www.palliativecareglasgow.info: Developing Online Palliative Care Information

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Citation

Abstract

The Glasgow Palliative Care Information Network provides an online source of information about palliative care and palliative care services to patients, their families and professionals, particularly generalists.

The information for patients and carers aims to clarify what palliative care is and how such services are accessed. The section for professionals includes guidelines, protocols, links and resources which can be used to support their practice in both hospital and community settings.

It is also planned to place public access terminals in relevant locations across the city to encourage access to the information available online and by so doing to improve awareness of palliative care and how it is delivered. In addition the network will offer internet access to a group of patients and assess the effect of the web based information on anxiety levels when compared to more traditional media.

INTRODUCTION

The provision of appropriate information to patients and professionals receiving and delivering palliative care has been and remains an area of concern (Houts et al, 1991) particularly as the importance of information in this area is increasingly well recognised (Addington-Hall and McCarthy, 1995), with many patients and their carers placing much importance upon this being given in a pro-active manner.

For patients and their families information is considered to be very important (Lecouturier et al, 1999) and may be a means of combating the uncertainty generated by their prognosis.

For those who deliver palliative care – many of whom work at the generalist level (SPPC, 1998) e.g. hospital and Primary Care Team staff – they often require information of a specialist nature at irregular intervals. The wide range of clinical situations they encounter may create problems with transferring the expertise gained in one situation to another.

It is also possible that the proliferation of specialist nurses in recent years has led to both professionals and patients becoming confused by the number and roles of the staff they encounter.

Internet technologies improve upon traditional methods of providing information (Sheppard and Charnock, 2002) by organising material in such a way that different users will find a personal path through the material that reflects their problems and their feelings about those problems. It also goes some way to meeting the wish for information to be available where and when people want it.

The net allows for quicker, and easier updating of information and of indicating responsiveness to users who may wish material added, moved or changed. Earlier concerns about quality of information on the internet have proved largely unfounded (Ferguson, 2002, Eysenbach and Kohler, 2002, Pandolfini and Bonati, 2002) and cancer strategies have expressed the view that information giving is of great importance (Eaton, 2002).

Palliative care prides itself upon openness and honesty in communication and the principles behind the development of the internet share that concern about access to information and the free sharing of knowledge.

It is no surprise then to find that there are already many Palliative Care sites available on the net (Sweeney, 2002)

and the development described here reflects an acceptance of the importance of the medium.

BACKGROUND

The New Opportunities Fund has funded the development of the Glasgow Palliative Care Information Network for 3 years until March 2005. Essentially it will be an online approach to meeting the information needs of both public and professionals and an opportunity to examine the impact on patients and service providers of this method of information provision.

A team of two staff with backgrounds in palliative care, IT and public information provision were employed to develop and maintain the site for the duration of the project

with a view to its survival in the longer term. It is also hoped that the increase in collaboration required by the formation of the West of Scotland Managed Clinical Network in Specialist Palliative Care (SPPC, 2001) will be facilitated by this network.

DESIGN

Presently the project has completed the first of its aims (see box 1)

Figure 1

Aims
- To create a website for the public and professionals which will provide information on services, service providers and service procedures for the former group and a method of accessing guidelines, protocols and the Glasgow palliative care community for the latter.
- The site will also include a database of palliative care educational opportunities, which it is hoped will lead to greater awareness and uptake of training courses.
- It is hoped that the role of palliative care services will be clarified and their profile raised leading to an increase in the uptake of services particularly by disadvantaged groups (Firth, 2001). Contacts have been made with Health Board staff working with Glasgow's growing Ethnic Minority population to explore how best the site can address their needs.
- Access will be encouraged by placing public terminals in relevant sites around the city, e.g. hospitals, hospices, pharmacies, health centres (Coulter, Entwhistle and Gilbert, 2002) and by raising awareness of other government sponsored initiatives that will improve public access to the internet (Scottish Executive, 2002)
- As the project develops it is planned to research the impact of net access on satisfaction with information; satisfaction with services; and anxiety levels. The project will identify a number of patients without, but interested in, internet access and provide this for them at home. Patient groups will be compared e.g. those with net access against those without and internet information will be compared with written material.

and the Network site went online at www.palliativecareglasgow.info in September 2002.

Various principles were incorporated into the design of the site (Neilsen, 1999) with simplicity being the key to ensuring widest possible use of the site and the information within it.

Usability principles (Neilsen, 1999) have been used to overcome the possibility of new net users being unsure of what links to which information, this also allows for the site to be used effectively by anyone using a touch screen monitor.

As the site is to be used in public places it was important that the links to sections of the site be clear at a glance. The network team has also encouraged those sites providing public access to ensure that screen reading software is available for visually impaired users.

Through informal discussions with patients in a community setting it was clear that people had particular concerns about referral to palliative care services.

They wanted to know what staff actually did should they visit, they wanted to know if there was a charge, they wanted to know if the services were one off visits or would be repeated and they wanted to know how to access the variety of services described to them. People also wanted to know which services dealt with their part of the city.
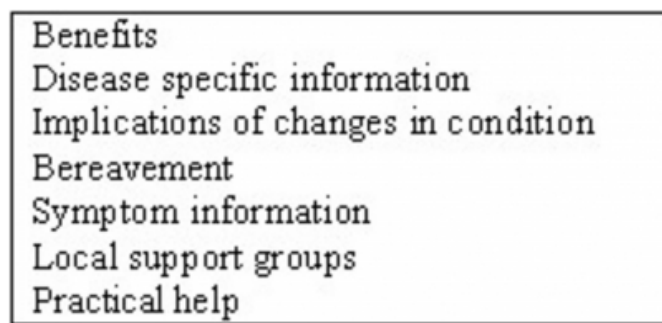
Professionals expressed an interest in being able to find guideline materials and useful clinical information without the difficulties of carrying out lengthy online searches and also of being able to suggest the site as a safe gateway to the internet for patients and carers.

These concerns about validity of information, however unfounded, allowed the network staff to engage palliative care professionals in the production of information for the site and by so doing ensure the accuracy and relevance of this material.

This also offers some ownership of the site and encourages the view that it is not a document but rather a tool through which they can communicate with those for whom they provide their services. It also raises the profile of the site within the professional community and encourages use by a wider number of people.

Information can therefore be found via geographical links and service links giving a choice of routes through the site. In addition a simple description of palliative care was included and a number of links to reputable sources of information on these areas (box 2).

Figure 2

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Benefits
Disease specific information
Implications of changes in condition
Bereavement
Symptom information
Local support groups
Practical help
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Professional resources have been divided into a number of categories including a selection of guideline documents, directories of services and links to palliative care

discussion groups one of which has been set up in conjunction with the recently formed West of Scotland Managed Clinical Network for Specialist Palliative Care.

It is hoped that such efforts will lead to

- Better satisfaction with services following clarification of service roles

- Reduced anxiety levels through having a clearer idea of what services can provide and knowing that support exists following initial treatment phase of their disease

- Wider use of guidelines and greater collaboration across Glasgow palliative care services – more sharing of information and less duplication of effort

- Closer links with the MCN will also reflect this aim and indicate relevant directions for the network to follow.

CONCLUSION

Evaluation of the three-year project will be through the aforementioned research and the hard data of web statistics (see attached) which have to date largely showed an upward trend which should increase following the public launch of the project planned for later this year.

Site users will be asked to complete a survey about the site and its contents thus offering users the chance to suggest future developments for the site. Focus groups and one to one meetings with users will add qualitative weight to this material.

Palliative care is undergoing much re-assessment (NICE, 2002) particularly with regard to the setting up of MCNs (SPPC, 2000), and the embracing of IT will surely continue apace.

The lessons already learned will be well used by the team as they respond to users and services to further develop the network and hopefully by others as they venture online and begin to integrate IT into daily clinical practice.

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