Diagnostic journeys in myeloma: How long does it take to diagnose?

Methodological issues and progress to date

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Background

Myeloma is a mature B cell malignancy with no set pattern of presentation. It is acknowledged as 'hard to diagnose' with multiple complexities contributing to time-to-diagnosis. There is limited literature to describe these pathways. Journey time intervals may be influenced in multiple domains:

- Bone pain/musculoskeletal pain/fatigue requiring opioids for symptom management with 13/30 patients having had 3 or more consultations with GPs
- 19/30 had 3 or more consultations with GPs
- 2/30 patients in a monitoring program for myeloma

Aims

- Quantify and describe how diagnostic journeys occur in myeloma patients across Wales
- Determine factors, interactions and experiences influencing the pathway to individual diagnosis
- Determine factors which facilitate timely diagnosis

Methods

Phase 1 Quantitative study:

- Designed disease specific questionnaires to patient, GP and diagnosing specialist collect complexities of the journey; triangulation and interpretation of data determining influences and exact time to diagnosis. Recruitment direct from diagnosing MDT allows collection of real time data on:
  - Pre-diagnosis symptomology and duration
  - Routes of presentation in PC and SC
  - Frequency of health care access
  - Demographics
  - Comorbidities
- Free text questions in all participant questionnaires help identify information-rich participants for interview

Phase 2 Qualitative study:

- Semi-structured interviews with patients and their GPs
- Evolving interview guide informed from Phase I data
- Personal social and contextual experience captured
- Sampled from prompt, longer and asymptomatic
- Determines what works well and what doesn't work so well

Analysis:

- Phase I and II data - independent reporting and publication
- Synthesis of two datasets – unique view and report of factors promoting timely diagnosis help influence policy and practice

Early findings: results from first 30 patients

- Recruitment Phase I

<table>
<thead>
<tr>
<th>Patient questionnaires returned vs screened</th>
<th>Primary Care questionnaires Returned</th>
<th>Secondary Care questionnaires returned</th>
<th>Full 3 dimensional profile available</th>
<th>No consent to clinicians questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>30/43 70%</td>
<td>13/30 43%</td>
<td>22/30 73%</td>
<td>13/30 43%</td>
<td>1/30 3%</td>
</tr>
</tbody>
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- Questionnaire Return Phase I

<table>
<thead>
<tr>
<th>Time to diagnosis</th>
<th>Appraisal interval</th>
<th>Diagnostic interval</th>
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<tr>
<td>Interval – median days (interquartile range)</td>
<td></td>
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<tr>
<td>144 (32-258)</td>
<td>43 (4-227)</td>
<td>62.5 (16-171)</td>
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<tr>
<td>Range 0-825</td>
<td>Range 0-714</td>
<td>Range 0-253</td>
</tr>
</tbody>
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Conclusions

Early findings:

- Primary care – problematic referral pathways onto SC
- Symptom attribution – patient – poor recognition of seriousness
- Symptoms attribution GP – misattribution of recognised myeloma related symptoms
- Symptom signature – ‘bone, musculoskeletal pain and fatigue
- Associations of variables will provide greater insight
- Qualitative interviews will add to the richness of data giving a unique context to the results.

For further information about this project please contact Tania Seale: Email t.d.seale@bangor.ac.uk