Strategies for counselling the 'worried well' in relation to AIDS: discussion paper

R Bor PhD MA **L Perry** RGN **R Miller** BA MSW *District AIDS Counselling Unit, Royal Free Hospital, London* **J Jackson** MB ChB MRCP *Department of Psychiatry, Royal Free Hospital, London*

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The psychosocial problems that patients with AIDS/HIV may face have now been well documented[1,2]. These problems manifest in a variety of ways. They may include fear, anxiety, anger, frustration, guilt, depression and shock among many others[3]. However, AIDS also has an impact on a considerable number of people in the wider population. Since public awareness about AIDS and HIV has increased, so the number of people who have AIDS-related worries continues to grow. For many AIDS counsellors, general practitioners or other health care staff involved in the care and management of patients, this group has come to be known as the 'worried well'[4]. In some clinical situations the 'worried well' may represent as much as a half of the total workload of a clinically-based AIDS counselling unit. In this paper we describe subgroups of people who represent the 'worried well' and strategies for counselling and managing them.

Who are the 'worried well'?

The 'worried well' are those people in the community who perceive themselves to have been at risk from AIDS/HIV. They may fear that they have either been infected with the virus or that they may already have signs and symptoms of the full AIDS syndrome. From our experience the presentation of the worried well can be broken into seven sub-groups:

Those with past sex or drug use history Those people who have had sexual relationships in the past or who may have shared needles when injecting drugs which may have put them at some risk for HIV may present as the 'worried well'. This is irrespective of the risk group in which they may fall (for example, homosexual or heterosexual) or the activities that took place (for example, touching a partner or unprotected sexual intercourse). This is, by far, the largest subgroup, accounting for about half the number of referrals to AIDS counsellors. Increased awareness of the main routes of transmission of HIV, through the Government Health Education Programme, has concomitantly aroused worries in those at risk.

Those with relationship problems Fear of AIDS can be presented as an indicator of difficulties in entering into, remaining in, and moving out of relationships. About 20% of patients present with these problems. An intractable AIDS worry may be a call for professional help in a troubled relationship.

The partners and spouse of those at risk A further group are the partners of those people who have been at risk for AIDS and HIV. In our experience, it is increasingly common to have the spouse or partner come in presenting with the main worry about AIDS. A fear of AIDS and indeed AIDS itself almost invariably has a considerable impact on relationships[5]. Nearly one in 10 patients who present with an AIDS worry is the partner or spouse of someone at risk.

Couples in individual and family life-cycle transitions It is increasingly common for couples who are thinking of getting married and people who are going through transitions within their own family to present with either AIDS-related worries or directly for an HIV antibody test. Points of transition in individual and family life-cycles may exacerbate existing stresses and problems in relationships. This especially includes the parents of adolescents; couples facing the 'empty nest' or who are experiencing a 'mid-life crisis'; people who are bereaved and for whom issues about death and loss seem uppermost in their minds; and individuals who have recently divorced or separated. The authors note that approximately one in 10 patients with AIDS worries are in developmental transitions. Patients from this subgroup seem to present more frequently suggesting a stronger correlation between worries about AIDS and individual and family tensions.

Past history of psychological problems Patients who have a history of psychological problems such as anxiety and depression also present as the 'worried well'. This may either be a new manifestation of psychological problems or indeed the depression or anxiety may follow testing for HIV. The authors have noted that up to 5% of the 'worried well' are ex-psychiatric patients who have been discharged back into the community. It could be that a number of these patients may be using AIDS counselling facilities as a way of engaging care and counselling from a new 'gateway' into the health care system. Some of the patients will have been at risk for HIV through sex and drug-related activities, but the majority may have an underlying psychiatric disorder[6].

Misunderstandings of health education material There is a small (between 2 and 3% of the total 'worried well') but important group of people who present for counselling who may have misunderstood statements concerning 'safer sex' or other means of avoiding HIV infection. In our experience, public health education in the form of television and media campaigns convey information only to a point. Many people then need to have a personal interview with someone who has experience in the field in order that they can have their specific questions and anxieties addressed. For some, misunderstandings of public information remain firmly held.

Pseudo and factitious AIDS Lastly, there are that

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group of patients who present either with 'pseudo-AIDS'[7,8], or 'factitious AIDS'[9,10], as it is known. These are both relatively uncommon but interesting presentations of the 'worried well'. They account for no more than about 2-5% of the total 'worried well'. In effect, the patient believes that he or she has full-blown AIDS. A number of symptoms may support this such as diarrhoea, weight-loss and night sweats. Those with 'factitious AIDS' will present in hospital departments saying that they have been tested for HIV, that their result has been positive and that they would like to be linked in for medical surveillance. A patient with 'pseudo-AIDS' essentially *fears* being infected with HIV and becoming ill; the anxiety leads to the somatic symptoms and may be interpreted as signs of AIDS by the patient, which feeds into a spiral of fear. Patients with factitious AIDS, on the other hand, experience some benefit in being defined as ill, being clinically investigated and treated. They may feign AIDS symptoms and perhaps relish the attention they receive.

Managing the worried well

Redefinition

In our view the 'worried well' is not a particularly accurate term for this group of patients. Nobody can be defined as 'well' until a doctor has examined them and perhaps tested them. Only after that point could they then be called 'worried and well'. For this reason, any patient who presents to a physician or AIDS counsellor with an AIDS-related worry should be considered at some risk for HIV until this can be ruled out. It is only through examination, testing and history-taking that the potential for being infected with HIV can be discounted. This can, however, pose dilemmas for the physician/counsellor.

Dilemmas

There are a number of dilemmas that counsellors and clinicians face in counselling the 'worried well'. These may include (a) whether to test the patient for HIV infection; (b) whether to refer the patient to a psychiatrist or psychologist; (c) whether or not the general practitioner should be involved so that he or she can share the care of the patient; (d) whether to reassure a patient without testing him or her; (e) how to interpret AIDS-like symptoms which may either be a manifestation of anxiety or indeed of AIDS itself; and (f) how to encourage a patient to bring in a sexual partner for counselling, without breaching confidentiality, among many others. Dealing with the 'worried well' is not always a straightforward task. Some patients may implicitly or explicitly say to the physician, 'Tell me that I do not have AIDS but do not test me for this'. We would suggest that there are a number of steps, procedures and skills needed in order to deal with the 'worried well'.

Recognition

There are a range of behaviours and symptoms which indicate that somebody may have a worry about AIDS. Often, patients are not explicit in this, adopting symptoms which hint at this worry about AIDS. The physician needs to be experienced to pick up this hint. Examples are persistent health checks, relationship anxieties, worries about sexual dysfunction, panic attacks and symptoms similar to AIDS in people who are sexually active. Other patients are more explicit about their worries, and ask for 'an AIDS test', AIDS counselling or for literature about AIDS. The worry may not always be claimed for themselves: it may be for a colleague, friend, relative or another member of the family.

In the wake of the Government Health Education Programme and increased public awareness about AIDS, it may save time in some cases if health care professionals were more forthcoming about AIDS. General practitioners or counsellors might ask their patients or clients if they have any worries about AIDS at the beginning of a consultation or interview. Foremost this conveys the message to the patient or client that AIDS concerns can be raised in that context. This in turn may circumvent the 'need' for vague hints or descriptions of a worry in a relative.

There is too a secondary concern for some of the 'worried well'-who can they take their worry to? As a consequence of social stigma and a fear of a breach of confidentiality, some patients may not want to consult their general practitioner or discuss their worries with their partner. A number of patients have close or long-standing family relationships with their general practitioner. Others may not have told their doctor that they are homosexual or wish their partner to know of a sexual liaison in the past. The anxiety symptom may be exacerbated as a result of these difficulties.

The start of counselling

There are a number of different strategies and approaches for counselling the 'worried well'[2,4]. The following guidelines have provided a useful framework for counselling patients, although there can be many variations of this.

(1) Ask the patient what concern it is that has brought him to see you. If AIDS is not mentioned, but perhaps hinted at, ask if AIDS is one of the worries he has. Assess his knowledge of the essential facts about AIDS and HIV, and provide information where necessary.

(2) Identify what activities may have put the patient or others at risk for HIV. Discuss sex, drugs and blood tranfusion history, if appropriate. Try to come to an understanding of why the patient has come at this point in time in relation to this worry. Identify other individual, family or work stresses or life-cycle transitions. Ask the patient what he thinks would best help him to get over his worry. Offer the HIV antibody test, if appropriate. (For more extensive discussion about counselling for the HIV antibody test, refer to Miller and Bor[2])

(3) Help the patient to consider the consequences of being tested for HIV and how he might cope with a positive result. Ask the patient if he will be reassured by a negative HIV antibody result. If the patient says that a negative result will not be reassuring, ask what would help him to get over his fear and belief he has AIDS. Refer the patient for testing; further counselling; to a voluntary AIDS organization or to an AIDS specialist. Offer a follow-up appointment, if this is indicated.

The other points that may be considered in counselling such a patient are to find out what he has done about his worries so far. It may be that he has had tests elsewhere or it may be that he had to keep his worry about AIDS a secret which has in its own right exacerbated his own anxiety. Also it is important to put AIDS into a perspective. If one of the presentations of the worried well is relationship difficulties, it is important also to ask patients, 'If

AIDS were not a problem now, what else might you be worrying about?' In our experience, we have found it helpful to ask patients to guide us in how we might manage them about their AIDS worry. Some will say, 'I need an AIDS test,' others will say, 'Perhaps I need to see a therapist', and so on.

The impact of the AIDS worry on the patient's relationships with others including the family, close contacts, sexual contacts and friends, should always be explored. Whether or not patients have AIDS or indeed an AIDS-related worry, this inevitably has an impact on their relationships with other people. It is sometimes easier to talk about the relationship problems associated with the AIDS worry than it is to explore that individual's AIDS worry in the first instance. An added advantage of this strategy is that the counsellor need not immediately focus on symptoms such as anxiety and depression. A useful question is always to ask, 'Who else knows that you have this worry?' This immediately gives some idea about the patient's support network; whether or not he is keeping secrets from others and how he has dealt with his AIDS worry up to this point.

Difficult counselling situations

Fear of death or dying

Having AIDS, and indeed, having a worry about AIDS inevitably concerns thoughts of death and bereavement. There are a number of approaches to deal with this. One approach, which we have found useful, is to address 'dreaded issues'[11]. The principal idea is to use hypothetical and future-oriented questions in order to explore the worst possible outcome of a patient's worry. This can have the effect of 'inoculating' him against stress and helping him to talk about the unmentionable. This approach has proved to be effective, particularly where a patient's AIDS worry seems intractable.

Immobilizing injunctions from patients

Some counsellors have faced difficult, if not immobilizing, messages from patients. These injunctions can lead to an impasse in counselling for an AIDS worry. The following are five examples of these injunctions:

(a) 'Test me for HIV; but don't tell me if the result is positive.'
(b) 'If I'm positive for HIV, I will kill myself.'
(c) 'I know this is my fifth visit to discuss my AIDS worry, but I am not having a test.'
(d) 'There must be a mistake. I don't believe the result is negative.'
(e) 'It's my husband. I won't sleep with him until you've tested him.'

In each case, the patient is either demanding from the counsellor what cannot realistically be given or is challenging the views and opinion of the care giver. Paradoxical communications of this kind can be stressful for the professional as decisions will be thwarted.

Displaying the patient's paradoxical injunction can help to focus on and remove this impasse. The following are examples of what may be said to patients in these circumstances:

(a) 'Now that you have told me that; how would you suggest I handle your request?'
(b) 'If you were the doctor, what would you be advising the patient if you had just heard a patient say that?'
(c) 'What will assure you that you are HIV antibody negative?'
(d) 'That's an impossible situation for me. I can't think how I can best help you.'

The drive for help

There is a small group of patients who present with AIDS-related worries but cannot be reassured by tests, counselling or literature about AIDS. It may be that this group will keep producing an AIDS worry in order to maintain access to and contact with the counsellor. In such cases, an AIDS worry is a ticket of entry. Unless the counsellor notes this, the patient will revert to the AIDS worry at the end of counselling sessions in order to re-engage the counsellor. It can be of some help in these circumstances to say to the patient: 'I will still see you for counselling even if you no longer have worries about AIDS.' The main concern behind the patient's symptom is then suggested and other issues can be explored. A referral to a psychiatrist, psychologist or psychotherapist may be appropriate in these circumstances.

Conclusion

General practitioners and hospital doctors need to be aware of the problem of the 'worried well' in the context of the AIDS crisis. In particular, they need to be sensitive to the different concerns of patients and the sometimes indirect ways patients have of expressing these concerns. The problem of the 'worried well' is not, however, new to medicine, and is, in many ways, similar to how patients express concerns about other life-threatening conditions, such as cancer. Psychiatrists and psychologists can offer back-up in some cases, particularly where the AIDS worry seems intractable. There is a need for further research into the prevalence of this patient group and the efficacy of different counselling approaches.

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