Cancer Survivorship: evaluating alternative strategies for follow-up care

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What is Cancer Survivorship?

‘Macmillan calls upon health and social care organisations and cancer charities to put in place services to meet the needs of people living with or beyond cancer and their carers. Whether a person thinks they “had” cancer or “have” cancer shouldn’t matter. We want them to be able to get the care and support they need.’

Ciarán Devane, Chief Executive, Macmillan Cancer Support

Cancer Survivors

- It is estimated that there are now 2 million cancer survivors in the UK
- 10% of the total UK population over the age of 65 years are now cancer survivors
- The number of cancer survivors is increasing by 3.2% each year

Policy context

• Cancer as a long term condition

• Current follow-up arrangements not meeting needs of survivors

• Patients want more information and advice

• Shift towards information provision

• Patients should be empowered to manage their condition based on needs and preferences

• Need new models of care
Risk stratified model of care

Cancer Care Pathway

Rehabilitation: surviving the first year
Early Monitoring: up to 5 and 10 years from diagnosis
Late Monitoring: more than 10 years from diagnosis
Progressive Illness: incurable disease but not in last year of life
End of life: last year of life

Cancer Care Pathway

• Not all stages of pathway have equal numbers
• Focus of policy has been on diagnosis, treatment and end of life
• In some cancers *majority* are in stages of rehab and monitoring
Breast cancer care pathway – number of women in the UK 2008

What happens post treatment?

• Care after treatment – ‘follow-up’/ ‘aftercare’
• Followed up in hospital OPD clinics
• Regular but decreasing intervals for 3-5 years (or longer)
• Often seen by more junior clinicians
• Using breast cancer as exemplar
Breast cancer in the UK

- Most commonly diagnosed cancer
- In 2009 over 48,000 women diagnosed
- 85% diagnosed in women aged 50 +.
- In 2007/2008 the NHS screening programmes detected 16,000 + cases
- More women are surviving breast cancer than ever before.
- Almost 2 out of 3 women survive their disease beyond 20 years.
- Breast cancer survival rates have been improving for 20+ years.
- 9 out of 10 of women diagnosed with stage I breast cancer survive their disease beyond 5 years.
What does follow-up/aftercare consist of for breast cancer?

Outpatient Department Visit:

- Consultation
- Clinical Examination
- Routine Mammography
Why?

• Aim to detect recurrent disease at an earlier stage

• Earlier detection will have a survival benefit

• ‘screening’ for recurrence/relapse
Are recurrences detected at hospital visits?

- Majority of recurrences are detected by patients or mammography
- Contribution of mammography is of increasing importance – approx 46%
- Patient detected: 30-40%
- Clinical examination: 13-15%
- No evidence to suggest that clinical examination confers a survival advantage

Costs to the NHS

- 2010-2011: NHS hospitals in England provided more than 366,000 outpatient appointments for patients following breast surgery.

- 2010-2011: NHS Reference Costs. OPD follow-up visit for breast surgery - £111.

- NICE (2002) - cost savings of £9.3m in England & Wales if follow-up limited to 3 years for breast cancer.
Focus of research

- Duration of follow-up
- Impact on survival
- Detection of recurrence
- Resources
What happens during follow-up consultations?

• What are clinicians views on follow-up?

• What are perceived benefits to patients?

• Is the consultation an opportunity to provide information and support for patients?
Observe what happens

Ethnographic approach (observing a culture)

- Observation of 104 consultations
  - Audio-recorded
  - Transcribed
  - Timed
- In depth interviews with 14 HCP’s
- Patient survey (87% response)

Follow-up appointments are brief

Allocated 10 mins
Mean of 6.2 minutes
Shortest : 1 min 23 secs
Looking for recurrence

- Clinicians focused on 3 factors:
  - Clinical examination
  - Checking that medication (when prescribed) was being taken
  - Clarification of mammography examination.

- Clinicians knew they were unlikely to detect recurrence
- A narrow focus on these 3 factors could inhibit some patients expressing their concerns
Consultation extract

Dr: How are you?
Pt: Well, I haven’t been too good.

Dr: Good, good, good, very good. Can I have a look at you?
Now how is the pain now? Is it resolved? The pain in the breast?
Pt: Oh, I’ve no pain in the breast. I’m fine as far as that’s concerned.

Dr: “Okay, let me have a look at it to see everything is ..... 

Pt: But I’ve got all the side effects of the ... of the ....
Dr: Tamoxifen.
Pt: Tablets. I’ve ..... 

Dr: When was this operation done?
Pt: Oh, I don’t know. About two years ago.
Dr: Oh right. When did you have a last ...did you have a mammogram recently?
Pt: No.
KB: So, if I were to ask you what you would consider to be the aim of the routine follow-up visits, of bringing women back up to clinic, what would you say?

Dr: No idea.

KB: And yet it continues.

Dr: And yet it continues, yes. On the one hand there’s no doubt they get (pause) the majority get agitated before they come. On the other hand if they go away with the advice that all is well they seem to get profound relief from it. But how long that lasts I’ve no idea. Most women seem grateful for it and I’ve never really come across anybody who has resented it or thought it was a waste of their time.

KB: I’ve noticed all the consultations I’ve observed there seems to be a clinical examination, either of the breast or the lymph nodes or the abdomen. Is the physical exam a vital component of the visit?

Dr: No, I suspect it’s a complete waste of time.
Patient benefit?

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<tbody>
<tr>
<td>Reassurance</td>
<td>Anxiety – fear of recurrence being detected (61%)</td>
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<tr>
<td>Friendly staff</td>
<td>Car parking</td>
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<td>54% over-estimated</td>
<td>Long waiting times</td>
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<td>duration of appointment</td>
<td>Travel costs</td>
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<td>Time out of work</td>
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Is this evidence based practice?

- Historically based practice
- Not sustainable given number of survivors
- New strategies for follow-up need to be evaluated
- How to incorporate opportunities for discussion of information and psycho-social needs?
What are the alternatives?

- Minimalist
- GP
- Radiographer
- Nurse-led clinics
- Telephone FU
Nurse led telephone follow-up

- If recurrences not detected at clinic visits why bring people to busy hospital clinics?
- Telephone people at home
- Specialist nurses
- Structured telephone intervention
- Specific questions
- Designed to meet patient needs (information)
- Guided by what patients want to know
# Information needs

<table>
<thead>
<tr>
<th>Newly diagnosed (n=150)</th>
<th>2 yrs from diagnosis (n=105)</th>
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<tbody>
<tr>
<td>1. Cure</td>
<td>1. Cure</td>
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<tr>
<td>2. Spread of disease</td>
<td>2. Genetic risk</td>
</tr>
<tr>
<td>3. Treatment</td>
<td>3. Spread of disease</td>
</tr>
<tr>
<td>4. Genetic risk</td>
<td>4. Treatment</td>
</tr>
<tr>
<td>5. Side effects</td>
<td>5. Side effects</td>
</tr>
<tr>
<td>7. Self care</td>
<td>7. Social life</td>
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<tr>
<td>8. Social life</td>
<td>8. Self care</td>
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Telephone Intervention

• Research instrument – Information Needs Questionnaire (INQ) – developed in Canada
• Adapted it for use as a telephone intervention
• Questions would directly relate to what patients had indicated they wanted to know
Telephone Intervention (20 mins)

- Previous issues
- Any changes?
- Information about cancer/spread of disease
- Information about treatments and side effects
- Information about genetic risk
- Information about sexual attractiveness
- Information about caring for self
- Concerns about how family are coping
- Anything else?
- Mammograms (request if necessary)
- Next Appointment
Why the telephone?

- Convenient for patients
  - No long waiting times in clinic
  - No parking problems
  - No travelling, own home (saves money)
Why specialist nurses?

- Specialist knowledge and expertise
- Meeting physical & psycho-social needs
  - histology, genetic risk, side effects, breast reconstruction, breast prosthesis, body image issues
- Appropriate referrals
  - lymphoedema, GP, surgeon, oncologist, psychologist
- Written information
- Continuity of care
Comparison - RCT

- Traditional hospital follow-up (control)
  vs
- Telephone follow-up by specialist nurses (intervention)

- Two centre study (Northwest England)
Complex intervention

• Interventions with several interacting components
  – Nurse (instead of doctor)
  – Telephone (instead of hospital)
  – Focus on information provision (instead of search for recurrence)
Evaluating complex interventions

Key questions

• Does the intervention work in everyday practice?
  ✓ RCT (hospital vs telephone)
• How does the intervention work?
  ✓ Qualitative work (explore experiences)
Getting up and running
Considerations

• No clinical examination for Telephone group
  – *something will be missed*
• Telephone group will be more anxious?
  – *will use other services instead* – *overburden GPs*
• Asking questions about cancer over the phone
  – *tip them over the edge*
• Credibility of phone calls/skilled intervention
  (experience/knowledge)
  – *anyone could be trained to make calls*
• At least it should be cheaper
Inclusion criteria

• Completion of primary treatment (surgery, R/T, chemo)
• No evidence of recurrence
• Low-moderate risk of recurrence (Nottingham Prognostic Index <4.1)
• Access to telephone
• Adequate hearing ability
Sample size

- Equivalence trial (equivalent for anxiety, better in other respects)
- Powered on primary outcome – psychological morbidity (STAI)
- Target sample size – 162 per group
- Recruited 374
- 60% agreed to participate
- Refusers – clinical examination, face to face contact, family preference
Findings

- 374 patients in study
- Telephone group were not more anxious
- Telephone group significantly more satisfied with information
- Telephone group significantly more satisfied with service
- No differences in time to detection of recurrence

Time to detection of recurrence

- 17 recurrences (6 hospital, 11 telephone)
- Median time to confirmation:
  - Hospital: 60 days (range 37 to 131)
  - Telephone: 39 days (range 10 to 152)

- This apparently large difference between groups, at least in terms of the medians, was not statistically significant (Mann-Whitney $U = 21.0, p = 0.228$).
Was telephone follow-up cheaper?

Data:

561 Telephone appointments

555 Hospital appointments
Cost effective?

- Telephone FU more expensive (£179 vs £124)
- Takes into account all tests, investigations, referrals, salary costs, training
- Nurses took longer over phone (mean 20 mins)
- Calls made by senior nurses (not cheap)
- Patients and carers saved money (travel, time out of work)
- Opportunity costs – frees up doctor time and clinic space
- Quality service but not necessarily cost savings for NHS

Qualitative work (experiences)

Interviews - 28 patients in T group
4 BCN’s

Patient interview guide
- Importance of follow-up
- Appointments conducted by a nurse rather than a doctor
- Appointments conducted over the telephone
- Likes and dislikes related to telephone follow-up
- Views on types of questions asked over the telephone
- Views on not physically attending hospital clinics

BCN interview guide
- Telephone rather than face to face
- Advantages and disadvantages of telephone follow-up for patients as well as themselves

Patient Interviews: Convenience

…it wasn’t rushed. You didn’t feel you were up against the clock and that you were wasting someone’s time… they weren’t hurrying you and hassling you…So that’s so completely different from a hospital consultation where you feel obliged to be in and out (ID04p)
Continuity

Well it’s a continuation and you feel...it makes you feel comforted that there is somebody to talk to. Because you go to your GP and they’re very good and very understanding but they’re not specialists and you don’t...it’s nicer to talk to somebody who knows what they’re talking about (ID17p)
Normalising

Because I am sure that there are a lot of people like me that return to normality. It’s a thing of the past. You have a full life. You function. You’re working. You’re living. You have a social life. You’re doing everything. It is much more relaxed to know that you don’t have the alien thing of the hospital. You can have it in your home [telephone follow-up]. You have it at work. You can have it on your mobile if you want sat in the car (ID02p)
Structure

I felt that being asked continually, then that there would be no... error, for want of a better word. It would be no error, because they were constantly asking you ...and that made me feel secure (ID10p)
Conclusions

- Specialist nurses can deliver a high quality follow-up service over the telephone
- Shifts focus away from clinical examinations with limited value to meeting the information needs of patients.
- High levels of patient satisfaction in Telephone group
- Reduced burden on hospital outpatient clinics
- Savings for patients (money, time)
- Not necessarily cost savings for NHS (opportunity costs)
- Suitable for patients with long travelling distances (reduces carbon footprint)
- Broader applicability for other patient groups (e.g. bowel, endometrial)
How does this fit with NCSI?

- New approach to follow-up
- Designed to meet information needs
- Providing people with information they need
- Promotes confidence to self manage
- Not all patients will want to be telephoned
- Negotiated approach based on patient preferences
- Offering choice
Thank you

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