Schizophrenia-Window-of-Hope.com: Development of a psycho-educational Internet resource for the South African setting

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Psycho-educational programmes for families of persons with schizophrenia have been shown to reduce relapse rates, subsequently reducing the burden on the family as well as health care systems. Although various South African helplines and psycho-educational websites exist, none of these focused specifically on schizophrenia. The South African Depression and Anxiety Group (SADAG) was approached for assistance to enable us to develop a piggy-back schizophrenia service on their already established helpline. A multidisciplinary mental health team compiled a manual for use by SADAG helpline operators, but owing to the huge amount of information it was realised that the resource would be more efficient if both a helpline and an Internet resource could be created. The website (www.schizophrenia-window-of-hope.com) was then developed with the help of an IT professional. This site represents the first attempt to create an Internet-based schizophrenia-specific educational resource for the South African setting. The next step will be to obtain formal feedback from helpline and website users in order to inform the ongoing development of the site.

Schizophrenia is a debilitating illness that impacts significantly on the lives of sufferers and their families.[1,2] Owing to a paucity of residential and day-care facilities, the shift to community mental health services has increased this burden in recent years.[3] Psycho-educational programmes for the families of persons with schizophrenia have been shown to improve relapse rates, and when relapse rates decrease, the burden on families as well as health care systems is reduced.[4] Unfortunately, in our setting psycho-educational initiatives are not always readily available or utilised by mental health care practitioners.

Leach *et al.* have shown that although mental health care users prefer a clinician to convey information regarding their illness, younger users in particular also find informational websites useful.[5] A survey has also suggested that the Internet may be beneficial in terms of psycho-education and information for people living far from health centres, and also particularly for those suffering from a stigmatised illness.[6,7] To date, no studies investigating the value of the Internet for distribution of mental health information have been conducted in our setting.

Several telephone helplines related to a variety of mental illnesses are currently available in South Africa. However, to our knowledge none of these specifically focus on schizophrenia. Furthermore, although a large number of international informational websites are available, such as www.schizophrenia.com and www.schizophreniaconnection.com, the information is not always applicable to the South African setting. Interactions with mental health care users and their families suggested that there is a need for a South Africa-specific resource regarding schizophrenia, leading us to explore the feasibility of developing such a resource.

Methodology

Taking into account our resource-limited setting, we decided to approach the South African Depression and Anxiety Group (SADAG), who are already running an established helpline for people with depression and anxiety disorders, in the hope of piggy-backing our service on theirs. After initial discussions, it was established that the helpline operators would require a manual to assist them to address queries appropriately.

A multidisciplinary team consisting of 3 consultant psychiatrists, a professional psychiatric nurse, 2 occupational therapists, a psychologist, a social worker and a registrar in psychiatry was therefore convened and tasked to focus on two aspects: (*i*) creating flowcharts for management of commonly occurring scenarios; and (*ii*) compiling and answering frequently asked questions (FAQs).

The list of FAQs was compiled on the basis of information obtained from personal interviews with clients, their friends and

families and fellow colleagues, as well as electronic and other informational resources. Answers to FAQs and flowcharts were then sourced using various data sources, i.e. textbooks, journals and websites such as www.schizophrenia.com and www.SANE.org.uk, with final outcomes based on multidisciplinary team consensus.

The helpline manual was subsequently printed in book form. In addition to the flowcharts it also contains: (*i*) definitions of terminology commonly used in the context of schizophrenia, explained in brief, as well as definitions for other medical terminology used in the manual; (*ii*) tables listing general side-effects experienced when on antipsychotic medication, explaining these and giving guidance on management of possible serious problems; and (*iii*) alphabetical lists of trade and generic names of medications, as well as general guidelines on the use of antipsychotic medication.

During the process of compilation it was immediately recognised that owing to the huge amount of information contained in the manual, it would be more efficient if an Internet resource could be developed in conjunction with the helpline. Therefore, with the help of an IT professional and funding made available by Pharmadynamics, for the hosting of a schizophrenia-specific psycho-educational website, www.schizophrenia-window-of-hope.com was created (Fig. 1). Helpline operators, comprising psychology students and trained counsellors, were then trained via teleconferencing to use the website as their information resource when handling calls. The website is navigated with a search function in order to quickly access questions and answers relating to the specific subject a particular caller needs addressed (Figs 2 and 3). If questions are beyond the scope of the information available on the site, operators re-direct callers to appropriate resources.
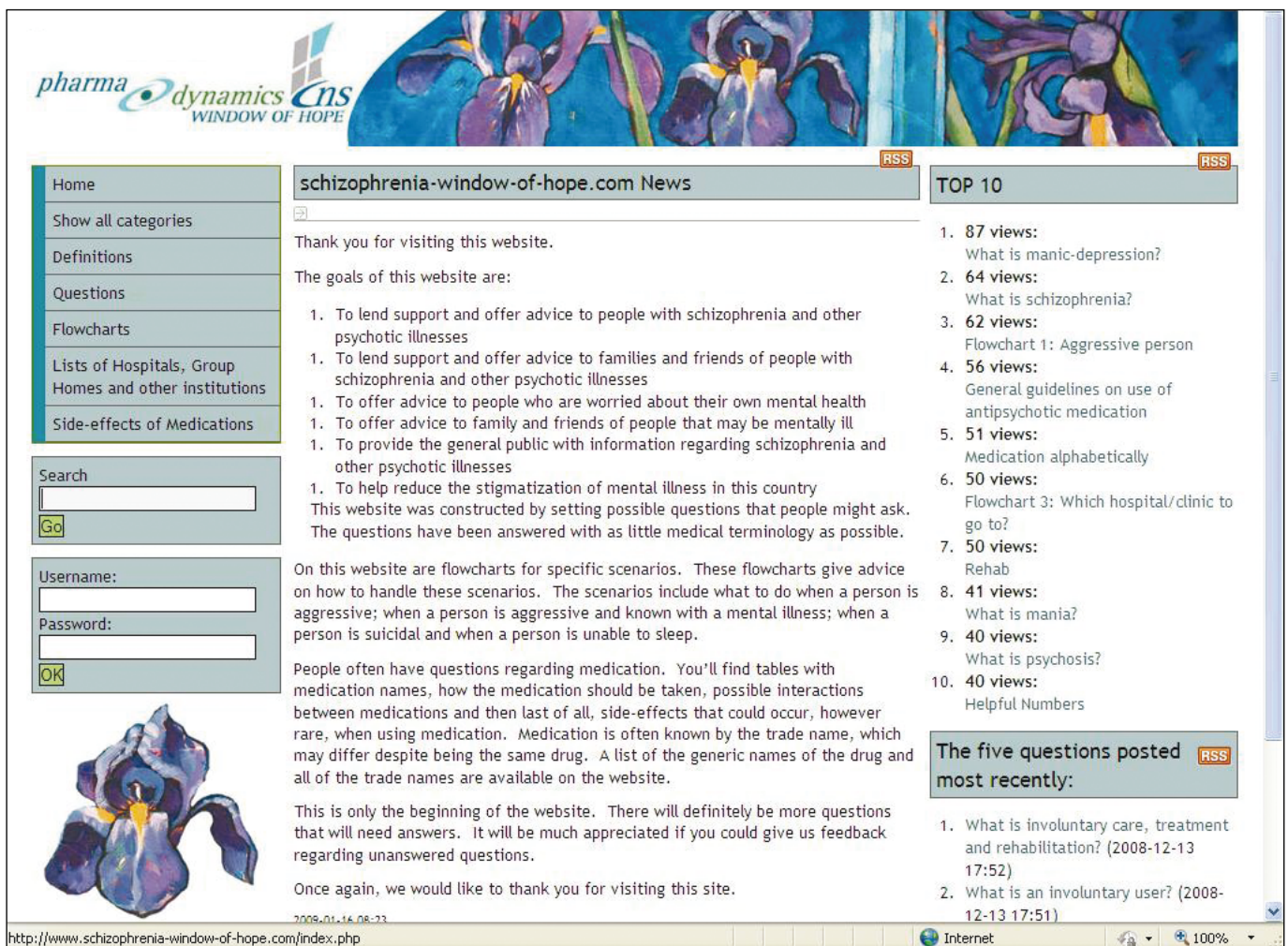

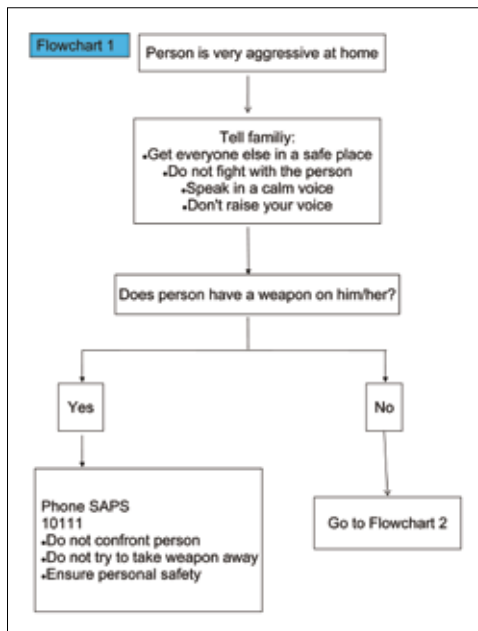Fig. 1. Home page, schizophrenia-window-of-hope.com.

Fig. 2. Example of a flow diagram, schizophrenia-window-of-hope.com.

Once the site was up and running, the availability and ease of use of the Internet expanded access to the resource to include use by medical professionals, allied health workers and the general public. All users (public and professional) can now access the website by using a specified username and password. Business cards with the above information, as well as the helpline number, were distributed to mental health care professionals, who then hand these to patients and their families. When accessing the site, users can click on different links, use the search function, post questions and download relevant information.

The site aims to be user-friendly, and a number of downloadable pdf files are also accessible, including Mental Health Care Act Forms. Information regarding some mental health resources is also accessible and is continuously updated.

Discussion

Schizophrenia is a chronic mental illness, impacting on the lives of both persons with the illness and their families. Often families do

Fig. 3. Example of a FAQ, schizophrenia-window-of-hope.com.

not understand why their loved one is having a relapse, or even why they need to take medication every day. Families are not always able to accompany the person with schizophrenia for his or her follow-up, and therefore miss valuable psycho-educational opportunities.

Owing to various constraints, mental health care professionals often do not devote adequate time to psycho-education. Clinics are overloaded, or emergencies arise. Clinicians do not always remember patients, and their families might not have an adequate understanding of the illness they are dealing with on a daily basis. However, proper psycho-education can help to prevent relapse.

Both www.schizophrenia-window-of-hope.com and the helpline were developed to be used as a psycho-educational tool for medical professionals, allied health workers, patients and their families. Although Internet resources are more comprehensive, lack of access in many communities within our setting dictates the need for both a helpline and an Internet site.

For the various reasons detailed above, an accessible psycho-educational tool may help to address the different needs. For family members unable to co-attend appointments, access to a telephone or a computer would provide much-needed answers. Clients themselves often feel ashamed of having a mental illness, or because of the illness may not feel comfortable asking questions about it, and find it easier to do so anonymously. Within a time-constrained clinical consultation, there is also often little opportunity to ensure that all questions have been satisfactorily addressed. Being able to provide a client or family with an informational resource can help with continuity of care.

As such, www.schizophrenia-window-of-hope.com represents the first attempt to create an Internet-based schizophrenia-specific educational resource for the South African setting. Already, informal feedback has led to improvements on the site, and we encourage patients, families and mental health professionals to visit the site and provide us with comments and suggestions. For future planning, the next step is now to obtain formal feedback from helpline and website users.

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