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GOOD PRACTICE AND
PHONE LISTENING

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1 DISCRIMINATION EXPERIENCED BY PEOPLE LIVING WITH HIV AND AIDS

3 POSITIVE LIVING

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FOREWORD

During the last two years the working group "Good Practice", has worked together on important guidelines for AIDS Helplines.

This work has been very valuable for the participants because it is always useful to focus on the actual practice of the work we do. In addition to this when focusing on specific topics, you often see alternative ways or perhaps more efficient ways of working.

Today we are a group with many years experience, not only within the working group, but within the whole ENAH network. Through EU funding it has become possible to join a network of high quality and high expectations between the participants.

The aim of this working group has been to develop recommendations and guidelines for AIDS Helplines. It became obvious to us, that our assignment could only cover some of the topics which we discussed during our meetings of ENAH.

The working group has representatives from United Kingdom, Germany, the Netherlands and Denmark. The work of the group has also been debated throughout the network of ENAH. We believe this report will represent a range of different experiences from AIDS Helplines and it will also show that some of the experiences are basically the same no matter what part of Europe you come from.

INTRODUCTION

We have chosen eleven different topics that we feel are important for any AIDS Helpline and AIDS/STI prevention organisation to consider in 2003. These however are not the only topics that an organisation should consider and priorities will vary from one organisation to the next.

FRAMEWORK OF A HELPLINE

Boundaries of the Helpline

A Helpline has to consider the context of the „counselling" it provides and what the boundaries of the information and counselling offered are.

During the years there has been an ongoing debate to define whether the Helpline gives information or offers counselling. The different and values of information and counselling is important to pay attention to as every Helpline will face this different ways which can depend on the ethos of their organisation or even just perhaps a matter of language or cultural differences.

Opening Hours

At Terrence Higgins Trust they started a pilot project to re-evaluate the opening hours of their service. It is interesting to see that opening hours should not be considered to be a static scale, but one should re-evaluate them on a regular basis to ensure a maximum number of callers are reached.

Staff working on Helplines

All over Europe there is a lot of experience where professionals work together with volunteers at a Helpline. This is a model that has been used by many Helplines for as long as they have existed. Berliner Aids-Hilfe (BAH) has continued to work with volunteers, the Dutch AIDS-SOA Infolijn works with paid staff only while at Terrence Higgins Trust (THT)in United Kingdom and AIDS-Linien in Denmark the Helpline consists of both paid staff and volunteers. We are glad to present some of our differing points of views and experiences on this issue.

POLICIES

Reading the chapter on policies could inspire you to look at your own policies or to develop new policies for your organisation. It was not possible to cover all policies that a Helpline should be aware of, but we have looked at some that should be considered.

Confidentiality, Privacy and Anonymity

Confidentiality is crucial to the ethos of most Helplines and many could not deliver a service of value if their callers were not able to rely on anonymity. Here we look at the issue and what it might mean to callers and the Helpline service.

Repeat Callers

Such is that nature of Helpline work that there will be a proportion of enquirers, who will make contact repeatedly but without any satisfactory outcome. These are sometimes termed "Repeat Callers". There will also be some callers who will be looking for short-term on-going support. These are sometimes referred to as "Regular Callers". Here we looked at the effects they have on Helplines and two differing strategies for dealing with them.

Suicidal Callers

Unfortunately it still appears that some callers are so desperate and unable to find solutions for their situation that they can become suicidal and express this during the tele counselling. AIDS Helplines have to be prepared for suicidal callers otherwise it can become a traumatic experience for the counsellor when they receive such a call.

HIV AND OTHER SEXUALLY TRANSMITTED INFECTIONS (STIS)

HIV Test Counselling

A major part of the helplines work is counselling on HIV testing. Making a test is a big decision and can have major consequences for the rest of someone's life. It is therefore most important that you have the ability to receive good counselling both before and after an HIV test.

STIs

Development of Helplines is a point of great interest and enlargement of the counselling to include Sexual Transmitted Infections could be an important trend for many organisations. Many AIDS Helplines already answer a lot of STI related questions during telephone counselling and we looked at the experience from the Dutch Aids (STI) Helpline, when they decided to extend their counselling to include STIs.

Harm Reduction

All AIDS Helplines have HIV prevention as their main aim. We know that changing behaviour is difficult and not without effort for many people. There is no doubt that our main target is to provide information and counselling about Safer Sex. However, we also need to have a strategy for those people who do not practice Safer Sex, and to whom it will never be a part of their strategy. For this group, AIDS Helplines could consider how or if, harm reduction can be used as a HIV prevention tool.

NEW TECHNOLOGICAL DEVELOPMENTS

Email, Internet and Voice Response systems

For many years Helplines have only used live telephone operators to deliver their service. With the development of the Internet it is however important to face the new opportunities of this media. Berliner Aids Hilfe and the Dutch AIDS-SOA Infolijn have gained important experience from email counselling and it is clear to the working group that Internet and email counselling are worth considering.

During the last three years the Dutch AIDS-SOA Infolijn has used voice response systems with great success; another way of getting in contact with people who need information.

It is our hope that these guidelines can be a valuable tool for other AIDS Helplines. It is our belief that not only can they be a help when you are establishing a new Helpline but also to established Helplines. We believe that these guidelines can be a valuable support when you aim to revisit the efforts and working practices of your AIDS Helpline or HIV prevention organisation.

In general it is clear that a Helpline is a dynamic organisation or structure which is constantly confronted with changes and new developments. Therefore as a Helpline you have to stay aware of what your aims are and how you reach them to make sure that you are up to date with the developments around the Helpline.

Even though many of the questions our Helplines receive have stayed the same over the years, it is obvious that there are always new demands and other ways to achieve our goals. We therefore have to ensure that these are guidelines and not a list with closed and finished issues. We recommend these guidelines need ongoing re-evaluation to ensure that AIDS Helplines stay intouch with the needs of the target-groups using them.

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FRAMEWORK OF A HELPLINE

HELPLINES, INFORMATION LINES AND COUNSELLING: THE VALUES AND DIFFERENCES FOR HELPLINES

INFORMATION LINES

There can be some confusion over the remit of phone lines and the roles that workers on phone lines take on and the skills that they use on the phone.

Phone services should be very clear in what they wish to achieve, how they are going to achieve these goals and the skills they expect their workers to use to achieve these goals. Here we will look at the differences between: Information Lines, Helplines using counselling skills or skills that counsellors use and Counselling. There may be confusion over some of these definitions as some countries may have no direct translations for Counselling or Helplines. The following is mostly based on the United Kingdom experience.

Information Lines normally only deal with factual information. They will present information to the caller and it will be up to the caller what they wish to do with this information. They will not attempt to look behind the reasons for the caller asking questions, to explore any underlying reasons for the caller's questions or try to put the answers into context of the caller's life and what it might mean to them. A problem that arises here is that factual information can be misconstrued and result in a higher level of anxiety at the end of the call.

Call Centres

With the expansion of Call Centres throughout the world, it could be that the operators answering the calls are dealing with a number of Information Lines at the same time. To do this they will be trained in the telephone and computer technology and be able to answer callers' enquiries from prepared scripts or information resources. These are often on computers where they can follow the scripts and answers that have been prepared by someone else and they therefore do not need to have any specialised training, knowledge or interest in the subject they are talking about.

Helplines

A Helpline will offer callers information and support on a specific subject. They often aim to "Empower" the caller. This might be defined as: offering the caller accurate and appropriate information and support that enables them to make decisions about their own situation.

To distinguish between an Information Line and a Helpline, this empowerment will try to look behind the reason for the caller's questions. They will try to put the answers into some sort of context for the caller and checking how the caller feels about the information. There will be reflection on how the caller sounds to the operator (e.g. worried, upset, confused). There will be exploration of underlying issues, perhaps asking why the caller might be asking a certain question, getting the caller to open up and reflect on how they feel after they have been given some information. These are often described as "counselling skills".

Many Helpline have evolved from the voluntary sector, being started and run by volunteers that have an interest in that specific subject. Often they themselves will have been affected by the subject themselves which can lead to feeling an affinity with the callers. They might not have any professional qualifications in the subject matter or professional Counselling qualifications but what they do bring to the Helpline is that they have certain personal traits and skills that enable them to 'connect' with callers. They have a willingness to learn and develop skills that mean they are able to offer callers this 'Empowerment'.

COUNSELLING

Counselling is normally a face to face service where the Counsellor will see the person for a set amount of time over a set amount of sessions or period. It will often be on a one to one basis with roles clearly defined: Counsellor and Client. The Counsellor will have professional Counselling qualifications and be bound by a professional code of ethics and practice. In Great Britain this is the British Association for Counselling (BAC).

The BAC Code of Ethics and Practice for Counsellors states:

> *"The term 'counselling' includes work with individuals, pairs or groups of people, often, but not always, referred to as 'clients'."*

Counselling may be concerned with developmental issues, addressing and resolving specific problems, making decisions, coping with crisis, developing personal insight and knowledge, working through feelings of inner conflict or improving relationships with others. The counsellor's role is to facilitate the client's work in ways which respect the client's values, personal resources and capacity for self-determination.

CONCLUSION

Counselling versus Counselling Skills

In terms of Helplines, it can be confusing as to whether the workers on the Helpline are Counsellors or not. Many callers to Helplines will ask to speak to a "Counsellor". This normally means that they wish to speak to someone who is trained to listen to them. They might get referred to as Helpliners, Listeners or Operators.

It should be clear to both the person calling and to the person answering the call what the relationship is and is not in terms of counselling. If they are going to enter into a "Counselling" relationship that has to be made quite clear from the outset. It could be argued that by calling a Helpline, the caller knows that it is not a Counselling relationship in that it is not a time or number of sessions restricted relationship and that it is not a form of on-going development work that a professional Counsellor would facilitate.

The BAC Code of Ethics and Practice for Counsellors states:

> *"Only when both the user and recipient explicitly agree to enter into a counselling relationship does it become 'counselling' rather than the use of 'counselling skills'*

When a phone service is being established it must decide what its role is going to be in terms of solely information, a Helpline service or a telephone Counselling service. This will help not only those who provide the service but also those who use it.

Both professionals and volunteers working on AIDS Helplines will have a lot of skills that counsellors will use during in a face-to-face situation. These, we feel, make the Helpline more effective and we think an AIDS Helpline should not restrict itself to offering information only.

Willie Turnbull,
Terrence Higgins Trust

References

Pete Sanders: An Incomplete Guide to using Counselling Skills on the Telephone; Revised 2nd edition, Redwood books, Manchester: 1993

OPENING HOURS: KEEPING UP WITH DEMAND ?

The opening hours of a Helpline are influenced by various factors such as:

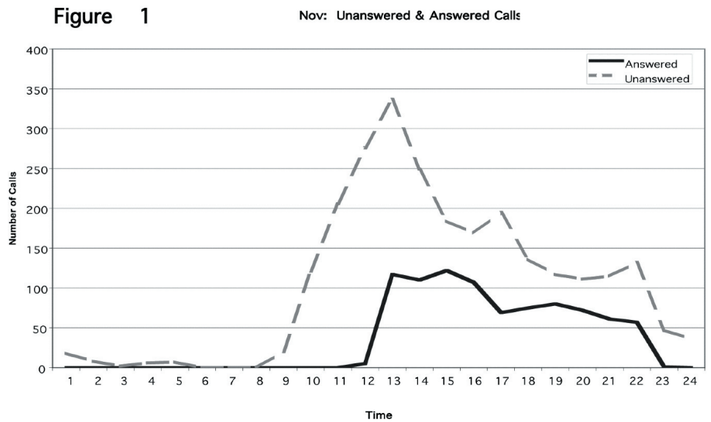
Staffing: where staffed only by volunteers they may have only been able to open when the volunteers were available. Where paid staff were used, the costs of employing people to work unsocial or out-of-normal office working-hours could be prohibitive.

Tradition/Advertising: Advertising is expensive and very often once a Helpline advertises its number and opening hours, it can prove costly to re-advertise.

Privacy/Confidentiality: In the early 1980's there was a high demand for HIV Helplines in the evening and weekends when people could call from a private and confidential setting, often a call box or from the privacy of their own home.

With the increase in factors such as mobile phones, demand for 24-hours services, email and Internet, have HIV Helplines kept up-to-date with their opening hours?

Figure 1



THT'S EXPERIENCE

Here at the THT Helpline there was growing anecdotal evidence that calls were coming into the Helpline on weekdays during the daytime when there were less volunteers available and many calls were going unanswered. Callers would complain of not being able to get a reply. When we looked at our call figures, we realised that we were receiving a lot of calls before the Helpline was open (Figure 1). This made us revisit the question – when is the Helpline most likely to be used?

Expanded Hours Trial

In February 2001, we ran an expanded access trial during which the Helpline would be open from 10am, instead of 12 noon, to see what affect this would have on the number of calls answered (Figure 2). The change to the service would not be advertised although the recorded message heard when the Helpline was engaged or closed would reflect the hours during this trial.

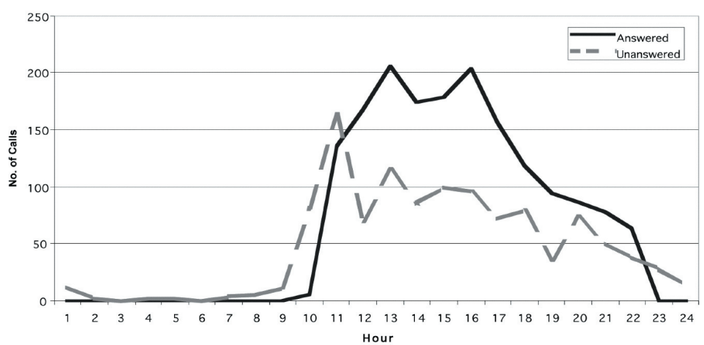
Results of the trial

- 62% increase in the number of calls answered
- 47% of this increase was answered during the hours of 10am and 12 noon
- 47% increase in the number of HIV infected people using the service
- 68% increase in the number who identified as a Carer, Friend or Relative of an HIV positive person

There was no change in the number of calls received to the Helpline would indicate that callers who had not been able to access the service in the mornings when the Helpline was closed, did not try to call back later in the day.

It was also notable that where a call was received from someone infected or affected by HIV during the extra hours, they were not calls that simply needed to be referred to other services, but were calls from people specifically seeking the emotional support and information that our Helpline offered.

Figure 2 1: Feb 2001, Ans/Unans/Hour



CONCLUSIONS FROM THE TRIAL

There was an obvious demonstration of the need for a telephone service to be available earlier than the Helpline is currently offering. A large number of callers are now wishing to access emotional support, information and advice on HIV and AIDS during what are traditionally known as "office hours". Why has this change come about and what can be done to meet the needs of the service users?

Why this change might have come about may raise more questions than we can answer here. Has there been a change in attitudes towards HIV and AIDS? Has the perceived "normalisation" of HIV and AIDS made it easier for people to talk about or is it just that people's expectations have changed?

As people in UK are living longer with the virus, many are returning to work or study and fitting their HIV care needs into what may be seen as part of their normal day-today life, similar to that as going to the dentist or going to visit their bank manager. Could it be therefore that they are also seeking the services of a Helpline at similar times?

Recommendations

Helplines must regularly monitor their opening times, that they reflect when demand is made on the service and if necessary change its hours to meet that demand.

Willie Turnbull,
Terrence Higgins Trust

WORKING WITH VOLUNTEERS ON THE PHONE[1]

LIMITS AND POSSIBILITIES OF THE HELPLINE

In the last two decades, many AIDS organisations in western Europe were founded by people who were directly concerned about HIV and AIDS, either because they themselves or people close to them had been infected with HIV. They tried to gather information about HIV/AIDS and, in turn they provided other people with this new information. This they did all on a voluntary basis.

After a while the AIDS organisations had to change to a more "professional" service in order to secure funding from the state authorities and so the first people were employed on a full time basis. Despite this, the work of AIDS organisations in many European countries would be inconceivable without the frequent help of volunteers. At the Berliner Aids-Hilfe, for example, the Helpline is run by 25 to 30 volunteers who are supervised by a single Helpline co-ordinator. In other countries such as the AIDS-Linien in Denmark organisations work with both volunteers and paid staff at the same time.

In general the information discussed on the telephone line has to be limited and the boundaries of the information the listeners can provide should be clear. The maintopics are: testing possibilities, risk assessment, risk management, basic information on the HIV virus and its pathological effect on the human body.

In Germany for example all medical, legal and social counselling activities (e.g. rent issues or HIV-treatment) are conducted by (paid) social workers, doctors or advocates. The law does not allow such topics to be conferred by laypersons. It is very important for the listeners as well as for the callers to know the limits of the Helpline service. Due to the different laws in Europe, the topics, which could be discussed on the phone, can change from country to country.

There are two very important aspects in offering a telephone Helpline:

Anonymity and Confidentiality

It is very important that callers know that they can bring forward every aspect they want to talk about regarding HIV prevention. In addition, to fostering a trusting atmosphere at the Helpline, volunteers have to be bound to anonymity and confidentiality.

Limits of the Helpline

It is further necessary that callers understand the limits of the services that an AIDS organisation provides. The objective of a Helpline is to enable and support their users to make their own decision. There are many questions, which cannot be dealt with on the phone but which have to be referred to other services (e.g. doctors, lawyers, or psychologists).

1 This article partly based on an article already published in Enable number 10 about working with volunteers at the Berliner Aids-Hilfe.

THE CALLERS

Over the years the callers changed and so did the information Helplines provide. In the early 1980's people who called were often HIV infected themselves or they knew of friends or family members who were infected. In Germany nowadays only about 10% of the callers are themselves HIV infected. The typical caller to the German Helpline for example is heterosexual, mainly with a low risk, who wants to have information about an "unclear situation" or about the possibilities of HIV prevention and testing. For some years now, we have accumulated a certain number of repeated callers with high anxiety levels as well as more and more questions on hepatitis or other sexual transmittable infections (STIs). They thus pose new problems and challenges to our traditional counselling service[2].

For many callers the listeners are the very first contact with an AIDS organisation. Therefore, the Helpline is also the first step into various other services AIDS organisations offer. It likewise functions as an advertisement for the quality and competence that it provides as a whole. The skills and experiences of the listeners will consequently have an impact on all the other services offered[3].

THE LISTENERS

We always ask people, who apply for the Helpline, what their motivations were to work in an AIDS organisation. We also want to know what they themselves are looking for in sparing their time for the Helpline services. It is essential for us to get to know what expectations they have about their work. There are a lot of different reasons why people engage in voluntary work: often they want to give back some of the good experiences to others that they themselves had experienced in the past. Some are studying social work and see counselling on the phone as one possibility to get practical experiences in their future fields of work. Others want to develop interpersonal and support skills. Thus, normally the group of volunteers who want to be engaged in telephone counselling is very diverse.

In order to work at a Helpline, there are some basic skills needed. Listeners should be able to show empathy to the problems of the callers, because they often present a whole set of intimate questions linked to their sexuality, anxieties, and problems they have

2 - For more information on STI counselling please see the article in this booklet.

3- See: Deutsche AIDS-Hilfe: Die Zukunft der Telefonberatung – Qualitätsentwicklung in der Telefonberatung von AIDS-Hilfen, herausgegeben von der AG Qualitätsentwicklung in der Telefonberatung von AIDS-Hilfen der DAH, 2. neubearbeitete Auflage, Berlin: Dezember 2000.

TRAINING

in their personal relationships. The listeners should be very sensitive when dealing with the callers' concerns. In addition to this, they should be capable of explaining complex issues with regard to the prevention and transmission of the HIV virus.

New volunteers should be able to work for the Helpline for a certain period of time not only in respect to the hours they work by week. They should also decide about the minimal amount of time that they will be able to stay and work with the organisation. For example, in Germany the minimum age of the volunteers in the telephone counselling service is 23 years and we expect new volunteers to work 6-8 hours a week during the first year. On the one hand this will give us the possibility to plan and to maintain the Helpline. On the other hand, and especially in the beginning, it is important for the listener to experience a lot of counselling situations in order to develop the necessary skills and to foster his or her knowledge.

It can be seen from the local experiences of the Helplines, that in most aspects it is not important if the listeners are volunteers or paid staff. They will receive the same training, regardless of their professional status. This ensures that every listener has the same knowledge background and that the listeners, on a personal level, feel like equal members of the team. Other aspects, e.g. the long-term motivation need special attention in the work with volunteers.

It is advisable that a basic training should focus on the different services and self-help groups provided by the AIDS organisation or other co-operating organisations.

In addition to the basic training on the infrastructure, the actual telephone education should cover essential aspects of the work at the Helpline. In Germany, for example, this consists of the following three topics :

1. training is given on basic knowledge about:

- medical aspects of HIV and AIDS
- HIV testing
- HIV infection treatment
- Hepatitis and STIs

2. training is provided in counselling skills and communication:

- HIV test counselling
- risk assessment
- training in communication and psychological perception skills
- self-awareness with regard to the main counselling topics: sexuality, dealing with anxiety, illness, or death
- boundaries of telephone counselling and how to end a phone call in a friendly assuring manner

3. training focuses on the listeners competence in:

- information about the infrastructure of the medical and public health system regarding all aspects of HIV and AIDS
- knowledge of reference and access modes to various other relevant public health organisations

MAINTAINING THE QUALITY

In addition there are several other important measures to develop and maintain the quality of a Helpline service:

Co-counselling shifts
For a certain time, new volunteers accompany and listen to volunteers who already work on the phone. They are invited to ask questions, over and over again, concerning different types of calls. The information is then further discussed.

Counselling material
Volunteers have to become familiar with the different material that an organisation works with on the phone. This often consists of a list of important addresses, counselling handbooks and brochures on medically important information about HIV/AIDS and STIs.

Training sessions
As said above, the callers and the questions asked change. It appears necessary to transform and to enlarge the training of the volunteers to envisage this process. In the past years for example the biggest change took place with the extension of information to be given on STIs. In terms of risk assessment there have also been many adjustments e.g. with the beginning of the post exposure prophylaxis (PEP) for sexual transmission risks. Safer sex policies can even change and may thus require new counselling strategies, as has just happened in Germany for condom use in anal sex[4]. To keep volunteers informed about new developments, counselling standards etc. there has to be further vocational training during their work.

Statistical records
It proves to be very useful to recorded the calls statistically, in order to observe changes in the topics discussed on the phone and to react to the various demands of the callers.

Supervision
In difference to other voluntary work fields the telephone counselling often appears as a "lonesome job". Despite this the training procedure should try to reassure and to comfort new volunteers by providing technical skills and social support. All telephone listeners should take part in supervision sessions which are given by an external supervisor. There, Helpline volunteers have the possibility to discuss problems they experienced with specific callers or topics within conversation. They may update their knowledge about HIV/AIDS or other relevant information within their groups. Conflict management, communication training and role plays form part of their supervision group in addition to being able to connect new and experienced volunteers to strengthen the group.

Recognition of voluntary work
Apart from the knowledge transfer, there is another important aspect in working with volunteers: the social esteem and recognition of their work by the whole organisation.

Some social events could be organised over the year for the volunteers to show that the work they provide for the organisation is appreciated. At the Berliner Aids-Hilfe for example some of the Helpline volunteers started a social group to provide a good opportunity for a group of regular volunteers to get to know each other on a private level. This is supported by the coordinator of the Helpline.

AIDS-Linien in Denmark organises weekend seminars for the whole group of listeners, not only on educational purposes but also for the strengthening the team building process. The quality of the training as well as these different ways of social recognition, ensure a high level of motivation to work for AIDS organisations.

It is through such experiences that most of the Helpline volunteers support the organisations for several years. They feel that they do an important work not only for the callers but also for the organisation they work with.

Katharina Stahnisch,
Berliner Aids-Hilfe

4 - A couple of studies have shown that there is no difference in using a regular or an extra strong condom in anal sex. More important than the thickness of the condom is the use of enough lubricant in anal sex to prevent the breaking of the condom.

CONFIDENTIALITY: CLARIFYING IMPORTANT ETHICS

Confidentiality is crucial to the ethos of most Helplines and many could not deliver a service of value if their callers were not able to rely on anonymity. Contrary to this, some Helplines have to collect details of their callers and calls to ensure that their service is focused, that they continue to meet the needs of the callers and the community and that they meet the target group that they are funded to provide the service to.

These three descriptions can often be confused and at times overlap and although in terms of Helplines they may be implied or expected by all parties (caller and the worker receiving the call) it is often valuable to explore what they mean.

Confidentiality refers to the treatment of information disclosed to the person taking the call by the caller.

Privacy normally refers to the setting in which the call takes place e.g. someone at home in a room on their own is a private place. Where privacy would be infringed upon would be if the person taking the call was in an area where other Helpline workers were.

Anonymous would mean that the caller did not divulge any information that would identify them. This doesn't have to be specific details such as name and address but could also be by circumstance e.g. a single mother of 8 children living in a small rural village. She could be identified by her circumstances without giving her name and address.

To put these into the context of a Helpline setting:

Calls are sometimes listened into by other Helpline workers for training and quality monitoring purposes. While this is not private from the Helpline's point of view, it does remain confidential as both workers listening to the call are governed by the way the Helpline deals with the information received during the call. The caller would still remain anonymous unless they divulged information that identified them.

The caller might not know that they are being listened to and it would be good practice for them not to be aware of a third party listening as this would undoubtedly have an effect on the call. Some Helplines may mention in their advertising or on their website that some calls may be listened to for training and quality monitoring. If a Helpline advertises as anonymous, they have to be clear in their practices and understanding of what this means.

DATA COLLECTION AND ACCESS TO SERVICES

Some Helplines will now ask callers for some information for statistical purposes. From these questions it should not be possible to identify the person calling and the asking of them should not affect the outcome of the call. The caller should also have the right to refuse to give the information should they wish to do so. At THT we ask callers the following questions:

- ethnicity
- sexuality
- gender
- year of birth
- area or nearest large town that they are calling from

Often a lot of this information will be covered during the course of the call and will not need to be asked again.

To access certain services of an organisation it may be necessary to get a lot more personal details from the caller, some services may only be available to people living in a certain area. If the Helpline acts as a referral service or a point of access to other services the operators will have to be able to explain this to the caller. If a Helpline offers legal advise, there may be different laws covering different parts of the country and therefore a caller would have to say where they were calling from. In terms of welfare benefits advise a caller would have to give details of their personal circumstances in order to get accurate advise on their situation.

It has been our experience at THT that if a caller is already accessing some services and wishes to access another service, then they are happy that they do not have to start right at the beginning again in giving their details. They see the relationship as being established and themselves as an on-going client.

Legal Disclosure

There may be times when a caller's details have to be given under duty of Law. These need to explored by each individual Helpline according to their countries laws. Some examples may be threats of terrorism, child abuse or threatening another individual's life.

Confidentiality Policies

All Helplines should have a policy on confidentiality and this needs to be covered not only during initial training but also reviewed and revisited as an on-going issue.

Such a policy should be:

- clearly written
- available to all workers
- made known to all callers at appropriate times
- fully explained in training and induction to all workers
- in a constant state of revision

It should cover:

- categories of information that are confidential
- under what circumstances and to whom confidential information can be disclosed
- the legal position on confidential records
- acknowledgement that confidentiality is shared between past, present and future workers

Willie Turnbull,
Terrence Higgins Trust

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POLICIES

REPEAT CALLERS: A COMMON PROBLEM FOR ALL HELPLINES. TWO DIFFERENT APPROACHES

IDENTIFYING REPEAT CALLERS

Such is that nature of Helpline work that there will be a proportion of callers, who will make contact repeatedly but without any satisfactory outcome. These are sometimes termed "Repeat Callers". There will also be some callers who will be looking for short-term on-going support. These are sometimes referred to as "Regular Callers".

It is important that the difference between these two types of caller are recognised, the methods for handling the different types of caller recognised and the effect these different types of calls can have on the service and those providing the service.

Some callers may contact the service looking for on-going support e.g. while waiting for a test result or during the window period. It is important that it be recognised that the phone service is not a substitute for long-term support such as counselling.

Importance of Repeat Caller identification

It is important to identify a Repeat Caller for three basic reasons:

A. The caller

- using the phone service does not tackle the root cause of their problem
- they can become dependant on calling the service
- their underlying problem may be made worse because it could be a psychological one
- using the phone line could be a substitute for a more appropriate source of help e.g. on-going counselling

B. The operator

- calls can be dis-empowering
- they may create feelings of frustration, anger and helplessness
- there is a risk of reduced ability to listen and concentrate

RECOGNISING REPEAT CALLERS

C. The service

- time taken up on the call and subsequent de-briefing
- operator dissatisfaction contributes to a higher turnover of staff/volunteers
- other callers unable to get through to the service
- the handling of subsequent or similar calls may be affected

definition of a "repeat caller" may :

- phone numerous times and ask the same questions often in exactly the same way
- perceive their problem to be hiv related when it isn't
- have an irrational fear of hiv
- have a problem that cannot be solved by the service e.g. asking questions that cannot be answered
- will continually return to the opening questions/situation
- only get temporary relief from their anxiety
- become dependant on the phone line
- often test information already given

Repeat Callers often have certain characteristics although because each can be so different, this may seem very general and may or may not apply to Repeat Caller that you know of.

1. Look out for "HIV-speak"

This may give a clue to the fact that they have spoken to someone on the subject before and have picked up terms that would not normally be used in everyday language e.g. seroconversion or window period.

2. The content

- their questions may assume the answer e.g. "is it true that i have to wait 3 months for a test?"
- they cling to a particular issue and cannot be steered to other things resulting in circular conversations
- the risk may be theoretical and require several unlikely coincidences for it to be a true risk
- the reported risk may be deemed weird or eccentric e.g. touching door knobs
- the caller may present new and exaggerated risk factors from the last time/call
- they become engrossed in the mechanics of transmission and/or testing procedures

3. Type of caller

- there is no introductory hesitation or gentle "feeler" questions
- they have a tendency to question anything that gives reassurance e.g. being unable to believe a negative hiv test result
- they play on insignificant inconsistencies e.g. 90% to 95%, 12 weeks to 3 months (12x7days=84days, 3 x 30 days/31 days = 90/93 days)
- they do not listen to advice given
- they do not respond positively to reassurance – always looking on the worse side
- they may try to catch the operator out or play one off against the other or one phone line off against the other.

4. Other clues

- they may tell you that they have called before
- they may apologise for calling again
- they recite advice or complain about advice given from other phone lines
- they mention having been to a clinic many times

MANAGEMENT OF REPEAT CALLER: TWO DIFFERING APPROACHES

There are different methods of managing Repeat Callers and it is up to the individual Helpline to decide which method they wish use. Here we look at the THT's method in the UK and that of AISD SOA Infolijn (ASI) in the Netherlands.

THT Direct Helpline, United Kingdom

As each Repeat Caller is an individual problem, both in terms of the type of worry and their personal character, only general advice and suggestions can be made:

Take care not to get caught in a "what if" scenario. This can result in the operators second guessing themselves and getting confused. A Repeat Caller will look for small inconsistencies and use that as a "hook" to justify their fears and continue the call.

Try to steer the call to examine the facts rather than hypothetical scenarios.

Watch out for a "closed agenda" in which the caller dictates the way the conversation goes and does not wish to discuss or explore other aspects that may be important.

It can be useful to say that you feel they are reluctant to look at other aspects and that you wonder why this is so.

The information given must remain accurate, impartial an unbiased. Words, phrases and statistics can be analysed by the caller and used in challenging the operator taking the call and lead to higher anxiety levels.

Try to avoid quoting statistics. Use phrases such as "a vast majority". Do not try to be the authoritative figure on HIV. Use phrases such as "as far as I am aware..."

Do not provide new or additional material for the caller to use to heighten anxiety e.g. "it would only be a risk if..."

Be careful of over-reassuring. This can have the opposite effect on the caller who might perceive that you are not wishing to give them bad news.

Avoid challenging the caller in an aggressive manner. This can make the caller feel defensive and can lead to both the caller and the operator playing a game of cat and mouse, trying to catch each other out. As it is a normal reaction to deny something when challenged, it is likely that a Repeat Caller will deny calling before. If you challenge them it will often be denied and this in itself can be very frustrating for the operator

- try asking the caller what sort of help they expect and/or want from the phone line
- if you have spoken to the caller before, make reference to it in a non-challenging way. refer to "the last time we spoke...."
- ask the caller what they have been told previously

DESIGNATING A CALLER AS A 'REPEAT CALLER'

Once persistent possible Repeat Callers are brought to the attention of management, they may decide that the caller should be officially designated a Repeat Caller and a suitable response decided. The suggested response should only be given when the operator is as certain as they can be that they are speaking to the Repeat Caller.

Example of suggested response:

"We are aware that we have spoken to you on numerous occasions and that we have offered you all the information and help that we can. We have also suggested other agencies that we feel would be more appropriate to you needs. We therefore strongly urge to contact them in future and refrain from calling us in the future. Thank you, goodbye"

All operators will be expected to adhere to the suggested response.

PROTECTING YOURSELF

As stated earlier, Repeat Callers can have a debilitating effect on those taking calls. It is therefor important that the effects of such callers are discussed in support groups and also on an individual basis.

- you are not alone in having repeat callers
- be aware if you are starting to feel disempowered
- be aware that as a phone service, we cannot solve every caller's problem. This is no reflection on your skills or knowledge
- remember that other operators may have similar feelings because of the same caller or similar callers
- it is not personal
- the next caller may be better served if you take a short break after a repeat caller
- talk to other staff/volunteers or managers about calls that you have received
- if you feel yourself getting angry, it is time to close the call

AIDS-SOA INFOLIJN

AIDS-SOA Infolijn Holland has another experience for dealing with repeat and regular callers.

The Dutch ASI has specific training, supervision and protocols to handle repeat callers. This has resulted in effective management of these callers.

Specific deals are made with repeat callers: they can call once a week/month and this is registered in a logbook. The caller is also referred to mental health care. This offers a structure to the caller and most of the time the number of calls reduce and some repeat callers report a decrease in anxiety and will perhaps have started anxiety therapy.

This method has proven to be effective in dealing with these specific callers. It is also less stressful for the Helpline workers and the counselling seems to be more effective because the callers are confronted with the cause of their repeat behaviour and are encouraged to seek the right kind of help.

Repeat callers are discussed at team meetings and it is decided if a caller is going to be confronted. This acknowledges the fact that we recognise their repeat calling and offer an appointment to regulate their calling. The Helpline worker will try to motivate the caller to seek specific counselling for their anxiety and explain the boundaries of the Helpline.

If the caller is willing to cooperate the following conditions will be agreed if:

- the caller will seek professional counselling/therapy for their anxiety problems
- the caller gives a name (real or fictitious) to give each time they call and will give this each time they call and mention that they have made an agreement with the phone line
- any calls received will note din a log book although the content will not be recorded
- any calls received will discussed among the team members to continue the assessment of the caller's situation
- the agreement will be for a limited period only

CONCLUSION

A Helpline should have a policy that reflects its ethos on Repeat Callers and provide adequate training and support to its workers. This is to support the workers on the service while helping to ensure that callers who have needs out-with the remit of the Helpline are given the appropriate service.

Willie Turnbull,
Terrence Higgins Trust
Bauke Kortleve ,
AIDS-SOA Infolijn

SUICIDAL CALLERS

AIDS Helplines can receive calls from people who wish to commit suicide or express suicidal thoughts. These are often associated with Mental Health issues, terminal illness or perceived terminal illness. The caller can see no way forward and can only see taking their own lives as an answer. While the prognosis of someone living with HIV has changed for many since the advent of multiple drug combinations, this might not be known to someone who has little or no experience of HIV or AIDS.

It is often the fear and ignorance of HIV that can cause someone to phone up an HIV Helpline in extreme anxiety or panic. Often they know next to nothing about HIV treatments and what living with HIV can mean. They only see a "death sentence". For some, when they reach this "death sentence" conclusion, that they might decide that there is no way forward and that suicide is the only choice left to them.

Workers on HIV Helplines over the years have had to keep themselves up-to-date with the many changes in HIV and when confronted with a suicidal caller, it may be something they have not heard of for a long time or perhaps something that they have never experienced at all.

This, understandably, can have a very profound effect not only on the worker listening to the call, but also on their co-workers and the whole service. When such calls are received it is vital that all workers on the Helpline are able to discuss their feelings on the issue, the effect it had on them and support, time and training must be offered as a priority.

There are many moral, ethical, legal and religious values attached to suicide and it is important that these issues are explored with the workers on the Helpline. Some Helplines may have the ethos that there should be no intervention, that the caller has the right to take their own life and it is their duty to listen to that caller to the point of death. Other Helplines may be of the opinion that advising the caller to seek urgent medical attention and therefore terminating the call is in the caller's best interests. There can also be a level of intervention i.e. asking the caller's permission to contact a family or friend or calling for an ambulance as way of trying to do something to help the caller.

As we are all individuals and have our own moral and ethical identities, it can be difficult to arrive at one definitive rule for everyone to adhere to and it may be that guidelines are more appropriate.

POSSIBLE GUIDELINES

Legislation

Each country will have its own legislation governing the right to commit suicide or assist a suicide. It is important that a Helpline is aware of the laws for their country when considering its policy on suicidal callers.

Code of Practice

While there may be legislation covering an individuals choice on whether to commit suicide or not, it may also be advisable that Helplines have a Code of Practice on Confidentiality and the Handling of Personal Information. This can help empower those dealing with such calls into what they can do in terms of disclosing caller's details and what they cannot. Very often they will not have any details i.e. name, address, location but it might help in guiding them if they are given the information during the course of the call.

Risk Assessment

There may be callers to Helplines that say that they are going to commit suicide but there may also be those that express "suicidal thoughts". It is important that the differences between these two are recognised as they can have a profound effect on the path the call will take. To help distinguish between them, a form of risk assessment might prove useful to the worker taking the call.

The assessment could include questions as to whether they are taking any medication such as anti-depressants or tranquillisers, whether they are in contact with other professionals such as a psychiatrist or psychologist or have had other forms of counselling in the past. This assessment can be on-going and may take some time to gather the information.

Coping mechanisms for the worker taking a suicide call

It is important that workers on a Helpline are offered appropriate training, support and coping mechanisms to deal with suicide calls. Workers taking suicide calls will often go through a range of emotions and hopefully with the appropriate support will feel enabled to come back into the Helpline and carry on the work that they do so well.

CONCLUSION

All Helplines should consider the morals and ethics around suicide, legislation, training and support to ensure that they have as adequate as possible policies and guidelines on handling suicide calls.

Willie Turnbull,
Terrence Higgins Trust

Acknowledgement to :
Christine Mead, Head of Counselling Services, Terrence Higgins Trust

HIV AND STIS

TEST COUNSELLING: THE ROLE OF AIDS HELPLINES

Many callers to HIV/AIDS Helplines wish to discuss whether to have an HIV test or not. Understandably this can be a very difficult time for callers. They may never have visited a sexual health clinic and are probably worried about the impact that having an HIV test will have upon their lives, whether it is a positive or negative result. Other than just telling callers where they can have a test done, it can also be beneficial to the caller to talk through the process and what should happen at the clinic and to be able to explore how they might feel about the result.

While many HIV testing clinics will themselves talk through the issues, it cannot be guaranteed and should be seen as "what should happen as best practice" rather than "what will happen". Clients of HIV clinics can be in such a state of high anxiety, embarrassment, shame or shock that often what is said while at a clinic will pass by in a blur and not be taken on board.

Most people will call Helplines from a place that they feel safe, secure and in control of the situation. They are the ones that have the power to end the call should they wish to do so. This can therefore be an ideal place for callers to discuss many of the issues surrounding HIV testing anonymously and at the pace and level that suits them.

Often the discussion taking place at an HIV testing clinic will be described as "Pre- and Post-test counselling" While it may not be Counselling in the traditional sense of a time or session-based contract it is sometimes described as a "Pre- and Post-test chat" with a Health Advisor.

PRE-TESTING

Pre-test counselling is likely to require consideration of:

- risk assessment has the individual been at risk?
- the accuracy of hiv testing
- understanding of safer sex and safer drug use
- the pros and cons of testing for this individual at this moment in time. how would the individual react to a positive result right now? Are there good clinical reasons why a test is advisable? Is the individual pregnant?
- the testing procedure, including how the test is done, the procedure of informing of the results and who to tell about taking the test
- confidentiality: a discussion of the procedures to protect as best possible the person's confidentiality

DISCUSSION OF POST-TEST COUNSELLING

It is important that callers know about what happens after the test result is given and to think through the practical implications of receiving their test result before it takes place.

Prior to getting the result a caller may wish to consider the following:

- who should be told about the test? What might the consequences be of telling those people?
- many people disclose widely in expectation of a negative result. This may create real problems of confidentiality if the result is positive
- should a partner be told of the result of the test? Does the clinic have a policy of encouraging partner notification? how would this be done?

Everyone should receive post-test counselling regardless of whether the result is positive or negative.

A negative result

Receiving a negative result can be such a relief that the person may not take in all that has been said to them at the clinic upon hearing the result. A negative test result does not offer any guarantees for the future. It does not mean that someone will automatically adopt Safer Sex or safer drug use. The caller may need additional support and information on negotiating Safer Sex or drug use to help prevent them being in the same situation in the future.

Even with a negative test result there may be a need for on-going emotional support as the person may have built themselves up so much for a positive result that they find it difficult top accept being told that they are negative. Another example could be that a gay man who himself is negative, may know friends or have a partner with HIV or AIDS, and may feel conflicting emotions. Such emotions can sometime lead to risk-taking behaviour.

A positive result

There are obviously a whole range of issues that might need to be covered in a post positive result some or all may have to covered at different times and in varying order depending on the person.

Just some of the issues that might be covered are :

- what happens next?
- treatment options
- who to tell
- when to tell
- relationships, current and any future
- partners
- disclosure to employers or friends
- confidentiality
- bereavement
- keeping healthy
- insurance

CONCLUSION

Given that Pre- and Post-test counselling is something that we think should take place as good practice at all HIV testing clinics, this cannot be guaranteed. It must also therefore be seen as good practice that all HIV/AIDS Helplines recognise the important role that they themselves play and offer test counselling to all callers wishing to discuss an HIV test.

Willie Turnbull,
Terrence Higgins Trust

References

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INFORMATION AND COUNSELLING ON STIs: A NEW CHALLENGE FOR AIDS HELPLINES

Reasons for the Dutch AIDS Helpline to provide information and counselling about STIs

The Dutch AIDS Helpline started to offer information and counselling on STIs during 2000 in addition to information and counselling on HIV/AIDS. Since then our Helpline has been re-named the Dutch AIDS/STI Helpline. Prior to this we only provided minimal basic information about STIs.

In 2002, 46% of our answered calls concerned questions about STIs, including calls about both STIs and HIV. The figures for 2003 show the same trend. This shows that questions on STIs have become a main part of the information and counselling given by our Helpline. In addition to this our email service receives a substantial amount of questions about STIs and our voice response system offers recorded information on STIs.

- AIDS Helplines are in general well equipped to offer STI counselling because of their experience with HIV/AIDS counselling and prevention together with sexual health counselling

- it became clear there was no other Helpline in the Netherlands offering information on STIs to the general public. Only some Helplines for specific target groups such as gay men offered this information

- since the 1990's there has been a clear rise of STI in the Netherlands. A rise that continues in 2003. For example a sharp rise of syphilis cases among MSM (men who have sex with men)

- STIs can cause serious health problems (serious liver problems, infertility in woman)

- STIs have for a large part the same transmission route as HIV, so combined prevention efforts can be effective

- STIs have an impact on HIV transmission: the chances of HIV transmission strongly increase when one or both partners have an STI

- when a caller concerned about STIs contacts the Helpline, it opens up the opportunity to the Helpline to counsel them about HIV and vice versa. This means that new groups of callers can be reached.

- STI counselling can help to increase the amount of calls and to counteract a drop in HIV/AIDS related calls, which some European Helplines are confronted with.

Aims of the STI information and counselling of the Dutch AIDS/STI Helpline

Our Helpline provides information, offers counselling/support and provides adequate referrals to callers with questions concerning HIV/AIDS and STIs.

The main aims for the STI service are :

1. To provide information about STI prevention and transmission.

2. To provide the possibility to discuss problems related to STIs; regarding the consequences, possible treatments, Safer Sex behaviour and anxiety.

3. To motivate people who might have an STI to consult a doctor or STI clinic for testing and treatment. At the same time the Helpline worker needs to make clear what the boundaries of the Helpline service are regarding STI counselling (no diagnosis and no medical treatment advice) and motivate the caller who reports symptoms and/or was at risk, to contact a doctor or STI clinic.

Quality standards for STI counselling

I. In general the knowledge and counselling skills of the Helpline workers concerning STIs should be of the same level as the requirements concerning HIV/AIDS counselling. General knowledge of STIs should be thorough. Providing STI counselling requires specific knowledge and training. To ensure a professional level of knowledge, regular training by STI specialised professionals is necessary. This involves training on both knowledge of STIs and counselling skills.

II. Regular team and supervision sessions for the Helpline team are important with specific attention given to problems or questions encountered regarding STI counselling. Discussing case examples is an effective way of exchanging experiences and so making sure counselling methods for the whole team are in tune with one another.

III. The boundaries of the STI counselling have to be clear. A diagnosis or treatment advice can never be given by a Helpline. Referrals to doctors and/or STI clinics are needed in those cases. It is important to regularly discuss the boundaries of the counselling within the Helpline team, using case examples, to ensure the

boundaries of the information and counselling remain clear.

IV. STI Factsheets can be useful. The Helpline workers can quickly access basic information on each STI. These fact sheets can also provide an indication of the boundaries of the information provided. Helpline workers do not need to know everything about STIs. Specific diagnostic and treatment skills are not required. These are for STI specialised nurses and doctors.

V. An up-to-date referral system for STI specialised referrals such as doctors, STI clinics, patient organisations and their websites is necessary to refer the callers to the appropriate services.

WHICH STIS DOES YOUR HELPLINE INCLUDE IN THE INFORMATION AND COUNSELLING SERVICE ?

A Helpline should decide on which specific STIs information will be provided. Each Helpline could consider leaving out some of these STIs and include others.

The Dutch AIDS/STI Helpline provides information on the following STIs :

Bacterial STIs
Gonorrhoea (Neisseria gonorrhoea), Chlamydia (chlamydia trachomatis) and Syphilis (Treponema pallidum)

Viral STIs
Hepatitis B virus (including very basic information about Hep. A & C), Herpes simplex virus - Type I and II (Herpes genitalis) and Genital Warts (Condylomata acuminata - HPV type 6 & 11)

Other STI related infections
Trichomoniasis vaginalis, Crab lice (Phtirus pubis), Scabies (Sarcoptes scabei), Candidiasis (Candida Albicans) and Bacterial Vaginosis (Gardnerella vaginalis and others)

NECESSARY BASIC KNOWLEDGE ABOUT STI PREVENTION AND TRANSMISSION

Necessary basic knowledge of Helpline workers should involve the following topics:

- knowledge of the general transmission routes of STIs and of each STI in specific. This should include knowledge of high and lower risk sexual transmission routes. Knowledge on other transmission routes: for example vertical transmission (mother to child) and transmission through blood
- it is important to inform callers that condoms can't give full protection against all STIs such as in the case of herpes, warts and syphilis. But condom use reduces the risks for these STIs
- knowledge of the similarities and differences between HIV and STI transmission.

Specific knowledge about the following topics:

I. Knowledge about the interactions between STI and HIV

Increased risks of HIV transmission

STIs increase the risk of HIV transmission. HIV positive partners who have a co-infection with an STI are more likely to transmit HIV. HIV negative partners who have an STI have a higher risk of getting infected with HIV.

Concerning people living with HIV

STIs can cause serious health problems for people with HIV, for example in the case of a co-infection with Syphilis. The HIV viral load can also rise due to an STI co-infection.

II. Knowledge of STI Symptoms

Knowledge of the general STI symptoms and of the specific symptoms of each STI is important. This involves knowledge on the long term complications STIs can cause.

For example: the 3 stages of Syphilis infection and acute and chronic symptoms of Hepatitis B.

III. Knowledge of Testing and diagnostics:

Testing depends on sexual contacts, gender and symptoms. Knowledge of the testing procedure and window-period for each STI is important.

IV. Knowledge of treatment and medication:

It is useful to have a list available of all the standard treatments for each STI, but these can only be prescribed by a doctor or STI specialised nurse in most EU countries. It is important that callers with specific questions about their medication are being referred to a doctor or STI specialised nurse.

V. Knowledge of legal Information concerning STIs:

Depending on the specific situation in your help line's country you may provide legal information on subjects such as disclosure to other sexual partners. Legal issues are usually less important and less complicated compared to HIV/AIDS.

VI. Knowledge on Epidemics

Providing information about epidemics on a National and European level, including recent epidemiological developments.

VII. General questions and specific questions: counselling issues.

General questions about STIs should get a general answer. Questions about one or more STIs in specific get more detailed answers. Often callers discuss symptoms with the aim of trying to get a diagnosis over the phone. The Helpline worker won't provide a diagnosis and should try to avoid becoming specific about which STI could cause the symptoms. The Helpline worker should concentrate on clarifying whether the caller had a risk for STIs and/or HIV.

The Helpline worker could emphasise the necessity of getting tested and treatment, which depends on the testing policy in your country. The Helpline worker could advise the caller to contact a doctor or STI clinic or STI specialised organisation. The boundaries of the Helpline worker should be kept in mind.

Even though STIs in general are not as life threatening as HIV, they can cause serious health problems and psychosocial problems. For example:

- chronic Hepatitis B & C can cause liver damage and liver cancer, which can be fatal
- chlamydia and Gonorrhoea can cause infertility

POINTS TO CONSIDER IF YOUR HELPLINE WANTS TO START OFFERING STI INFORMATION AND COUNSELLING

- herpes is an infection which cannot be completely cured. It can be stigmatising and can make it difficult for people to start new sexual relationships as there is the risk of transmission to a new partner.

For the Helpline worker it is important to acknowledge these problems and to have accurate knowledge and counselling skills to offer to the caller.

VIII. Knowledge about special STI policies:

Many countries have specific policies regarding STIs: policies on testing, vaccination, treatment and partner-notification. It is important a Helpline has accurate and up to date information on these policies.

- which Helplines and other services provide information and counselling on STIs in your country?
- what kind of (possible) partnerships or joint projects are there between your Helpline and other organisations?
- what role does your government take in STI prevention?
- to which extent does your Helpline already provide information on STIs?
- how many questions (phone - email) does your Helpline currently receive concerning STIs?
- does your Helpline have enough resources and can your Helpline handle the extra workload involved with extending the services to other STIs?

The Dutch AIDS/STI Helpline values our information and counselling on STIs as an important addition to our services. We have seen that information and counselling on HIV and STIs can be combined and have improved our services.

Bauke Kortleve ,
AIDS-SOA Infolijn

HIV PREVENTION AND HARM REDUCTION FOR MEN WHO HAVE SEX WITH MEN (MSM)

Since the success of the anti-viral combination therapies (HAART) has been widely acknowledged, a wave of optimism was felt among people with HIV and among MSM.

It became clear things have changed for many MSM with HIV. Their perspective on life and the future has often changed for the better, and further emancipation and liberation of many MSM with HIV followed. Instead of being patients with an often very limited life expectancy, MSM with HIV can make long term plans again and many have re-integrated in a work environment. In addition to this, in some countries PEP (Post Exposure Prophylaxis) became available for 'sexual accidents'. Information also became available that someone with an undetectable viral load might also be less infectious. This meant the risks of getting HIV infected could be re-evaluated.

All over Europe HIV/AIDS organisations are currently confronted with an increase of STIs and HIV among MSM. It is generally believed a significant rise of unsafe sex among MSM has occurred since the mid 1990's. This however remains difficult to measure. In 2002 STI clinics in the Netherlands reported a significant rise of new HIV infections (130% since 2000), mainly among MSM. The was also an explosive rise of Syphilis (118% since 2000) also mainly among MSM. These are clear indicators of an increase of unsafe sex among MSM in the Netherlands[1]. This is a trend which cannot be ignored.

A new trend called 'barebacking' also appeared to start. This meant unsafe sex was being openly practised and promoted by some MSM. Barebacking has become an often used term on the Internet for men who are looking for unprotected sex. Giving it this name removed the negative and patronising identity of unsafe sex and replaced it with a more attractive and liberating sexual trend. It was easy to dismiss barebacking as wrong or immoral behaviour. It was interesting to try to understand this trend and to asses the implications it had for MSM and for HIV prevention organisations such as AIDS Helplines.

1 - RIVM and Stichting Soa-bestrijding - Yearly report 2002 - "Registration of STI and HIV-consulting at GGD's and STI-policlinics" To be found on: http:// www.soa.nl (12.11.2003)

BACKGROUND

There has been a significant change in Safer Sex behaviour and attitudes towards Safer Sex among many MSM. This, in some cases, resulted in a gap between MSM and HIV prevention organisations. MSM became a more varied group. Some HIV prevention organisations noticed that MSM were having more sex again. The fear of AIDS had reduced, the gay infrastructure had developed with the gay scene becoming more accessible with the Internet providing opportunities for MSM who were looking for more meetings with a view to sexual encounters.

In general, research figures in the Netherlands indicate that 1/3 of MSM never engage in anal sex, 1/3 have protected anal sex and 1/3 sometimes engage in unsafe anal sex[2]. This latter group seems to be increasing. The group of MSM who exclusively engage in unsafe sex is probably still quite small.

Studies were conducted in the Netherlands to asses the current situation. From one study it appeared that the group of men who sometimes had unsafe sex (20%) there was no need for support with Safer Sex: they did not see their unsafe behaviour as a problem. In general it became clear STIs & HIV were not main priorities for the men in this study. Love and relationships scored highest. The question "how can I grow old happily?" was important for MSM. This seemed to have an important impact on MSM choices regarding unsafe sex[3].

One of the things which seemed to have changed, was that often well informed MSM (both HIV positive and negative) made a conscious choice to have unsafe sex, based on balancing the risks and the personal pro's and con's of unsafe sex. These men increasingly chose to have unsafe sex. Their unsafe sex behaviour was not an accident but a chosen sexual life style, often referred to as bareback-ing. It was this group of men the HIV prevention organisations seemed to have lost contact with. Some MSM consciously chose to have unsafe sex based on an extensive personal risk assessment which was in turn based on balancing the personal pro's and con's of unsafe sex.

THE RESPONSE

The testing policy in the Netherlands has changed towards a pro-active HIV and STI testing policy. People at risk for HIV or STIs are encouraged to get tested, because of the rise of new infections and improved HIV treatments.

To reach those MSM who engage in unsafe sex, specific interventions and campaigns were developed to establish open communication between prevention organisations and MSM who like unsafe sex.

The response of the Dutch AIDS/STI Helpline.

Our Helpline regularly receives calls and emails from MSM who had unsafe sex. From our experience on the Dutch Helpline, MSM who call us because they had unsafe sex are usually not having unsafe sex exclusively, it is often an accident or a one time mistake. More MSM who regularly practice unsafe sex or barebacking are contacting our Helpline as well.

I. We concentrated on getting reliable and updated information on trends regarding MSM and unsafe sex in a special training session for the Helpline team.

II. We discussed this topic on a European level during an ENAH meeting workshop. This workshop confirmed that the other member Helplines member countries were seeing similar trends developing.

III. Our Helpline team discussed experiences regarding unsafe sex trends among MSM in team sessions.

IV. We shared experiences with other organisations and gave input to other organisations who were developing specific interventions and campaigns regarding unsafe sex trends among MSM.

V. Recognising the interaction between HIV and other STIs is an important issue for the Dutch AIDS/STI Helpline. Our Helpline counsellors can give useful additional information on this interaction, which could influence the callers choices regarding Safer Sex.

2 - S. Zacharias (schorerstichting) and C. Blom (Aids Fonds): Oral presentation about barebacking trends among MSM - 12 December 2002
3 - S. Zacharias, L. Schenk (Schorerstichting - Amsterdam - www.schorer.nl): "Intervention aimed at gay men who like unprotected sex and look for partners on the Internet: a first evaluation." to be found on: http:// www.gayhealth.nl/bbs (12.11.2003)

HARM REDUCTION AS A PREVENTION TOOL FOR MSM

Harm reduction is focused on MSM who might sometimes have unsafe sex, while being well informed about the risks of HIV transmission. The aim of harm reduction is to provide additional information and counselling which, instead of rejecting their choices about unsafe sex, tries to support MSM who have unsafe sex to make choices which could help them to reduce the risks they take or to have Safer Sex.

Harm reduction can involve providing accurate up-to-date sexual health information and counselling on the following topics:

I. Choices concerning Sex techniques and styles: Providing information on reducing the risks of unsafe sex.

II. Making choices about unsafe sex in relationships: Before starting to have unprotected sex, MSM in a relationship could consider getting tested for HIV so for both their HIV status is clear.

III. Undetectable viral load and HIV transmission: It is likely that an undetectable viral load in the blood reduces the chances of HIV transmission. Research has also shown that an undetectable viral load in the blood does not always relate to the viral load in semen.

IV. Re-infection and super-infection: Medical specialists and researchers come with contradictory results and advice. There appears to be a real possibility of getting re-infected while having an low or undetectable viral load. Re-infection with a resistant virus strain or a more aggressive virus strain could reduce chances of successful anti-viral treatments.

V. Negotiating techniques about safe/unsafe sex and insight in decision making: Being well informed about risks doesn't always mean someone is trained in negotiating about safe or unsafe sex.

VI. Insight in emotional aspects: Counselling could focus on questioning which emotional aspects are involved with someone's choice for unsafe sex and this insight could lead of a re-evaluation of that choice.

VII. STI prevention, check-ups and treatment: STIs increase the local HIV viral load and as a result the viral load of the semen can be much higher than in the blood. In such cases someone with an undetectable viral load in the blood can still be very infectious. For HIV negative MSM who have a STI,

IS HARM REDUCTION RELEVANT FOR AIDS HELPLINES ?

the chances of getting infected with HIV are much higher (see section on STIs).

VIII. Information on PEP (Post Exposure Prophylaxis) and HAART: Clear information about the pro's and con's of HIV treatments should be part of harm reduction counselling.

IX. Legal consequences of having HIV: Providing information on the possible consequences of having HIV such as discrimination and legal consequences and even criminal prosecution.

Harm reduction can be a useful counselling tool for AIDS Helplines. It should be a topic of discussion within AIDS Helplines, to see how to incorporate this in their counselling.

AIDS Helplines can offer a valuable and attractive service, even for those MSM who choose to have unsafe sex.

The Dutch AIDS/STI Helpline offers anonymous and easily accessible information and counselling on HIV and STIs. The exact number of MSM calling us is not known but it is clear it is a substantial share of the callers. By answering questions about safe sex, HIV and STIs we often have the chance to talk intimately with MSM about their sex lives. This gives us an opportunity to offer counselling that goes beyond the simple message to always use a condom. It is an opportunity to offer counselling which connects with the sexual lifestyle of the caller, including harm reduction.

Orientation by AIDS Helplines on harm reduction could involve:

- training of Helpline workers on harm reduction information and counselling
- discussion within the Helpline team what the boundaries of the counselling are, both professionally and personally focusing on how harm reduction can co-exist with general HIV prevention counselling
- offering anonymous email services to gay men through (gay) websites. The Internet is a popular way of making contact for MSM who like unsafe sex. Helplines might reach men who are not using their phone services
- helplines could participate in the development of harm reduction counselling techniques

We have concluded our Helpline has the ability to offer effective counselling to MSM who choose to have unsafe sex. There needs to be attention for the emotional aspects of this counselling in so far as this could conflict with the personal ideas the Helpline counsellor has about Safer Sex. Extra attention during supervision and training sessions is important.

GOOD PRACTICE RECOMMENDATIONS FOR AIDS HELPLINES

- promoting the service of AIDS Helplines among MSM so we reach all kinds of (gay) men
- offering non judgmental anonymous services so the callers feel free to openly discuss their safer or unsafe sex lifestyles
- a flexible approach towards Safer Sex, non-judgmental and open minded. Keeping in mind the variety of sexual lifestyles MSM have
- the ability of Helpline workers to talk about sexual techniques and preferences in an open non-judgmental way
- knowledge about the different reasons and motivations for having safe or unsafe sex which are important for MSM
- a discussion and re-evaluation within the Helpline team on the topics:
  - how do we counsel gay men who have unsafe sex?
  - how do we counsel gay men who want to continue having Safer Sex?

The Dutch AIDS/STI Helpline will aim to stay intouch with the developments regarding MSM and Safer Sex. Developing new strategies within our team and together with other organisations will keep us tuned in on the situation and will hopefully guarantee our Helpline continues to be an useful and effective resource of HIV information and counselling for MSM. On an European level it is important the Helplines of the ENAH network exchange experiences, ideas and information about harm reduction counselling. One of the things AIDS Helplines have to realise is that if we want to continue to be a relevant service for MSM, we need to connect with the sexual reality of MSM with and without HIV, including those who have unsafe sex. Only then can we offer effective counselling and prevention.

Bauke Kortleve ,
AIDS-SOA Infolijn

NEW DEVELOPMENTS

EMAIL SERVICES - A DIGITAL CHALLENGE FOR AIDS HELPLINES

PROVIDING A RELIABLE COUNSELLING SERVICE

In the last few years more and more social and health organisations started to extend their work by using the relatively new medium of the Internet. AIDS organisations also started to recognise the possibilities of the Internet with regards to information and prevention. During the last few years the Internet has developed to a mass medium, which is not only accessible to highly educated people but to a greater part of the western European population.

In Germany, for example, about 39% of the population use the Internet on a regular basis[1]. As far as we can see, at the moment, it is very likely that the clientèle which AIDS organisations could reach over the Internet, partly differs to those recipients we reach by telephone Helplines or by face to face counselling. Thus, on using the Internet, AIDS organisations could expand their services to new clients, and may offer information that is more easily accessible to a broader public.

Apart from the innovative possibilities, there are some aspects to be taken into account, regarding the technical and the counselling aspects of the Internet. In the following description we will give an overview of the most important aspects in developing an Internet service.

Every organisation that wants to set up Internet services should clarify beforehand if there is enough time, money and manpower to run an Internet service for a long period. Homepages have to be updated on a regular basis and answering emails could be more time consuming than answering a phone call.

In addition to organisational aspects of this new service, there are new skills needed for the counsellors, too. Similar to the work at a telephone Helpline, the Internet could be the first step to other services that AIDS organisations offer. It also functions as an advertisement for the quality and competence it provides as a whole. The skills and experiences of the counsellors as well as the information provided on the homepage will consequently have an impact on all the other services offered.

The provision of information through the Internet is restricted mainly to general information about HIV/AIDS, ways of virus transmission, testing possibilities as well as a referral point tp other services for clients and to other relevant organisations in the field. The aim of an email service is seen as an enablement of the clients to reach their own interpretation of given information by so called "informed decision making".

The homepage:

- should be easily accessible (even with very basic computer and Internet equipment)
- has to be reliable (somebody is to be responsible for the maintenance of the content and the layout of the homepage)
- provides information about the data security in the Internet and how the user could secure his or her own data
- offers information about the fact that AIDS organisations are not legally responsible for the things and decisions people do with the given information; a disclaimer must be added for defence of law trails
- provides the contact and the Internet address of the organisation and the webmaster

The presentation of the homepage of the organisation should include information about :

- the aim and the work of the organisation

- the financial background and interests of the organisation

- who is responsible for the counselling (training etc.)
- how long it will take for the email answering process

- what kind of questions are being answered by email and what boundaries of these services exist (e.g. information about PEP, which is required to be taken urgently whereas it may take some days until a counsellor will answer an email. Nevertheless it is possible to provide general information on PEP

- opportunities of getting necessary information faster than by email (telephone or personal counselling etc.)

- what the organisation does with the data and information the user provides

- who could be contacted if the user has questions or complaints about the counselling service

There should be a special training for counsellors on the Internet especially regarding the competence in understanding and answering written texts. In Germany, for example, most Internet counsellors are long term experienced counsellors that have worked in face to face or phone counselling beforehand.

THE EMAIL SERVICE EXPERIENCE OF THE DUTCH AIDS/STI HELPLINE

In January 2002 the Dutch AIDS/STI Helpline started to answer questions that came in through websites from the two organisations we work with: the Dutch Aids Fund and the Dutch STI Foundation[2].

Until November 2002, the service was not actively promoted. However, at this time, we started a pilot scheme in which we presented a Frequently Asked Questions (FAQ) list on both websites and invited the visitors of the websites to send their questions if they were unable to find the answers in the previously existing FAQ list.

The general email service concentrates on providing basic information on HIV and AIDS and is not to be seen as an extensive counselling service.

Before this pilot scheme, our email service was organised on a low profile basis and we received only a small number of approximately 40 emails per month. By promoting our service we tested whether we would receive more emails in general and used this to explore whether we would be able to handle more incoming mails at all.

1- Birgit van Eimeren, Heinz Gerhard, Beate Frees: Entwicklung der Onlinemedien in Deutschland: ARD/ZDF-Online-Studie 2001: Internetnutzung stark zweckgebunden. In: Media Perspektiven 8 (2001); S. 382-397. This text is to be found under: (http://www.daserste.de/service/ardonl01.pdf); (18.08.2003).

2- Both organisations could be found under the following addresses: the Dutch Aids Fund: http://www.aidsfonds.nl; Dutch STI Foundation: http://www.soa.nl.

The results of this pilot scheme are summarised in the following list:

- the amount of incoming email has increased significantly in this period (140 emails instead of 40 a month). This indicates that when advertising the service the amount of incoming emails may significantly increase. By January 2003 we received 250 emails monthly and by the end of 2003 we expect to have received a total of 3.500 emails

- for our Helpline it interesting to note that a main part of the emails we received came from young people who were concerned with STI symptoms and ways of transmission. Through this email service we reach a much younger population, that seems to use email communication more often than a phone Helpline

In the future, we want to expand this email service by promoting it further through the existing websites, by our promotion cards and leaflets and through other publicity channels. As we are regularly featured in the media and during campaigns, this may support our advertisement schemes. There are also strategic reasons: if we do not expand our service, other organisations may start to offer counselling on STI and HIV by the Internet and we would miss the opportunity to reach these clients especially young people.

METHODS OF ANSWERING AN EMAIL

I. Exploration of the email by answering the following questions:

- what is the core sentence of an incoming email? Search the sentence that contains the main question

- what is the core sentence expressing the emotions of the client? Does the email express emotions that are important?

- what kind of emotional condition does the emailer express to you?

- what other information in the email is important for the answer? Explore the language use of the emailer, his or her social support system, coping mechanisms etc.

II. It is necessary to determine what the main question is (or main questions are). Decide which questions need to be answered although be careful with quick interpretations.

III. The answer needs to be written by taking those main questions determined earlier on as a starting point. The focus in the email answer may be on questions of:

- support
- counselling
- information and practical advice
- referral to relevant organisation

In general, the email service proves to be more useful for support, information and practical advice and referrals. Real counselling is difficult to achieve by means of email writing. In this case it might be more useful to clarify the problem and to refer to relevant organisations (for example your own Helpline).

IV. It is advisable to use a clear structure for every answer: an opening, a core body of text as a response to the questions and closing phrases and sections.

The opening reflects a formal style. Please keep in mind that you do not write a personal email, but that you act on behalf of an organisation. In the opening sentence it may appear helpful to reflect on the core question(s) and emotions of the incoming email.

The core text provides the answers to those questions. Decide if your answer mainly provides support or counselling advice or whether it is focused on providing information and practical advice. It is always advisable to try to increase the

GOOD PRACTICE RECOMMENDATIONS REGARDING EMAIL COUNSELLING

self support of the emailer to avoid getting them in a dependant position.

If you refer someone to other institutions, please explain why the referral could be useful. An expression of assumptions and condemnations should be avoided, while staying objective and acting from the policy and aims of the respective organisation should be seen as the key principle and orientation.

V. A double-checking system of the answer by bringing in a team member (editor) is advisable before sending it out. This provides an extra quality check.

- offering email counselling can be seen as a principal part of the work of AIDS organisations. It can count as good practice for a Helpline to offer this email service, because the use of the Internet has become an important way of general communication process in European societies. Even if the number of those people who call our Helplines declines, the rising number of clients who contact us though the Internet indicates that there is a lack of knowledge concerning the information and prevention of HIV and other sexual transmittable infections

- email services do not replace phone counselling. It should be seen as an additional service and as being quite different from telephone counselling. The communication though the Internet is more orientated on giving information, than on counselling. This implies that the given information should be as clear and short as possible

- make clear to the public what kind of questions will be answered and what the boundaries of the service are

- quality control is essential for the maintenance of the service: For example at the ASI writers answer the incoming email and their outgoing replies are checked by a secondary editor from the Helpline team. This secures that no mistakes are made

- the Helpline should make clear guidelines on the way emails are answered, especially as it is written information, using systems and protocols such as structure and use of language

- standard answers appear to be useful as they save on the amount of work involved and add to uniformity which is important in case of written information.

Email services appear to be a useful addition to the services AIDS organisations already offer. The chance to reach people other than through face to face or telephone counselling offers the possibility to enlarge the field of prevention of STIs and HIV.

Katharina Stahnisch,
Berliner Aids-Hilfe
Bauke Kortleve,
AIDS-SOA Infolijn

WORKING WITH VOICE RESPONSE SYSTEMS (RECORDED INFORMATION SYSTEMS)

THE VOICE RESPONSE SYSTEM

The Dutch AIDS/STI Helpline has provided an interactive voice response system since 2000. The aim of this service is that our Helpline can offer reliable information about Safer Sex, HIV/AIDS and STIs, 24 hours a day. Through the voice response system we can provide our callers accurate and up to date information outside the live response opening hours (Monday till Friday 14.00-22.00) during which our Helpline workers answer the incoming calls. The voice response system is not open during our live response opening hours. It offers recorded information accessible through our Helpline number which costs 10 cts per minute.

Outside our live response opening hours, callers are offered a choice menu consisting of 4 maintopics, both in Dutch and English. The menu offers the following choices:

I. General information on STIs and HIV:

- transmission, symptoms, testing, treatment

II. Specific information on each of the STIs including HIV:

- HIV/AIDS, hepatitis B, herpes, genital warts, syphilis, chlamydia, gonorrhoea, trichomonas vaginalis, bacterial vaginosis and crablice.

III. Safer sex information:

- general Safer Sex information, condom and dental dam use

IV. Referral addresses for STI and HIV testing and personal advice

- including testing clinics, other relevant Helplines and our websites.

At each topic callers are informed that if they prefer a live response they can call our Helpline during our live response opening hours. At each point in the menu the

caller can move back and forth between the different topics or can end the call.

Before we opened our voice response system in 2000 it became clear from our telephone company statistics that many people tried to reach our Helpline outside our opening hours

- in 2002 almost 19.000 callers used our voice response system. An increase of 33% compared to 2001 (14.200 v.r.s contacts)

- our live response answered 13.500 calls in 2002 compared to 15.000 in 2001 . For 2003 the estimate is 13.000

- we received and answered 700 emails in 2002 and for 2003 the estimate is 3.500 emails

By expanding our service with an voice response system the total amount of contacts with our Helpline (voice response system, live response and email service) exceeds the contacts we had before starting our voice response system.

Although the amount of incoming calls at our live response has been dropping the last years the amount of incoming emails has risen sharply. The number of contacts we have through our live response and email service combined, for 2003 is higher as the live response contacts we had in 2001.

This indicates that our voice response system hasn't replaced the need for people to contact our Helpline through our live response and email service. The voice response system is an valuable **additional** service for our callers.

From our telephone company statistics we can see that callers who call our voice response system use the system for an average of 4 minutes. This proves callers actually listen to the information or else they would end their call much sooner. Regularly our live response callers inform us they've first used our voice response system before calling us for more information or counselling. This could be compared to people first looking up information on our website and then sending us an email with a personal question.

RECOMMENDATIONS ON GOOD PRACTICE

- offer accurate information, which is provided by your own Helpline, to keep quality control over the content

- it is important to use of an effective professional system for the voice response system Using regular answering machines for recorded information limits the callers choices for accessing the recorded information. A modern system allows callers to move back and forth between the different options

- offer the caller the opportunity to decide how long and often they want to listen to the information by providing a selective menu

- keep the information up to date. A problem can be the re-recording of the information for updates. If your Helpline uses a professional reader to record the information this reader has to record follow-up sessions to update the information which can be expensive. The Dutch AIDS/STI Helpline has chosen to ask a professional news reader to record the texts

- use short and clear information, not extensive text

- offer referral addresses, so callers can contact the right organisations and websites if they need to. For example an AIDS Helpline could consider offering referral information on PEP (Post Exposure Profylaxis)

CONCLUSION

Offering a voice response system should be seen as an **additional service**. It can never replace live response because only basic information can be provided, there's no opportunity to offer personal information and counselling. Counselling is only possible during live response.

By extending your service as a Helpline to a voice response system your Helpline can offer easily accessible information outside opening hours, especially for those people who do not have access to the Internet or written information. It can also provide valuable information to callers in distress outside opening hours, for example information on Post Exposure Prophylaxis (P.E.P)

The experiences of the Dutch AIDS/STI Helpline show that an interactive voice response system can be an valuable additional information service for Helpline callers.

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1 DISCRIMINATION

2 GOOD PRACTICE AND PHONE LISTENING

3 POSITIVE LIVING

EUROPEAN NETWORK OF AIDS HELPLINES
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