The value of a nursing review of the PID patient on home therapy with Immunoglobulin

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AIMS

• Explore nurse’s perceptions of the review process
• Analyse the impact of the review process on nursing
• Examine the value of the review process to nursing
• Determine if there is a need for a nursing review
• Determine the type of review required if any
• Determine the content of the review
Research Method

• Exploratory qualitative study
• Orem’s Self-Care Framework provided the theoretical framework
• Sampling
  – Minimum 2 years experience in area
  – Established Home therapy programme
  – 52 nurses at 46 centres
• Semi-structured telephone interviews
• Burnard’s method of thematic content analysis provided structure to the analysis, validity and reliability of the study.

Higher order categories

- The role of the nurse and their perceived value of a nursing review process
- What nurses perceive the value of review is to the patient
- The review process
- Immunology nursing
## Results; Demographic data

<table>
<thead>
<tr>
<th>Patient cohort</th>
<th>Paeds</th>
<th>Adult</th>
<th>Paeds/Adult</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>10</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Years of experience</td>
<td>12</td>
<td>103</td>
<td>30</td>
<td>145</td>
</tr>
<tr>
<td>Home therapy patients</td>
<td>IVIG-2</td>
<td>IVIG-203</td>
<td>IVIG-142</td>
<td>IVIG-247</td>
</tr>
<tr>
<td></td>
<td>SCI G-34</td>
<td>SCI G-189</td>
<td>SCI G-55</td>
<td>SCI G-278</td>
</tr>
<tr>
<td>Nursing fields</td>
<td>PID ± Allergy, HIV, Haematology or Respiratory</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Study findings; Value of review

- Support
- Patients requiring more support
- Rating of home review
- Perceived value to the patient
Value of review / why do it?

- Provide support to the patient (n=6)
- Opportunity for education (n=2)
- Maintaining/ monitoring standards and compliance (n=12)
- Need to feel reassured/ satisfied that patients were happy or safe at home
- Maintaining and developing the relationship with the patient (n=6)

“What can we do to improve our service”
Support

• Intensity of the nurse patient relationship varying with the patients capabilities to self care

• Review seen as a means of ensuring support is maintained

• Nurses keen to maintain contact with patients (n=17)
  “Concern of patients falling through the loop as patient numbers grew”
Support

- Parents
- The new home infuser
- Teenager, young adult
- Infusion partners
- 30-50 age group
- Co-morbidity
- The older patient

Supporting the new home infuser
Teenager/ young adult

- Reluctance to infuse, ‘why me?’
- Complained infusions interfered with their lifestyle – one returned to hospital infusions
- No recollection of being sick
- Interpersonal problems with parents - one returned to hospital infusions
- Lack of knowledge - most information given to parents at diagnoses
Work related priority scale of the review process
## Perceived value to the patient

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Reassurance (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Re-empowering (n=1)</td>
</tr>
<tr>
<td></td>
<td>Like the attention (n=2)</td>
</tr>
<tr>
<td></td>
<td>Feel supported, helped (n=6)</td>
</tr>
<tr>
<td>Relationship</td>
<td>Partnership (n=1)</td>
</tr>
<tr>
<td></td>
<td>We still care (n=1)</td>
</tr>
<tr>
<td></td>
<td>Maintains contact (n=1)</td>
</tr>
<tr>
<td></td>
<td>Relationship building (n=2)</td>
</tr>
<tr>
<td></td>
<td>Exclusive time (n=1)</td>
</tr>
</tbody>
</table>
## Perceived value to the patient

<table>
<thead>
<tr>
<th>Functional</th>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Sort problems (n=2)</td>
<td>Patient is nervous (n=2)</td>
</tr>
<tr>
<td>Review gives them a voice (n=5)</td>
<td></td>
</tr>
<tr>
<td>Refresher course (n=1)</td>
<td></td>
</tr>
<tr>
<td>Risk assessment (n=1)</td>
<td></td>
</tr>
</tbody>
</table>
Study findings; The review

- Duration of review
- Frequency of review
- Location of the review
- Content of the review
- Structure of the review
Duration of Review

Number of nurses

- <15 min
- 15-30 min
- 15-45 min
- 1 hour
- 1-2 hours
- 2-3 hours
- 1 day
- 1-2 days
Frequency of review of home therapy patients

- **Planned frequency**
- **Achieved Frequency**
- **Delayed frequency**

- 6 months
- 1 year
- 1.5 - 2 years
- >2 years
Location of the review

- Home
- Hospital
- Hospital and home
# Review in patients’ home

<table>
<thead>
<tr>
<th>Participant centre</th>
<th>c</th>
<th>d</th>
<th>g</th>
<th>h</th>
<th>i</th>
<th>l</th>
<th>o*</th>
<th>p</th>
<th>r</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of patients</strong></td>
<td>12</td>
<td>90</td>
<td>14</td>
<td>2</td>
<td>23</td>
<td>18</td>
<td>20</td>
<td>20</td>
<td>27</td>
</tr>
<tr>
<td><strong>Number of nurses</strong> (Involved in home therapy)</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

* = Reviews approximately half of patients at home and half in hospital. Total number of patients = 40
# Review in Hospital

<table>
<thead>
<tr>
<th>Participant centre</th>
<th>e</th>
<th>f</th>
<th>m</th>
<th>S</th>
<th>O *</th>
<th>Q ^</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>90</td>
<td>160</td>
<td>50</td>
<td>68</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>Number of nurses (Involved in home therapy)</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

* = Reviews approximately half of patients at home and half in hospital
^ = Minimal review
μ = Previously did home visits
Cumulative summary of contents of review

- Reconfirm demographics and contact details
- Observation of patient self-infusion
- Discussion of home infusions no observation of technique
- Discussion on problems with technique
- Discussion on psychosocial issues raised by diagnosis and infusing at home (n=15)
- Coping, keeping to infusion day -barriers to this-. 
- Discussion with infusion partner
Cumulative summary of contents of review

- Discussion on the delivery service
- Universal precautions
- Discuss adverse reactions, are they having any, 48 hour rule, monitoring during infusion
- Have they required GP to assist with venepuncture
- Compliance with other management plans e.g. chest physiotherapy
- Any Immunology service issues
- Has patient got follow up Clinic appointments
Structure of the review

• Local guideline in place (n=15)
• Support for national guidelines (n=11)
  - Trigger to ask right questions
  - Act as a comprehensive check list
  - Useful for audit
  - Opportunity for nurses to learn from the experiences of others
  - Support clinical governance
Structure of the review

Wary of a guideline

“Because I think people don’t look around the outside of them.”

Recommendation for a national guideline

“content of the review still evolving and would benefit with the input from a wide variety of experiences”
In conclusion

- Participants valued the provision of support as being fundamental to patients staying on home therapy.
- All nurses wanted patient contact
  - Variable 5 weeks to 6-12 months
- Increased levels of support are transition related and when a self care deficit occurs.
- The study supports that review of home therapy patients is needed and is a valuable exercise.
- This is a very positive finding in light of the considerable resources required.
Recommendations

• To determine the need and/or frequency for competency assessment of PID patients who self infuse Immunoglobulin at home.

• To determine whether PID patients who self infuse Immunoglobulin at home require routine home visits by the Immunology Nurse.

• To establish the relationship between review of home therapy patients, patient compliance and those who discontinue with home infusions.
Acknowledgements

- Immunology nurses UK and Ireland who participated in this study
- Study supervisor, Professor C Cox, City University, London.
- J. McDonald & M English who independently reviewed transcripts to enhance validity and reduce bias.