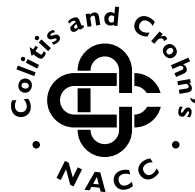


This is an extract from the Report on the NACC Counselling Project produced by NACC in September 2001.

The extract provides an overview of what the project achieved and lessons learned that we feel may be helpful to others who are considering setting up specialist counselling for patients with a long-term medical condition.

***Summary of the Project's Outcomes
and
Keys to Making Counselling for IBD Patients Work
Well***

Further information about the Project and the Report can be obtained by contacting Stella Leigh at NACC on 01727 734474 or email: s.leigh@nacc.org.uk



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The full report incorporated an independent evaluation of the development and provision of counselling through the project undertaken on behalf of NACC by Dr Stephen Goss.

PART THREE:

SUMMARY OF THE PROJECT'S OUTCOMES

- 1** We recruited and trained eleven experienced counsellors to work as part of the Project using what we had learned from the previous NACC-funded research into 'The Place of Counselling in IBD' to inform the design of the training provided. In the latter stages of the Project, the evaluation interviews with the counsellors and their feedback at the subsequent 'debriefing' meeting confirmed their professional support for the approach to counselling in IBD that NACC had adopted.
- 2.** Gastroenterologists showed a significant level of interest in making counselling available to IBD patients when they were first invited to be involved in the Project. There were 62 positive replies out of 96 gastroenterologists who were approached.
- 3.** When it became clear that NACC would have to provide the funds for the majority of the counselling sessions, a very successful fundraising appeal was launched, raising £53,000 from companies, charitable trusts and NACC Groups, mostly within a period of eight months.
- 4.** In order to provide proper accountability both for the NACC funds that were transferred to participating hospitals and for the counselling itself, model legal agreements were prepared. These took a disappointingly long

time to be approved within most hospitals but were eventually signed with minor modifications by thirteen health trusts. They could in future be used as a ready-made format for any secondary care counselling within hospitals using charitable funds and using independent counsellors.

5. Counselling was offered at 13 hospitals and was provided for just over 100 people up until June 2000. Take-up of the counselling was slow initially at most sites and possible reasons for this were as follows:
 - Difficulty for doctors in identifying patients who would benefit from counselling.
 - Practical constraints on advertising the service and initial over-concern that this pilot service would be overwhelmed.
 - Difficulty of the counsellors becoming known to the Hospital Care Team
 - Reluctance of some patients to receive counselling, possibly due to fear of being labelled as “someone with mental health problems.”
 - Clients’ difficulty in fitting in with the set times of the limited number of counselling sessions available with the Project.

6. Counselling has continued to be provided through the Project at eleven of the hospitals since June 2000. It was prematurely finished at the other two Hospitals. In one the counsellor moved to another area necessitating the end of the scheme there, and in the other the counselling came to an end before the Project finished due to the lack of commitment at the Hospital.

7. At one Hospital, the Princess of Wales at Bridgend, the counselling was funded by the NHS from the start. In three Hospitals the gastroenterologists provided some funding from their Gastroenterology Departmental funds which was supplemented by NACC funds. NACC provided between £1000 and £8550 to fund the counselling in the 12 other Hospitals. It became apparent that in most of the Hospitals the funding provided would not be used by the end of the two years' Project period. The Council of NACC Trustees agreed in April 2001, that any remaining NACC funds can continue to be used by the Hospital for counselling. The donors, who gave funds to the Project, have been asked to confirm their agreement and all but one have done so. This gives a breathing space for the gastroenterologists to seek further funding for the counselling, if they wish to do so.
8. Nine out of the ten consultants interviewed as part of the independent evaluation in 2000, said they would like to see the service continue in their hospital beyond the end of the Project. One NHS Trust has definitely committed itself to taking over the counselling service. Another gastroenterologist has undertaken to continue the funding of the counsellor for the rest of the financial year, 2001 – 2002, once the NACC funding comes to an end. The situation at the other Hospitals is unknown at the present time.
9. Some potentially difficult issues or dilemmas have been identified that are probably inherent in providing confidential counselling, involving part-time independent counsellors attached to secondary care services. Examples of these are differing perceptions between the counsellor and staff as to which

patients might benefit from counselling, varying approaches to the referral of patients and communication between a part-time freelance counsellor and hospital staff. For the counsellors there is the dilemma of maintaining complete confidentiality for their client whilst recognising the importance to hospital staff of some feedback on the value of the counselling to their individual patients.

- 10.** The independent evaluation confirms high overall satisfaction ratings from the clients. 72 % of clients used one of the two most positive ratings for the overall helpfulness of the counselling. (See page 75.)

- 11.** The experience gained through the Project can provide guidance to improve the effectiveness of IBD counselling in hospitals, and can help others who wish to make part-time specialist counselling services available in hospitals.

PART FOUR:
KEYS TO MAKING COUNSELLING FOR IBD
PATIENTS WORK WELL

***PRINCIPLES UNDERPINNING THE APPROACH TO IBD
COUNSELLING***

Counsellors with an Understanding of IBD

The Project was predicated on the assumption that IBD patients and their families would put a high value on the existence of experienced counsellors who had a knowledge and understanding of IBD. Although the evaluation was not set up to investigate this assumption, several clients mentioned that the counsellor's understanding of IBD was an important positive factor in their experience of counselling.

Qualified Counsellors with Experience and Good Skills

Counsellors with considerable experience, knowledge and ability are needed to work in this situation. The range and depth of issues raised with the counsellors gives an indication of the complex and demanding work which is required of them. NACC specified that the counsellors selected for the training needed to be professionally qualified with at least two years full-time experience. The training of unqualified volunteers would probably not inspire the same confidence from health professionals, nor would it sit comfortably with the codes of ethics of professional counselling organisations.

Flexible Approach to Counselling

NACC feels that a flexible and pragmatic approach to counselling is preferable: one where there is no set duration or fixed model to the counselling provided. The duration and frequency of counselling should reflect the client's needs and not be predetermined. The counsellors should be selected on the basis of the quality of their counselling skills, not their adherence to a particular model of counselling. The high level of satisfaction reported by the clients in the NACC Project confirms the validity of this approach.

ESTABLISHING COUNSELLING IN A SECONDARY CARE SETTING.

Plan for 3 Years to Establish a Hospital Counselling Service

Examples of formal counselling in secondary care are relatively rare, and in choosing to focus on the provision of IBD counselling in hospitals we were undertaking pioneering work. It is becoming increasingly recognised that counselling services can take 2-3 years to become established and well-used. Our experience has shown that at least three years are needed.

It is important that in setting up a counselling service Hospitals are aware of the time that is needed, in order to allow counselling to become understood and embedded in the structure of the services available to patients. Plans for starting a counselling service need to take account of the likelihood of a slow take-up of the service in the initial stages.

Good Introductory Material for Patients and Staff

Clear and straight forward explanations of counselling are needed for patients and hospital staff. This point was reinforced in the research interviews with the doctors and counsellors. Such material helps create a positive attitude in Hospital team, who feel they understand what to expect and what is expected of them. It also helps the patients to understand more about the counselling process and the relevance of counselling to their situation, so that they have better information on which to base a decision about whether they will try counselling or not.

COMMUNICATION BETWEEN THE COUNSELLOR AND HOSPITAL STAFF

Review Meetings between Doctors and Counsellors

One of the contributory causes of the slow take-up of the IBD counselling services in the NACC Project was the learning that needed to take place between the doctors and counsellors, concerning ways to refer patients. If doctors do not know what to anticipate, they are hesitant in making referrals. The counsellors and gastroenterologists are both entering unknown territory and regular review meetings between them are important and necessary to enable learning to take place. A dialogue can then take place to enable the gastroenterologists to broaden their view of counselling and its role in the care of their patients, and the counsellors to understand more of the doctors' expectations. Some counsellors reported that the consultant at first saw the service as being for people near crisis, and that this changed to a perception of it as a potential support for anyone with IBD.

***Differences between Doctors' and Counsellors'
Understanding of Confidentiality.***

Different interpretations of confidentiality can also result in a hesitancy to make referrals. The fact that counsellors observe complete confidentiality and do not reveal any information about the client's counselling, creates a tension with the situation in the hospital where the boundary of confidentiality allows information to be shared within the staff team. Doctors have the sense that they refer a patient for counselling and that there is no feedback on what happens. This is in contrast to a referral to another medical specialist, or a psychologist, who will provide a report to the referring doctor. In the NACC Project consultants clearly found this difficult, and observed that the lack of feedback left them not knowing who was receiving counselling or, more particularly, what benefit was being derived, unless a patient volunteered the information.

Feedback of some kind is clearly essential to building confidence in the value of the counselling, and is probably essential if consultants are to become sufficiently convinced of its merits to give priority to funding counselling over other demands on resources. Counsellors, therefore, need to consider how they can provide general feedback without compromising the individual client's confidentiality.

This highly complex situation requires maturity understanding and trust and illustrates the reasons why establishing good personal relationships is essential for the successful operation of a counselling service in this setting.

RELATIONSHIP BETWEEN THE COUNSELLOR AND THE HOSPITAL

Good Rapport between the Counsellor and Doctor Essential

In the NACC Project it was clear that one of the keys to the successful implementation of the counselling was the establishment of good rapport between the counsellor and the gastroenterologist. Although relationships were generally good, in half the hospitals they were rather distant, generally due to the lack of time that the doctors were able to devote to overseeing the counselling service.

Introduction of the Counsellor to the Health Care Team and Administrative Staff at the Beginning

Time devoted to the introduction of the counsellor to other health professionals and administrative staff before the service starts is important to the successful implementation of the scheme. Time taken to introduce them within the Department to explain their role will help in their acceptance within the Hospital and enable a quicker take-up of the service. One of the difficulties in the NACC Project was that counsellors were only there on a fortnightly basis, making the build up of relationships within the Department very difficult.

Understanding of the Counsellor's Relationship within the Department

The counsellor needs to be seen as an integral part of the service, but not integrated within it. They should have good links and communication with the Department, but from the therapeutic point of view should be separate.

In retrospect the development of relationships within the Hospital is an area where more training for the counsellors should have been provided in our course programme. They are generally used to working independently and usually have little experience of working in a Hospital. It can therefore be difficult for them to identify ways of getting known among the various hospital staff.

REFERRAL PRACTICES

Flexible Approach to Referral Process

The research within the NACC Project was not designed to test which was the best method for hospital referrals to the counsellors. However, from the evaluation we can say that the referral process seemed to work best where it was easy and quick for the client to make an appointment. For example, in one Hospital there was an appointment book kept at the reception desk, where the patient or doctor could enter the appointment. More research would be needed to identify the optimum referral system.

Active not Prescriptive Referrals from Doctors

Some doctors formally referred people in much the same style as they would send a patient to another specialist. The evaluation suggests that this approach may have caused some patients to arrive at the first counselling session unsure of why they were there, and what to expect. It may also have led to a number of patients not attending their appointments. It became clear that the hospital staff needed to be active, but not prescriptive, in referring to the counselling service, and needed to give some time to explaining what counselling might offer to a patient. It is

important that the counselling is perceived as a 'normal' service not as a service for those who are in need psychiatric help.

ACCESS AND AVAILABILITY

Weekly Counselling Sessions

NACC could only supply funding to the Hospitals to enable the counsellors to be available on a fortnightly basis, although some weekly sessions were provided by some counsellors. Comments noted in the evaluation strongly suggest that counsellor should be available within the hospital at least once each week. A weekly session would make access for patients quicker and also help the counsellor be seen by all the hospital staff and patients as a normal part of the IBD service.

Flexible Appointment Times

It would seem also that where possible there should be some flexibility with the time of appointment. The data analysis shows a high proportion of clients who were not employed and this may mean that potential clients who were in work could not attend.

The Option of Telephone Counselling

During the evaluation it was suggested that where circumstances rendered it absolutely impossible for face to face counselling to take place, telephone counselling might be considered. It might be considered for instance in circumstances where illness or lack of transport prevented attendance at counselling.

FUNDING

External Funding to Initiate Counselling

The Project has shown that in most cases the NHS Trusts have been unwilling to commit funds to counselling, as other services have been seen to have a greater priority. NACC provided funding to the Hospitals for two years with the intention that it would be seed money, to enable the counselling to prove its value and become embedded in the range of care provided for IBD patients. Once the counselling had become established it was hoped that the NHS Trust would take over the funding. The success of this approach remains unproven as in most cases counselling is still continuing beyond the two years of the counselling scheme with the use of the remaining NACC funds, and applications for continuation funding by the NHS have not been decided.

Level of Funding Required

Based on the experience of the Project, we would suggest that counselling should be provided on a weekly basis for half a day, as a minimum to build up sufficient recognition and awareness among both patients and Hospital staff. The Project has shown that this can be done with an expenditure of £5,000 a year. The number of sessions varies from client to client a few requiring ongoing sessions and some needing very few, so that there will be a reasonable turnover of clients being seen. Based on the typical number of sessions in the NACC Project the service was relatively inexpensive per patient – around £200/£250 per client. Given the levels of satisfaction and perceived benefit reported by clients in the evaluation, this would seem to be cost-effective in comparison with other health service costs.

Department of Health Support for Specialist Counselling in IBD

There is a role for the Department of Health in promoting the recognition of the value of specialist IBD counselling, so that local Health Authorities are encouraged to provide professional counselling for patients with Ulcerative Colitis and Crohn's disease. They may also wish to consider the value of the NACC model for counselling in other chronic conditions. We hope that this report will assist in both these endeavours.

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