent treatment with 35 going on to receive it.
- Small numbers but intensive pathway
Methodology

- Single centre, qualitative study
- Semi-structured interviews
- N = 20 participants (10-15 with/without carer dyads)
- Recruiting patients pre-treatment, during treatment, during initial post treatment scans/reviews and at follow up
- Thematic analysis
Participants

- Recruited N = 20 participants (15 Patients, 5 Patient-Carer dyads)
- 3 Pre-treatment, 3 during treatment, 6 end of treatment, 3 in follow up.
Age range of patients at start of treatment

- 40-50
- 50-60
- 60-70
- 70+

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Patient Experience

Information needs

Emerging themes

Emotional impact

Managing Side Effects

Lifestyle impact
Treatment affecting quality of life

- **Physical Symptoms**
  - Breathlessness, fatigue, oesophagitis, (Painful swallowing), night sweats, nausea, dysgeusia (loss of taste/metallic taste), skin reaction, weight loss, hair loss, tinnitus

- **Emotional Impact**
  - Recurrence anxiety
  - Feeling overwhelmed and isolated (especially where no family or carers involved)
  - Depression/distress

- **Lifestyle impact**
  - Frequency of visits/change of routine
  - Long treatment waiting times
  - Reliance on others to help
  - Unsure of self help measures e.g. exercise
Level of Information Given

- ‘I thought it was going to be awful and I wouldn’t be able to eat anything, but it wasn’t that bad. It was the skin burn that was horrendous’. Pt1004
- ‘The side effects were toned down a bit too much’ Pt 1002
- ‘I don’t think they prepare you for how gruelling it is’ Pt 1008
- ‘It wasn’t that I couldn’t be bothered…I just didn’t want to know all those things’ Pt1005
- ‘I just want to know everything, I’m just one of them people’ Pt 1008.
- ‘I think nobody wants to hear a horror story’ Pt 1003
- ‘I don’t want to be told bad things’ Pt 1001
Emotional Impact

- ‘It’s a tough treatment, mainly because of the mask. You can’t see, hear, or speak with it on’. Pt 1004.
- ‘I’m not a woman but I still don’t particularly want to lose my hair’ Pt 1010
- ‘I even give it a name, Harry,. I used to talk to it. You’re not getting the better of me’. Pt 1008
- ‘No information once you’ve completed treatment’ Pt 1008
- ‘Maybe having a booklet or something with general information in about getting over treatment’ Pt 1006
- ‘So much going on’. Pt 1015 (pre treatment)
- The information tells you about the medical information, but it doesn’t tell you about the psychological impact. It needs to focus more on your psyche’. Pt 1008
- ‘I’ve remained positive, I’ve not stopped working’. Pt 1003
Lifestyle Impact

- ‘It’s been quite an assault on your body’ pt1003.
- ‘It’s just been tough’ Pt 1011
- ‘I’ve been going to bed at 8pm everynight’ Pt 1012
- ‘Get ready for the fight of your life. It really was’. Pt. 1002
- ‘Once the fatigue set’s in its there for the day. Not the sort of tiredness where you can say, right I’ll have a 20 minute sleep’ Pt 1003.
- ‘Knowing when to start to get walking, get moving, starting to push your exercise tolerance’. Pt 1006
- ‘I had a conscious thing because I need to be here for the children, so I carried on eating even though many times I could have given up. How I ate I don’t know’. Pt 1008
- ‘I think if I keep myself fit it might stop this tumour coming back’ Pt 1004
“They did tell me because the cancer was near my oesophagus that it may affect my swallowing and that. But I didn’t know how severe that would be, and it’s been really severe, I’ve been living on Rice Krispies for about a week.” I011, Patient

“The pain management team were fantastic but actually need to be tied in much earlier for patient’s who are demonstrating pain”. Pt 1006

“Well I would have wanted them to actually say to me, this can make you really depressed. Because a few times I thought, I’m not going back there, I’m not having any more of this. I’m just going down to that big building in town, the Beetham Tower, going upstairs and jumping right off the roof, right onto the floor. I’m not living anymore. “ I012, Patient
Ways of coping

– Accessing support
  • Maggie’s Centre
  • Macmillan Nurse
  • Clinical Nurse Specialist
  • Family
  • Psycho oncology

– Motivations
  • Family
  • Maintaining positive attitude
  • Focus on completing treatment
  • Idea that there is “no alternative”
Improving the Information

- Ways of receiving information & when (verbal/written/internet)
- Specific information on concurrent treatment rather than separate information sheets
- Mask! (who needs one)
“Well, I was looking for a booklet on the chemo and the radiation together, because you get a radiation and you get a chemo, but you don’t get a chemo/radiation booklet together. You don’t get a booklet that’s how you feel when it’s together like that. There was nothing out there that was specifically aimed at the treatment of them together.” I004, Carer

“The other thing is, what advice is available on things like diet, exercise, lifestyle, going out, mixing with people and all this sort of paraphernalia. I think that’s a vital part of it. Because what I find, there is a risk of sitting at home all day and not doing anything.” I013, Patient
Support needs

- Living with and beyond - What happens next?
- Early progressive disease (20-25% of patients having this treatment will not have recurrent disease)
- Earlier links with Palliative/Supportive Care, work on-going to pilot this collaborative approach to managing this patient cohort
“We got up on the Monday and we were sort of on our own. We knew that things were going to get worse and everything, and it started to get worse, but I didn’t really know what to do about it.” C04, Carer

“I thought you always die if you get lung cancer” Pt 1006.
Emerging Learning Outcomes

• Tailor information and support to the individual;
  Where is treatment targeted? What side effects likely as a result? Will this patient need a mask?
  – Do we adjust information giving (verbal/written) More personalised approach to information giving?
  – Develop specific pathway information for concurrent treatment. Information on additional support
    • Dietary information (soft diet/liquidised)
    • Exercise (boundaries/tolerance)
    • Life after Treatment (LWBC/Survivorship)
What I’ve learnt about nursing research

- Rewarding experience
- Time consuming, so much Data!
- Part of my nurse clinician role/ time factored in?
- Get help/you can’t do this alone
- Improving the experience for lung patients is the goal
- The treatment pathway seems even tougher than I first thought!
- Lets get more clinical nurses actively taking part in patient centred research/service review/audit
Lung cancer: Building hope in challenging times
Thank you
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