Training and support to enable home immunoglobulin therapy

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This article describes the development of an immunoglobulin home therapy and support service. The service provides patients with the education and training that they need to be able to undertake immunoglobulin therapy at home. To facilitate this the trust’s competency-based enhanced practice framework was adapted. Evaluation through clinical audit and a patient satisfaction survey has yielded positive results, indicating that the enhanced practice framework provides a robust and effective approach to patient education.

During the last decade patient education has increasingly been recognised as an integral part of the nurse’s role in health care delivery. There are a number of reasons behind this (Luker and Caress, 1989), including:

- Demands for knowledge through empowerment of patients and their families;
- Informed consent;
- Political policies;
- Promotion of independence;
- Self-care;
- Shorter hospital stays;
- Reduction in convalescent facilities.

Current health care management involves finding effective ways to facilitate care within the community, resulting in a growing population of patients being cared for and managed at home. Specialist medical treatment and nursing care, once initiated and delivered in hospitals, have become commonplace within the home environment (Sewell et al, 1997; Gardulf et al, 1991; Stevens, 1989). For example, different types of therapy that can be carried out in the home include: intravenous antibiotic therapy, factor VIII infusions, chemotherapy and palliative care. For both the patient and his or her carers/family, education and training are fundamental requisites before specialist care can be effectively and safely delivered at home.

Initiating a home therapy service

The lung defence clinic at Papworth Hospital NHS Trust provides multidisciplinary, specialist care for individuals with bronchiectasis and/or recurrent respiratory infection. In collaboration with this team of professionals, a home therapy training, education and support service was developed aimed at patients diagnosed with antibody deficiency and recurrent infection requiring immunoglobulin therapy.

Low levels of antibodies in the blood result in a failure to fight infection. This can lead to repeated prolonged infections particularly of the lungs, sinuses and gut. Immunoglobulin replacement therapy is a standard therapeutic intervention in the holistic management of patients with antibody deficiency and recurrent infection (Chapel et al, 2000). The therapeutic benefits and lack of adverse reactions are well documented (Brennan et al, 2003; Hammarstrom and Smith, 1986). Patients with antibody deficiencies often require lifelong immunoglobulin replacement therapy.

The preferred methods of administration of immunoglobulin are via intravenous or subcutaneous routes. Traditionally this has required patients to attend the hospital frequently as outpatients. Through the development of the specialist home therapy service, however, patients have been given the opportunity to learn how to manage their intravenous or subcutaneous immunoglobulin at home.

Providing an educational framework

The development of the specialist home therapy service at Papworth Hospital NHS Trust started in 2001. Early in the planning stages the team recognised that in order to ensure a safe and effective service, any strategy for educating patients during their transition from hospital to home-based immunoglobulin infusions would need to be systematic and robust.

Patient education may be defined as a planned series of information giving directed towards the participants’ learning needs. The aim of the immunoglobulin home therapy service was to promote patient independence and help patients to be in control of their health care treatment. In collaboration with the practice development adviser at Papworth Hospital NHS Trust, the team identified a trustwide competency-based enhanced practice educational framework that could be adapted for use with adult patient education and assessment.

The enhanced practice educational framework is concerned with the training and education of enhanced practice undertaken by qualified and unqualified nursing staff such as venous access skills, and other skills that have not been learned in pre or postregistration training. The framework was developed at Papworth Hospital NHS Trust by the quality action development team to provide a systematic, valid and reliable educational programme, based on competency as the key outcome, for staff at all levels. Validation of the framework is ongoing.

However, the enhanced practice initiative builds on the
principles explored by Calman (1994), in describing a profession, stating that it determines its own standards, sets its own examinations, and has a distinctive knowledge base.

The framework reflects professional accountability through professional knowledge and competency and acknowledges that ‘to practise competently, you must possess the knowledge, skills and abilities required for lawful, safe and effective practice’ (NMC, 2001).

The main components of the enhanced practice framework include developing evidence-based working documents such as:

- Guidelines;
- Work instructions;
- Competency-based assessments.

The immunology nurse specialist used the components of this framework as a template to develop specific home therapy guidelines, work instruction documents, teaching plans, learning outcomes and a competency assessment tool for the immunoglobulin home therapy service (see Box 1).

Running the home therapy service

The dedicated home therapy outpatient service is run by the immunology nurse specialist and immunology support nurse. All patients are trained on an individual basis over a period of 8–12 weeks (this occurs at weekly intervals for subcutaneous immunoglobulin training or at a frequency of twice each month for intravenous immunoglobulin training).

Patient guidelines

The guidelines provide clear objectives for the educational programme and are shared with the patient prior to the training programme. The guidelines clarify:

- Who will deliver the training;
- How the training process will be documented;
- How the training process will be evaluated and assessed;
- The provision of patient follow-up and support once established on home therapy.

Work instructions

These were developed to act as a written resource and step-by-step guide to administering immunoglobulin. Each patient is given a training manual before starting the programme, which acts as a resource while he or she is on home therapy.

Teaching plans

The teaching plans were developed with several uses in mind:

- To act as a record of the contents of each session and incorporate learning outcomes to be achieved;
- To be shared with the patient and his or her infusion training partner at the start of each training session, to provide a systematic and focused approach to the training;
- To assist in the evaluation of learning.

BOX 1. COMPONENTS OF THE FRAMEWORK AS APPLIED TO IMMUNOGLOBULIN HOME THERAPY

Guidelines

The guidelines act as the major reference source, containing evidence to support what is being taught for the purpose of immunoglobulin home therapy.

The guidelines state clear objectives for the service, including:

- How it will be managed;
- How the training will be delivered;
- Who will provide training and assessment;
- How the training and service will be evaluated;
- How quality assurance will be maintained.

Work instructions

- User-friendly step-by-step instructions stating how to perform an immunoglobulin infusion
- Training manuals that incorporate written and illustrated information for the practical aspects of administering either subcutaneous or intravenous immunoglobulin in a patient-friendly format
- Every patient is given a manual to act as a key resource during training and once at home

Teaching plans and learning outcomes

- Identify outcomes to be achieved at each session
- Provide a systematic and focused format for each step of the training process

For example, the stages of training for the administration of intravenous immunoglobulin are:

Stage

1 = Preparation of infusion
2 = Venous access
3 = Blood sampling
4 = Starting the infusion
5 = Completing the infusion/record keeping
6 = Management of adverse reactions

Teaching plans and learning outcomes are shared with the patient at the beginning of each session.

Assessment strategy

- Competency-based assessment tool for practical and verbal assessment
- Competency-based documents reflecting each stage of the training process
- Can be used to assess and evaluate learning at each stage of training
- Final assessment prior to first home infusion
- Provides clear, documented evidence of the training process and achieved competency

REFERENCES


Prior to the first home infusion patients are required to demonstrate their competence in the practical skills of administering immunoglobulin. Patients must also be able to demonstrate that they are knowledgeable regarding the treatment and know how to manage potential adverse reactions. The competency-based assessment document provides clear, easy-to-use assessment criteria and provides documented evidence of the training and assessment process.

**Home support and clinical review mechanisms**

The consultant immunologist and nurse specialist have developed clinical review mechanisms to provide continued support for patients once established on home therapy. The aim is to provide a seamless service between hospital and home-based infusions. When setting the standards for support and clinical review the consultant immunologist and nurse specialist adapted benchmarks from current protocols used in clinical practice for managing patients with antibody deficiency receiving antibody replacement therapy (Helbert et al, 2001) (see Box 2).

**Audit of home therapy service**

To assess the effectiveness of the home therapy service an audit of the training programme was performed in May 2002. Audit standards were devised by the immunology nurse specialist to reflect the learning outcomes of the training programme and current clinical practice in immunology.

The objective of audit standards is to measure the aspects of care in a given setting by means of comparing actual practice with established good practice, such as evidence from the literature. The data was collected by the immunology support nurse who systematically reviewed the patients’ hospital notes addressing each audit standard question.

The aim is that every patient achieves 100 per cent for the following learning outcomes:

- Attend training for 8–12 sessions;
- Training partner attends at least 50 per cent of training sessions;
- Competency is achieved in the final home therapy assessment;
- Competency is achieved in the use of the EpiPen (adrenaline syringe) training device for the management of serious adverse reactions.

The results of the audit confirmed compliance with the audit standards and ensured competence was achieved for home-based infusions. The results were reinforced by:

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**Box 2. Standards for support and clinical review for patients on home therapy**

<table>
<thead>
<tr>
<th>Home support</th>
<th>Hospital support and clinical review at first home infusion</th>
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<tbody>
<tr>
<td>Hospital support and clinical review at first home infusion</td>
<td>Patient offered home visit by the immunology nurse</td>
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<tr>
<td>Patient offered home visit by the immunology nurse</td>
<td>Specialist or telephone support call</td>
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<td>Specialist or telephone support call</td>
<td>Ongoing support</td>
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<td>Ongoing support</td>
<td>Telephone support/advice provided by immunology</td>
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<tr>
<td>Telephone support/advice provided by immunology</td>
<td>Nurse specialist and immunology support nurse available throughout home therapy</td>
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<tr>
<td>Nurse specialist and immunology support nurse available throughout home therapy</td>
<td>Annual home visit by immunology nurse specialist, offering advice, support and continuous education of infusion technique</td>
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</tbody>
</table>

**Box 3. Examples of questions in the patient satisfaction survey**

- Do you understand why you require immunoglobulin therapy?
- How long have you been administering your infusions at home?
- Who told you about the possibility of learning how to self-administer immunoglobulin at home?
- When the possibility of training to self-administer immunoglobulin at home was first mentioned were you anxious about the training?
- Were the training sessions given in a manner that was easy for you to follow?
- Did you think the period of the training was satisfactory?
- Do you know when to seek advice before giving your treatment?
- Do you have contact numbers for support and advice if you have any concerns about your treatment?
- What parts of your training were you most concerned about?
- Please give examples of what you feel are the advantages of home therapy.
- Please give any examples of what you feel are the disadvantages of home therapy.
the fact that no patient errors were reported during home administration of immunoglobulin. This also highlighted that compliance with the audit standards during training ensures effective teaching and ultimately patient competence.

Patient satisfaction survey
In collaboration with the clinical effectiveness coordinator at Papworth Hospital NHS Trust, the team developed a patient satisfaction survey. By means of a questionnaire, patients were asked about their experiences of home therapy and the home therapy service.

The survey contained 20 short questions plus a section of open questions asking patients to comment on their perception of the possible advantages and disadvantages of administering immunoglobulin at home (Box 3). This pilot survey was sent by mail to all 10 patients on home therapy at the time of the audit and all questionnaires were returned completed.

All patients received training at Papworth Hospital NHS Trust by the immunology nurse specialist. The average duration of administering immunoglobulin at home was 12 months. The administration route used was split as follows: two patients administered intravenous immunoglobulin; eight patients administered subcutaneous immunoglobulin.

The questionnaires were returned anonymously and the data was collated by the clinical effectiveness department.

Survey results
The survey showed that overall, patients felt satisfied with the training programme and its contents. Some examples of their comments follow.

Advantages of home treatment:
- ‘Home comforts during infusion’;
- ‘Flexibility over the time of day the infusion is given’;
- ‘Less disruption to my family’;
- ‘I am more relaxed’;
- ‘No longer take up a hospital bed needed for others’.

Disadvantages of home treatment:
- ‘None that I can see!’;
- ‘Miss the social aspect of meeting others in a similar position’;
- ‘Have to fit in with chores at home rather than making time’;
- ‘[There would be a disadvantage to home treatment] if I did not have my infusion partner’.

Although it is difficult to interpret these quotes fully, the survey provides evidence that our patients have experienced benefits from home therapy. It seems that convenience is a key advantage.

Discussion
A specialist service can be delivered effectively at a patient’s home for both subcutaneous and intravenous immunoglobulin therapy. The enhanced educational practice framework provides a robust, reproducible and systematic approach to staff development with emphasis on competency as an outcome measure (Box 4). The principles of this framework have been effectively transferred to the development of a home immunoglobulin therapy service which requires an effective education and training programme for patients.

We have gained a comprehensive set of working documents that provide a systematic and reliable basis from which we are able to educate patients for immunoglobulin home therapy. In our experience, these documents are easy to use and provide clear, concise documentation of the training and assessment process. The documents can be conveniently held within the patient’s case notes.

Through the process of a clinical audit and a patient satisfaction survey we have established that patients are content with the training, education and support provided by the immunoglobulin home therapy service. As a follow-up to the patient survey the immunology nurse specialist intends to conduct in-depth interviews and analysis of the patients’ perspectives and experiences of home therapy.

The future
The RCN immunology and allergy nurse group is interested in validating this questionnaire so that it can be used by immunology nurses throughout the UK as a generic questionnaire for patients on home therapy.

Following its implementation at Papworth Hospital NHS Trust, the patient survey has been extended to two other hospitals with established home therapy services, the Northern General Hospital in Sheffield, and the University Hospital of Wales, Cardiff.

The findings from these further patient surveys are still in the process of being collated and analysed. Once complete the findings from these surveys will be disseminated through the RCN immunology and allergy interest group.

Although there is limited up-to-date clinical evidence to substantiate patients’ experiences of administering immunoglobulin at home, the clinical audit as described in this article has provided invaluable data in support of the efficacy of immunoglobulin home care therapy.

REFERENCES


