MANY VOICES IN DIALOGUE

MANY VOICES IN DIALOGUE:

TRANSLATING RESEARCH EVIDENCE INTO

COMMUNITY-BASED HIV INTERVENTIONS

By

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ABSTRACT

This applied research project responds to a critical problem in health and development: how to effectively translate our research evidence to the communities with and for whom we work in order to stimulate successful, sustainable health promotion activities and social change. The tangible product of this research is a handbook for health and outreach workers from immigrant communities from the Horn of Africa living in Toronto. The handbook is a resource which will be used as a starting point for the generation of community-based health initiatives, in this case, HIV/AIDS prevention programs.

The research applies a conceptual approach which emphasizes participatory action research theory and methodology, and equitable, transcontextual research partnerships. It uses a model which merges both scientific evidence and experiential (ethnographic) evidence of risk and vulnerability to create new understandings on which to base the development of health programs.

Stories, grounded in ethnographic evidence, are at the heart of the research strategy. The handbook is an example of experimental ethnographic writing: dialogue is used to communicate research evidence, health, and skills information; and a number of personal narratives have been constructed as resources to help health workers generate dialogue on issues of risk and vulnerability, and begin a process of reflection and action.

In a larger context, the lessons learned as this work is implemented and evaluated in the community will contribute to the knowledge of intervention science.

The research also serves as an example of ethical anthropology and raises for discussion ethnography's future project at the turn of the century. With attention to how anthropologists represent their work, 'moral ethnography' can serve a larger human project, helping us better understand what it is to be human and stimulating moral conversations about how we want to live.

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To my supervisor, Dr. Dennis Willms, I am truly indebted. Thank you for your guidance, wisdom, and patience; your vision is inspiring, and your support and friendship are treasured. And to my family who sustain me – Irwin, Matthew, and Tim – I give my heartfelt thanks for your support, love, understanding, and for keeping your sense of humour. To all of you, thank you for believing in me and being part of my journey.

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FOREWORD

Applied health and development researchers in an academic environment often struggle with the critical and ethical problem of how to effectively and creatively represent or communicate the work they do together with communities. The challenge of disseminating this knowledge in a way that bridges the very different cultural worlds of the academic researcher and the lived reality of those who are the focus of the research is particularly important when the goal of the research is to promote action and social change.

The applied research in which my thesis is grounded attempts to respond to this challenge. It draws upon a variety of theoretical and methodological influences to demonstrate how research evidence can be translated back to individuals and community participants, with a view to stimulating the development of participatory community-based health promotion activities. The product of this work is a handbook called *Many Voices in Dialogue: A Handbook for Community Health and Outreach Workers*, which is the centrepiece of the thesis. It is an experiment in representation, written as a narrative, with stories based on the ethnographic research data collected in partnership with community members.

My search for and struggle with ways of doing this work constitutes a story of its own. The main part of the story concerns the process of writing the handbook and the representational challenge of communicating our research so that it is accessible and meaningful to community members. But a somewhat unexpected twist of plot occurred when I tried communicating the work as a master's thesis, raising representational issues of another kind.

Initially, I planned for the handbook to stand alone – a tangible product of the

research, written for and with the community using a style and language in keeping with its aims and philosophy. In a supplement which would accompany the handbook, I planned to elaborate on the academic point of view: examine and discuss more deeply other substantive issues, expand on and analyse the processes and thinking that occurred during the work, and reflect on its significance in a larger context. This would tell the story to another important audience – my colleagues in anthropology, and other applied researchers and social scientists. At the same time, it would fulfil the norms and expectations of my academic requirements. However, I also wanted the academic discussion to be available to members of the community who might be interested, because I was committed to honouring and building on the equitable, participatory research process developed during the project. I was seeking a way to merge the different ways of knowing – the too often silenced voices from the community with their lived experience, and the usually dominant voices from academia and their privileged understandings – so that we could question and reflect on our taken-for-granted assumptions, and stimulate conversations from which we could learn together [1]. However, finding a format and language which would suit the community audience but which would also satisfy the expectations of an academic audience was, to say the least, problematic.

The representational issues proved to be formidable. I struggled with questions of how much of the content would be of interest and use to the community? Which parts might be alienating, perceived as irrelevant and belonging only to the world of the 'ivory tower researcher'? And in my quest to avoid using language which would antagonize and distance those outside academia, I wondered how effectively I could

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1.   Sandra Wallman (1997) has said, and I agree, that for our research to have value, we must communicate it to an increasingly diverse and knowledgeable audience. What she calls an appropriate anthropology "will need representation of context and capacity of 'others' which can be readily grasped by a non-specialist." (:246)

debate issues of academic interest without using the specialist language we develop specifically to capture subtleties of thought and preciseness of meaning. It was an ambitious attempt at building bridges of understanding between our various worlds and very different ways of knowing and communicating. In the end, this idealized format served neither audience very well and was a little too unusual for thesis requirements.

The experience, ironically, highlighted the very problem the research sought to explore: I had come full circle with the problem of representation. In seeking to effectively communicate the work to an audience which is usually silenced by hierarchy and structural inequalty, I was, in a sense, silent in my own world. The process demonstrated, by looking at its own reflection, that the many voices which speak in the academic and grounded worlds of applied research are indeed different. If we are to open up new opportunities for knowing and being in the world, this experience further emphasizes the need for us, as academics, to continue to seek creative ways of accommodating and bridging this difference.

In the mean time, the handbook will be published separately for use by community health and outreach workers, and for use as a training resource by other organisations. The academic discussion will be available to them in the form of the thesis, but a more user-friendly version of the work may still be written if this is something they desire.

The thesis document also metaphorically stands alone. It consists of the *Many Voices in Dialogue* handbook, as the product of the research; a Prologue, which discusses the rationale and context for the project, elaborates on the theory and methodology involved in developing of the handbook, and reflects on the process; and an Epilogue, which contemplates and discusses the significance and implications of the work in a wider context.

PROLOGUE

The work in this thesis attempts to address a number of challenging issues of practical and theoretical importance to those of us working in the area of health and development [1]. In its most practical sense, it seeks ways of applying the theory and methodology of anthropology, and that of other disciplines, to real world problems – in this case, the work of HIV/AIDS prevention. Fundamental to this endeavour are issues of representation: it is a search for how we might translate our research evidence in a way that respects, acknowledges, reflects, and relates to the experiences and life worlds of the individuals and communities who are our research partners. As a work that illustrates how a partnership which includes university researchers, community influentials, health advocates, government funding agencies, health promotion groups, and non-governmental organizations, it is also about creating opportunities for learning and moving forward together as researchers, colleagues, and fellow human beings.

From a theoretical point of view, it aims to contribute to the thinking about what is needed to do health promotion and disease prevention work well. And, at the cusp of the 21st century, it explores what implications this might have for us as social scientists and our academic discipline. In its largest context, it is very much a human project – a search for, and implicit response to the question "What kind of world do we want to live in?"

In this prologue, I will provide the context for the actual product of the research, the *Many Voices in Dialogue* handbook, which follows in the next section. The first

part of the story behind the *Many Voices* project will look at how such a work came

about. Then, I will elaborate on the theoretical understandings which guided the

production of the handbook, and discuss how these influenced the approach. Next, I

will describe and reflect on the methodology and actual process of writing the

handbook, and will follow this with a discussion of next steps for the project.

4.1   BACKGROUND

The story behind the *Many Voices in Dialogue* project began a number of

years ago, when immigrant communities from the Horn of Africa (Eritrea, Ethiopia, and

Somalia) living in Toronto were asked to participate in a national study on HIV/AIDS in

ethno-cultural communities [2]. Sponsored by Health Canada, the Ethno-cultural

Communities Facing AIDS (ECFA) [3] study sought to determine the factors which made

these communities vulnerable to transmission of HIV/AIDS. From the beginning,

researchers and representatives from the communities were committed to a

participatory, accountable research process (Adrien et al 1996; Willms et al 1996a).

Community members advised the researchers on the study design and activities

through regional research groups, and they actively participated in the gathering of

ethnographic data and drafting of reports and recommendations. The nature of the

partnerships was one of shared ownership and goals – the production of relevant,

usable information for the communities.

One of the recommendations to come out of the study (ECFA Report 1993) was

for the development of culturally appropriate HIV/AIDS intervention strategies. As the

study finished, a community-driven project – the Horn of Africa Health Project (HAHP) –

was launched to keep the dialogue going and maintain the momentum built up in the

communities about AIDS during the ECFA study. Community representatives wanted

to follow up on the recommendations and see some tangible results come out of the

process; thus, the HAHP represented a shift from a research-driven project focused on

data gathering to a community-driven project focused on prevention programming [4]. As

part of the project, a number of community outreach workers were recruited and

trained, and discussions began about possible educational programs. The idea for the

Many Voices handbook for health and outreach workers [5] came out of this process.

Work began on the project shortly after with the support of a number of funders, and

some of the community members and university researchers previously involved in the

HAHP [6].

The task identified by the HAHP was clear: produce a resource for health and

outreach workers to help them deal with the specific challenges facing community

members, particularly as these relate to HIV/AIDS. Those involved were committed to

the basic principles and values of a participatory, community-driven health promotion

approach, and all agreed that information in the handbook would be based on the

ethnographic data collected in the ECFA study. In fact, the production of a handbook

would be a way of returning the data to the community as part of the accountable

research process begun earlier. The question – and the challenge – then became,

"How to translate research evidence into the generation of culturally and personally

compelling health interventions ?" [7].

4.2   AN APPROACH TO TRANSLATING EVIDENCE INTO ACTION

This, of course, is not just a practical question relating to this particular project; it

involves philosophical, theoretical, and methodological issues which are critical to the

development of successful health promotion and disease prevention programs in

general. The design of interventions which are culturally appropriate and which will change behaviour is too often an unrealized goal.

To respond to this theoretical and practical challenge, our approach draws on almost a decade of health and development work by Dr. Dennis Willms and his colleagues in Africa and Canada. The lessons learned from this experience have led to a number of assumptions about what is needed for successful, sustainable interventions [8]. Primarily, these assumptions concern: community involvement in the design, implementation and evaluation of interventions; equitable partnerships with researchers; a research process which is dialogical and participatory; an approach which combines scientific and experience-based evidence, and an understanding of the relationship between risk, vulnerability and responsibility. These principles are discussed briefly in various parts of the handbook, but since they form an essential part of the strategy for the *Many Voices* project, I will elaborate on the central and related theoretical elements underlying the approach in a bit more detail here, to show how and why they have been applied in this specific project.

4.2.1. The use of both scientific and experience based evidence

Most health promotion and intervention work has traditionally been based on scientific evidence of risk, which identifies the causes, incidence, and prevalence of disease (Dunn and Janes 1986). For example, scientific evidence tells us that we can become infected with HIV through unprotected sexual activity with an HIV infected person. Traditional approaches to prevention are based on this measurable and objective kind of evidence. These use a 'rational man/woman' argument, presuming that if people know the risks for disease they will live in a way that reflects this [9]. However, what people know about risk for disease does not necessarily translate into

what they do to prevent it. As with the HIV example, we see that people often do not use condoms, even when they know that these provide protection from HIV transmission. Clearly, scientific evidence is not persuasive or even relevant to many individuals' day-to-day decision making. This is because scientific evidence is a kind of 'distant' evidence and is often not related to our actual experience in the world (Willms 1999). Individuals then deny that the evidence is true for them, or become fatalistic in face of other more overwhelming practical and emotional factors which permeate their daily lives. At the same time, they are blamed for ignoring their "culturally defined moral responsibility" (Frankenberg 1994:1329).

Understanding this seemingly "irrational" response to evidence of risk is a vital component of successful intervention work, and raises the critical question, "What governs human behaviour?" If we could know how people understand, experience, and respond to evidence of risk, it would help us see why knowledge is often separated from behaviour. But this question of how people reason about risk and the influences which make them vulnerable requires a different methodology – an approach which illuminates the relationship between knowledge and action.

A social science perspective can provide such evidence and inform this understanding; it shows that a different kind of logic influences people's actions – what could be called an experiential logic (illustrated below in Figure 1). This situational reasoning comes from people's socio-cultural context – their experiences, life situations, day to day reality, their relationships, environment, values and spiritual understandings [10]. These are the "truths that govern our lives" (Willms 1999) – the personal and situational influences that generate our assumptions about the world. This is the knowledge which shapes our lives and identities, influences our decision-making and governs our behaviour.

The evidence of this experiential logic is in our personal and collective life stories, which reflect our experience with, and reasoning about risk.   These reveal the inherent vulnerability that is part of our lived realities – a vulnerability which is often associated with powerlessness due to political, economic and social factors, such as access to care, employment, dependency, and age/gender/ethnic inequalities. A critical awareness of these influences on health decision-making emphasizes the moral and political implications of thinking about risk in purely scientific terms. A re-conceptualization of risk which includes notions of vulnerability works to redistribute responsibility and alleviate the issue of blame (Walker 1997).

Figure 1.   Experiential Logic: The relationship between our socio-cultural context, knowledge and behaviour. (Walker and Willms 1998)
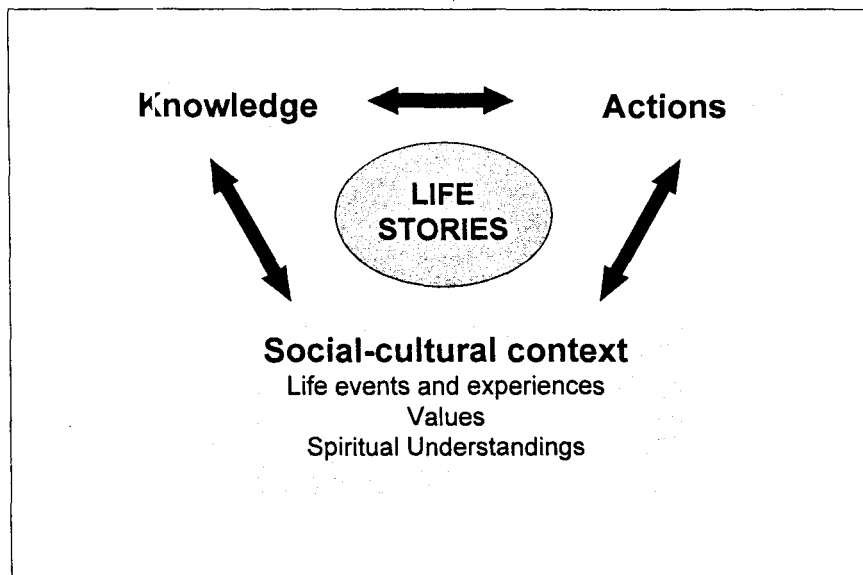
The merging of experiential and scientific evidence of risk broadens the evidence base from which interventions are generated. This results in an approach (illustrated below in Figure 2) which looks at risk not just as a technical problem, but illuminates the elements of people's life worlds which make them vulnerable and

incorporates their reasoning about risk. This blending of different assumptions and

realities promotes a more dynamic, interactive approach to health promotion which is

open to new understandings of risk and the context in which individual decisions are

made.

Figure 2.   Broadening the Evidence Base: Generating interventions from a broadened
evidence base. (Walker and Willms 1998)
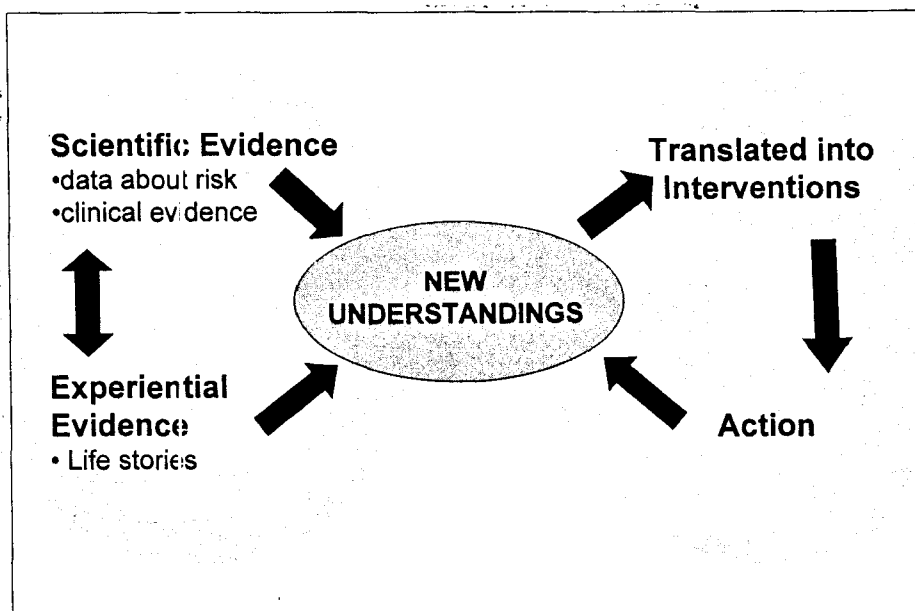
This approach is fundamental to the research behind the *Many Voices*

handbook [9]. The EC=A study used both kinds of evidence to determine elements of

risk and vulnerability: quantitative epidemiological evidence, which showed a higher

than usual incidence and prevalence of HIV infection in the Horn of Africa communities

(Remis 1999); and qualitative experiential evidence, in the form of ethnographic

accounts from members of these communities about their journeys and new lives in

Canada. It is these understandings which are reflected back to the communities in the

Many Voices handbook, and these data the community members will use to generate community-based HIV prevention activities.

4.2.2   The use of stories [12]

The preceding discussion emphasizes the importance of considering experiential evidence when developing interventions, and indicates that we can obtain this evidence by listening to people's life stories. Using stories as evidence is just one of the ways stories are fundamental to the *Many Voices* strategy. They are also used in this project as a resource to get people talking about health concerns, thinking about what this information means to them personally, and together with community members, problem-solving around the issues. A story concept is also used to communicate the research evidence from the ECFA study back to the community, and to provide skills and health information to health and outreach workers. In the handbook, the reasoning behind the use of stories is both implicit and explicit, but I will now elaborate on how and why I have applied this strategy in the project.

4.2.2.1 Stories as evidence

A look at some of the ethnographic evidence obtained in the ECFA study will show just how critical this kind of experiential evidence can be to the design of future interventions. It is difficult to imagine that prevention programs in the Horn of Africa communities could be successful without knowing and considering that community members have taboos against discussing matters relating to sex and sexuality, that they feel immune to HIV because of their religious beliefs and cultural values, that there are strong social sanctions against homosexuality and HIV positive individuals, or that people struggle with such difficult lives that day-to-day survival is more a priority than

thinking about HIV. In fact, the ECFA research discovered that existing prevention programs, which focus primarily on homosexuals, bisexuals, and intravenous drug users within dominant English and French cultures do not address what appear to be predominantly heterosexual ethno-cultural concerns, and they do not begin to address the many other issues which are part of the complex lived reality of community members' lives.

The stories told by immigrants and refugees from the Horn of Africa provide vivid and moving evidence of their experience with risk and vulnerability. As the handbook describes, the stories told by community members talk of terrible loss, alienation and suffering experienced by people fleeing distant homelands because of political conflict and economic hardship [13]. They also reveal the complex socio-cultural contingencies and constraints of their new lives as immigrants which make them vulnerable to health concerns – the risk realities and situations mentioned earlier. However, many people's stories also tell of courage, dignity, resilience, and the strength of individuals to survive and endure. In this, the stories also offer hope – they reveal the enormous capacity of the human spirit.

Threads of these elements are woven throughout the text of the *Many Voices* handbook, but specifically, the ethnographic evidence is reflected back to the community in the "Learning about the Issues" section (pages H-8 to H-18 in the handbook). This is powerful information through which community members can come to recognize their inherent strengths and vulnerabilities and work toward overcoming their health concerns. Knowledge alone, however, is not enough, and this brings us to the next part of the strategy.

4.2.2.2 Stories as a resource for stimulating dialogue

A central goal of the strategy is to encourage community members to talk about HIV/AIDS and the factors which make them vulnerable. It is clear from the ethnographic evidence – which showed the denial, feelings of immunity, discomfort with talking about sexuality, and a lack of knowledge about the disease – that we need to stimulate dialogue in a way that is comfortable and safe, and build on what people already know about their life situations.

To do this, I compiled a number of narrative first-person stories whose story lines contain various elements of risk from the ethnographic evidence (pages H-81 to H-115 in the handbook). The health workers will use these stories as a way of introducing the issues and beginning the dialogue process. Because the storied situations belong to someone else, discussion can be less personal, making it easier and safer for people to participate. This is especially important with sensitive issues involving sexuality and family relationships.

The stories will also function as rich narrative metaphors which permit people to recognize their own story, and its elements of risk, in the stories of other people. The stories in the handbook, as well as those which will inevitably emerge during group discussions, offer people other possibilities for living their lives [14] , and with this new knowledge, begin to problem-solve around issues which affect their health. The plots of these stories may vary, but their characters express the same deeply human emotions which connect us all – fear, hope, despair, frustration, joy, anger, and love [15]. As people tell their stories, and others listen with openness, respect, empathy and compassion – "with their hearts" – new learning and understanding can occur.

The new learning and knowledge which takes place is facilitated through careful, respectful questioning by the health workers [16] . Some practitioners feel that the questioning activity which follows a story is the most important and most difficult part of such a strategy (Lowry 1999). To assist in this process, the story resource section of the handbook contains space for 'discussion probes' – questions to help start the dialogue. As part of their training sessions, the health workers will develop these questions and later add others from their own and each others' experiences. In the skills section of the handbook (pages H-19 to H-50), I have also tried to highlight the qualities the health workers need for effective questioning and facilitation, including the need to be non-judgmental, mindful about confidentiality, and aware of possible power relations with people in workshops, as these might relate to gender, age, class, culture, and sexual preferences.

The process generated by this strategy – listening and talking, reflecting on the meaning of the new knowledge, and moving toward possible solutions with others – is the methodology of participatory action research (PAR), which will be discussed in more detail below. Dialogue [17] is a critical element in PAR methodology, and the story strategy provides a space and facilitates a process for this to happen. The story resources in the handbook are only the beginning of many others that will be generated through this dialogical process, as health workers and community members draw on their richly diverse experiences and author new stories for their lives.

The idea of using stories also influences another aspect of the handbook project – the communication of research data, health and skills information to the health workers.

4.2.2.3 Stories to communicate research evidence and information

One of the first issues I struggled with as I approached the writing of the handbook was how to effectively communicate the ethnographic data, information relating to the skills of outreach work, and material about HIV/AIDS to the health/outreach workers. I wanted the style of writing be 'popular' – informal, conversational, and engaging, with simple, clear, jargon-free language – to reflect the fact that this was a community-driven initiative. Above all, I wanted to avoid the dry, academic, sermonizing (and marginalising) style of communication common to many research documents, public health reports, handbooks and manuals produced by hierarchical institutions.

I also wanted to be consistent with the theoretical underpinnings of our overall approach, which emphasized dialogical, egalitarian, contextual, and relational principles, and decided on the concept of a narrative story to communicate the ethnographic and skills information. The narrative involves conversations among a group of health workers who meet regularly to discuss their work. The reader joins these conversations, and the ethnographic research evidence and the skills information emerge through the dialogue as the health workers speak with two new recruits who have come to learn the work. My intention for using this representational style was to produce something that would convey the necessary information, yet at the same time, maintain the reader's interest by being simple and entertaining to read. Presenting the information as a story also gave me the opportunity to humanize and personalize the role of a health worker, develop relational themes, and model both collaboration and the value of individual experience that each person brings to the work.

Other parts of the handbook – the introduction, HIV/AIDS information, the story

section pre-amble, ard the conclusion – did not lend themselves quite as well to the

narrative genre, but I have tried to maintain the conversational tone by writing those

sections in the first-person voice of a community member, and sometimes the

researcher, who speak directly to the reader.

Thus, the *Many Voices* handbook became an experiment in ethnographic

representation, and the process of writing it raised many of the issues brought to light

by the mid-1980's revolution in representation and critique of ethnographic writing [18] –

authority, rhetoric, truth, fiction, literary style, authenticity, and appropriation of voice. I

will elaborate and reflect on some of these later in the discussion on methodology

4.2.3   The use of participatory action research (PAR) methodology

The third element of the *Many Voices* approach I wish to highlight is the

application of a participatory action research philosophy and methodology because it is

fundamental to the planning, implementation and evaluation of the project.

Briefly, this approach originates with the emergence of a liberation ideal and the

popular education movement in Latin America (Freire 1970; Fals-Borda 1991). PAR is

a form of investigation which mobilizes the knowledge, experience and skills of

individuals and groups to promote participation and social and personal change. Its

main focus is on consciousness raising and social mobilization. In this methodology,

researchers use facilitative methods to work with people in an alternating process of

reflection and action to produce knowledge that is personally and socially transforming,

and which can be used to effect long-term sustainable change. The centre of power

lies not with the outside researcher, but with the people, who define the research

problem, design and manage the research, and own and act on the knowledge generated. In this sense, knowledge is power (Smith and Willms with Johnson1997).

Clearly, issues of agency, representation, power and control are at the heart of participatory research approaches (Cornwall and Jewkes 1995). These have been developed in response to problems with more conventional research, which is 'top down', does not consider local knowledge and priorities, and therefore is generally ineffective at generating social change. On the other hand, research methods which emphasize participation and involve people at the grass roots level in the design, implementation and evaluation of the research are considered to be more effective and efficient because they are 'bottom up'.

While the above discussion reflects the ideals of participatory action research, in practice the actual conceptualization and application of 'participation' differs considerably [19]. For some projects it implies that local people just take part; for others, it means local people have power and control over defining the problem, generating research evidence, analysing, representing, owning and acting on the information. These typify two opposite ends in a continuum of what is considered to be 'participation' [20]. In any one project at various times there can be different kinds of participation by both researchers and the people with whom they work. This has certainly been the case in the *Many Voices* project, as people's time, interest, commitment, funding ambitions and life situations have influenced their degree of involvement.

Regardless of how participation is defined or employed in practice, there are some important fundamental principles which drive participatory action research and the work on this project. These include an understanding and respect for those we

work with and for; an acknowledgement and valuing of their knowledge and capabilities in the research process; and a recognition of their rights to set the research agenda and to own the process [21].

Ultimately, the values and agendas we bring to the research are key factors which determine the outcome of participation, and in this project we strive to honour the intent of a PAR philosophy while responding pragmatically to situational contingencies. During the ECFA study, which was initiated by researchers outside the community, community representatives were actively involved in advising on the research design, collecting ethnographic data, confirming the data analysis, and writing reports and recommendations. The outside researchers had control of project management and data analysis.

The participatory process shifted to a more community driven initiative as the Horn of Africa Health Project began. The outside researcher's role was to synthesize the research findings from the initial research into usable information, and return this to the owners of the research in a way that would stimulate future action and enable the generation of community based interventions. Community consultants advised and collaborated on the overall conceptualization of the handbook, its content, style of writing and language, and accuracy of information throughout the production.

As the project moves into its next phase – the training of health workers and evaluation of the handbook – PAR methodology will be used to build the community participation critical to the success, appropriateness and sustainability of future interventions. Community participants have a unique awareness of how to communicate research results to their fellow community members, how to mobilize and engage them, implement interventions, and identify criteria for evaluating outcomes.

Community control and ownership of the next phase is particularly important, given the expressed concern by ethno-cultural communities about discrimination and social stigmatization. In the past, this fear has lead to a closed and secretive approach to problems, and an unwillingness to discuss issues outside the community to avoid causing shame (Willms 1996a). Opportunities developed *within* the communities for dialogue and problem solving about health concerns should promote a more open, trusting approach to prevention.

With community control and ownership of the next phase of the project, the outside researchers will support the process with their own unique knowledge and skills, but they will function more as resource persons, facilitators and catalysts for generating participation and future funding opportunities. The health workers and community members will themselves become researchers in a broader sense, as they re-search, re-discover and re-author their personal and social realities (Smith and Willms with Johnson1997).

4.3   METHODOLOGY AND DISCUSSION OF CONSTRUCTING THE HANDBOOK

The foregoing discussion provides the context and underlying thinking which has influenced the approach used in the *Many Voices* handbook. Now, I will elaborate and reflect on the actual process of developing the handbook and writing the narratives and story resources -- a process, as I have said, that became an intriguing experiment in representation. It was a journey of another kind, with a story of its own.

This quest took me into a realm of imagination and creative writing, to the borders of narrative and fiction. It was foreign territory: at times I felt tentative and uncertain about where I was going and what I would find there; at others, there was the pleasure that comes with exploring the rich experiences of another world. This was an

adventure in imaginative ethnography of a sort, and it carried me to places of new possibilities and opportunities for creative expression.

My journey was guided by a variety of practical, theoretical and philosophical influences from within the field of anthropology and outside the boundaries of our discipline. Some of these pertain to the basic questions about why we do the work we do, while others concern issues of representation. At first glance, these two areas may not seem to be directly related, but a second look will show how closely connected they really are.

Ethnography is what we do in anthropology; it is the historical foundation of our profession. However, in recent years, as I mentioned earlier, traditional approaches to representation and our methodology have undergone a re-evaluation; our ideas about research have adapted to today's changing imperatives, and we no longer write the kind of objective, descriptive ethnographies which speak authoritatively for 'others'. We now explore our modes of representation for their limits and possibilities, seeking creative ways to express multiple voices and points of viewing, with new awareness of historical, political and economic influences in and on our writing. We have developed a self-consciousness about how and why we construct knowledge, and ask ourselves, of the knowledge we produce with our ethnographic work, 'for whom? about whom? by whom? for what ends? by what method?' (to paraphrase Clifford 1986:13 and Gupta and Ferguson 1997:38). These reflective questions have caused us to re-think why we do what we do, and a growing number of anthropologists acknowledge a social and political responsibility to apply our methodology and theory to real world problems. Many of us now feel compelled to action and advocacy in our work [22] – what might be described as an ethical anthropology. Some of us have reflected on the role of

ethnography in an ethical anthropology and look to representation as a means for praxis, through which anthropologists can enhance social capacity and social change (Denzin 1998; Wallman 1997; Walker 1998) [23]. Others write about the need to apply our work in a way that witnesses and honours the suffering of people whose lives are affected by unimaginable tragedy, inequality, deprivation, violence, or illness (Kleinman 1995; Farmer 1992; Good 1994), so that we may support them and come to greater existential understandings.

These themes have heavily influenced the thinking behind the production of *Many Voices*, and the handbook embodies them in a number of ways. It is a work about a certain social and political location [24], built on an awareness of how dominant social, political, and economic power structures can drastically change the lives and silence the voices of those struggling at the margins of life. The handbook gives voice to their stories, connecting us with their suffering and inspiring us with their courage – teaching us lessons in what it is to be human. It is an evolving space both about and for dialogue and conversations, including voices yet to speak. It is a work meant to spark the creativity and imagination of its readers, and enhance their capacity for action. In the end, it is about caring for and supporting individuals in the context of their relationships and communities in their struggle to triumph over the difficulties and dilemmas of their daily lives.

These are the ways the theoretical and philosophical influences shaped the conceptualization and eventual outcome of the handbook, but I will start at the beginning of the story and discuss some of the interesting challenges and dilemmas involved in its actual production and writing.

As I began to think about what this enabling resource might look like, my first concern was that this project was to be a text-based product. I suspected that many of its users might have a cultural preference for an oral tradition, and many would be struggling with a new language. I wondered whether some form of visual or verbal resource might be better received and more appropriate [25]. The second concern, which followed closely on the first, was my discomfort at having to write about the lives of people I had only just recently met and did not know in any meaningful way. Right from the beginning, I struggled with questions of authenticity and feelings of guilt at being an 'ivory tower researcher', as well as doubts about whether I could make this work, or feel good about doing it.

I tried to take comfort in the fact that the community HAHP committee had *asked* for a text-based handbook and that it was only an initial enabling resource to start the process of generating community-based interventions. Then I met with the community health workers who were my advisors. They were enthusiastic about the story concept for the handbook, and talked about other information they thought should be included. We agreed to meet and discuss each section as it was written, and they would provide a critique of it for clarity, style, use of language (jargon, appropriate idiom, level of understanding), and gaps or errors in content. They would also add details which would enrich cultural authenticity and the reality of doing the work of a health worker. With this support, and my discomfort somewhat allayed, the work began.

While I did not know exactly what the handbook would look like at this stage, I had a number of aims in mind. As discussed earlier, it had to be written in a style and language that would be readable, understandable, and appropriate for the audience,

while at the same time communicate the necessary information. I wanted it to be

entertaining and engaging – not an endless lecture filled with lists of dos and don'ts,

and pages dense with statistics and stuffy reports. I felt it was important also to include

information about the underlying theory and methodology that is implicit in the work of a

health worker – to include the 'why' along with the 'how' as part of building skills and

capacity. At the same time, I was seeking a format that would allow the handbook to

be used easily and quickly as a continuing reference resource. My intention was also

for the handbook to be an interactive space, a workbook where the health workers

could have a dialogue with the material, add their own knowledge, reflect on the

information in the handbook and their experiences, generate new knowledge, and plan

future activities. I particularly wanted the handbook to model caring and collaboration,

and emphasize the value and potential that each person brings to the process – to

demonstrate that they themselves already bring valuable knowledge and experience to

their work. This, and the interactive-reflective themes, would model the participatory

principles which underpin the project.

The content also had to be sensitive to community feelings and beliefs about

sexuality and spirituality, concerns about stigmatization and racism, and mindful of the

tragic journeys that brought members of the communities to this place. I wanted it to

show the respect I had for their capacity to endure, survive, and hope for better futures,

as well as reflect the compassion I felt for their difficult situations.

The process of creating a work with these ambitions was a challenge. Guided

by these specific aims and armed with an ethnographic data base of focus group and

individual interviews, I started work. The ethnographic data contained information

about people's lives at home in Africa, their journeys to Canada, their lives here in their

new country, and discussions on issues relating to HIV/AIDS. I was to use this evidence as the basis for stories which could help people talk about health concerns, particularly HIV/AIDS.

As I read through the data, voices of the immigrants and refugees carried me into their fractured world and disrupted lives [26]. They helped me imagine what it was like to be suddenly uprooted from all that was familiar, torn from beloved family members, dear friends, life-sustaining work, and the comfort of accustomed landscapes. I pictured with horror and outrage the violence and inhumanity that many of them had endured, and was filled with respect and admiration at their ability to survive and go on. What is it, this capacity of the human spirit; this intangible essence which bonds us, inspires us and gives people hope?

As they spoke about their new lives in Canada, I ached at their expressions of loss – loss of partners, traditional family roles, respect, language, customs, values, careers, and familiar networks of friends and relations. Their stories told me that they had not just lost their homelands; they had lost themselves. Their journey stories were not just about journeys of geography, they were also about journeys of selves, struggling to regain and retain who they had been, and to become who they must, in order to survive their new lives in Canada.

After reading the interviews, I was certain that I would not be able to fully represent the issues and capture the dilemmas faced by members of these communities with an individual story, or even several people's stories. So, it was with a great measure of representational angst that I decided to compose the stories of 'fictionalized' people. With this technique, I reasoned, the story could connect with

more people's experiences and trigger discussion on a wider variety of concerns than might be available in any one individual's 'authentic' story.

As I struggled to construct the characters and imagine their words, I quickly began to question whether this was the right approach. I worried about authenticity, appropriation of voice, and the ethics of trying to represent 'fictional' lives. In what sense would this make the stories "partial truths" [27] ? In what sense would they be "positioned truths" [28], written with an "informed subjectivity"? It was not a process I was at all happy about; I wanted to be true to the voices and experiences of those who gave their 'evidence' and did not want to be yet another example of the scorned outside researcher who didn't get it right. Most certainly, I did not want to let the community down, when they trusted and expected me to do this work.

I went back to the data again, hoping for answers. Back again. And again. Finally, I felt myself beginning to move in the rhythm of their words, carried to places of the mind and spirit through their conversations. The relationships, the losses, the broken dreams, the dilemmas, the denial. I began to realize that I didn't need fiction; I could weave the stories with the threads of all their voices. The process became clearer – I would fashion the stories by collecting the words from many voices and many stories and give them to a character who would bring them to life. I read the data again, noting and separating dialogue that could relate to the life situations of a health worker, a man, woman, or young person, and which could be spoken by each of them.

As I collected the narrative fragments, the stories emerged from the data – the single mother whose daughter wanted to talk about sex; the father who agonized over the loss of his children to the values of the new society; the homosexual who feared the alienation of his community and hid his sexuality; the HIV positive woman who was

isolated and abandoned by her friends; the married woman who worried about her husband's affairs and family conflict; her husband, who felt he was no longer respected because he was unemployed. Gathered almost verbatim, the words of many people became the stories of a few, stitched together by the imagination.

These became "ethnographies of the particular" [29] – stories of individuals at particular times, in particular places, with particular realities. At one level their stories metaphorically highlight the basic similarities in everyone's lives, helping people to connect and empathize with one another and opening doors for self-reflection. At this other level, they illustrate alternative possibilities for living which can help people to re-story their lives.

What are the ethics involved in constructing such 'fictions', and crafting praxis-oriented representations [30] intended to influence, provoke, move, compel, or inspire? It is a question I struggled with throughout the process. In spite of my 'post modern' sensitivities, I still wanted to 'get it right' and be 'authentic'. The question took on an added dimension as I added personality to the characters and plot to the narratives which modelled 'moral reasoning' around health action and decision-making. Were the stories too progressive [31] ? Did they reflect realistic possibilities or did the story lines impose unintended, and possibly unwelcome ideologies on the communities? This is something I want to explore in the next phase of the project.

Certainly, there were limitations imposed by working with an existing database, and I hope these have not affected the work to any great extent. Because the evidence was collected by others, it was 'distant' from my own experience and difficult to relate to without the proper context. I missed the component of what Chiseri-Strater and Sunstein (1997:234) call 'collaborative listening', where the researcher does not

just extract information, but together with the participant "make[s] meaning together like two dancers". More interaction with the participants would have given me a better sense of their day-to-day lives and provided more depth to the stories. As well, the interview questions had been designed for the purposes of the initial study, and did not touch on or go as deeply into some of areas as I would have liked. There were also other people who would have been interesting and useful to have interviewed [32].

In spite of these misgivings, to my relief our community consultants accepted the narratives enthusiastically, and added some of their own wisdom and words. In the end, I think we got it "right enough" [33] for now, but the pilot testing and evaluation will tell us more.

This brings me to the last part of the discussion – the next steps for the project.

4.4   NEXT STEPS FOR THE PROJECT

The next phase of the project is aimed at generating community-based health initiatives, with the handbook as a resource to assist in this process. As I discussed in the earlier section on PAR, this phase of the project will be community owned and driven, so the initial work will be on building a participatory process within the communities.

4.4.1   Building the participatory process; training health workers

Authentic participation is critical at this stage, for reasons previously mentioned, and this will require that a number of things happen. First, health workers will be recruited and hired from within their communities [34]. They will participate in training sessions in which they will learn about participatory methodology and community health and outreach work, including sessions on how to work with the handbook.

Since this is a community-based project, the next steps would be to develop a community strategy for implementing the project. There are some participatory planning models which have worked well in other programs [35] and these will be suggested as possibilities for guiding the process. Ultimately however, the outreach workers, other members of the community, and community organizations will collaborate on the decision-making around planning, implementing and evaluating the project. It would be advantageous to negotiate this process within the community's larger political and social context [36] to maintain and develop good relationships. Having people and organizations 'on side' from the beginning could facilitate future negotiations relating to support and resources for the project or potential policy changes.

To begin the process, the health workers may have to generate activities in their communities which develop awareness of and interest in the project and build on the dialogue begun during the ECFA study and the Horn of Africa Health Project. They will also have to re-affirm and build on partnerships with a number of existing community networks and organizations, and develop connections with others, to ensure participation from key stakeholders in the planning process. Once there is a plan in place, the health workers can begin their outreach work with people in the community and the evaluation of the handbook resource.

4.4.2   Evaluation of the handbook

In keeping with the participatory nature of this phase of the project, a participatory approach will be used in its evaluation [37]. Using a participatory evaluation process will enable us to obtain practical, useful information which is grounded in the experience of participants. Thus, it responds to the interests and concerns of those

who will be using it – the community decision-makers – in a way that is empowering, gives ownership and builds community capacity.

Participatory evaluation approaches were developed because the design and findings of traditional approaches are not particularly useful or relevant to the participants of research. A participatory approach draws on the same Freirian theories as PAR, and differs from traditional approaches in a number of ways. These include: its focus, scope, flexibility of design, balance of power and control, role of outsiders, and intent. There is a focus on participant ownership, rather than outside (eg. donor) ownership, and is oriented to the information needs of community participants. Anyone with an interest in the program may be actively involved, and the roles they play may vary and be negotiated. Agreement on findings, solving of problems, and plans to improve programs are achieved through discussion, negotiation, and consensus. Power and control are centred in the community, and views are sought and recognized from all participants. The emphasis is on lessons learned which will improve the process, rather than achieving outcomes. Participatory evaluation methods often involve rapid appraisal methods (individual and community group interviews, focus groups, direct observation, case studies which illustrate problems or successes, or visual images.

Briefly, with a participatory evaluation approach, the health workers, community members and organizations, and outside researchers will work together to identify who should be involved from within and from outside the community, what their roles should be in the process, and how the evaluation will be done (eg. methods, schedule, logistics, funding). Working with a facilitator, community members will decide on the aims of the evaluation and identify the evaluation questions they want answered. They

will also select the methods required to answer the questions and will be trained in the skills needed to participate in basic data collection, analysis, interpretation. They will also decide how to reach common understandings on the results, how and when to prepare and disseminate recommendations, and develop an action plan for implementing the lessons learned. Evaluation will occur throughout the course of the project (ie. it will be formative) so that community decision-makers will have regular information for program improvement and organizational development.

I recognize that we need to ensure that community participants are committed to the suggested evaluation process, and that sufficient resources (time and financial) are available to support the activities. If full participation is not possible throughout the project, the priorities from my perspective for community participation would be in the generation of evaluative questions and design of the strategy at the beginning, and developing conclusions from the data at agreed upon intervals.

My own questions for evaluation relate to the handbook itself and its use, as well as the participatory process. They are as follows:

- *Regarding the contents of the handbook:* How do the health workers respond to it? What do they think about it? What do they like about it? What do they not like about it? What is missing that they would add to it? What does not make sense? What does it mean to them that this work was done; that they have this resource?

- *Regarding the use of the handbook:* How are they using it? Are they sharing information with each other? Does it generate their own reflection on knowledge-action-reflection on outcome cycle? What problems are they having with it? Do the stories help people talk about HIV/AIDS and other health concerns?

- *Regarding the training/preparation of health and outreach workers*: Did the training prepare them for their work? Did it prepare them for using the handbook? What was missing that would have helped? What was not helpful? What suggestions would they make for next time? What problems are they having? What would help them with these? Who could help them with these? What successes have they had? How do they feel about their role?

- *Regarding the participatory process*: What does 'participation' mean to the community? What kind of leadership exists? What kind of leadership development is needed, or has occurred during the project? How was this achieved? What organization exists now, is needed, or has been developed during the project? What resources exist now, are needed, or have been developed during the project? How have they been used? What is the nature of the relationship between community and outside organizations and power structures? How can these be nurtured and utilised? What problems have arisen, and how have they been solved? What activities have been planned or held within the communities? Are these broader health or specifically HIV/AIDS related? How are they organised and who is involved? Do people come out to community events? Who comes, and who doesn't?

This is just a start to the many questions that will be part of the evaluation process. Together with community decision-makers, we will identify what evidence and which methodologies will give the answers.

In essence then, the project will begin a process of individual and community development using participatory methods. It will be a starting point for developing personal, professional, and community knowledge, and translating this into new

understandings. The result of developing personal capacities and active community participation is community development and social transformation.

The leadership development which is part of the health workers' training will help them discover that they have special knowledge that can make a difference in their communities. As they apply their leadership abilities and intentionally nudge people toward healthier lives, they will develop their own and others' capacities, which builds and strengthens their communities. Their leadership skills will be key to promoting the active participation of community members in problem-solving the issues which affect their lives and their communities which can, in the longer term, contribute to sustainable community development. As the project builds and supports systems and processes that already exist in the community, community capacity may be further enhanced. For example, individuals who are already involved as health workers could become trainers and recruiters; while organizations already involved in community development and health activities could get much needed help mobilizing community members, as more health workers are trained. As changes occur, additional processes which support the community may also be developed.

The goal, in the short term, is to get people in the communities talking about HIV/AIDS and the issues which affect their lives and their health. From this dialogue, we hope to see the development of health promotion initiatives which are generated through the active participation of individuals within the Horn of Africa communities.

With this, it is now time to have a look at the handbook, which follows in the next section. When you are finished reading it, please reflect on what this experience was like for you and let me know (see below). Add your voice to the many others, for true participation includes everyone.

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ENDNOTES

1.   If one considers a more broadly based definition of health, which includes the economic, environmental, and political determinants of health in the social contexts of people's lives, then the distinction between health and development becomes blurred. In this context, I prefer to think of development more broadly as social change. As it is commonly used, the concept of development carries with it the implication of a somewhat paternalistic enterprise, externally driven, and primarily economically focused.

2.   The term "ethno-cultural" is one used in the ECFA study, and is used to refer to immigrant and refugee groups who have recently come to Canada (since 1986), and which are cohesive (tend to retain language, culture, and religion over time) and well organized. The author recognises the sensitivity involved in using such a term, which is especially problematic when associated with HIV/AIDS research. Cappon et al (1996) discusses the issues involved.

3.   The ECFA study (Manson Singer et al 1996) determined the personal and sociocultural elements that increase the risk for HIV transmission and contribute to higher infection rates for immigrants and refugees in these communities. These include:
*   an inadequate basic knowledge about HIV transmission.
*   a lack of culturally specific education and prevention programming. Existing programs focus on homosexuals, bisexuals, and intravenous drug users within dominant English and French cultures. HIV/AIDS is therefore considered to be a "gay white man's disease", which contributes to feelings of immunity.
*   complex attitudes relating to sexuality. Cultural prescriptions are for heterosexual acts, and there is great distress, fear, stigmatization and denial attached to homosexual and bisexual practices.
*   taboos against talking about sex; denial of sexuality and risky behaviours.
*   religious beliefs which promote feelings of immunity and denial, and contribute to taboos against talking about sexuality.
*   negative attitudes toward HIV positive individuals leads to under-utilization of testing and counselling services.
*   social influences related to the immigration process, such as poverty, unemployment, language differences, lack of suitable housing, lack of access to appropriate health and social services, loss of professional status, discrimination.
*   dislocation from families through immigration and war, which leads to isolation, loss of social support and control.
*   separation from or loss of spouse, which contributes to emotional vulnerability and other sexual encounters.
*   perceived threats to traditional values. Role reversals from cultural norms, and difficulty in maintaining family values and cultural traditions lead to parenting problems, conflicting directives for behaviour relating to dating, and marital discord.
*   inequalities in male/female interpersonal relationships, which affects negotiation of safer sexual practices.
*   low condom use, especially with spouses, yet extra-marital activity is frequent and expected
*   increased vulnerability of women, who are particularly isolated and marginalised, to abuse and loss of economic security.
*   use of'qat' (an amphetamine drug) and alcohol, which decreases personal control
*   fatalism, which prevents action.
Other related articles on the study have been written by Adrien et al 1996; Cappon et al 1996; Willms et al 1996a, 1996b.

4.   During the course of the ECFA study, strong partnerships and communication links were developed between the communities and outside researcher teams, who collaborated on research design, implementation, and data collection.   Researchers involved in the ECFA study remarked that the Horn of Africa communities were committed and willing participants and noted that this makes success and sustainability of community-based interventions more likely (Willms et al 1996a). While the ECFA study had participatory elements, it was initiated and managed from outside the communities. The *Many Voices in Dialogue* handbook project has utilized these established community relationships, and will build on them to develop a full community-driven participatory process in the implementation and evaluation phases of the project.

5.   Health and outreach workers are individuals recruited from within their communities who work to educate and counsel community members about issues that affect their health, and facilitate their access to services and care. Their work encompasses health in its broadest definition, and in many ways involves community development. The term "health worker" does not imply the necessity for professional health care credentials, although some individuals recruited for this work in the past have previously worked as doctors or as allied health professionals in their home countries. As the project moves forward, the 'job description', 'credentials', and training requirements of the health and outreach workers will be reviewed.

6.   These are acknowledged on page iv of the thesis.

7.   Culturally compelling interventions are those which are co-developed in partnership with community members; incorporate the language, nuances of meaning, metaphors and analogies of particular social-cultural experiences, and are considered catalysts for action and behaviour change (Sewankambo and Willms 1994 and 1995; Willms 1999).
        A deconstruction of the term intervention "reveals implicit and powerful assumptions about the process, its purposes, and the role of the participants" (Hoyt 1998:15). I prefer to think of the *Many Voices* handbook as an *enabling resource* (Sewankambo and Willms 1994).   Enabling resources are the kinds of resources that enable individuals to make healthy lifestyle choices. Individuals are able to draw on resources from within themselves (eg. values, will, intention) as well as "outside themselves" (eg. health care services, role models, medicines).

8.   These have been articulated elsewhere (Willms 1998a;1998b;1999) and conceptualized as part of an emerging "Intervention Science".
        A survey of the peer-reviewed literature confirmed many of these factors as being important to the development of successful interventions. While the papers reviewed discuss what the interventions look like, they generally did not discuss why they look like they do. Questions about translation of research evidence remain unanswered.

9.   A number of writers' works have been useful in elaborating the differences between scientific and social science perspectives on risk, and the implications of these for intervention work. Among the most helpful are: Backett et al 1984; Davidson et al 1992; Douglas 1986 and 1992; Dunn and Janes 1986; Frankenberg 1993 and 1994; Franzkowiak and Wenzel 1994; Gifford 1986; Hayes 1992; MacCormack 1994.

10.   The Risk Reality Model (Willms and Sewankanbo 1995) is an emergent theoretical framework derived from nine years of research experience with communities at risk for HIV/AIDS in Uganda. The model suggests that risk be understood as a series of interconnected domains – the *risk reality, risk situation,* and *risk event.* These three constructs are used to demonstrate the complex socio-cultural influences on sexual health and well being which have contributed to the HIV/AIDS problem. The *risk reality* is the socio-culturally constructed physical life world of individuals, which together with political, economic and environmental influences, lead persons to involvement in high risk

activities. *Risk situations* are social situations where individuals, caught in these positions either out of necessity or social circumstance, are compelled to participate in these high risk activities. *Risk events* are the critical moments located in the risk situation when an individual is faced with a choice (often a "choiceless choice"). This model emphasises the idea of social risk – the notion that experiences of risk are linked to social, political and economic circumstances all of which increase people's vulnerability to HIV transmission. Thus interventions, or what are called *enabling resources* in terms of this model, need to be based on evidence which uncovers the precipitating factors of high risk behaviour, and need to be co-developed in partnership with community members. This approach is the basis for understanding the *risk reality* of members from ethno-cultural communities, and dictates the methodology and evidence to be used for intervention design, dissemination and evaluation in this project.

11.   This discussion is elaborated in the handbook on page H-4 to H-5 and H-51 to H-56.

12.   The concept of using stories as a vehicle for understanding different experiential logics and using these in dialogue with others to create new ways of knowing was successfully developed and applied by Dr. Dennis Willms and colleagues in a project involving traditional healers and HIV prevention in Zimbabwe (Willms et al 1995). The *Many Voices* project is applying this strategy using the immigrants' and refugees' "journey stories".

13.   While many of these individuals are victims of major political and economic turmoil and have experienced and escaped from violence, the intent here is not to reduce them to a "core cultural image of victimization" and "standardized sufferer" – which is another form of victimization (K einman 1995:176). Rather, the representation of complicated life situations as told in the journey stories of these immigrants is done in order that we may honour their courage, witness their suffering, acknowledge its consequences, and support its healing. As a rich and privileged nation, we are proud of our ability to offer sanctuary and protection to those who need it, but we forget that this is not the end of their story. Our commitment should extend to providing an enabling environment in which they can restore, and re-story their lives.

14.   Our story strategy has interesting parallels in the field of psychiatry, in what are called constructive therapies – an umbrella term for a group of theoretical models such as solution-focused, narrative, interactional therapies (and others). In this therapeutic movement, the profession shifts its sensibilities away from its traditional modernist influences based in scientific objectivity (pathologizing, disease categories, measurable symptoms, hierarchical clinician/patient relationships, rationality) to a 'postmodern' stance which recognizes a "fuller appreciation of human agency and potential ... a more optimistic view of people as unique and resourceful creators ... of their own realities" (Hoyt 1998:2).
         Constructive therapies focus on languaged ways of knowing – that is, how language constructs our worldview and how it can be used to offer alternative possibilities for viewing and constructing ourselves and realities. The therapeutic process is seen as a special kind of conversation, where "change is the evolution of new meaning through dialogue" (Anderson and Goolishian 1998:372). Through telling their stories and a dialogue which involves deconstructive listening and questioning "people [come] to see their stories from different perspectives and notice how they are constructed (or that they *are* constructed), note their limits, and discover that there are other possible narratives" (Freeman and Combs 1996:57). As Anderson and Levin (1998) put it, "Each person is the narrator of his or her own story, the expert on his or her life, and the knower of his or her narrative experience. At the same time a story is used to convey an experience, in its telling it simultaneously creates and potentially transforms that experience ... In our

experience the natural consequence of dialogic conversation is transformation."

The constructive therapies come out of the social construction theory in psychology. Where constructivism emphasizes the individual's role in constructing reality, social constructionism emphasizes the communal/relational aspects of constructing meaning and reality (Gergen 1994). I would like to think that these two movements are not mutually exclusive, but represent a dynamic relationship between individual self-consciousness and people's relational interactions with the social environment. I have made this assumption in the **Many Voices** project.

15.   Carolyn Ellis (1993) uses emotions as metaphors in her ethnographic writing to bridge different understandings and "incorporate[s] feelings and participatory experience as dimensions of knowing" (:726). Readers (listeners) become active interpreters of the story teller's and, through the connections generated by shared emotions, their own experiences. For similar reasons, Lila Abu-Lughod (1991) advocates 'ethnographies of the particular', rather than those which objectify and ignore meaning through generalization. By writing ethnographies of the particular, she says, we see that "others live as we perceive ourselves living ... agonizing over decisions, making mistakes, trying to make themselves look good, enduring tragedies and personal losses, enjoying others, and finding moments of happiness" (:158). She calls this a "discourse of familiarity"; a "tactile humanism" which works to connect us as fellow human beings.

This connecting at a basic human level with others has important social implications. Philosopher Richard Rorty (1989), in discussing his ideas of a liberal utopia, says that we can build human solidarity through being able to imagine other people as fellow sufferers – "increasing our sensitivity to the particular detail of the pain and humiliation of other, unfamiliar sorts of people ... [which] makes it more difficult to marginalize people different from ourselves." (:xvi). Developing this "ethics of kindness', he says, "is a task not for theory, but for genres such as ethnography, the journalist's report ... and especially the novel" (xvi).

16.   There are a variety of questioning techniques which can be used with the story strategy. I again draw on the constructive therapies for parallels. Among these techniques are: deconstructive questioning – curiosity and questioning with a 'not-knowing' attitude (Freedman and Coombs 1996); behavioural questioning – questions which elicit behavioural responses, for example "What do you do (say) when ..." (Chang 1998); 'internalized other' or reflexive questioning – designed to help people feel as others do (Jenkins 1992 ref. in Nylund and Corsiglia 1998); questions grammatically designed to predict possible futures, moments of freedom, victories over life situations (Madigan and Goldner 1998); 'mystery' questioning – questions which do not represent the truth and command an explanation (Lund and Eron 1998).

As well, Shafer (1983) has developed an inductive questioning guide with the acronym S-H-O-W-E-D. Wallerstein et al (1997: 201) developed some sample questions based on this guide:

What do we <u>s</u>ee, or how do we name this problem?
What's really <u>h</u>appening to this individual in his or her life?
How does this story relate to <u>o</u>ur lives, and how do we feel about it?
<u>W</u>hy has this person experienced these problems at an individual and family or community level?
How might we become <u>e</u>mpowered now that we better understand the problem?
What can we <u>d</u>o about these problems?

Essentially, the questions ask participants to describe the problem, think about how this problem relates to their own lives, critically assess the context of the problem, and plan social action strategies.

17.   Hoyt (1998:3) points out that terms like dialogue and conversation "seem to focus more on the exchange of words and may gloss over certain social complexities", omitting aspects of the non-verbal. He quotes Goldner (1993:159) as preferring the term 'discourse', which "brings together language, meaning, knowledge, and power." In the practice of participatory action research, where dialogue does bring together language, meaning, knowledge, and power, I still prefer to use the terms 'dialogue' and 'conversation' – they imply a more communitarian, relational dynamic than 'discourse', which carries a more formal, critical/political connotation for those of us working in an academic context. In doing this, I still recognize that power inequalities and politics are often significant influences on the life situations of people with whom we do participatory action research.

18.   There are many authors who have raised these issues and whose writings have been useful to my thinking about the way we represent ethnographic work, particularly Abu-Lughod 1991; Clifford (1986); Denzin (1998); Ellis (1993); Kleinman (1995); Marcus and Fisher (1986); Tyler (1987). Many other authors have responded to the critique of ethnographic representation with creative, and often controversial, experimental ethnographies. See Denzin 1998:xvii for examples of these.

19.   Participation occurs in many ways, and has several different aspects. Cornwall and Jewkes (1995) review a number of different participatory methodologies, noting that participation should be judged by who has control and how people are involved. There are many examples of differing kinds of participation, and the authors quote some researchers who have developed models with criteria for assessing it, such as Biggs (1989). Using the extent of researcher participation and control as criteria, the four modes of participation he suggests are: *Contractual* – local people are contracted to take part; *Consultative* – people are asked for their opinions before interventions are designed; *Collaborative* – researchers initiate, control and manage the project, but work together with local people on it; *Collegial* – control over process is with local people who work together as colleagues with researchers, each bringing different skills.
        Cornwall and Jewkes (1995) note that in theory, participatory research is 'collegial', but in practice it is often contractual or collaborative. However, because of the diverse and creative nature of participatory research methods, it does not lend itself to rigid classification or definition. Allman et al (1997) also provide a comprehensive, albeit rather confusing and institutional review of participatory/community-based research concepts, definitions, and models. It also contains a useful planning guide for community-based prevention research, which raises the questions which should be considered when doing participatory research.

20.   I would be interested to know how the community defines participation.

21.   To some, participatory action research is considered just another western ideology, with its emphasis on democracy and liberalism. There is no question that the choice of this methodology is political, with its emphasis on empowerment, social transformation and advocacy, but criticism based on a general indictment of western ideology is unfair. Clearly we must be mindful of the imperialistic and hegemonic effects that accompany western 'interference' in the affairs of others, but participatory research can be an ethical and humanistic undertaking if the research is truly community driven, people's knowledge and authority are considered paramount, the aims are made explicit, the process is transparent, and we are careful to 'do no harm'.
        Some of the unintended negative consequences this research process can have are reviewed by Cornwall and Jewkes (1995). They cite authors who describe repressive backlash against empowered participants who challenge established power structures in the form of political violence, exploitation, and cultural deprivation; increased unhappiness of participants when awareness is raised without means of change, or when unrealistic

expectations are encouraged; alienation of community members by their own community for participating in the research; community distress and conflict when local norms are inadvertently breached in the research process.

22.   Useful discussions can be found in Denzin 1998; Gupta and Ferguson 1997; Singer 1994; Wallman 1997; Warry 1992; Walker 1998, among many others.

23.   Singer (1994) makes an important point when he speaks about hope being central to praxis. Representing hope is a crucial component in how we practice, and how we help others tell their stories. This becomes a form of ethical action.

24.   In discussing changing ideas in anthropology about where we do research, Gupta and Ferguson (1997) talk about political and epistemological locations rather than geographical ones. Malkki (1997:91) applies the idea of location to "communities of memory". I think both these ideas about location apply to the work being done in the Horn of Africa communities.

25.   Some comments in the ethnographic data indicated that members of these communities generally do not like to read and prefer other modes of communication. As well, community members' problems with language barriers were a theme in the data.

26.   Gay Becker (1997) uses this term, and has contributed to the study of how people make sense of suffering caused by disruption and discontinuity in their lives.

27.   This concept is discussed in great detail by Clifford (1986:6). I felt these stories would indeed be partial truths – more partial than simply that described by Clifford. They would not be a 'real' individual's version of the 'truth'; nor would they be an ethnographer's representation of a 'real' individual's 'truth'. The stories would be guesses at the 'truth' based on my interpretation of evidence – words that I would construct, not simply present as verbatim accounts in ethnographic "sound-bites". I think, given my relatively short relationship with members of the community, and the fact that I was doing this with already existing ethnographic data, these would be a *very* partial truths.

28.   This concept is discussed by Abu-Lughod (1991:142). The truths I refer to are very much 'positioned truths', and came from a position of 'informed subjectivity'. I have tried to make this subjective position explicit in discussing my aims for the handbook and philosophical inclinations earlier in the chapter. And, as the reader will see, the technique for writing evolved and I became comfortable with the 'informed' nature of my position. This self-reflection and questioning of one's motivation, perspective and interpretation is what Zich and Temoshok (quoted in Singer 1994:339) call 'informed subjectivity'.

29.   This is Abu Lughod's (1991) phrase; see also Good (1994); and Ellis (1993) for discussion on the value of narrative ethnography as a way of communicating meaning and similarities in people's lives.

30.   I prefer to think of 'fiction' in the context of **Many Voices** as Clifford (1986:6) discusses it – as "something made or fashioned ... systems, or economies, of truth". He goes on to say that 'fiction' has "lost its connotation of falsehood, of something merely opposed to truth ... lies of exclusion and rhetoric".
I also looked more deeply into Clifford's concept of "partial truths" to answer the ethical question about constructing 'fictions'. If all ethnographic representations are "partial truths", just one of many versions of reality, and these truths are constructed not only by the speaker, but by the writer, and the reader who interprets the message through his or

her own reality, then we can never hope to capture an ultimate truth. So, perhaps the ethical part comes with the intentions of the writer. In the tenets of ethical practice, if the intention is to do good, or at the very least do no harm, then shaping representation to achieve certain ends may still remain ethical. If the practitioner's intentions address the "contingencies of language, rhetoric, power and history" (:25); if they stem from a belief in the inherent capacity of humans to survive and adapt to their circumstances; and if he or she shares author-ity with those for whom s/he is writing, then I would say that these kinds of representations could be considered ethical.

31.   One of the project advisors questioned whether some of the story resources were too progressive, in that the characters modelled health promoting decisions and attitudes not commonly found in the communities. Community members thought the example promoted by this modelling was plausible and positive, and we agreed to leave the stories as is. However, if Freirian praxis is meant to develop critical thinking, and the stories are meant to trigger this, I wonder whether they need to be more open-ended. This dilemma further emphasizes the importance of good questions that develop critical thinking to follow the telling of a story, for as Wallerstein et al (1997:201) say "critical thinking does not occur spontaneously."

32.   Some examples of questions that I had which arose from the evidence: What is the role of women in religion when they come to Canada? Are they able to influence things? Is anything changing? How can religious leaders be involved? How can pre-marital counselling sessions which they lead be helpful to HIV education/prevention? What do people think when they see news of HIV in their African homeland? What proverbs or stories exist which could be used to talk about HIV/AIDS? What cultural figures might there be who traditionally talk about sexuality? Could condom use become a matter of cultural pride? Do programs exist in the schools geared to immigrant children? How could teachers be used as resources for these communities? How do community members think they could help their communities be more open to homosexuals/bisexuals? How will intra-community diversity affect prevention programs (eg. clans, tribes, religions)? Are there traditional healers in the community, and what is their role concerning HIV? What arts-based capacity exists in the community? What economic development opportunities are there in these communities? Given the extent of religious and tribal conflict in homelands, there was an obvious lack of any discussion on the implication of this for life in Canada. One health worker I spoke to while getting community feedback mentioned an incident where a man would not come to see her because he was from a particular tribe and was too afraid of what might happen based on his tribal affiliation. She was able to convince him that these things did not matter to her, but it had affected his health seeking.
        Examples of other people I would have liked to talk to: more younger teens, youth; religious leaders; HIV + people; relatives of HIV+ people; more married men and homosexuals/bisexuals.

33.   An interesting contestation of content occurred in the process of getting community feedback which highlighted the problem of 'getting it right' and 'partial truths'. One community member, who had been here a number of years, told me that "Prevention is not a concept we use at home. When you can't find enough to eat, you don't even think about nutrition. Prevention is a luxury." I put this in the handbook, and another community member took issue with the statement, saying, "We think about prevention, but not like you do. It is about keeping good relations." A second example concerns how a busy health worker copes with a heavy work load. One very caring health worker said pragmatically, "I get a commitment from people that they will try. If I see them trying, I will help all I can. But you can always tell who is using you. If they are using me, I don't waste my time." This raised quite a reaction from others when it appeared in the handbook, and was subsequently modified.

The lesson from these two examples of contested knowledge shows that it is probably impossible to 'get it right' and that there will always be different points of viewing and different interpretations of what we write about. Our work needs to consider that the data represent the few speaking for the many. For example, what people think and feel will vary with the length of time they have been in Canada, their own personal resources, and whether their thinking is more traditional or liberal. Hopefully, when all is said and done, we get it 'right enough'.

34.   Funding for this phase of the project is currently being sought from the Ontario HIV Treatment Network (OHTN). Currently, an OHTN Studentship Award partially supports the work on the current phase.

35.   One of these is a process called 'community diagnosis' (Bennet 1979). Elizabeth and Pål Jareg (1994), offer an example and description what this looks like in practice (pp. 96-112). To over-simplify the process, community members work with facilitators to identify 'where they are now (here)', 'where do we want to go?(there)', and 'how do we get from here to there?' It has similar features to what is also being called an ecosystem health approach (Walter-Toews and Wall 1997), which involves a participatory process with communities focused on identifying what they see as the issues or problems (environmental, health, socio-economic); identifying what is currently being done; discussing the constraints against and opportunities for change, with goals they would like; developing a plan; identifying what they think is important for health, and how these are connected; and listing indicators to determine success of the plan and how these will be measured.

36.   For example, existing public health officers and programs, local hospitals, family doctors, school principals, immigrant assistance programs, local government officials, provincial government officials, funding agencies, social service agencies, special interest advocates, multicultural officials, religious leaders.

37.   Helpful information on participatory evaluation appears in USAID (1996); Davis-Case (1990); Upshur and Barreto-Cortez (1995); Guba (1989); Rifkin (1988).

Many Voices in Dialogue:
An HIV/AIDS Handbook
for Health and Outreach Workers

by

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Contents

Acknowledgements

Our thanks goes to members of the Horn of Africa communities who have played a central role in the creation and production of this handbook. They have gathered information, told their stories, and given advice and encouragement to the project. This version of the handbook is only the beginning of what we hope will be the generation of many other projects aimed at promoting health – a sustainable health which builds on the rich and creative capacity which exists within the African communities.

Asante sana!

Thank you very much!

Many Voices in Dialogue: An HIV/AIDS Handbook for Health and Outreach Workers

Many Voices in Dialogue is a handbook created for people like you - people who want to serve as health and outreach workers and help their community members cope with the challenges of their new lives in Canada.

The main goal of the handbook is to help you create opportunities for people to talk about the issues that affect their health, particularly HIV/AIDS. This is important because people in our communities face many hardships and problems which make them vulnerable, and they are not comfortable talking about issues related to sexuality.

The goal of outreach work is to get people talking

Thus, your challenge as a health worker is to create open, honest discussions about these issues, in a way that helps people recognize how they are personally vulnerable, and moves them toward making healthy choices.

The *Many Voices* handbook contains resources that will help you with this challenge. These resources, however, are only part of what you will use in your work. A very important resource, perhaps the most important resource you have is yourself.

The most important resource you have is yourself

Each of us has valuable knowledge and wisdom within us that comes from our experiences, our beliefs and values, and our relationships. All these things make up our personal life story. As you go about your work, you will find that sharing your own story will become a powerful way of helping people talk about issues in their lives. As they tell their stories, they will add their own wisdom, knowledge and experience to yours.

The heart of the *Many Voices* approach is people's stories

It is for this reason that the handbook contains the voices of Africans living in our communities. Their voices tell stories of past experiences, journeys from their home countries, and the challenges of changing lives in Canada. They express great suffering, loss, and vulnerability, reflecting the overwhelming realities of life faced by refugees and immigrants. But these voices also speak compellingly of survival; their stories bear witness to the strength and resilience of the human spirit. Your own voice, along with the voices of others, create and reflect a community which is strong and proud; together, we can use our stories to help one another on our journey together.

The first voices you will hear, or read, are those of a group of experienced health and outreach workers. We will join them as they discuss their work, and their conversations will help us understand the issues which affect peoples lives and health, especially as these relate to HIV/AIDS.

In the second section of the handbook we will continue our conversation with the health workers and they will talk to us about doing community outreach work. They will help us learn how to meet with people and discuss their concerns in safe, comfortable, supportive ways. They will also share some helpful ideas and techniques you can use in your work to create discussion, raise awareness and stimulate change. The handbook calls these "skill tips", and they are summarized at the end of the section for quick and easy reference.

The third section will help us learn and talk about HIV/AIDS, both from the way scientists explain it and the way people in the community understand it. Knowing the scientific facts about HIV/AIDS will help us answer people's questions and give good information about prevention. But it is also very important to learn how community members understand the disease and how certain social and cultural realities contribute to their vulnerability. This will help us talk about HIV/AIDS in a way that makes sense to people and helps us be more effective in our work. We will also hear from researchers who will talk about why the approach used in the *Many Voices* handbook is effective at

The handbook has five sections:
- Learning about the issues
- Becoming a health worker
- Learning and talking about HIV/AIDS
- Telling stories
- Community Resources

helping people find solutions to their problems and feel more in control of their lives. This section will help you think about your work in the context of what people have learned about successful health promotion.

The fourth part of the handbook contains people's stories which you can use as resources to get people involved in discussions and problem-solving around the issues which affect their health. Using stories during discussions lets people talk about private and uncomfortable issues in a way that is safe because it is not personal.

The final section of the handbook contains a list of community resources you can use to help people find assistance for many of their concerns and problems.

The approach used in *Many Voices* is different from that of many other health promotion strategies. Here is a little background to help you understand why we are using the approach in *Many Voices*.

Understanding the *Many Voices* approach

Health promotion programs are often based on the idea that if people know something is not good for their health, they will change their behaviour to avoid getting sick. So, public health educators give people information (scientific evidence) about the causes of a disease, the chances of becoming sick, and how to prevent this. However, people often ignore the warnings and continue to do the things which put them at risk for disease. Why is this? Unfortunately, it is because people's decision-making is often influenced more by the social, cultural, political and economic factors which affect their lives than by scientific information. Therefore, to be effective, health promotion programs need to consider these other influences on people's health and look at the idea of health more broadly.

As well, health education messages often do not make sense to people, and are rejected or denied because the information ignores what people already know about a disease and ignores the reality of their everyday lives. Therefore, health promotion

should actively involve people in the process so that educational messages are appropriate and people become committed to working toward change.

The approach used in *Many Voices* emphasizes what is needed for successful health promotion. It considers not only scientific evidence about disease, but also the many complexities, constraints and challenges which make up our lives and influence our behaviour. It sees that our everyday social environment – our experiences with life and death, hope and suffering, illness and healing – has the biggest influence on the choices we make. Thus, it deals with the problem of HIV/AIDS in the context of other pressing issues in people's lives.

These social determinants of health can be seen through the telling of our life stories, and stories are the heart of the approach in *Many Voices*. They show us what individuals know and understand about a disease, and how they experience risk. Stories are also tools for actively involving people in the discussion of health information in the context of their own lives. They create an experience of personal vulnerability through real situations people can relate to.

The approach also uses the idea that "knowledge is power". It believes that if people are given health information in a way that considers the realities of their own lives and beliefs, and they are actively involved in the process of examining what this information means on a personal level, they can move toward making healthy choices and developing solutions.

As a health and outreach worker using the *Many Voices* approach, you become part of the process. You are both a public health educator and a "researcher". The kind of research you are doing is called "participatory action research", or PAR for short. The methods you are using – getting people to talk about the issues, respecting and using what they already know to think about new ideas, and nudging them toward using this awareness to work out and try solutions – are all part of the PAR research process.

The *Many Voices* approach:
- considers what people know and values this
- discusses health information in the context of people's actual lives, beliefs, and values
- creates opportunities for people to actively participate and reflect on what the information means to them personally
- respects and mobilizes people's strength and creativity as human beings to develop their own solutions
- uses stories as a way of doing each of these

PAR is about change, and it requires a safe, comfortable, supportive environment which encourages sharing, trust, and dialogue among individuals. Especially with a sensitive topic like sexuality, which is private and difficult to talk about, people need to feel they can safely discuss issues which mean the difference between life and death.

These methods work to encourage change in individuals, but people do not live in isolation from their relationships in families and communities. In taking responsibility for their sexual health, individuals show they respect and care about themselves and each other. Therefore, the approach is also about hope - about people asking themselves, "Given our present situation, how should we be, in this place, at this time?" It has the potential for transforming not only individuals, but also the communities in which people live. And as a health and outreach worker, you become a catalyst for this hope.

How to use this handbook

The *Many Voices in Dialogue* handbook is meant to function in a number of ways to help you with your work. It is:
- a source of information about HIV/AIDS, the health of our communities, and the work of health promotion
- a resource for skills and tools that you can use in your work
- a place for you to think about and record your experiences
- a tool to help you generate new knowledge about our communities and your work.

The *Many Voices* handbook considers the idea that there are many ways of knowing – we can know something from what others tell us, from our own experiences, and from reflecting on both of these. The more you add your own voice to the voices of the others in the handbook – the health workers, researchers, scientists and people in our communities – the more it will become a rich and personal resource for doing your work.

To help you do this, the handbook contains:
- three story sections for you to read and learn from
- thinking exercises for you to reflect on your knowledge and experiences
- spaces for you to write notes and thoughts
- summaries at the end of each section so you can go quickly to the resources as you do your work
- a section of story resources you can use to generate discussion
- a section of other resources you might need in your work

Once you have read over the narrative story sections containing the voices of experienced health and outreach workers, and the HIV/AIDS section, which contains the voices of researchers and scientists, you will notice some exercises called "*thinking points*". You can do these at any time, as you feel ready. They will help you reflect on what you have read and learned and

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The *Many Voices* handbook will help you:

☼ **Learn** - it contains information for you to read

✍ **Reflect** - it contains exercises called "Thinking Points" to help you reflect on your work and what you have learned

☻ **Do** - it contains helpful "skill tips", and space to apply your knowledge, and add your own notes, ideas, stories and experiences

on your own personal experiences. As you record your answers, your insights will become new knowledge you can work with.

When you go on to read the story resources, try relating these to what you have already read. They will further deepen your understanding of the issues and give you a better feel for how the approach used in the *Many Voices* handbook works.

Once you have read through the handbook and done the "*thinking point*" exercises, you can use the handbook as a resource and reference book when doing your work. To help you find the important points quickly, there are summary boxes along side the story line and review pages at the end of each story section. There is also a special section which summarizes the helpful "*skill tips*". You will notice too that there are spaces for you to make notes in the handbook. Here you can apply your knowledge and add your own ideas, stories, and experiences, so as to make this handbook your own.

Learning About the Issues

First, we are going to meet with a group of health and outreach workers who are having coffee in the lunchroom at the health centre. They get together every week to talk about their work and share ideas, so they can tell us a lot about what is happening in the community. Understanding the issues people are struggling with in their daily lives, and how they are thinking about HIV/AIDS, will help us be more effective with our work.

Sidamo, Aman, Aladin and Saida are sitting together in the meeting room...let's join them.

"Hi everybody. I'd like you to meet a friend of mine who is interested in becoming an outreach worker. We are hoping you can help her get started."

"Hi," the group calls out cheerfully. "Welcome! Get a coffee and sit with us." They shuffle their chairs around to make room and pass a plate of cookies down our way. The room is small but comfortable, with brightly coloured posters on the walls and a sunny window at one end. The people at the table have become close over the last year, so the atmosphere is friendly and relaxed. After introductions, they talk about why they became interested in being community health workers.

Sidamo sums up the sentiments of the group when he says, " I guess we wanted to learn more about health issues so we could get involved and help our community."

"Yes, that's right," Saida agrees. "We have been through so much together. I feel like we have to do what we can to take care of each other." The others nod.

What are the issues that affect our communities?

"Maybe we could start by talking about what we see as issues that affect our community," Aman begins.

"OK, but remember, we are all not the same," Aladin cautions. "Even though we are all immigrants or refugees from Africa, there are still differences in our education, religion, social and economic backgrounds. There is no such thing as a typical Ethiopian, Eritrean, or Somali family, for example. The people we work with are all individuals, each has his or her own particular experiences and situation – each has his or her own story."

"You're right Aladin, I hear this when people talk in my groups. They all have different stories." Aman says. She turns to us and continues.

"Because you are from our community you know that people who come here have had very difficult journeys and have had to leave many parts of their old lives behind. Here, they have many problems because there are so many changes from what we know. After a while, like two or three years, people adjust and begin to think about their lives. It is tough – the culture, the language. Many people who are or were professionals back home all of a sudden work at parking lots. Many are depressed and worried about their future."

Issues of changing lives:
- Loss of identity and culture
- Learning a new language
- New roles
- Different values
- Loneliness and depression

Aladin nods in agreement. "Yes, I see this in my community. People fear having to start life all over again. They fear a loss of identity. We have some people who try to hold on to their old lives and retain their culture, and others who feel that they do not belong to anything. They are unable to adapt or take the Canadian way of life. Many people talk about going back home, but I see the people at home changing too."

"How was your visit?" Sidamo asks, very interested in hearing news from home. He is still waiting for his wife and son to come, and often feels like going back himself.

"Well, Somalia has changed totally ... great damage has been done to the country and the people by the war. It made me very sad to see this ... it wasn't the same as I remembered."

The group is quiet for a minute as they think about what each of them has left behind.

Saida reflects on what all these changes mean to the people she meets as a health worker. "Many of the people we talk to are so lonely and depressed about leaving their homelands and the changes that have happened to their lives. We are supposed to talk to them about health problems like HIV/AIDS, but health is more than not having a disease. It is also having a job, a place to live, friends in the community to talk to and have fun with. It is having a safe and happy family and people to go to when we need help with our problems. The people we meet in our work want to talk about these things. Their lives are about survival, and when people have to deal with survival, something like HIV/AIDS, for example, becomes a low priority."

Their lives are about survival:
- Housing problems
- Unemployment
- The immigration process
So, AIDS has a low priority

"But people should know about the risk of catching AIDS," Aman interjects. "That is about survival too. We have to warn people."

"Yes, you're right about that, Aman. But they want our help with other things too. People want to talk about housing, family reunification, jobs ... these are the things they talk about. This is one of the most important issues in the community that makes us vulnerable to AIDS ... people don't want to discuss it. We have to keep talking until people are convinced that it is important."

"Do you remember when we did some research in the community a few years ago?" Aladin asks, shuffling through his papers looking for the report [1]. "We found a number of things that increase our vulnerability. One of the biggest factors is that people just don't believe that HIV/AIDS is in our community. They think it is not our problem, that we are immune."

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1.   "Many Voices: HIV/AIDS in the context of culture." A report for the Communities from the Horn of Africa who participated in the Ethnocultural Communities Facing AIDS National Study. The report is available from the National AIDS Clearinghouse, 1565 Carling Avenue, Suite 400, Ottawa, Ontario, K1Z 8R1.

"Yeah," Sidamo agrees, turning to us. "There are people in our communities who do not believe that people from their country are affected by HIV/AIDS. Even when they see pictures in the papers from home of people with AIDS, they argue that these people are not from their country. Even when someone in the community dies from AIDS people do not accept it. It will take some time for people to realize that this can happen in our communities too."

"Another thing that I've found is that our communities do not have enough awareness or knowledge about HIV/AIDS compared to the mainstream Canadian community," Aman comments. "There is a lot of ignorance ... some people think that if they have affairs with married women they are safe. Or if they and their partners feel healthy they don't have to use a condom. And they also think that it is a disease of homosexuals and prostitutes, and if they don't socialize with them, they will not get it."

Lack of knowledge about HIV

Prevention information lacks community focus

"Yeah," Aladin agrees. "I think this is because the education programs here say mostly homosexuals, prostitutes and IV drug users get AIDS. People forget that at home it is a mostly heterosexual disease."

" Many people in our communities say we don't even have homosexuals or prostitutes, so we don't need to worry. They think these people are only in the mainstream Canadian community. But they are wrong." Sidamo has worked for many months trying to gain the trust of a few people in his community who are gay, after being introduced by a friend in another community.

Denial of homosexuality and prostitution

"I meet with a group of homosexuals regularly and they talk about how much they suffer because of the way our communities feel about them. Most of them are married to hide the way they are, because the community will not accept them. They are forced to be bisexual. Bisexuals tend to be in more than one relationship at a time ... they have a monogamous relationship with

Negative attitudes toward homosexuals and bisexuals

a woman, and they hide the other side. This often puts several people at risk since condoms are not often used."

"I think we should stop alienating homosexuals," Aman declares with feeling. "We should help our community to open up and not judge its members. We don't discuss sexuality, let alone homosexuality. We should introduce the topic to our community otherwise there is no way of talking about these issues. If we are not open, it is not possible to solve the problem."

"Yes, and the community also isolates people who are HIV positive, if they know them," Saida adds. "People are afraid to use the health facilities for fear that someone will think they are HIV positive. They are scared of the disease, but also scared of being abandoned by their family and friends. This is bad for these people because they need support."

Negative attitudes to HIV positive people and people with AIDS

Fear of discovery affects health seeking behaviour

"But it is also bad for the community if we don't take care of one another," Aman insists. She cares deeply for the people in her community, and believes that together they can learn to solve their problems and build new lives. "We need to come forward and address these issues publicly, but it takes time for people to change attitudes...we need a lot of education on the topic of AIDS."

Saida continues. "Yes, it is the same for the girls in our communities who are involved in prostitution. They are also afraid to go for testing in case someone recognizes them." She has managed to become friends with one girl who talks to her in the donut shop. "These girls know the dangers but they are poor and need money, not only for themselves but to support their family members back home. They are afraid to ask the men to wear condoms because it might mean the men would go to someone else."

Cultural taboos make talking about sex uncomfortable and embarrassing

Aman, who has had the most experience as a health worker, looks thoughtful. "I think one of the biggest challenges we have is getting people to talk about anything to do with sex ... it is

something that most people find very embarrassing," she says. "In general, we are very conservative and private about such things, and talking about sex is not something we are supposed to do."

"I find this particularly about certain kinds of performance, like oral or anal sex. And because many women are circumcised and their experience with sex is painful, this also causes them to be not comfortable talking about it. In small groups they may discuss contraception - like the pill and IUDs, but rarely condoms."

Circumcision issues make talking more difficult

"Sometimes, when I am with women and we have begun to know each other, they will talk about sexuality, especially if they see that I am just like them." She starts to smile. "The other day, we even put condoms on the wooden penis! At first everyone was very embarrassed, but then they started to laugh and it was OK."

Sidamo grins at Aman's story, trying to picture a group of women doing this. He thinks about some of his contacts. "The men I know will talk about it with their friends too. And for sure the young people are much more open. They learn about sex at school and from the media, and especially from their friends. But not from their parents ... lots of parents don't think their children should even date or have relationships unless they are getting married, and they think that when the schools give them information about condoms, this will encourage them to participate in sex."

Parents fear changing values and talking with children about sex

"Many parents are afraid for their children because of the values of the Canadian culture. But I think a lack of information is more dangerous for them, since they will be influenced by what their friends do."

Fear that talking about sex might encourage sexual participation

"It's true what you say about the young people, Sidamo," Aladin agrees. "But these kids get a lot of wrong information from friends. We need to work hard to make sure they know the

facts. It's important that they know early and not wait until misinformation leads to problems. A boy I was talking with last week said that he only uses condoms with the Canadians and doesn't worry with the girls in our community. Even then, he says it is too easy to forget when he is at a party and under the influence of drugs or alcohol."

This issue of condom use seems to be important, and we ask the health workers to talk more about people's attitudes to condom use and safer sex. They tell us it is a complicated area because it involves relationships, communication, religious beliefs, gender issues, and community values – and probably a lot more. They get up to refill their coffee cups and settle in for the discussion. Aladin starts by summarizing what they have already touched on.

"Well, you've got the people who think condoms aren't necessary because they are in monogamous relationships, and others who believe in abstinence until they are married. Then, you've got the people who date and might have sex but don't think they are at risk because they trust their partners. Then, there are people who have sexual relationships with partners from outside the community and use condoms because they know HIV is there, but they might not with people from inside the community because they believe HIV is not our problem. Then, there are people who are in total denial and don't bother at all to protect themselves."

"Yeah, some guys think it is macho to have unsafe sex ... they don't do anything and just let the women worry about it," Saida adds, obviously annoyed. "Men seem to have a problem with condoms ... they consider them offensive, or uncomfortable, or unsatisfying sexually. Many have sex without contemplating safety. But if a woman asks a man to wear a condom, she may think she is insulting him, so women in our community are scared to ask them to produce condoms."

Issues around safer sex and condom use:
• monogamous relationships (but are they really?)
• the fear of trusting
• inter-cultural relationships (it's not our problem)
• macho mind sets
• let women worry
• men don't like them
• the "insult" of not trusting
• the vulnerability of multiple relationships and polygamy

Negotiating sexual health is difficult

Aman nods her head and joins in. "It is even more complicated in a marriage or other long term relationship, especially if there is a tradition of polygamy. If a woman is worried that her husband might be with another women, it shows she doesn't trust if she asks him to wear a condom. Sometimes the husband gets angry and beats her, or the woman is afraid he will leave if she insists. We need to help people learn to communicate about these things and be responsible to each other. The reality is that people need to protect themselves."

"I think accepting condoms is a new way of looking at sexuality. Some people are starting to be responsible and respect themselves ... they are afraid and it is making them look at relationships differently. They are being strong and proud of who they are," Sidamo joins in. "Others have decided it just isn't worth the risk and they abstain."

Reflecting on our sexuality

"Well, that ties in with many of our cultural values," Aladin comments. He goes to the Mosque to meet with a group of men on Thursdays. "The religious teachings say it is a sin to talk about sex or safe sex. They preach for the young people not to date or have relationships before they are married. They say that the wife must be faithful to her husband and the husband must be faithful to the wife."

Religious teachings (including Moslem and Christian) and cultural values

Abstinence and faithfulness - the only really safe sex?

"But the husband may be fooling around ..." Saida interrupts. "The problem is, our community attitudes toward homosexuals, prostitutes and people who are HIV positive are based on the belief that AIDS is a punishment from God, because these people have sinned. How can we help people change their attitudes when they are so deeply rooted in these beliefs?"

The group is quiet. We know Saida has asked an important question and we don't have many answers. Yet, this is what we hope our work will do ... we hope that all of us together can talk and think about these issues and find ways of working out solutions. In the process, we hope this work helps us find new

Working out answers together

ways of being in the world as we re-make our lives and re-build our communities.

We have learned a lot about the issues that make our community members vulnerable to HIV/AIDS as well as many other things that concern them. It has given us much to think about. As we pick up our empty cups and take them to the sink, the health workers ask us if we can come back for another chat, and they will talk to us about how they do their work.

Thinking Points:

Spend some time thinking about the issues raised in the health workers' conversation. What do these mean to you? What do you think about them? Then write a short story (one page) which describes your thoughts and feelings about these issues in your community. Try to include answers to the following questions:

- *Why do you want to be a health worker?*
- *What would you like to know more about that would help you?*
- *Who could help you with this?*
- *Do you have any questions about the issues raised by the health workers?*
- *Are there other issues not raised in this conversation that you think are important to consider?*
- *How can you find answers to your question?*

When you are finished, arrange to meet with another health worker, or a small group to share your stories, questions and ideas. Keep a diary of these meetings...the thoughts you have, the questions they raise...it will be a good resource for you.

Summary of the Issues

What makes people vulnerable?

- Issues of changing lives
    - loss of identity and culture
    - language difficulties
    - different values
    - new roles
    - family fragmentation, loss
    - culture and value differences between parents and children
- Dealing with survival, so HIV/AIDS has low priority
    - housing problems
    - unemployment
    - immigration
- Lack of knowledge about HIV
    - existing prevention lacks community focus
    - misinformation
- Feeling immune - denial of HIV in our communities
- Denial of and negative attitudes about homosexuality, bisexuality, prostitution
- Negative attitudes to people who are HIV + or have AIDS
- Taboos against talking about sexual issues and reproductive lives
- *Qat* and alcohol parties

Issues around safer sex and condom use

- Issues relate to relationships, communication, religious beliefs, gender issues, and community values
- Asking a partner to use condoms considered a sign of not trusting
- HIV/AIDS considered a white person's disease, so condoms might be used only with Canadians, not with people in our communities
- Some men think it is macho to have unsafe sex – they let women worry about it
- Dating is new to us, and some boys think if a girl says yes to a date, she is saying yes to sex
- Some men find condoms offensive, uncomfortable, or unsatisfying sexually
- Some women are afraid to ask men to produce condoms
- People worry about extra-marital relationships
- People have problems negotiating safer sex

Notes:

Becoming a Health Worker

The week has gone by quickly, and we are back again to see the health workers. As we walk down the wide, brightly lit hall of the health centre, the familiar, vibrant pictures of Africa on the walls and the smell of coffee are friendly reminders of our last visit. Our new friends are waiting for us, and greet us warmly.

What does a health worker need to know?

"Welcome back!" they call out together. "Glad we didn't scare you off last week! Pull up a chair."

Aladin brings over the coffee and we help ourselves, feeling quite at home in these once unfamiliar surroundings. It didn't take us long to start feeling like one of the health workers, especially after hearing their stories. It helped us imagine what being a health worker would be like, and made us want to know more about how they actually do this work. We assure them that last week's session gave us much to think about ... but we have come back with a lot more questions to ask.

"Great," Saida says, smiling. "We'll do our best to try and answer them.   But you know, even though we have some experience, we still have lots of questions too. That's why we meet regularly like this ... to talk about our problems and share ideas. It really helps to hear about everyone else's experiences."

"Oh, and I thought it was for my great coffee!" Aladin jokes. They all groan and tell him his coffee is almost as bad as his sense of humour.

"If I can be serious," he continues, trying to ignore their teasing, "we really do learn a lot from each other. When we talk about our work – things like how to get a group together, how to get a discussion going, how to talk about topics that are sensitive – it really helps with our work. Talking and thinking about what we

have learned, and trying to work out the problems makes you feel good ... like you are growing and can really help people."

Well, these are exactly the kinds of things we want to know, so we ask them to give us more details about what they have learned that helps them do their work. Sidamo begins.

"Mostly, we meet and talk with people in the community about the many things we discussed last week which affect their health – employment, housing, nutrition, parenting, family violence, adjusting to their new lives. As health and outreach workers we talk about prevention of disease, but we think of health in a broader sense that includes all these issues. Even so, prevention is still different than the way we thought of it back home. There, it was more about keeping good relationships with your family, the neighbours, and the spirits by not angering them ... it involved ways of acting that maintained healthy relationships. This is still a very important concept, so with our work we try to include all these ideas ... and we especially try to draw on each person's own resources. If we listen, and talk, and give support and information, we can nudge people toward thinking of solutions to their problems and better health."

"Yes," Saida adds. "Sometimes people feel so lost ... they have left much behind in their journey ... sometimes it feels like everything. But in many ways, they still have the roots of who they are – they are strong and proud people. This they have not lost ... it's just that sometimes they need help to work through all the changes. It is hard to put our lives back together and build new relationships. In a way, I think much of what we do is community development."

Thinking Point:

What does 'health' and prevention mean to you?
What does it mean to be healthy?

Aladin agrees. "A lot of what we do is helping people through the system. A simple phone call to correct a misjudgement at the unemployment office, translating documents, making referrals to various agencies that can best handle specific problems. Your handbook has a list of these contacts with their phone numbers on page 117, by the way. We make sure we tell each other who is

helpful and who is not ... sometimes you can't believe how some of these people keep their jobs."

"That's for sure!" Saida says, pouring herself another cup of coffee. "You really need to learn who can help you."

"There is another thing, too," she continues. "The people we meet have been through such painful and difficult times they are often hopeless and fatalistic about changing their situations. It is hard to help them, and it takes a lot of time, and listening, and support before they feel able to help themselves. You see them go back and forth between hopelessness and thoughts of maybe being able to move their lives forward. We kind of help them to help themselves. You get the odd person who is just using you, but you also recognize who is really needing you. For these people you will keep trying. In the end it has to be two ways – you help them, and they help themselves. I find it works better to let people know what I expect and get a commitment from them. We take it from there...if there is follow-through, it's good. If there isn't, then they might need a lot more time and support. The problem comes when we're so busy – you have to be realistic about what you can do and what you can't. Sometimes I have had to decide who to give my time to."

Aladin nods, looking serious. "Yes, that's a tough one. If we aren't careful we can burn out. Outreach work is difficult ... so many people want our time and we have to be very flexible with the hours we work. Whether you work part-time or full-time, the hours will likely be spread all over the week, including evenings and weekends. You don't want to get to the point where your heart just isn't in it anymore, because we're not much good to anyone if we don't care."

"Yes, you're right," Aman says thoughtfully, "Maybe what we should talk about first are the kinds of personal qualities that make someone a good health and outreach worker." The others murmur their agreement and she turns to us. "You know, we can learn the skills, like how to lead discussions and all that sort of

thing, but mostly being a good health worker comes from inside you ... your attitudes. You think about the human part; it's more than just a job. You may meet people who just do their job, but the best workers are the ones who remember the human part." The others nod.

Her soft black eyes are gentle as she continues, "Your heart must be in your work ... you listen with your heart, and you talk from your heart."

You listen with your heart and you talk from your heart

The room is quiet, except for the whirr of the fan in the corner. After a moment, Sidamo adds his thoughts. "I think it is also important to be non-judgmental ... you know, be open to what we see and hear without being shocked or saying it is bad or good. If you respect and value the experience and knowledge of people who come to you, and have an equal relationship with them, they will more likely trust and be open with you. I guess part of this is being sensitive to cultural and individual differences ..."

Thinking Points:

What personal qualities does a health worker need to do a good job?

"And I find that if they know that I am no different from them ... that I have my own problems just like they do, they are more likely to talk," Aladin adds. "I tell them about my own experiences and problems...and try to communicate openly and honestly."

What experience and attitudes do you have that can

Saida joins in too. "I think it is important that they see I am interested in them and care about them more than just because it is my job, so I try to be involved in the community too. How can you build trust with your groups if you just go there for one thing? If you can develop an on-going dialogue with people in a trusting way, it helps you do a better job and is good for your community. I think we have a certain role in the community because we see what is really going on ... we have a different understanding. This is especially important in ethno-cultural communities, because we understand what people have gone through, what their lives were like, and what their special needs are."

Thinking Point:

Reflect on your own health risks and how you respond to these. How can you use this experience

It sounds like trust is one of the most important things a health worker needs to develop, so we ask them to tell us a bit more about it and how they know when they have people's trust.

"Hmmm," muses Saida, the space between her eyebrows wrinkling as she thinks about this. "I guess the best way of knowing whether you have people's trust is that they will talk openly at the meetings ... or if they are too shy, they might come and see you after, or call you. You can also get some idea by looking at their faces and bodies to see if they are comfortable and relaxed. People who trust might also bring other friends to the meetings or ask you to run more sessions."

"Yes, but it takes a long time to develop enough trust to talk about sensitive issues," Aladin adds. "I try to build trust by talking about easier things first – telling them my own stories, which lets them know that I too had to learn about these things. Then they know that I am one of them, and that we will be learning together. I also plan a discussion around a topic people will have an interest n, like parenting, religion in the new country, relationships, or loneliness. Then I think about how this topic relates to something more difficult to talk about, like HIV/AIDS, so I can nudge the conversation in that direction. It really helps to think of some starter questions ahead of time, before you meet."

"That's a good idea, Aladin. I find it helps me break the ice," Aman comments. "I also tell them that whatever they say, I will not be surprised ... I have heard it all. But I must say, when I first started doing this job I heard many things that upset me. Now I see it is more important to understand everyone's thoughts and accept people. They won't talk if they think their ideas won't be accepted, so we start our meetings deciding on the "ground rules" for how we will talk and listen to each other."

"Like what, Aman?" we ask. We have never heard about rules for conversations. We thought people just knew how to talk naturally, so we were very curious.

Gaining people's trust -
tip #1 (see page 35)

Talking about sensitive issues -
tip #2 and #9 (see page 36 and 44)

Thinking Point:

Think about your own assumptions, beliefs and values. How might such things as gender, age, class, and ethnic origin affect your work? Which of these will help you? Are there any which could be a problem?

"Well," she began, "I start by saying that everything we talk about at our meetings is confidential ... and we all agree to keep our conversations just in our group. If people know that we won't discuss what they say outside the group, they feel safer and are more open. Then we agree to stick to the topic of discussion so that we can talk about all the important points before we go on to something else. And we also agree that everyone in the group should get a chance to talk if they want to, and that one person talks at a time, so we all have a chance to listen carefully. I also mention the idea that everyone's opinion is important, and everyone needs to be heard. Sometimes this is a difficult one...I have one guy in my group who likes to talk and talk. Anyhow, your handbook has some hints in it for managing the discussion. Then we agree to respect everyone's opinion, even if we don't agree with it. This really helps me facilitate the meetings because the group members have agreed ahead of time about listening and talking rules, and I just remind them about this if things get a little crazy."

"It also helps people learn to listen and respect each other, so we get the most benefit from the discussion, don't you think?" asks Sidamo. The others all agree, but we can see that Aladin is getting restless.

"Let's go get a pizza for lunch," he suggests, jumping up and dancing his way around the table. He is snapping his fingers, and moving his hips to some imaginary band in his head. "Time for a break ... it looks like this is going to be a long session ... a man has to keep his energy up!"

Aladin's enthusiasm is infectious, and we all get up and follow him out the door, laughing.

As we leave the health centre, we walk past a group of young mothers and their new babies who are waiting to meet with the health worker. Some of the babies are feeding, tucked quietly behind the fabric of their mother's brightly coloured *garbasar*. Others play with their toes while their mums chat. An old man

sits in the tattered chair at the end of the hall, staring vacantly into space, his thoughts in another world. A couple sit on the bench across from him. The man looks angry; his arms are folded across his chest, while the woman looks down, not speaking. We are reminded of the reality of our work, and think about how each of these people have a story to tell about the life they live. We glance at each other and wonder how we can possibly learn everything we need to know.

When we get to the pizza place and are seated at the table, we pose this question to the others. They look knowingly at each other, and Sidamo says, "We all felt the same way when we started ... it's kind of scary, isn't it? We can help you learn about interviewing, leading discussions and recruiting people ... the skills that help us do our work. But you have to trust yourself too ... your life experience and your caring attitude are the most important things you have. Just be yourself; the rest will fall into place."

> Trust yourself - your caring attitude and experience are the most important things you have.

"Well, maybe we could talk about how we meet with people, for starters," says Saida, sensing our growing uneasiness. "Finding a discussion group and keeping them together and coming to meetings is over half the battle in outreach work."

> Organizing a group - tip #4
> (How to meet people - see page 38)

"That's for sure," Sidamo agrees. "I try to drop in where people gather socially, like the places of faith and the community centre, and I meet people informally. After a few weeks of hanging around talking, people get to know you and you can begin to talk about the issues. If people are interested, I invite them to come to a discussion group."

"I like to get involved with existing groups or programs ... like the soccer teams or men's clubs, and go to their sports events," Aladin adds. "This is one of the easiest ways to locate and involve people because the group is already together and people already know each other, so they are more comfortable talking. I approach the group or program leader to explain what I do and

how the group may benefit from this. We talk about what the group needs and I plan our discussions to suit their interests."

Aman joins in with a strategy that works for her. "It is good to use your own networks. You can bring people you already know to your discussion groups, and you can ask them to bring friends too, so your contacts grow. You can also find a well known or influential person who can introduce you to others and give you phone numbers. Then, you can invite these people to an information session where you talk to them about the kind of work you do."

"It's a lot of work," Saida says with a sigh. "Written materials such as flyers just don't work with people from the Horn as they do in the western setting ... you have to call person by person, and follow-up the day before the meeting too. You phone people and they aren't home, and it's not enough to leave a message. Then they tell you 'I can't come on Monday, how about Saturday?' Then you phone everyone again to see if Saturday is OK. After half the people agree, you find some people who can only come on Sunday, and you have to phone everyone again. It makes me crazy!"

The others all chorus their agreement as the waiter comes to take our order. Aladin recognizes him as someone on the soccer team, and they chat about next week's game. There is going to be a party afterwards, and Aladin invites us all to come along. He says even if we don't like soccer, it's a fun way meet people and build our networks. The waiter leaves with our order, and we resume our discussion.

"Where were we?" Sidamo asks. "Oh yeah, doing all that phoning ... Well, some people say that what is missing from our program is knocking on doors, talking to the people who really need this type of education. Going into the buildings where people live is the ideal because it reaches the most vulnerable people – those who have little contact with the community and its support programs. This takes time, and is difficult to do, but to some extent it is necessary. Networks are the easiest though ... and if

people like your programs, they will come to you with their friends."

The next thing we wanted to know was where to hold our meetings. Everyone had an opinion about that too.

"Well," Saida begins, "women often like to meet in someone's home, or at the health centre ... it is different for different groups. Young people may feel more comfortable meeting in a coffee shop or cafeteria.

"Men may feel more like meeting in a bar or at the Church or Mosque. Wherever you go, the idea is to meet where people will feel comfortable and talk openly ... someplace neutral," Sidamo adds.

"And safe," points out Aman. "You need to be conscious of that, too. Especially if you are knocking on doors or going places you haven't been before."

Sidamo nods in agreement. "Good point," he says. He goes on to tell us more from his experience about how he likes to organize his groups. There are a number of things to consider.

"I've found that people are more comfortable talking if they think the other people in the group are like them, so I usually have a group of men together without the women, and have people of similar ages together. Sometimes it is good when they are mixed, because you get a wider range of feelings and experience ... it just may be more difficult getting them to talk."

" Meeting people for the first time is very difficult and one meeting is usually not enough to get people comfortable, especially with an issue like HIV/AIDS. It works better to focus the discussion on issues that people are interested in and can talk about before coming around to AIDS. Therefore, I think it is more useful to have multiple discussions. The advantage with one-time outreach is that it gives you the potential to contact more

people; on-going outreach puts you in touch with fewer people, but has the potential for much greater impact."

"I agree, Aladin," says Aman. "If it is anything like I am doing, you try to have a regular group with whom you meet once a week, if possible. At the same time, you encourage your regulars to bring new people with them. In this way, the outreach is wider. But it is good to have a regular group, because as people get used to each other there are a lot of things that they can share. I find that a smaller group of maybe four to ten people is the best size ... this is enough people to have a good discussion, but not too many to handle. It gets harder to facilitate when there are more than ten ... people like to talk to the person who sits near them rather than the rest of the group."

"That's what I find too.   The big groups are harder to manage. I like the small informal discussions I have in the coffee shop the best. But sometimes a short conversation will turn into one that lasts well into the night. Last week I met some folks and we chatted for a while, then went to someone's house around six p.m. We talked about lots of issues, had something to eat, and I had to stop the discussion at one in the morning! Usually I aim for a two to three hour session, but everyone was keen to keep talking. It was great, but it sure was hard to get up the next morning."

"We can imagine that, Aladin!" Saida says with a grin. She turns to us and explains, "He is not known as a morning person at the best of times. That's why he makes the coffee. He comes to work looking like something the cat dragged in, and no one talks to him until at least 10 a.m." She gives him a playful punch on the arm.

" But after that watch out ... there's no stopping him then!" says Sidamo laughing loudly.

Just then the pizza comes and we all dig in.   Our conversation turns from teasing Aladin to news from home and

gossip about friends. Soon it is time to go back to the health centre and return to work.

Aman has a group coming and she invites us to stay with her. She says she will talk to us about facilitating a discussion, and Saida asks if she can join us. She knows how good Aman is at her job and wants to get some tips too.

We all go into the meeting room and Aman arranges the chairs informally so people are comfortable and can see and hear each other when they talk. "That way, we have more interaction. You can really encourage people to talk if you arrange the seating more informally," she says.

"It is also very important to prepare for your sessions when you do this kind of work. The planning starts before the meeting, when I arrange with my group the week before which topics we will discuss at the next meeting. That gives people a chance to think about the issues and bring some friends who might be interested too. Then I plan some questions which will start the discussion – we call those 'icebreakers'.

And then I think of some other questions to use during the discussion - we call those 'probes' - which help get to the main points we need to talk about. You'll see how that works after we start."

She gets out the juice and a few plates for the cookies the group members bring each week. Everyone takes turns contributing an afternoon treat. People start arriving and Aman greets them as they come in. She chats with them informally until everyone is there. We notice that Aman knows all their names and makes sure she introduces those who don't know each other.

When she starts the session, she reminds everybody of the topic for the week, and goes over the 'ground rules' so the new people know what to expect. The topic is about relationships this week, and it is obvious people are very shy to talk about their

An example of a meeting

situations. Aman doesn't seem to mind, and tells them she has a hard time talking about her situation too, so she tells them a story from the handbook.

It is "Arwa's story" from the resource section of the handbook, (see page 88), and the group members listen intently as the story is told. We see some of the women nod their heads when Arwa talks about family relationships, her conflict over the housework, and her worry about HIV. As the story ends, a couple of women have their heads together and are whispering to each other.

Aman asks the group what they think might be going on between the woman and her husband, and looks at the women who are whispering. She has their attention, and one of them starts to speak. Soon the others are joining in with their opinions.

Aman starts to ask her 'probe' questions: 'What reasons might cause the husband to get so angry?'...'What would happen if Arwa asked her husband to cooperate more?'... 'How could she handle the conflict?' Soon the women are talking about what they would do and the problems they have. Aman is nudging them towards thinking about their own situations and how they might be vulnerable. They end up talking about how it might be possible for women to talk to their husbands about condoms, and how they can buy some.

Aman looks at us and smiles. All the time, she keeps the discussion conversational and interesting. Even though she has a plan, it is flexible to the interests of the women. She lets the conversation go where the women want to take it, but if it gets too far off topic, she reminds them what they came to discuss, and suggests they could talk about the new issues at another session.

Not everyone seems willing to join in, but she gives the quiet ones a chance to talk by asking them what they think. They don't

want to comment, but at least they know that she is interested in their ideas. At one point, a couple of women disagree about what they should do if their husbands hit them, and it looks like things might get out of hand. But Aman just lets everyone have a chance to be heard, and reminds them that different points of view are common and that hearing what others think can help open their own thinking. Then, we notice that one woman, who had been quiet throughout the disagreement is crying. Aman and a couple of the women go over and comfort her, and it seems that her husband is violent and she had never told anyone. They talk quietly about what she could do. One woman offers to let her stay over if it happens again and gives her a phone number to call. This woman has had the same experience.

Near the end of the time, Aman asks them how they thought the session went, and they tell her it was a really helpful discussion. She thanks them for coming and participating so well. Together they decide on the topic for next time. The women don't seem to want to go, so she leaves them to chat.

Measuring your success - tip #11 (see page 48)

From the look on Aman's face, we can tell she is satisfied with how it has gone, and we know that we have seen some valuable lessons. She takes us to her tiny office down the hall and shows us how she makes notes about the discussion.

Reflecting on your work- Learning from your experience - tip #10 (see page 46)

"I really need to do this right after I've been with a group or I'll get busy and forget the details," she says. "Doing this gives me ideas for next time. I feel like I'm always learning from the people in my groups ... you know, their experiences, the way they respond to my questions, the questions they ask, the questions I have. I write down whatever strikes me as memorable or useful ... or troubling for that matter. I spend a few minutes thinking about the session and ask myself things like 'How did it make me feel? How can I use this with other groups? How would someone else have handled a certain situation?' When I look back over some of my notes from the last few years, it amazes me how much I've learned and grown. And sometimes, when life gets a bit too

much, it's good to read about the times you were successful at helping someone, or the time you had a fantastic session."

We look around her office, and notice the yellow walls covered with reminders, memos and schedules. But most of all we see the photographs – pictures of people she has worked with, and helped to build new lives. They are smiling out at us from the jumble of paper, and behind each we know there is a story.

It has been quite a day. As we leave, we meet Sidamo, who invites us to meet him at the community centre next week for a discussion on HIV/AIDS. The young people there have asked for an information session and he is pleased because they hear a lot of strange things about what causes HIV infection and how to prevent it. He gives us a pile of reading to do in preparation. But first, we have lots to think about from today's session and want to get home and make some notes.

Thinking Point:

After your first few interviews, think about the following questions as you write your notes:

- *What questions did you have difficulty asking? Why?*
- *What did you do to make people comfortable? Why do you think these things worked?*
- *Were people ever uncomfortable? How did you know? What did you do to get things back in a safe space?*
- *What do you think worked particularly well?*
- *What would you do differently next time?*

Notes:

Review: Putting the skill tips together -
Guidelines for Successful Facilitating

- *prepare (Skill tip #4, #6)*
- *make people feel at ease (Skill tip #7)*
- *learn everyone's names*
- *describe the purpose of the session and how long it will be*
- *discuss the ground rules (Skill tip #3)*
- *introduce discussion topics*
- *build trust and respect (Skill tip #1)*
- *encourage participants to be non-judgmental of others' opinions*
- *try not to express your personal opinions*
- *encourage participation from everyone (Skill tip #8, #9)*
- *probe key points of discussion (Skill tip #8)*
- *keep the discussion on track (Skill tip #9)*
- *give your group support and praise - thank them for coming*
- *reflect on your work (Skill tip #10)*
- *measure your success (Skill tip #11)*

Notes:

Skill tip #1:   Gaining people's trust

- *use safe questions first*
- *tell your own story*
- *let them know that nothing surprises you*
- *be non-judgmental*
- *talk about topics they are interested in*
- *tell them your discussions are confidential*

Notes:

Skill tip #2:   Talking about sensitive issues

- start with something safe
- create a relaxed, comfortable, non-judgmental atmosphere
- use indirect questions - see skill tip # 8
- look at people's body language to see if they are comfortable
- keep the tone conversational
- explain why it is important to talk about the topic
- let them know you have heard it all and won't be shocked
- be respectful of participants' cultural backgrounds
- be sensitive to risk situations people might have experienced

Notes:

Skill tip #3: Ground Rules for talking and listening

- everyone gets a chance to talk
- respect everyone's opinion
- everyone's opinion is important
- respect everyone's experience
- one person talks at a time
- everything that is said will be confidential
- stick to the topic

Notes:

Skill tip #4:   Organizing a group

How to locate people
- drop in at informal social gathering places
- become involved with existing groups
- use your own social networks
- go door to door
- find an influential person to introduce you and give you phone
- numbers
- be involved in your community

Make-up of the group: Will people be more comfortable in a mixed group or with the same gender, age etc.? Mixed groups may give you a greater variety of opinions, but people may also not be as willing to talk.

Number of meetings: One-time meetings will let you reach more people, and can be informal and spontaneous. On-going discussions will give you more time to cover more topics, give people a chance to feel more comfortable with each other, and give you a chance to see changes in people.

Location: Meet where people feel comfortable.

Group size: You can have a good conversation with one person, but if you want people to share and discuss ideas, a group of 3 to 15 people is not too hard to manage. If you have more than that, people tend to talk in small groups and it is more difficult to facilitate.

Length of the session: You probably should have at least 2 hours so that people can get familiar with each other and get into a good discussion.

Notes:

Skill tip #5: Safety

- try to stay in a public or semi-public setting if you are interviewing someone alone
- let someone know where you plan to be and what time you will be home
- leave a phone number and address where you can be reached, and call before you go and when you are finished
- go with another person to a strange person's house

Notes:

Skill tip #6: Preparing for an interview or discussion

- *let people know ahead of time what the discussion topic is*
- *plan questions and probes ahead of time, keeping in mind the time you have*
- *arrange the seating informally so everyone can see and hear each other*
- *talk informally as people arrive, to make them comfortable*
- *if there are refreshments, invite people to help themselves*
- *know people's names and make introductions*

Notes:

Skill tip # 7 - Icebreakers

Icebreakers relax a group and start discussion at a safe and comfortable level

- *start out with introductions and social time*
- *make it fun by telling a story about yourself*
- *you can use word association games - "what do people think of when they hear this word?" (for example: HIV/AIDS, safe sex, condoms). This will help you understand what people know about a topic and what they are willing to talk about.*
- *people can bring photographs, which they can talk about to start discussions (for example: photos of family, home, parents, friends)*
- *use one of the stories in the handbook to introduce an issue and talk about it indirectly*

Notes:

Skill tip # 8: Asking questions

General points to think about when you ask questions:

- ask "open-ended" questions , which means questions with more than a "yes" or "no" answer – you will get more information.
- ask about one idea at a time – it is easier for people to think about and answer.
- watch for jargon -- use words your group will understand
- keep questions indirect, for example: "How would a <u>person</u> do...?", rather than "How would <u>you</u> do...?"
- keep questions non-judgmental and conversational

Using probe questions:

Probe questions are used to follow-up on your original question. They help you ask for more details or clarification on something someone has said, or lead a general question deeper into related issues. Some examples are:
- Tell me about....?
- What happens when....?
- What reasons might cause....?
- How do you find out about...?
- How is it you decide....?
- Why is it that....?

Your strategy for leading discussions will be different depending on who is there and how well people know each other. The example below shows how a more comfortable general question can lead to a more sensitive topic. Notice how the health worker takes a lead from what someone in the group says to start the conversation about HIV/AIDS.

When I meet with my group I might start by saying "Let's talk about dating. Is there anybody here who knows about dating?" (A general question) Then people will come up with ideas. Somebody may say, "Yes it means going out with a boy." Somebody else might say something different.

Eventually, I might ask if we had dating back home. (A probe question) Then people will start talking about how it was back in our country, how we date. For instance,

"My mother had not even seen my father when she accepted to marry him. It was just arranged." Or, "I went out with my husband three or four times before we were married, but we were always at home. Compared to here we never had this sort of dating."

To relate this to AIDS I would then ask "When we date here in Canada, what happens?" (Another probe question) And someone would say, "Here, when young people go out, the mother waits up and gets very angry. The parents want to know who the boy is ..." And then I can ask, "What do you think the parents are worried about?" (Another probe, and an indirect question which lets people talk about something uncomfortable in a safe way.)

Notes:

Skill tip # 9 - Managing discussion

Your role is to encourage and develop a discussion in which everyone feels he or she has an equal voice and something important to say. Think of the discussion as a conversation ... informal, friendly, relaxed and interesting. The discussion is based on a few questions you think of before the session, which will get people talking about a certain topic. Then, you guide them, but let the conversation flow naturally from one topic area to another. The idea is to give information and share opinions, so try to keep comments (yours and others') non-judgmental. Use verbal and non-verbal cues to encourage participation. However, there are times when managing discussion is not so easy, so here are a few simple guidelines to help you with this:

- ***If the discussion strays off topic:*** *You can politely break in and move it back by reviewing what has been said so far, reminding people about the topic, and asking someone who has not spoken before to comment. Sometimes discussion strays when people have not understood the question, so you can ask it again - perhaps with an example.*
- ***If someone's response relates to another topic:*** *if the original topic has not been fully explored, you can refocus the discussion when (s)he has finished by saying "That is an interesting point and we will come back to it, but there are a couple of things that maybe we could finish first relating to .....topic"*
- ***If people lose interest:*** *It is best to go on to another topic, but if you think there is still more to discuss, you might be able to lead back to it through an opening in the new discussion.*
- ***If someone is not participating:*** *You can draw them into the discussion by asking them to comment on someone else's ideas, or offer something from his or her own experience. Sometimes making eye contact encourages someone to participate.*
- ***If someone talks so much that others don't get a chance:*** *You can discourage him or her by avoiding eye contact or changing the subject and asking someone else to comment. If this fails, you can politely say that others might like to speak.*
- ***If there are disagreements which become upsetting or angry:*** *When there are disagreements you should make sure everyone has a chance to be heard. Hearing different points of view can help people revise or open up the way they think about things. If people get too upset, you can remind them that different points of view are common and then leave the topic and go on to something else. If you cannot stop the conflict verbally, refocus attention on yourself by standing and walking around the participants, stopping at one point in the room, and verbally interrupting again. When you move back to your place, remind everyone about the ground rules they agreed to - particularly to respect everyone's experiences and opinions.*

Notes:

Skill Tip #10 - Reflecting on your work:
Learning from your experience

Reflecting:

As you do your work in the community, your experience can be a form of learning for yourself and others. The people you talk with in the community will become your teachers, as you become theirs, and they become each other's. You will learn from them how they experience the world, and this knowledge becomes part of an understanding which guides your work. Spending time thinking about this, and what it means - both for your work and yourself - will make what you do, and your community richer.

Making Notes:

An important part of learning from your work is recording it. It is hard to take notes during meetings or discussions. Sometimes it makes people uncomfortable; they worry about what you are writing and what you are going to do with it. Just jot down words or phrases which capture the things that stand out for you. This will help your memory later when you make notes. Right after the session, you can write a summary of topics people discussed, what prompted their discussion, and what you thought about as people were talking. Try to do this as soon as possible after the session; you might not remember the details later and it is easy to get busy with other things. In the long run, this can save you time because you can use the notes for writing reports.

Double Mapping:

A helpful practice is something called "double mapping". This is a way of taking notes that is more than an account of what happened; it gives you a way of thinking about what happened and using your thoughts as new knowledge. This is what it looks like:

What Happened?	What did I think or feel?
-I told "Arwa's story" in the group today. One of the women started to cry because her husband was also very angry and was beating her. In the end, another woman came and sat beside her told her story too, and we talked about what people could do if it happened to them.	- At first I was afraid when she cried because I didn't know what to do. I worried that everyone would be too uncomfortable. But I just went over to her and comforted her. It felt natural, and I realized that I don't need to be afraid of people's feelings, and that the others are there to offer their experience and wisdom too. I will have to add these stories to the ones I have to share with another group. I will also ask the other health workers what their experience has been.

This example shows that the health worker not only thought about how and why she reacted to the woman's emotion but also how she was going to use her new knowledge.

Notes:

Skill tip #11 - How to measure your success

How do you know whether you efforts are working? How will you know if you need to change strategies? Because outreach work is very demanding, it is good to know whether you are making a difference. Measuring your work with numbers is not very helpful with this kind of question. Just knowing the number of meetings you have held will not tell you whether or how it is helping people. But people's reactions will give you clues that your work is important to them. Here is an example from one of the health workers:

"Sometimes when people I have been working with are having trouble with someone who refuses to wear a condom, they come to me and ask if I can tell that person how important it is, and teach them about AIDS. This makes me feel that what I am doing is beneficial."

You can listen in your discussion groups for signs that people are thinking in new ways. Your notes might help you with this, if you record what kinds of things people talk about. Also, if the group has been meeting over a long period of time, it means they are probably getting something out of the sessions. If you are comfortable with each other, you can ask them what coming to the sessions has meant to them. You can start yourself by talking about what the meetings have meant to you ... talking from the heart, or speaking with your feelings. Each person can take turns talking from the heart if they are comfortable. Sometimes people might find it easier to talk with you privately, or write a short story about the experience of being in the group. In the end, you will need to have faith that what you are doing is slowly working. As another health worker said,

"It is like the principles of advertising. We hope that these things sink in. It may not even have an immediate effect, but someday, if it is in the back of their head, when they encounter some situation they will have the tools to think about it. We are not talking about the here and now...it is about the future."

Notes:

Worksheet for Discussion / Interviews				
Date:	Time:	Place:	Booked:	Contact:

PRE-PLANNING: What are we going to talk about? List your main questions and probes. (Remember a probe question is one which helps you get to the main points, or more details)

AFTER: What topics did we discuss?

Brief description of the discussion.

Interpretation - what really happened; what does it mean; what are the implications?

How can this be used next time?

Worksheet for Discussion / Interviews

What was good about the session?

What could I improve next time?

Review and analysis of session management:

	Good	Fair	Needs work - what to try next time
Comfort established?			
Did everyone participate?			
Length of time OK?			

Which questions worked the best?

General Notes:

Learning and Talking about HIV/AIDS:
The Many Voices Approach to Health Promotion

The focus of this section of the handbook is to look at what we know about HIV/AIDS, both from the scientific perspective and the community perspective. We will also look at what we need to know about risk for HIV/AIDS, and why this information is important for successful health promotion. You will see how we are applying this knowledge when we look more closely at the approach used in the *Many Voices* handbook.

What do we know.. what do we need to know for health promotion?

We know a great deal of information about HIV/AIDS - such things as what causes it, how it is transmitted, and how people can avoid it. We also know something about our chances of getting it and how many people have been infected. This kind of information is called the 'scientific evidence' about risk for disease, and it is important to know so we can give people accurate information for prevention. We will spend the last part of this section reviewing the basic scientific facts about HIV/AIDS, and compare this to what people in the community believe about it.

Scientific evidence of risk - the facts about HIV/AIDS

First, we are going to look at another kind of information we need to know for talking about the risks for HIV/AIDS and doing successful health promotion. This is information about how people actually *experience* risk for disease in their daily lives. **People's experience with risk - that is, the way we think about our personal risks for disease and make decisions which affect our health - is greatly influenced by factors in our social environment.** Such things as past events and experiences, our present life situation, our relationships, beliefs, values, and hopes, all colour the way we actually respond when we hear information about risk. These parts of our social environment have such a strong influence on our behaviour that we need to know what these are and how they affect our health decision-making for our prevention strategies to be successful.

Social-cultural evidence of risk - how people actually experience risk and vulnerability

If we look at the experiences of people in communities from the Horn of Africa, we can see the importance of knowing about people's social environment when doing health promotion. We still have much to learn about our communities' vulnerability to HIV/AIDS, but the stories gathered from religious leaders, single mothers, young people, and husbands and wives, tell of the many hardships and problems people face on a daily basis which contribute to their vulnerability to HIV/AIDS. You saw many of the issues which affect people's lives in the first section of this handbook [1], but we'll briefly review them again now. The knowledge that people in our community are at risk for many other concerns than HIV/AIDS will guide the development of our health promotion strategy.

Many of our community members have told their stories of coming to this country from the Horn of Africa after long and difficult journeys, often fleeing violence and war. As immigrants and refugees, we share a common experience of pain, loss, and family fragmentation after leaving old lives behind. Life in our new country is hard and full of compromises - immigration to a new country means language problems, changing values, economic difficulties, and loneliness. With all these things to deal with, health issues, including the threat of HIV/AIDS, is not necessarily a high priority in our lives. The dilemmas and hardships we face on a daily basis make decisions about such things as condom use, monogamy, or abstinence extremely difficult to make.

As well, many people in our communities deny that HIV/AIDS is even a problem for us. The Canadian HIV prevention messages tell us it is a disease of homosexuals, prostitutes and intravenous drug users. Some people think these individuals are not in our community and that they only exist outside in the mainstream

Social-cultural evidence of risk in communities from the Horn of Africa:

- denial that HIV is our problem
- feeling like we are immune
- talking about sexual matters is taboo
- fear of the stigma of HIV/AIDS
- challenges and dilemmas of changing lives, values, relationships
- dealing with HIV is not a high priority

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1.   Most of what we know about HIV/AIDS and our communities comes from a research study done in 1992-4 in which some of our community members participated. A report on this study appears in a supplement of the Canadian Journal of Public Health, Volume 87, 1996. A specific report which pertains to the Horn of Africa ethnocultural communities called "Many Voices: HIV/AIDS in the context of culture" can be obtained from the National AIDS Clearinghouse, 1565 Carling Avenue, Suite 400, Ottawa, Ontario, K1Z 8R1.

community. People say that HIV is for others – for those who have sinned – not for ourselves. At the same time, we fear and deny the disease because of the alienation and stigma in our community that comes with being HIV positive or homosexual. Many people also feel immune and protected from this disease because of our religious and cultural beliefs and values. These people do not see themselves at risk for HIV infection, so they reject or ignore information about HIV/AIDS, and this makes them vulnerable.

Some people also reject information about HIV/AIDS because it threatens many of our beliefs and values. Many of us, particularly the older generations, fear that we are losing our culture to the values of the new country. We want to protect things that help us keep our identities – like our taboos against discussing sexual issues. These are considered to be private; talking about them is difficult and embarrassing, and is considered unacceptable by many people in the community. However, this silence contributes to our vulnerability. It prevents us from talking about the things in our lives which influence our risk for HIV/AIDS .

So, as you can see, health promotion is not as simple as just giving people the facts about HIV/AIDS – there is much more about our lives that influences the way we think about risk and make decisions which affect our health. As health and outreach workers, we need to know the scientific information about HIV/AIDS, but also consider how it is that people think about and experience risk, in order to understand how they are vulnerable.

Successful approaches to health promotion consider both scientific and social - cultural information about risk.

For example, we may meet people who feel they have no control over what happens in their lives; their life situations may be so difficult and full of suffering that they have lost hope and have become fatalistic about what happens. Even with good health information such people are likely to think that healthy decisions are irrelevant or just not a choice within their power. In trying to help such people, we start with trying to understand their situation, and give respectful, compassionate, and non-judgmental support. Slowly, we can assist them to find resources to rebuild their shattered lives. For them, a necessary first step towards a healthy

life is to feel that they are valued, not alone, and that someone cares.

We will also meet other people in our work who might not feel as hopeless, but whose life realities still make them vulnerable to HIV/AIDS. Some people may be more concerned about what is happening in their daily lives – such things as employment, housing, family conflict – than health promotion messages. Others may make decisions which adversely affect their health because of strong beliefs and values they hold. Still others may already understand that they need to protect themselves but have never learned to negotiate sexual matters in relationships. Through our work, we can help such people recognize the factors in their lives that influence their risk for HIV/AIDS. By finding out how our community members experience risk, we can help them acknowledge the realities of risk in their lives and move towards sexual health. These are the things from our social environment that we *need* to know about risk for HIV/AIDS for our work to be successful.

How can we know this information? It is revealed in the stories people tell about their lives. From these stories of past and present lives, we gain understandings about risk as these occur in the context of relationships, and the social and cultural dilemmas that are part and parcel of their situations. They show us what individuals know and understand about disease, and how they experience risk. We can use this information in our work.

Stories are also useful because when we use other people's stories to discuss the issues which make us vulnerable, it helps us do this in a safe and indirect way. This is especially important when we are uncomfortable talking about issues involving sex. We can often talk about other people's lives more easily than our own, but in the process, we might come to see what these issues mean for our own personal lives. With this new awareness, we can begin to explore the possible paths we need to take to protect the health of ourselves and our families.

So far, we have seen that our health promotion strategy considers both the scientific information about risk as well as a

Stories are a tool for learning and talking about risk for HIV/AIDS:
- stories help us understand risk as it occurs in people's lives
- stories help us discuss issues which make us vulnerable in a safe and indirect way
- stories help us see other possibilities for our lives

social-cultural understanding of risk in the context of people's lives. We have also seen that stories are at the heart of our strategy as a way of helping us understand how people experience risk, and as a way of talking about the issues that make us vulnerable. Now we'll look at another principle which we use in our strategy for health promotion, the idea that 'knowledge is power'.

This involves the belief that people can actively examine, reflect on and make decisions about issues that affect their lives. With participatory methods of health education, we start with what people already know and feel. If we just give people factual information about HIV and impose a different agenda on them, they will usually ignore or deny it - they don't just accept new information at face value. This is because all of us try to make sense of new ideas based on what we already know.

For example, some of our community members think we are immune to HIV and that it is a problem for others outside our community. So they might ask 'Why do we even need to talk about it?' When we start with what people know and believe about HIV/AIDS, like the idea of our community being immune to this disease, we can discuss what people mean by this idea, and what effect it might have on the community. In this way, people's existing knowledge is respected and used to introduce new ideas. Re-examining and reflecting on what we know and believe in light of new possibilities can move us toward a changing awareness.

With HIV, this new knowledge can move people toward facing their fears, developing new understandings, and making decisions about what to do next.

What members of our communities know about HIV/AIDS varies considerably. People come to Canada with different levels of awareness, and sometimes they have had very unhappy experiences with risk for HIV. Some people might already have had lives full of sexual compromise or have seen the death of a family member from HIV at home. Others may have seen women in the refugee camps having sex for food to feed their children. Still others may be worried about their own teenagers becoming lost to the

Participatory methods:
- start with and value what people already know
- actively involve people in discussing the issues and reflecting on what these mean personally
- encourage people to explore their own solutions and move toward change

apparently different ideas toward sexual behaviour of the new country. As we do our work, we need to give people the compassion and opportunity to disclose these more difficult aspects of their lives.

Our approach to prevention, therefore, creates possibilities for people to discuss these various experiences and beliefs through open and honest dialogue. This helps people examine their own realities and reflect on what these other ideas might mean for their own situations. Using this new awareness, we can start to work out solutions.

The strategy in *Many Voices* is an approach which actively involves people in the process and nudges them toward change. It requires sharing, trust and dialogue among individuals. To encourage this, we need to create an environment which is comfortable, open, supportive and non-judgmental so that people can feel safe having conversations about issues that make them vulnerable and at times uncomfortable. It builds on an individual's own strengths and courage to develop solutions to the troubling realities of their lives – and with HIV/AIDS, helps them to make safer, healthier sexual decisions.

We have just looked at the importance of discussing information about risk for HIV/AIDS in the context of people's lives. Since part of our job as health and outreach workers is to make sure people have accurate information about HIV/AIDS, we will now look at what we know about HIV/AIDS from the scientific perspective [2].

We will begin by looking at some statistics on HIV/AIDS to see the size of the problem both locally and globally. Next we will look at the basic scientific facts about HIV – what it is, how it is transmitted, how it makes us sick. We will also talk about HIV testing and prevention. Of course a lot of the information in this

Principles of the *Many Voices* approach to health promotion:
- broad-based - considers scientific evidence of risk in the social context of people actual lives
- uses stories as a way of raising awareness and creating safe, supportive dialogue about what makes us vulnerable
- uses participatory methodology to actively involve people in discussing the issues, reflecting on what these mean personally, and moving toward change
- respects and values people's inner resources - their strength and capability

2.   The information in this section was obtained from http://www.avert.org and http://www.hc-sc.gc.ca

section will change as time goes on, so you might want to update your information once in a while to keep it current.

AIDS or Acquired Immuno-Deficiency Syndrome is a world-wide concern. The number of people who have this disease increases every day, and no matter what age, sex, or cultural background, we are all at risk. Unfortunately, there is no cure or vaccine for this disease. So far, the only defence we have is to protect ourselves from HIV, the Human Immunodeficiency Virus, which causes AIDS.

The scientific evidence: the facts about HIV/AIDS

The numbers given here are estimates, and are probably lower than what actually exist, because many people who are HIV positive do not go for testing. The numbers below are from the latest UNAIDS report for 1998, the Health Canada report for 1996 and Toronto Public Health documentation.

Statistics on HIV/AIDS

- **Global:** 16,000 new infections each day; 33.4 million people living with HIV.
- **Horn of Africa:** (high prevalence countries, but figures are estimates due to lack of data) Eritrea - 49,000 people infected; Ethiopia -2,500,000 people infected; Somalia - 11,000 people infected.
- **North America:** 860,000 people living with HIV; 40,000 new infections each year - over ⅓ in women, and ⅔ in ethnic minorities
- **Canada:** (1996 figures) 44,000 people living with HIV; 4,200 new infections – with 16.7% among heterosexuals
- **Local:** Recent trends see an increasing proportion of cases in women and youth due to heterosexual contact, and in ethnic minorities. In the **Horn of Africa communities in Toronto**, 3-400 people are infected with HIV, and Africans in Canada have a prevalence rate 40 times that of other heterosexual populations.[3]

HIV is in our community

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3.   Statistics obtained by professional communication with Dr. Robert Remis, Department of Public Health Sciences, University of Toronto.

HIV (Human Immuno-deficiency Virus) is a virus, a small germ. It attacks the system in our bodies which keeps us healthy. This is called the immune system, and it fights off anything foreign or dangerous that enters our bodies. For example, it helps us get rid of colds and protects us against certain infections. If we become infected with HIV, the virus slowly grows more of itself, and as it does this, it gradually weakens our immune system so that we are no longer protected from diseases.

What is HIV and how does it make us sick?

AIDS (Acquired Immuno-deficiency Syndrome) happens when we are infected with HIV and our immune system becomes so badly damaged it cannot fight off certain serious diseases. A person then becomes sick, needs medical care and emotional support from family and friends. People with HIV will survive longer if they have good living conditions and a proper diet, but eventually they will die of AIDS because there is no cure.

What is AIDS?

Exposure to HIV

| Asymptomatic | Symptomatic | AIDS | Death |

Window Period
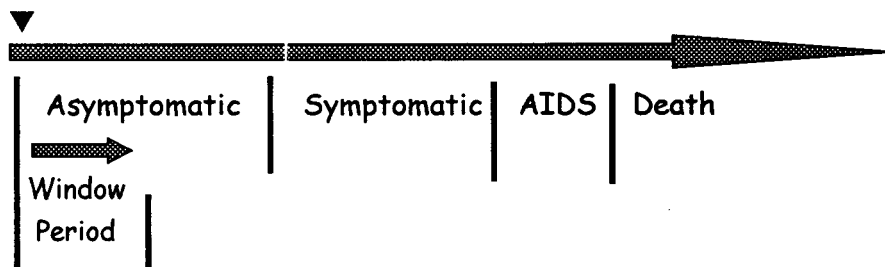
What are the symptoms of HIV infection, and what is the time line?

In the first few weeks after people become infected with HIV they may get flu-like symptoms of fever, headache, sore throat, and rash. Often people do not have symptoms, and they look and feel well. At the beginning of the infection – usually for about 6 months – a person would not have a positive test for HIV. This is called the 'window period'. At this stage, the test for HIV is negative, but a person can still infect someone else even though he or she might look well and feel fine.

Next there is a period which may last several years, where a person will still look healthy, have no symptoms of illness, and may not be aware that he or she is infected. Meanwhile, the virus is increasing in the body and the immune system is being damaged.

During this time, the test for HIV becomes positive and the person is capable of infecting others.

Gradually, as time passes, the infected person will begin to get symptoms for other diseases commonly seen in people with HIV infection, as the virus increases rapidly in the body and the immune system breaks down. The symptoms people have are those of the infections, since HIV infection and AIDS do not have specific symptoms themselves. Once a person is diagnosed with having one of the diseases typical of those which occur with AIDS, he or she is considered to have AIDS.   Death results from infections or tumours which become increasingly difficult to treat.

HIV is transmitted from one infected person to another through contact with body fluids containing the virus. HIV is found in mostly in blood, semen, vaginal fluids, and in trace amounts in tears, sweat and saliva.

How is HIV passed on?

There are five factors which need to be present for HIV transmission, and *all* five need to be present for transmission to readily occur:
- An infected person
- A way for the virus to exit his/her body
- A second person
- A way for the virus to enter his/her body
- A sufficient quantity of the virus

The virus is usually transmitted through 'risky activities' – that is, anything which makes it possible for the virus to pass from one person to another.   The most common of these is unprotected sexual contact (sexual intercourse without a condom). When this happens, the virus, which is present in an infected person's sexual fluids, can pass directly into the body of his or her partner.

'Risky activities'

Another risky activity is needle-sharing among injection drug users, because the virus can be passed using a needle or syringe which has already been used by someone who is infected.

Less commonly, HIV can also be transmitted by infected mothers to their unborn babies during pregnancy, at birth, or through breastfeeding. Some people have also been infected after receiving infected blood or blood products, but this is no longer a problem in Canada.

You will find in your work with the community that many people have misconceptions about how HIV is transmitted. This makes them more vulnerable to HIV infection, and it also affects the way they act towards someone who is HIV positive. So, knowing how to respond to these ideas when talking about HIV/AIDS is important. We will look at a number of the misconceptions which make people fearful and confused at the end of this section.

Anyone can become infected with HIV – who you are has nothing to do with whether you are in danger of being infected with HIV. What matters is what you do. Only our behaviour determines our risk for HIV infection. Some education programs tell us that certain groups of people are more at risk for HIV infection, such as homosexuals, injection drug users, and prostitutes. This doesn't mean that everyone else is safe; we are all vulnerable. Unprotected sex is risky behaviour, whether you are a homosexual, a prostitute, or a heterosexual man / woman. No matter what group we belong to, if we understand how the virus is transmitted, everyone can try to protect themselves from exposure to the virus and avoid infection.

Who can get HIV?

Statistics show that women and young people are the most at risk for HIV. Women are more susceptible (male to female transmission is three times more efficient than female to male transmission). This is because the vaginal and genital areas are more prone to tearing, and the vaginal tissue is absorbent, thus creating easier entry for HIV. With young girls, their immature cervixes and vaginal mucus offer less of a barrier to HIV.

The problem of risk becomes more complicated if you take this basic biological evidence of risk for HIV/AIDS and add social and age-related factors. In some ways, these become the biggest challenges in addressing the problem of HIV transmission. For

example, women are more at risk because of the gender power gap. Women have difficulty negotiating safer sex practices with men, especially if they are economically dependent on them. As well, women, more than men, are coerced into having sex and other forms of sexual abuse.

Youth are also more at risk because many are experimenting with sex, and while some adults think they can prevent this, we need to acknowledge a young person's chances of having sex. People argue against sex education because they think it will encourage sexual activity, but research has shown that this is not the case. Unfortunately, youth don't always have good information about prevention and thus will not have the opportunity to make responsible sexual decisions early in their lives.

Young people are also at risk because negotiating safer sex or abstinence is often difficult when one is insecure and easily influenced by peers and relationships. As well, young people are often embarrassed about buying condoms.

At the present time, there is no cure or vaccine for HIV. The way people can protect themselves is to know as much as possible about HIV infection, and avoid situations where they can contract the virus. These fall generally into two areas – sexual and non-sexual activities – and we will look briefly at each.

HIV prevention

As you read earlier, the main way HIV is transmitted is through sexual activity – whether you are male, female, heterosexual, homosexual or bisexual. HIV is found in the sexual fluids of an infected person. For a man, this means in the fluids which come out of the penis before and during sex. For a woman, it means HIV is in the fluids produced by the vagina before and during sex to help make intercourse easier.

Minimizing sexual risk

If a man with HIV has vaginal intercourse without a condom, infected fluid could pass into the woman's blood stream through a tiny cut or sore inside her body. This can be so small that you don't know about it. If a couple has anal intercourse the risk of infection is greater than with vaginal intercourse because the lining of the

anus is more delicate and is more likely to be damaged during intercourse.

If a woman with HIV has sexual intercourse without a condom, HIV could get into the man's blood through an open sore on his penis or by getting into the tube which runs down the penis. If there is any contact with blood during sex, this increases the risk of infection.

Some sexual activities are more risky than others, so let's have a look at these and see how to protect ourselves.

High risk sexual activities: unprotected sexual intercourse, either penile-vaginal or penile-anal. People can protect themselves against infection through:

Protection against high risk sexual activities

- Abstinence (complete absence of penetration or fluid exchange between two people)
- Mutual monogamy (having one sexual partner during a life time of sexual activity)
- Even with the tradition of polygamy - the practice of having more than one partner at the same time - it does not necessarily mean that people are more at risk, as long as all those involved in the marriage arrangement up do not engage in extramarital sexual activities.
- Serial monogamy - being involved with more than one sexual partner, but only active with one at a time.
- Condom use - male or female condoms greatly reduce risk of HIV transmission, but do not entirely eliminate risk (see below for information on condom use)
- Communication - sexual partners can learn to develop open communication about their sex lives and their concerns.

Low risk sexual activities or isolated case reports of transmission: other forms of sexual activity such as cunnilingus (oral female genital contact), fellatio (oral male genital contact), and oral-anal contact.

Protection with low risk sexual activities

- Use of condoms or another barrier can reduce risk.

No risk sexual activities: kissing, and masturbation.

Condoms are not 100% effective in preventing HIV infection, STDs or pregnancy. However, studies show that if they are used consistently and properly they are very effective.

Research has demonstrated that planning to use condoms is influenced by certain types of beliefs, norms and attitudes. The person most likely to use a condom in a new sexual partnership

- sets using a condom as a personal standard - has a sense of obligation to oneself; sees using condoms as "the right thing to do"
- believes barriers to condom use can be overcome - having condoms available, relying on them for protection, not being embarrassed to suggest their use, not being afraid of threats or violence from their partner
- believes that using condoms is appropriate to someone of their age or gender, cultural group, in a relationship such as theirs
- community rules and expectations have an important influence on plans to use condoms

In ethno-cultural communities, community norms about the appropriateness of condom use has a particularly significant influence on people's intention to use condoms.

Having condoms available and knowing how to use them strengthens people's intentions to use them for protection.

There are a number of different types of condoms available now. The 'male' condom is a sheath or covering which is closed at one end and fits over a man's penis. There is also a 'female' condom, which is used by a woman and which fits inside her vagina. First, we will talk about the male condom.

The male condom

Condoms are made of latex (rubber), plastic or animal tissue. If possible, people should use a latex condom because these are most effective against viruses such as HIV, and are the most readily available. The pore size of the condom is smaller than the HIV so it can not escape. Polyurethane condoms are thinner and therefore increase sensitivity, but are more likely to break than latex condoms. For people with latex allergies, polyurethane

condoms are helpful. Natural condoms **do not** protect against HIV because the pore size in the skin is bigger than the virus, and it can escape.

Condoms come in a variety of shapes. Most have a reservoir tip, although some have a plain tip. Some 'novelty' kinds are textured with ribs or bumps; some come in a variety of colours; others are flavoured. There is just one standard length for condoms, but some vary slightly in width to give a closer fit.

The lubrication of condoms varies too. Some are not lubricated at all, some are lubricated with a silicone substance, and some have a water-based lubricant. Many also have a spermicide (*Nonoxynol 9*) added. The lubrication helps make them easier to put on and more comfortable to use.

People should use a new condom every time they have sexual intercourse. You put the condom on after the penis is erect and before any contact is made between the penis and any part of the partner's body.

With anal intercourse, there can be more strain placed on the condom. It is better to use stronger condoms and plenty of lubricant.

How to use a male condom:

How to use a
male condom

1. Take off watches and rings that might puncture the condom. Open the condom package at one corner being careful not to tear the condom with fingernails, your teeth, or through being too rough. Make sure the package and condom appear to be in good condition, and check that the expiry date has not passed. Condoms can deteriorate if not stored properly, and are affected by both heat and light. It is best not to use a condom that has been stored in your back pocket, your wallet, or the glove compartment of a car.

2. Place the rolled condom over the tip of the hard penis, and if the condom does not have a reservoir tip, pinch the tip of the condom enough to leave a half inch space for semen to collect. If the man

is not circumcised, then pull back the foreskin before rolling on the condom.

3. Pinch the air out of the condom tip with one hand and unroll the condom over the penis with the other hand. Roll the condom all the way down to the base of the penis, and smooth out any air bubbles. These cause the condom to break. You can use extra lubricant on the outside of the condom, but always use a water-based lubricant (such as KY Jelly) because an oil-based lubricant will cause latex to break.

What to do if it won't unroll: The condom should unroll smoothly from the rim on the outside, but if it won't and takes more than a few seconds, it is probably upside down. Don't try to roll it back up; hold it near the rim and slide it off. Then start again with a new condom.

If a condom breaks: If it breaks while having intercourse, pull out quickly and replace the condom. While you are having sex, check the condom from time to time to make sure it hasn't split or slipped off.

4. Before the penis softens, hold the condom against the base of the penis while you pull out, so that the semen doesn't spill. Then tie a knot in the condom and throw it away.

Myths about condom usage:

Myth 1. Condoms reduce sensitivity in sexual sensations
Response: Women seem to have equal sexual stimulation with or without a condom. If you add a dab of water-based lubricant into the tip of the condom, it increases stimulation for the man. Condoms help the man to retain his erection for a longer period of time. Also couples have reported that the use of condoms has *increased* their sexual pleasure as they have incorporated it into their foreplay.

Myth 2. Condoms break easily.

Response: Condoms are not likely to break if they are used and stored properly. The greatest cause of condom breakage is due to improper use. Women and men should both practice condom application. Condoms will also break if used after the expiry date.

The female condom (often known as the 'Femidom' or by the name 'Reality') is a polyurethane sheath or pouch about 15 cm. in length and is worn by the woman during sex. It entirely lines the vagina. At each end of the condom there is a flexible ring. At the closed end of the sheath, the flexible ring is inserted into the vagina to hold the condom in place. At the other open end of the sheath, the ring stays outside the vulva at the entrance to the vagina. This ring acts as a guide during penetration, and it also stops the sheath bunching up inside the vagina.

The female condom

There is a silicone-based lubricant on the inside of the condom, but additional lubrication can be used. The condom does not contain spermicide, and it should not be used at the same time as the male condom.

How to use the female condom:

How to use the female condom

1. Remove the condom from its package and rub the outside of the pouch together to be sure the lubrication is evenly spread within it. Make sure the inner ring is at the bottom closed end of the pouch. Hold the pouch with the open end hanging down.

2. Squeeze the inner ring with the thumb and middle finger, and then insert the inner ring and pouch into the vaginal opening. With the index finger, push the inner ring and pouch all the way up into the vagina. Because the female condom is lubricated it is slippery, so you need to do this slowly and carefully. Make sure the condom is inserted straight, and is not twisted inside the vagina. The outer ring and about an inch of the pouch will now lie outside the body. The penis should be guided into the condom in order to ensure that the penis does not slip into the vagina outside the condom. If the condom slips during intercourse, or if it enters the vagina, then you

should stop immediately and take the condom out. Insert a new one and add extra lubricant to the opening of the pouch or on the penis.

3. After intercourse, squeeze and twist the outer ring gently and then pull the condom out keeping the sperm inside. Then tie and discard. It should not be reused.

Now, let's look at protection with non-sexual activities.

Minimizing non-sexual risk

• *Mother-to-child transmission.* An HIV positive mother has a one-in-six chance of passing the virus on to her baby. To protect her baby, the mother can take medication during her pregnancy, and use powdered formula as a substitute for breast milk.

• *Injection drug use.* If people are involved with injection drugs, they should never use a syringe more than once or share needles. New, sealed needles are available in drug stores and hospital clinics. Syringes and needles should be disposed of in tight, sealed containers, so children playing will not pick them up.

• *Traditional practices, tatoos, birth marks.* If people are involved with traditional practices which involve body fluids such as blood, precautions should be taken to avoid exposure to HIV. Make sure any instruments used are sterilized (or supply your own), and that people are aware of the risks of HIV transmission.

HIV Testing

The test for HIV looks for antibodies to the virus. When germs invade the body, special chemicals called antibodies are produced to fight the germs. The body makes a different antibody for each germ, so if individuals have antibodies to fight HIV in their blood, we know that they must have HIV.

The antibodies that the test looks for take a number of weeks to appear in the blood, and if someone has become infected with HIV within the last 12 weeks or so, it may not show up on the test. Sometimes this period can be even longer. A test which finds HIV antibodies is reported as HIV positive, and when this occurs, the person is tested again using a more specific test, which checks that the first test was not a mistake. People with positive tests will be

given counselling about how to protect their health and their sexual partners. A test which finds no antibodies to HIV is reported as HIV negative.

There are a number of advantages to being tested. Many people who have an HIV test have been worrying unnecessarily, so getting a negative result can put their minds at rest. If someone's test turns out positive, then a doctor can keep an eye on the person's health and give treatment to slow down the damage done by the virus. People who are positive can also take steps to protect other people: they can do this by avoiding sex which puts their partners at risk, and telling past sexual partners so they can be tested. For people who are thinking of starting a family, knowing whether they are HIV positive may affect this decision.

Advantages and disadvantages of testing

There are also some possible disadvantages to being tested. Some people would rather not know, because they are afraid they would not be able to cope with the diagnosis. In fact, most people do cope – even those who thought they couldn't. Also, it is possible that some insurance companies will not give life insurance to people who are infected with HIV. However, becoming HIV positive does not affect the insurance someone already has. As well, some countries, for instance the USA, place entry restrictions on people who are known to be HIV positive. And lastly, some employers may be reluctant to employ someone who has HIV, but in Canada, employers are not allowed to discriminate against people who are HIV positive. If an employer, or a potential employer, asks someone to be tested, the person has a right to refuse.

People who don't want to be tested but think they might be HIV positive can still be responsible and ethical with sexual partners by taking precautions as if they were positive.

People who are worried about the possibility of HIV infection should see their family doctor. He or she can discuss the risks involved and help the person get an HIV test. Counselling is confidential, and tests can be done anonymously (without a person's name attached). There are also clinics where people can be tested without others knowing, such as the "Hassle-free Clinics" at 556

Where to go for testing

Church St. Toronto (2nd floor). The phone number for men is (416) 922-0603, and for women is (416) 922-0566 to book an appointment. People can also call the Sexual Health and AIDS Hot Line at (416) 392-2437 for the address of the closest clinic, and for any other questions they have relating to HIV/AIDS.

People who go for testing and are HIV positive receive counselling which helps them manage their health and be responsible to their sexual partners. Books recommended as good sources of information are: "Managing Your Health: A Guide for People Living with HIV/AIDS", available from The Community AIDS Treatment Information Exchange (CATIE), and "Living with HIV Infections", produced by the Ministry of Health and available from your local health unit. There are also a number of agencies which provide support for people from Africa – Africans in Partnership Against AIDS (416) 340-9943, and Africans United to Control AIDS (416) 591-7600.

Support for those with HIV and AIDS

As you talk to people in the community, you will hear many misconceptions about HIV/AIDS. People may say things that you think are strange, but these are very real voices, and very real beliefs. Here are only a few examples of things people are saying, and some information you can use to present an alternative perspective:

Voices from our communities

What people are saying and asking	*Responding with another perspective*
"AIDS only happens to specific people – like homosexuals, drug users, and prostitutes."	As you read earlier, anyone can get HIV/AIDS. Believing that it is only a problem for certain groups, and that these groups do not exist in our communities is a distortion of what we know is true, and if they believe this, it makes people vulnerable.

What people are saying and asking	Responding with another perspective
"People make the connection that since they do not have homosexuals in their community, or go with prostitutes, they do not have a problem with AIDS."	You can help people see that HIV/AIDS is real for their communities by giving them statistics on HIV/AIDS at home and in ethno-cultural communities in Canada. Since people in our communities often do not have good information, education can help change their ideas.
"I have never seen or heard anybody who has this disease in our community but there are a lot of whites who have it. And because they don't like blacks, they try to give our people the disease." "The children said they were told that AIDS originated in Africa and that Africans are hypersexual. It causes a lot of psychological torture."	There are many theories about where AIDS comes from, and nobody really knows for sure. Over the course of the epidemic, fear, moral and racial discrimination, politics and economics have caused homosexuals, blacks, and whites to be blamed for starting AIDS. It helps to explain this to people, and ask them whether knowing the origins of AIDS is going to help. What is important is that we deal with the reality and do something to protect ourselves.

What people are saying and asking	Responding with another perspective
"I think AIDS is a punishment from God or Allah."	This is a powerful belief which can motivate safe sex practices, but also serve to promote intolerance and discrimination toward members of the community who get HIV/AIDS.
"People are afraid of public toilets for fear of AIDS."	You cannot catch the virus from toilet seats. You can remind people about the five factors needed for transmission – in this case there is unlikely to be a way for the virus to enter a person's body, and there would not be sufficient quantity of the virus to cause infection. As well, HIV does not survive very long outside the body.
"I heard that a kiss, a handshake or just sitting beside an infected person can infect you."	You cannot get HIV infection from any of these activities. With kissing, even though there could be tiny quantities of HIV in saliva, there is not a sufficient amount to cause infection. This also applies to telephones, sharing cups, eating utensils, and cigarettes too. There is no danger with handshakes, hugging, or just being with someone who is infected with HIV/AIDS. HIV does not survive well in the open air, and no case of environmental transmission has been seen.
"You get the virus from dentists, cigarette sharing, drinking from other people's cup, telephones, the swimming pool, mosquitoes, and toothbrushes."	Mosquitoes do not transmit HIV when the insect bites because the mosquito does not become infected itself. People might be familiar with mosquito transmission of malaria, but this does not happen with HIV. Many studies have been done which show no evidence of HIV transmission through insects.

What people are saying and asking	Responding with another perspective
	With toothbrushes, there is a slight risk of transmission if people have bleeding gums or sores in their mouths. HIV is in higher quantities in blood than saliva, and sores provide an entry and exit point for the virus. Dentists practice infection control precautions by sterilizing instruments, so HIV transmission this way is no more a concern than with other medical treatment.
"Even though I don't have a steady person, I don't consider myself to be at risk...it's only those women who go out and sleep with men outside our community."	We saw earlier that it is common for people in our community to feel immune. Your discussions should try to personalize the issue of HIV/AIDS in the community. People might discuss what would happen if someone had sex outside the community, then had unprotected sex with someone inside the community. How would they know? How can they protect themselves and their partners within the community?
"Wild sex is another cause of AIDS. If the vagina is small the man's penis will be scratched so the condom may break. On the other hand if the vagina is big and large you don't need to use a condom because there is no contact between the penis and the vagina - you don't feel."	Condoms sometimes do break which is why they do not give 100% protection from HIV. This happens if the condoms are not worn properly or if they are old, but not because of scratches from the vagina or wild sex. Condoms should be worn because no matter what size the vagina is, there is always contact with the sexual fluids.

What people are saying and asking	Responding with another perspective
If people have unprotected sex and within a month there is no disease, they think unprotected sex is not a problem."	We know that unprotected sex *is* a problem. These people may have been lucky enough to have sex with someone who was not HIV positive, and the next time will not be so fortunate. Or, they may indeed be positive but still in the window period (the period at the beginning of HIV infection where a person feels well and his or her test is negative). This is no guarantee that infection is not present. If someone is worried about an instance of unprotected sex, he or she should use protection or abstain for at least six months, then go for testing.
"Many people think that if they feel healthy and so does their partner, then there is no reason to use a condom."	Again, we know that feeling healthy does not guarantee someone is negative for HIV.
"I am a married woman, and don't need to worry about HIV/AIDS." "People having affairs with married women believe they are safe."	Even marriage is no guarantee against HIV/AIDS if a husband or wife is having a relationship outside the marriage. Trust is a big issue in a relationship, and some people worry that discussing condom use means they don't trust, or aren't trusted. People might want to talk about this issue and the importance of communication in their relationships. They could also discuss personal responsibility for condom use to protect their partners and families.

What people are saying and asking	Responding with another perspective
"People are afraid to get blood and blood products...sometimes language and culture barriers in hospital contributes to the confusion."	In Canada, donors are screened carefully for HIV risk factors and the blood that is collected is tested and treated for HIV. People can be confident about receiving these products.
"People are afraid of being isolated if they get HIV. They are scared of the disease, but hardly talk about it. In general we do not use health facilities because there is a stigma attached to being sick of any disease, not just AIDS"	When we isolate or abandon people with HIV/AIDS, it greatly affects their lives. They need our support more than ever. Fear, due to our misconceptions about how HIV is spread, and our reluctance to talk about such things only hurts individuals and our communities. Here are a few examples of what people in the community are starting to say once they understand about HIV: *"We have to be open to ourselves. We should help and encourage our community to open up."* *"Let us not judge our community. We should introduce issues like homosexuality and HIV/AIDS to our community otherwise there is no way of talking about these issues. We have to educate people to be open. If we are not open, it is not possible to solve problems."*

What people are saying and asking	Responding with another perspective
"How can I persuade my partner that we should use a condom?"	People use many reasons to avoid condom use, but men and women can practice how to negotiate safer sex with their partners. Modelling and practice in communication, negotiation and refusal skills will help people gain the confidence they need to protect their health. Here are a few examples of comments that might be made and answers people could try. Your can add more as other people share their stories.

Excuse	Response
"Don't you trust me?	"Trust isn't the point. People can have infections without realizing it."
"I don't stay hard when I put on a condom"	"I'll help you put it on, that will help you keep it."
"I don't have a condom with me."	"I do."
"I don't feel a thing when I wear a condom. It is not as much pleasure."	"Maybe that way you'll last even longer and that will make up for it."
"I'm on the pill, you don't need a condom."	"I'd like to use it anyway. It will help to protect us from infections we may not
"But I love you."	"Then you'll help us to protect ourselves."
"Just this once."	"Once is all it takes."

We have just finished talking about HIV/AIDS from a scientific perspective and from a community perspective. As health workers, you now have knowledge about both of these ways of thinking about HIV/AIDS. It is a challenge to find a way to talk about HIV/AIDS in a way that respects and combines them both, and makes your health promotion messages effective. It is probably a good idea to spend some time thinking about the pros and cons of these points of view, and how you feel about each, so that you are comfortable and prepared to discuss them with your groups.

HIV /AIDS as a moral issue: As we saw, many people in our communities believe that contracting AIDS is God's way of punishing people who sin. This is looking at HIV/AIDS as a moral issue. In encouraging healthy choices, religious beliefs about sexual abstinence and faithfulness within a marriage can be motivating forces for HIV prevention for those with strong beliefs. However, these same beliefs can also serve to alienate and blame those who are HIV positive within the community, and affect their care.

HIV/AIDS as a health issue: We also know HIV/AIDS is caused by a germ which can infect anyone. This is looking at HIV/AIDS as a health issue. If we help people see it as a health issue, they will be better prepared to help themselves and be more willing to care for people who are HIV positive. We can try to counter the AIDS phobia and bring about the sympathy and concern of the community. However, if we think about HIV/AIDS strictly as a health issue, it will reduce our ability to deal effectively with those who hold other ideas. We still need to think about health in a broader way which includes the social, psychological and spiritual aspects of people's lives. HIV/AIDS has all of these dimensions.

HIV/AIDS as a moral issue or a health issue?

Thinking Point:

HIV/AIDS as a moral issue and a health issue

As you have just read, there are pros and cons to looking at HIV/AIDS from a moral or health perspective.
In your opinion, what do you think about each of these perspectives?
Is there a way to combine the moral aspect with the health aspect?

Thinking Point: How well do you know yourself?

The questions below will help you identify some of your personal biases and prejudices about HIV/AIDS and think constructively about doing your work. It is a good idea to answer these questions from time to time because experience often changes our ideas, our thinking and our beliefs. You may find over time that your own attitudes about HIV/AIDS change as you talk about this topic with people.

1.   What type of person do I interact with the best?
2.   What are my religious beliefs, and how do these influence my thinking about HIV/AIDS?
3.   What are my views on premarital sex and extramarital sexual activities?
4.   How freely can I talk about sex?
5.   Why am I interested in HIV/AIDS?
6.   What are my beliefs about HIV/AIDS? Why do I have these beliefs?
7.   When I talk to people about HIV/AIDS what do I do well? What could I improve? What, or who, could help me with this?
8.   Where can I offer my expertise in this issue?
9.   Who am I willing to educate? Why?
10. Do I want to present the ideas alone? With a partner? In a group? Why?

Notes:

Telling Stories

This section of the handbook contains stories which you can use as resources for starting discussions. Why tell stories? These are the heart of the *Many Voices* approach to health promotion, so let's see how they can help us do our work.

Everybody has a story. These come from our experiences and life events and are coloured by our values, relationships, culture and spiritual understandings. They show how our world has shaped us and how we have shaped our lives.

Because of this, **stories are a way of seeing how people experience life** – their fears and hopes, their pain and suffering, their creativity and imagination, their strength and pride, their anger, their relationships and their caring. By hearing stories, we discover that many people share the same experiences as we do, and feel in similar ways. Knowing this is comforting because we learn that we are not alone.

Stories also help us see that sometimes people have experiences which are different from our own, and their stories help us see other ways for living our lives. We also find out that people with different stories are in many ways really people like ourselves, and this helps us understand and accept them better.

Stories are helpful in another way. Sometimes people feel shy talking about certain issues, such as sexuality, because this is taboo or private. Sometimes people won't talk because they are afraid of what people in the community will think and how they will react. Talking about things that are important is more comfortable through stories because it is less personal and embarrassing.

Representative Stories

The stories in this section of the handbook are the words of people from our communities, so they are about real

experiences and concerns shared by many of us. The stories will therefore be relevant and meaningful to the people you talk to, and using them will help you raise issues for discussion. Drawing on and telling stories helps people learn and think about the factors which affect their lives, and using this new awareness, begin to work out solutions to the problems which affect their health.

To give you some examples of the kind of stories you could use in your outreach and health work, nine stories of a cross-section of persons in the Horn of Africa communities are represented here. You can pick and choose the kind of story that will help your discussion; the most effective exmples, however, will be the ones you collect yourself. Here is how you can use these stories:

Each story begins with a 'profile' which explains who is telling the story - a male or female; his or her country of origin and length of time in Canada; his or her age and family relationships. This information should help you find stories from individuals who are most like people in your audience and the issues you wish to discuss in your groups.

Next, each story's 'talking points' are listed. These are the issues each storyteller talks about in his or her story, which you can raise for discussion after reading the story. For example, if you want to talk about family conflict with your group, there is a story in which the storyteller talks about her husband beating her when he gets angry. You could use this to begin talking about the issue of family conflict. So, if you would like to use a story to help you talk about a certain issue with your group, look through the talking points to find a story with the ones you need. You don't have to tell the whole story if you don't want to; just use the parts (or anecdotes) you need to illustrate a point or introduce a particular topic. You may even want to change some of the details in the story to make it more appropriate for your audience.

How to work with the stories:
  Each story has
- a *profile* of the story teller - these will help you find a storyteller your group can relate to
- *talking points* which tell you what issues are in the story - these will help you chose a story with the issues you are interested in
- a *narrative* - this is the actual story which can be read all at once or just the parts with the issues you want
- *discussion probes* - these are questions you can prepare to begin and lead discussion

At the end of each story, there is a section called 'discussion probes'. These are questions you could use to begin discussion (see skill tip # 8 - page 42), which explains what probe questions are). Because all discussion groups are different, you will probably want to think of probe questions ahead of time which are suited to the context of your group. You can also write down questions that have worked well for you and share them with other community health workers.

You will hear many stories from people about their journeys and changing lives in Canada as you meet and talk with them in your community. As you become familiar with how the stories in the handbook are used, you will naturally add new ones which will help you with your work. Because you are aware of the issues people struggle with, think about how these new stories might help you generate discussion, how they could be examples of certain points you want to make, and how they might help people reflect on issues of concern to them and to the community. The goal is to get people talking about the issues, and creatively thinking about what they can do to work out solutions. You may want to write some of these new stories down and share them with other health workers, so you can all benefit from new resources. When you use people's stories, be careful to respect their privacy by not using real names, and change details which would make it easy to guess whose story it is. Let's go to the stories now.

Collect the stories you hear

Rukia's Story

Profile

Rukia is a 40 year-old woman from Somalia who has been in Canada for two years. Her husband died there in the war. She has a boyfriend named Waaberi, whom she sees regularly, and a 15 year-old daughter named Nuura, who lives with her.

Talking Points

- ▸ **realities of life in Canada:**
  - different food, clothing
  - changing values
  - grief
  - fear of immigration, Children's Aid
  - lack of family support networks
- ▸ **relationship with her community:**
  - the value of a close community; developing a network of people who can help
  - worry about what the community thinks about her male relationship
- ▸ **relationship with her daughter:**
  - changing values – daughter's lack of respect for her
  - issues about sex, dating
- ▸ **relationship with boyfriend:**
  - pressure to have sex and fear of losing him
  - loneliness and her desire for intimacy
  - vulnerability to HIV/AIDS
  - embarrassment and uncertainty about raising the issue of pregnancy and disease prevention; condom use
  - community attitudes to people who are HIV+

Rukia's Story

"My name is Rukia. We came to Canada from Somalia, my daughter Nuura and I, two years ago. My husband was killed in the war ... we have seen a lot of people die ... many of my family and friends. We were lucky to get away, and the journey was very hard. I am happy to be in a safe place now, but I miss the people of my village and my life in Somalia. Many terrible things have happened to cause my journey here, and sometimes I think this journey has no end. I left the fears of my old life, but now have different kinds of fears and problems. But people from my community give me strength and support ... we have come a long way together."

"Life in Canada is too difficult ... there is a big difference between living here and in Somalia. There are many things I don't understand, especially the language and it is very embarrassing when I go to the shops and don't know what to say. Everything is strange ... the food is so processed and I don't know what is in it. The weather is another thing ... we used to wear one type of clothing all year round, not changing four times like we do here in Canada. The friends we are living with helped us find warm clothes and they are also helping me with the immigration people. I am very afraid of the officers and what will happen if they won't let us stay. Also the social workers from the Children's Aid make me afraid. They don't understand our situation."

"Mostly though, I worry about my daughter. She has many friendships outside the community with the white children, and she is learning their values. She talks with no respect, and wants to go out with boys. At home we didn't do this until we were ready to be married. She comes home from school and tells me what she hears about sex. We didn't discuss sex with our parents ... my mother told me about menstruation, but not contraception or diseases. But I decided to discuss everything with my daughter. If I don't she will be lost. At first I was ashamed and embarrassed to talk to her about it, but now I am more comfortable ... I have to. Children learn sex in school here in the fourth grade. This is Canada."

Rukia's story....

"It is strange, because now I have to think of these things for myself.
I have been dating a man, but I am worried about what my friends
think. Married families are highly valued and many of my friends do
not approve of casual relationships. But I am very lonely and miss my
husband. Being with Waaberi helps me forget how hard it is to face all
my problems alone."

"Sometimes when Waaberi and I are together we want to make sex,
but I think he may be with other women too and this makes me afraid
of getting HIV. People say it is not a problem in our community,
especially if we follow our religion. But yesterday I met a woman at
the health centre who was HIV positive, and she is very religious.
Maybe it really is in our community and people hide it because they are
afraid they will be abandoned."

"I know that if I am going to make sex, I must think of protecting
myself, but how can I talk about using condoms? It is too
embarrassing. And what if he gets angry and says no? It is expected
for the man to produce it, and if a woman asks a man to wear it, he may
think that she is insulting him. I wonder how other women think about
these things and what they do, but it is so private. It is taboo to talk
of these things, but maybe with our new lives it is something we must
try to do to protect each other and our children."

Discussion Probes

Negaso's Story

Profile

Negaso is a 50 year-old man from Ethiopia who has been in Canada for five
years. He lives with his wife, his 18 year-old son, and 15 year-old daughter.

Talking Points

- ▶ realities of life in Canada:
  - unemployment
  - changing values as these relate to women and children
  - loneliness and homesickness; wanting to go back home
  - little social life
- ▶ relationship with his community:
  - role of the religious community as a source of support and community values
- ▶ relationship with his wife:
  - anger and powerlessness at his changed status in the family
  - wife's demands for his help in the house – family conflict and violence
  - other sexual relationships
  - vulnerability to HIV/AIDS - his own and his wife's
  - trust, sexual responsibility; condom use
- ▶ relationship with children
  - fears changing values and loss of culture
  - issues about sex, dating; changes in his own ideas because of HIV/AIDS
- ▶ community issues
  - community attitudes to people who are HIV positive

Negaso's Story

"My name is Negaso, and my family and I came from Ethiopia to Canada about five years ago. I came here because at home it was hard to look after my family and we thought things would be better here. In some ways they are, but it is very frustrating trying to find work ... being unemployed makes me so angry. I was a good teacher at home, but here they want you to have the Canadian papers and experience. How can you do this if they don't let you work?

"I also get very homesick for my country and all the friends we had there. I used to go out all the time with the other men, but now I just stay at home. Once in a while I go to the Church to meet with the men, and I can get someone to help with my problems. I like it; we sit around and talk about our lives at home. Some of the men have just come back from a visit and they say it is different there now. I don't know ... I often think about going back ... life is hard here. When I talk with the men, we all agree that this new culture is ruining our children. Under the pretext of democracy, our children are getting wild. We also talk about how the women are given a lot of freedom here, and they cannot handle it."

"My wife goes to work at the community centre, but I don't like it. She doesn't listen to me anymore and I feel that I am no longer the head of the family. I am the one who is supposed to be breadwinner and she should be at home, not me. She even wants me to do the woman's work, since I am home and she is at work. We argue about this all the time ... I don't know what has happened to her. I used to beat her to make her listen, but a few weeks ago the police came. It is not good when police interfere in family affairs, but the kids are told to call them when an argument breaks out in the family. It is very embarrassing because the police do not understand the life in an Ethiopian family. They say I must follow the laws of this new country, but all these changes make me feel powerless."

"My kids think they know things better than me because they go to school and know English better. It makes it hard to teach them what I know and my values. I raise my children in the strict traditional sense."

Negaso's Story...

"Because of cultural taboo, I don't want my children to have dates or relationships. Last year, when I found out my son has a relationship with a girl I was very mad. I told him there is only one option and that is marriage. I decided to leave my job to straighten things out. I am opposed to sex without marriage ... I told my son to be pure and the lady he would marry must be pure."

"But lately, we have been hearing about AIDS at the community centre. I am very concerned with my kids, especially since they want to follow the new culture. In North America, 13-14 year-olds do date and have boyfriends and girlfriends. We live in this environment and our kids grow in this environment, so I am thinking maybe we have to be more open and understand the dangers our kids are facing. I don't want them to date or have relationships, but if you tell them don't date they will not take that, so maybe it is better to talk to them about the risks involved in having sex. It is difficult to talk to them about these things, but I am going to try to be more open."

"It also makes me think about myself and what I should do about my relationships. Men by nature need two or three women, and occasionally I am with other women. They say HIV is not in our community, so I have never worried. Recently, one of the women wanted me to wear a condom, and I was very surprised. She said she wouldn't have sex unless I wore one. My wife would never do that. But it makes you think about how you can't know everything about people - I don't know whether these women have been with someone from outside our community, even if they say they haven't. There is a lot of cross-cultural sex here. I suppose it is right to protect yourself. At least I don't have to worry about being with my wife."

Discussion Probes

Arwa's Story

Profile

Arwa is a 35 year-old woman from Somalia. She lives with her husband and daughter, and they have been in Canada for 6 years. She works in a day care.

Talking Points

- ▶ **realities of life in Canada:**
  - misses family and community support networks back home
  - problems with the language
  - women have to work hard
  - trouble with the school system
  - unemployment; changing roles
- ▶ **relationship with her community:**
  - community help when they arrived
- ▶ **relationship with her husband:**
  - family conflict over housework; violence
  - divorce
  - contraception
  - vulnerability to HIV; issues of trust
- ▶ **relationship with children**
  - changing values; changing relationships
  - dating and talking about sex
- ▶ **community issues**
  - seeing cultural norms change
  - breaking taboos about HIV

Arwa's Story

"My name is Arwa. My family and I came to Canada six years ago from Somalia. We had to leave everything – our home, our friends. Everyone left. Some are still in the refugee camps in Italy, but we were lucky to come here together. Some of my friends are still waiting for their husbands. Now we have our papers, and we don't have to worry about the immigration process any more. We worried every day that they would send us away from here – every time we saw the police, we would be afraid. I miss a lot the friends and family we haven't seen for so long, and think all the time about us being together again."

"Life in Canada is very different and very hard. It is fast and everyone has to work. In Canada, many men we know cannot find a job and they feel angry and frustrated. My husband is not working right now and he gets depressed. I think it is harder for him to adapt because he is unemployed and his role has changed. It is hard for him that I work and earn money. But I have to or we cannot live. For me, I like the freedom we have, and in many ways it is easier to adapt. I miss a lot of the ways we had at home, where we did not have to worry about baby sitters, day care and so on. Back at home a mother could leave her kids with a neighbour and the neighbour would take care of the kids without complaining or charging the parent. Here, if a woman has a baby, she will not get family support. We no longer have a small, closely knit community where everyone works together in educating the children. Here, our children can be lost if we do not know the system."

"I am starting to see that a lot of things are dictated by our religion. It says things like the place of women is at home, and the men's role is to do the outside work, and he should be served at home like a king. It cannot be the same in Canada. Here life is different and hard for both, and everybody's contribution at home is a must. I get very angry with my husband when I come home and he has done nothing for dinner, and I have to clean and do the laundry too. Sometimes I talk with my friends about roles in the family, and they also have big arguments."

Arwa's story continues...

Arwa's story....

*"One woman said to me, 'If a man is not cooking then I don't want him!'
It is a big issue, and several of my friends have got divorced because
there is so much stress. The men do not realize that in Somalia life
was easier because relatives used to help and men's participation was
not needed."*

*"My husband gets very angry with my daughter. He thinks she does
not respect him because she talks to him just like she talks to her
friends. We are concerned about her future here ... the education
system is very different and we do not know the best way to teach
her about the Moslem religion and Islamic values. We feel powerless
to give her the right parenting. It is hard to communicate with her
because of the language. We don't understand each other when there
is a problem. We want to speak to her in Somali, because it is easier
for us to say what we mean. She doesn't understand us very well and
wants to speak English because it is easier and faster for her. It is
hard to have a meaningful conversation. I know that there is always a
difference in the way of thinking between generations, and there is a
need from the parents side to meet the needs of the new generation.
But, certain behaviour is difficult for us to understand and tolerate.
Of course we welcome the positive values of the Canadian culture and
we encourage her to become part of her new country, but we want
also that she has the values of our own culture."*

*"Now she wants to start dating because she sees the girls at school
going out with boys. The children here do this so freely, and far away
from their parents' sight. When my husband was interested in me, he
came to our house and spent time with me there. My parents
understood we would be married because we had a relationship.
Sometimes she asks me questions about sex and I am embarrassed –
it is not something parents talk about with their children. My
daughter tells me about the things she learns at school ... I think she
knows more than me! We tell her about the Moslem traditions, but we
know she does not want to listen. I feel like I must try to be more
open with her because I worry about what will happen to her –
especially because of HIV."*

Arwa's story....

"We heard about this at the health clinic, that HIV is in our community. We didn't think it was an issue for us because we follow the teachings of our religion. But they are teaching us that none of us is safe ... women whose husbands have more than one woman, boys who are going with girls from outside our community, single women who have boyfriends ... even people in a marriage. One of my friends says some married women may be doing the same as their husbands. She said to me, 'You know, if a husband never shows up at home, or if he is in a far away place, I mean what is the woman to do.' She thinks there are a lot of things that are not talked about that are happening. So, I went to the clinic last week to talk about contraception. Even though it is against our religion, we can't afford more children, and I can't look after them when I am working."

"I can't talk about it with my husband, but our customs say that men are allowed to have more than one wife. I sometimes think he sees other women, but if I talk to him about the condoms, he gets angry and says 'I am innocent, why should I wear a condom?' The health worker asked me if I wanted to give him some, just so he has them if he gets into a situation. It made me afraid, but the more I think about it, I think I should protect myself. I am not so afraid of his anger because now if he hits me, I know this is wrong and I sleep at a friend's house. My friend comes home with me and helps us discuss the situation. We have come through so much together, I don't want a divorce. But I don't want to die either."

Discussion Probes

Sheba's Story

Profile

Sheba is an Ethiopiar woman, aged 49. She has been in Canada for 10 years, and lives with her husband Me<elle. They have four children (ages 15, 18, 21 and 22). The oldest child is away at university and the other children still live at home.

Talking Points

- **realities of life in Canada:**
  - many changes and how they adapted
  - both husband and wife need to work
  - the journey may not have ended
- **relationship with her community:**
  - volunteers at the health centre; wants to help her community
  - helps new immigrants; sees many problems
- **relationship with her husband:**
  - acknowledges the reality of his other sexual relationships
  - talks about how she feels about these relationships
  - introducing condoms; husband's reaction; how she deals with this
  - coming to terms with the realities of HIV/AIDS
  - feeling strong and proud
- **relationship with children**
  - regrets over lost culture
  - how the older child is returning to his culture; growing up proud

Sheba's Story

"My name is Sheba and I have lived in Canada for 10 years now. It seems so long ago that we left our homeland ... the children were very young, and for my husband and I it was a lifetime ago. Our journey has been very difficult ... we have made so many changes. At first, it was all the new things to get used to - the cold weather, the strange food, and the language. I still feel embarrassed about my English and like it when I can talk to my friends in our language. It is much easier to express what we are feeling ... sometimes in English there are no words. Now I help the new immigrants with their English and translate for them at the community centre. They are so lost with all the changes, and it helps them that I understand how they feel. It makes me feel good too ... at home, our community was so close, and I want to help my community here ... it is important to take care of each other."

"When we first came here, we felt like we had lost everything ... our beautiful home, our friends and families, our business. We only had the memories of our old lives. For a long time we felt like we didn't belong to this new country - it is hard to belong when you have no place of your own to live, people do not accept your qualifications for a job, you can't understand what people are saying, and you don't know how to solve your problems anymore. For a long time, I felt like I was lost ... my husband too."

" Now it is easier for us because both my husband and I have found work. It took so long and we had nearly given up hope. This was a very bad time for us ... my husband was always angry because he no longer felt that he was respected as head of our family. At home, he was the one to earn the money, but here everything changed. No one wanted him to work and for us to survive I had to look for a job. It was very hard for me to work all day and come home to do all the cooking and cleaning and be with the children. I was always tired and worried and we had many arguments because he didn't want to help. He was so depressed about being unemployed and missed home so much. I didn't know what to do, and a friend told me they could help at the health centre. I didn't want to go at first because I didn't know the people and it is hard to talk about private things.

Sheba's story....

"But when the health worker told me how her husband treated her it was easier to tell her my story. She helped me understand my husband and we worked out ways to make things better."

"There have been many changes in our relationship. I always knew that he was with other women besides me, but we never spoke about it. One time when I was at the health centre, the health worker told me about HIV and how my life might be in danger if my husband was having sex with other women. She told me how condoms could protect me and showed me how they work. It was embarrassing to talk of such private things at first, but she made jokes and we were laughing. We practised together how to use them and how I would talk to my husband."

"It was a long time before I got the courage to talk to him, and he was very angry and said I didn't trust him. I didn't mention it again for a while, but the more I thought about it, the more it made me angry that he was risking our lives. It wasn't just that I was unhappy and jealous about his affairs, even though he did deny them. It was just that I realized my life, and his, were more important than his flirtations. I was being realistic about what could happen ... there wasn't much choice. So, I went back to the health centre and got some pamphlets about the problem of HIV in our community and some condoms and brought them home. He didn't like me to talk about it, but he saw how difficult it was for me and how I was showing him that I cared about our lives, not just his other relationships. I think he was surprised that I was not just being a jealous wife and that I would do this thing. In the end I think he respects me more and thinks more about his family."

"For me, all these experiences have made me feel strong. The freedom I have in my new country is good; it has given me new experiences as a woman. When we first came here, I was even afraid to go out and work, but now, when I see what I have done and what I have survived, it makes me proud. Now, when I work in the community with the new immigrants, I am also proud when I see how strong we are together."

Sheba's story continues.....

Sheba's story....

"*For my children, we worry that they do not have our traditional values. They are growing up with the values of their new country and it makes us afraid for them. We talk with them about the things we think are important ... things like respect and following the religious teachings. It is important to talk about these things, even when they don't want to hear it. For many years our oldest boy pushed our ideas away and tried hard to be like his Canadian friends and we thought he was lost. But now, when he comes home from university, he asks many questions and we can see that he is becoming proud of his traditions. We are all changing and growing, and our journey is not over.*"

Discussion Probes

Mekelle's Story

Profile

Mekelle is a 50 year old Ethiopian man, who has been in Canada 10 years. He is married to Sheba (the woman in the previous story), and they have four children ages 15, 18, 21, 22. The three youngest still live at home and the oldest is away at university.

Talking Points

- ► realities of life in Canada:
  - unemployment; frustration and depression
  - missing home and family
- ► relationship with his community:
  - help with his job seeking
  - network at the community centre
- ► relationship with his wife:
  - family conflict over housework
  - lack of respect
  - other sexual relationships
  - vulnerability to HIV
  - condom use
  - new respect for wife
  - the importance of communication

Mekelle's Story

"My name is Mekelle, and my family and I have been in Canada for 10 years. Since we have left Africa our lives have changed completely. I still dream of my homeland and seeing our families ... the loneliness is always there. Some of the men have gone there for visits and bring us news, and they say things have changed. When I think about maybe going back, I look at my children who don't remember and don't feel the same ... and I know they have a better chance for their lives here, but it makes me sad to think they cannot know my homeland as I do. Even my wife and I are changed, but we cannot forget the way it was."

"When we first came here it was very confusing and stressful. We had to find a place to live, and deal with immigration, and find a job. That was the hardest part. Back home, you go to school and get the qualifications and get the job. Here, that isn't good enough, and you have to have Canadian experience. How can you get experience if you can't get a job? I had my own business back home, but here, they don't want to help you get started again. So eventually my friends at the community centre helped me get a job in a parking lot and then driving a cab. It was hard to do this, but better than not working."

"I used to think my wife didn't respect me because she was working and I wasn't, and she wanted me to do her work in the house. We had many arguments and things were very bad. I was afraid she would go and ask for divorce like the other women ... they get a taste of freedom from the new culture and they think they do not need a husband. Sometimes things got so bad I would hit her... she would go to stay with her friend, but they would come back the next day and things would continue. Strange, but she would always want to discuss what happened. After a while I realized that what I was doing wrong, and that I was angry because I had lost myself. My wife told me that she would fight with me because she was so tired from working all the time and worrying about the children and all the stress, but she still respected me even though I didn't earn the money. Her friend from the health centre said it was important for us to take care of each other, especially when we had been through so much."

Mekelle's story continues...

Mekelle's story...

" Another thing that caused us problems was my girlfriends." One day my wife said if I was sleeping with other women, I could get HIV and then give it to her and we would both die. I got angry because I didn't want to admit about the affairs. She didn't trust me, and I guess she was right. Just the same, I was afraid of what would really happen if she found out for sure, so I pretended that there were no other women. But one day I came home and she showed me a pamphlet she got from the health centre about AIDS in our community. It said that HIV is not just a disease of homosexuals and prostitutes like we think it is, and that we can all get it if we don't have safer sex. I thought about the women I had slept with ... I didn't know anything about them and who else they had been with. They might even have dated men from outside the community. I thought about how it would be if I got HIV and infected my Sheba, and I knew she was right about the condoms. But I still couldn't let her know about the other women ... it was too hard to admit and I was afraid she would be angry."

"The next thing I knew, she gives me some condoms! I was so shocked that she would even think of this that I don't even remember what I said. Somehow it was out in the open that if they were ever needed, here they were, and she expected me to use them. I could see how scared she was to do this, to stand up to her husband, but how strong she was about it too. I have to listen. Now when I talk with the men about things at the community centre, I tell them that being married doesn't prevent AIDS, because even if you are married you see a beautiful girl and you may want to make love with her, you have to use a condom or you may get AIDS and infect your wife. I think about my wife's courage, and I have a great respect for her for this, and for showing me that she valued our lives and relationship so much. And I make sure there are always the same number of condoms in the drawer."

Discussion Probes

Young Adults' Stories

Profile

These are the stories of two young men - Kareem and Suju, and their female friends Anna and Shamis. They have come from Somalia, Ethiopia and Eritrea and have lived in Canada for about four years. They met and became friends through their high school and spend time helping other new immigrants from Africa learn about their new country. The boys work at various part-time jobs and go to College. The girls work full time at a restaurant and still live at home.

Talking Points

- ▸ **realities of life in Canada:**
  - leaving family at home and living with relatives
  - the journey from Africa
  - different values - conflict with parents
  - language barriers
- ▸ **relationship with their community:**
  - helping the new immigrant kids
- ▸ **learning about sex**
  - cultural expectations
  - what really happens; learning from school and friends
- ▸ **talking about HIV/AIDS**
  - what makes you vulnerable - *qat* and alcohol; misconceptions
  - condom use
  - how HIV affects relationships
  - attitudes of community

The Young Adults' Stories - Kareem, Suju, Anna, and Shamis

"My name is Kareem. I am with my good friends Suju, Anna, and Shamis ... we usually hang out together. In our spare time we work with a group of teenagers at the high school who are new to Canada. We are all from Africa and have been here about the same length of time. We feel close in many ways because we are all new immigrants and have struggled with many of the same problems. I am here by myself ... I came to my uncle in Canada, but my parents and brothers and sisters are still back home. My relatives here are trying to find money to send for them. When I left home, I went to a refugee camp in Kenya, and then to Italy. For Suju it was the same story, except he went to Russia too. It is a different kind of life for us here ... back home the parents decide the future of their children ... here I have to take charge of my life ... cooking, budgeting, paying rent and so on. We have to think about parents, sisters, friends, relatives who are not with us ... Canadian youth only need to think about their own lives. It is very hard and lonely for us. Suju and I spend a lot of time with Anna and Shamis, and their families have practically adopted us. The girls complain about living with their parents, and this has its problems, but for us, it is something we envy."

"Right, Kareem, you just try living with people who won't let you go out at night alone." Shamis interrupts. "My parents think that you finish university, then you get married, and you are not supposed to know about boys and sex. There is a lot of pressure to succeed and get married, but you don't even know what you are in for. I learned all about sex from my friends ... all that stuff about HIV and condoms. Mind you, a lot of my friends are really stupid when it comes to sex. I had a friend who had sex three times and each time the condom broke! But even if they don't know everything, it is easier to talk with your friends. At home it is taboo."

"Yeah, it is much easier to talk to your friends, and not just because of the language," Anna agrees. "My mother keeps telling me when a woman gets married she is supposed to be a virgin. Eventually she used a book to talk to me about sex."

Young adults' stories.....

She was so embarrassed. Parents don't want their daughters to have sex, but there is leeway for you boys. The tendency here is that boys' dating and cohabitation is tolerated while for the girls it is something shameful and a sin. We have to keep a relationship with a boy secret. If a boy were to take advantage of any of my sisters or myself, my father would kill him. My father is really protective. My mother sees that there are different values here, but she is always shocked when I tell her what I hear from my friends."

"Yeah, like what?" Suju asks with a wicked grin. He likes to hear the latest gossip.

"Well, here in Canada being virgin at the age of 14 is almost ridiculous. To be accepted among your peers you should have had a sex experience. This concept is having an impact on Somali boys who think that they cannot build a serious relationship with girls without having sex with her."

Anna adds, "There is a misconception, especially among boys, on understanding the spirit of dating. They think that if you accept a date you are a 'modern girl', which means ready to have sex. Boys expect that you may accept their sexual approach. I think that more than girls, boys need to be more educated on the subject, don't you Kareem?"

"I know my young cousin is getting busy having sex with girls right now, so I try to give a man-to-man talk every so often and let him know that while sex is fun, it's serious, and he can't just assume that a girl is willing. Whenever I get condoms, or if I have the money, I'll buy him condoms so he can protect himself and be responsible."

Kareem laughs at the look of disbelief on Anna's face.

Young adults' stories...

"That's a cool thing to do Kareem," Suju says. "I wish I'd had an older cousin like you! We learned how to use condoms at school, but there was no way I could walk into a store and buy them."

"Kids these days use them, but they still have to keep it a secret. No way they can let their parents find them."

"Yeah, I know," Shamis agrees. "But some young people are comfortable picking up condoms. Others feel that it is not part of their problem. One guy told me that he uses condoms whenever he has sex with Canadians, but he doesn't need to with our own people ... he thinks AIDS is not a risk in our community ... it is a white person's disease."

Kareem shakes his head. "Oh man! I want to say to some of my friends who don't think it's a problem, 'I can't save your life for you, you have to want to save your own life.'"

Anna, who has been very quiet until now, chips in, "This is all OK for you guys, but for me, sex comes after marriage. Every girl has to pay attention to the prestige of the family. My boyfriend wants to marry and we are allowed to date, but we can't kiss or touch."

"Yes, I think there are many like you Anna." Kareem says, "Abstinence is an option, but not for everyone. And it's true what you say about boys. But now even the girls are buying condoms so they can offer them to a friend. It's socially acceptable now to tell a friend to wear a condom."

"I think it's good that women buy condoms...it's liberating," Shamis joins in. "I think as women you should be prepared. Condoms protect you both, so you should both be responsible." She feels strongly about the responsibility thing. "Men think it is macho to have unsafe sex (to not wear condoms). Many don't do anything. They let the women worry about it."

Young adults' stories ...

"I want to tell them 'It's no big deal guys, just wear the condom!' It is so selfish when they put something like that ahead of someone's life. And that whole thing about there being less pleasure with the condom ... it makes me really mad. Depending on how it is used, it can be even more pleasurable."

Suju agrees. "I know, it is really scary. AIDS has made me more selective about who I get involved with. I'll buy condoms and be prepared, rather than take a chance."

Shamis is still steaming over the way many guys look at sex and says, "For men, sex is sex, but for women it is something else too...sex is love."

Suju, who likes to go to qat parties and dancing with his friends, chuckles and says, "Some girls behave just like men and go to clubs to pick up guys, you know."

Kareem grins back and wonders, "Why can't I ever meet some of those girls?"

Shamis gives him a poke and responds to Suju, "Well, it's OK if girls want sex, but it depends on both people. You need to talk it out ... there has to be communication. Many times a couple will talk to their friends rather than each other. Sex should be shared. Most guys just want to score."

"I don't know, Shamis, " Kareem says thoughtfully. "I think we are all realizing that we have to protect ourselves. Accepting condoms is a new way of looking at sexuality. It's ironic, but I think AIDS has made relationships better. People are much more cautious. They are becoming much more committed."

Young adults' stories continue...

Young adults' stories ...

> *"I think we need to become more tolerant too," Suju adds. "What bothers me a lot is how we treat people who get HIV. Before I knew anything about the virus I would stay away from the person, but now I know something about it, I see that attitude is wrong. Now I would probably help the person, or at least treat him the same way I treated him before he got the disease. What if it were one of us? I think our community needs to talk about this more. We need to take care of each other."*

Discussion Probes

Menelik's Story

Profile

Menelik is an Ethiopian man, 34 years old, who is gay. He lives with his wife and two small children, ages 5 and 7. He and his family have been in Canada for 3 years.

Talking Points

- ► **realities of life in Canada:**
  - unemployment
  - greater freedom to express sexual identity
- ► **community attitudes to homosexuals**
  - ostracism, violence
  - religious/cultural values
  - the reality of homosexuality and bisexuality in the community
- ► **relationship with his wife:**
  - dual life
  - HIV and personal responsibility
- ► **relationship with children**
  - worries about losing culture
  - worries about losing children

Menelik's Story

"My name is Menelik. My wife and I came to Canada three years ago with our two small children. Our parents and many of our friends are still at home. We are always lonely for them and we are sad that the grandparents do not see the little ones. It is hard for my wife too because she does not have the babysitters like she would at home. But we are trying to make new lives and make adjustment to the changes. The hardest thing is the work. I have no job since last summer and I always worry about looking after my family. My wife understands how hard it is for me and tries not to show how worried she is too. But I know. She sometimes can find work and with the welfare and help from our friends we manage."

"We shared an apartment with one family for a while, and they were able to give us the clothing from their children. You need so many different clothes in this country! Now we have our own apartment which is closer to the children's school, and it is easier to get them there. My wife has trouble with the teachers ... we don't understand them very well and it is hard to find out what is going on with your children. But they are learning English so fast ... they don't want to speak our language anymore. We keep trying because we are worried they will lose everything about our culture."

"Now I want to tell you about something that is very hard for me, but it is important for our community that we talk about this. What I want to tell you is that I am homosexual. Yes, I have a wife and we love each other, and my children, they are the best thing in my life. But I hide my homosexuality this way because the community would not accept me; they do not tolerate it. I can see how they think about homosexuals, so how can I tell them? The hardest part was admitting to myself that I was homosexual."

"They say we do not have homosexuals in our culture because our religion has saved us from that, but they are wrong. We **do** have homosexuals in our culture ... our religion has nothing to do with it. When I was a soldier back home, I had some gay friends, and here I also know a group of friends like me in our community. Some day I will tell you how difficult it was to find them. They say that people like us are sinners, but I believe in my God, and I pray, and live according to the teachings, so how can they say those things?"

Menelik's story continues....

Menelik's story ....

"We are all afraid to be open about this because some people say they would kill us for being gay - there are even songs that tell people to be violent towards gays. So we are forced to be bisexual if we want to be accepted by the community. We will have a monogamous relationship with a woman and hide the other side. I wish homosexuality would become acceptable in my culture because it is something I cannot change. It is very difficult to know one's sexuality when you have such a fear of being isolated. This hiding of yourself makes you feel like you are not your true person, that your spirit is not in harmony. I want to be myself, but my world will not allow it. It is a constant struggle which causes me a deep sadness."

"And it makes me angry at my community that it is so intolerant, especially when I see how the Canadian homosexuals are. Last year there was even a parade where all the gay people could walk around in public and show everyone! And they have lounges in the high school for gays, lesbians and bisexuals. Here, there are more places I can go to meet people and places to be more open with relationships. It is good to be with people who understand your fear and accept you. It took a long time for Canadians to accept the gay people who live in their communities, but now they almost have the same rights as everyone else."

"I think if we start to talk about it in our community it will slowly start to happen for us too. Some people I know feel that if we are open in talking about homosexuality, then we are very corrupted by the new culture, not liberated. But I think when people see and hear and get to know homosexuals, they will lose their fear and accept us. More people need to speak up about how they think it is wrong not to accept people the way they are."

"But that is not the only reason I want to talk about homosexuality. We also need to talk about it because when our community thinks homosexuality does not exist, we make a danger for ourselves. People think that HIV is only a disease for homosexuals and prostitutes so they don't have to worry, since they think we do not have those people.

Menelik's story continues....

Menelik's story ....

*"But HIV is a problem for **everybody**, not just homosexuals and prostitutes, so they are wrong about HIV and wrong about homosexuals and prostitutes. They need to realize that everyone is open to getting HIV if they don't protect themselves. That is why I speak up."*

Discussion Probes

Aseb's Story

Profile

Aseb is a 30 year-old female, who came to Canada eight years ago from Eritrea. She is HIV positive. She was married for six years, but her husband left a few years ago and she hasn't seen h m since. She has a five year old daughter who lives with her.

Talking Points

- ► **realities of life in Canada:**
  - difficulties with language
  - unemployment
- ► **relationship with her community:**
  - community attitudes to HIV
  - isolation and loneliness
  - support group at the health centre
- ► **relationship with her husband:**
  - family conflict
  - extramarital relationships
  - economic dependency
  - vulnerability to HIV
- ► **relationship with child**
  - changing values
  - worry about future

Aseb's Story

"My name is Aseb. I am 30 years old, and came to Canada eight years ago. When I came, I was just a young woman and very excited to be coming here to go to school ... it was a big adventure. It was very different from my home, and I stayed with relatives who had come here a few years before, and they helped me get settled and figure out how to live in such a different culture."

"I missed my family and friends back home, but then I started dating a man who was from our community and I wasn't as lonely. We got married a year or so later and I had my daughter the next year. There were so many adjustments to make. We had no money: I couldn't work because there was no day care, and my husband could only find work occasionally. He was really frustrated by being unemployed ... he had been trying for several years to find something permanent."

" Anyhow, we used to fight all the time because of the stress, and our relationship was not very good. He used to spend all his time at his friend's apartment doing 'qat' and drinking. I knew he was with other women because sometimes he didn't come home for a couple of days. I started to worry about HIV after hearing about it from the health worker, and decided to talk to my husband about how he should be protecting himself and me. He said he didn't like to wear condoms and wouldn't listen to me. I didn't know what to do ... I was afraid if I made a big deal of it that he would get really angry and leave me, and then how would I live? It would have been better if he had, because now he's gone, and I'm HIV positive and on my own with this disease. I didn't know how to protect myself and he didn't care, so this is what happened. You have to protect yourself, even if the man won't. Now I know, but it is too late."

"I was so scared to get tested after he left, but the health worker said I should for my own peace of mind, and she told me the results would be confidential. I was so worried, not just for me, but for my daughter, because I am the only one she has. When the test was positive, they checked to make sure, and it was still positive."

Aseb's story continues...

Aseb's story...

They were very kind to me when the results came back and told me what would happen and how I could stay as healthy as possible. It was like my world fell apart when I found out, and I felt so alone. All I could think about was my little girl without her mother."

"I couldn't tell anyone in the community because the community isolates and abandons anyone with AIDS. They think if you get HIV you get it from sinning, that it is God's punishment. They don't think you can be an innocent wife with a husband who is a beast. They are the ones who are punishing me, not God."

"One day, when I was in despair, I told my good friends. They didn't know what to say and were really shocked. They started to treat me differently and it made me really angry. It is so cruel how people treat you when they think you are sick. I am no different ... I am the same person I was before. I just have HIV. What they don't see is that I am no different from them. Many of my friends have husbands like mine, who go with other women and are not being responsible for their lives. They will probably end up like me too. They don't see that all women must protect themselves and be strong in their lives."

"And this is not just for women ... no one can know the complete picture of the sexual life of a partner. They might have slept with lots of different people and you wouldn't know. And it only takes one. You cannot trust ... if you trust, you get AIDS."

"So, in the last few years I have managed to stay pretty healthy, but I know this will not last. Every week I go to the health centre to help the nurses talk with people who are new HIV cases. They need to talk to someone who knows what they are feeling ... it helps me too, to be with people and talk about our problems and not have to hide who we are. It makes me sad that some people think they will catch AIDS by looking at us or touching us. Some people say their relatives even avoid them and won't touch them. We are very lonely and isolated."

Aseb's story continues...

Aseb's story continues...

> *"Many people in our community say that HIV is not a problem for us, that it is only a disease of the whites. They pretend not to see those of us who have HIV, but we want the community to know we exist. We need to talk about it so they will see the reality. One of my friends who died from AIDS didn't care what the community thought, and she actually led some workshops on AIDS. I am willing to talk ... I want to tell my story so others will know how it can happen to them too."*

Discussion Probes

Issak's Story

Profile

Issak is 34 year old man from Somalia. He is single and lives with some other single men to save on rent. He has been in Canada for four years. He works at odd jobs and saves money so he can bring his parents and brothers over.

Talking Points

- ► **realities of life in Canada:**
  - • unemployment
  - • changing values
  - • missing home
  - • feeling lost
- ► **relationship with his community:**
  - • networks with friends
- ► **male/female relationships:**
  - • dating
  - • vulnerability to HIV
  - • cross-cultural dating
  - • freedom of women
  - • condom use

Issak's Story

"My name is Issak, and I came to Canada four years ago from Somalia. It took me two years to get here because I was in refugee camps in Kenya and Italy before I could come here. I don't like to think about that time ... it bruised my mind ... such terrible things happened at home that I want to forget. It is impossible though because I miss my home and the town where my family lived ... I feel lost and this feeling will remain with me forever. Even though Canada is like a haven for refugees, still we feel we miss something. And when your family is scattered everywhere, and you might not see them again, it is sometimes too much to bear."

"Here, I do not feel like I belong to anything. It is so hard to adapt or take to the Canadian way of life. I wear the Canadian clothes, and eat the food, but I do not like the values. We used to have a focus on family values ... now people are scared of marriage ... marriage has lost its respect, both among males and females. Singles boast they are going out with four or five women. Adults are acting like boys and teens. We do not uphold our culture."

"However, Somalis in Somalia are also changing because I visited last month. Somalia is changed totally ... great damage has been done to the country and its people by the civil war. I get together with my friends to talk about life back home. We sit with a coffee for hours and talk about the politics and the starvation and the civil war that has ravaged our homeland and how one day we might go back."

"At home I had a good job as a teacher, but right now I work in the video store during the day and teach swimming at night. It is hard to take this, when no one wants you because you do not have Canadian qualifications and experience. You feel worthless. I don't know who I am anymore. My friends have the same problem, and they are saying it is discrimination. We fear the discrimination here ... on the surface it looks like it doesn't exist, but it does and it is humiliating."

Issak's story continues....

Issak's story ....

"But I miss my teaching and I try to be with the young people at the community centre whenever I can. We play soccer on the weekend and then bring out our music. It is a great time and I love the kids. I don't like to see them becoming like the Canadian teens ... they do not respect, and they will be lost if we do not work to teach them our culture. I try to speak to them in Somali and they will do it for a while, but they get impatient. I try to teach them to be proud through the music and stories of home. They need to hear how strong their parents are to have made their journeys ... the Canadians cannot imagine how it was for us. But also I tell them that this country has many good things for them, but just that they should not forget themselves."

"I think I am like a hero to some of the boys ... they ask me about the girls I met in the refugee camps and what happens when I go to the clubs or parties here. They know so much about sex from school and are not shy to talk ... nothing is private! And it's not just the boys either. What they tell me about the girls, it is no wonder the boys want to date. Next week I am going to talk to them about HIV and being responsible ... they probably have heard it already, but it might mean more if it comes from me."

"I think I will tell them about my foolishness with all those women and prostitutes in the camp, and how I worried I had HIV and was too afraid to be tested because of the stigma in our community. I have learned that it isn't worth it to be so afraid that you might die. It is real, even if they say it is not in our community, I know it is. My friend Nuh, whom I share my apartment with, thought that because he and his partner felt healthy there was no reason to use a condom, but he found out last week that he was positive. I will stick with him because we have come through so much together and need to take care of each other ... it doesn't matter to me. We used to think that we only needed to wear condoms with the Canadians, but now we know it is also in our community."

Issak's story continues....

Issak's story ....

"Sometimes we have been exposed to the disease before we even come here, and once we are here we are very lonely ... you want to have a relationship. And so it goes. No one is safe unless they abstain, and not everyone can do that."

"I like to go out to the clubs, and sometimes the girls there are pretty outgoing and make it clear they are interested in more than dancing. I try to stay away from these girls ... they have had too many partners. There is a lot of freedom here for women, and generally I think it is better for the women to have this freedom. But I am more cautious and selective about who I date now. At the 'qat' parties there are always situations where someone drinks and becomes hot and makes love ... usually without thinking about using a condom. Both people need to think about it and protect themselves. I try not to let it get to that point. That kind of life is too risky."

"So here I am...trying to piece a life together. One day, I want to settle down and have my own kids. I might even get to be a teacher again. It might not be here...it could be anywhere...the journey never ends."

Discussion Probes

Community Resources

There are may community-based organisations, agencies, businesses, volunteer groups and individuals who can be of help to you or to whom you can refer your clients. Here are some useful addresses and telephone numbers you may need to get information on HIV/AIDS. You can add to these as you develop a network of people who are good resources.

City of Toronto Department of Public Health   Phone 392-0898
1884 Davenport Rd.,   Fax   591-7317
Toronto, Ontario   M6N 4Y2

Africans United to Control AIDS   Phone 591-7600
339 Bloor St. West, Suite 219   Fax   591-7317
Toronto, Ontario   M5S 1W8

Etobicoke Health Department   Phone 394-8792
399 The West Mall   Fax   394-8792
Etobicoke, Ontario M9C 2Y2

AIDS Hotline   Phone 392-2347

Africans in Partnership Against AIDS   Phone 392-9943
15 A Elm St. Suite 105   Fax   340-1219
Toronto, Ontario M5G 1H1

AIDS Committee of Toronto   Phone 340-8484
399 Church St.   Fax   340-8224
Toronto, Ontario M5B 2J6

Hassle Free Clinics (Anonymous testing)   Phone (Men) 922-0603
556 Church St., Toronto   (Women) 922-0566

Alexander Park Health Centre(Anon. Testing)   Phone 703-0985
64 Augusta Ave. Toronto

Birth Control and STD Info Centre (Anon. Testing)   Phone 789-4541
2828 Bathurst, #501, North York

Conclusion

Coming to the end of this handbook is as much about beginnings as it is about endings. The handbook itself is only the beginning of a larger resource you will create as you add your own voice and experience to those of others and make the handbook your own. In a larger context, however, it is about the possibilities for new beginnings and understandings in people's lives.

As you work with the knowledge, methods and skills outlined in the handbook, you are embarking on a journey which has the potential to transform the lives of many people, including your own. Not only will you be helping people deal with the practical difficulties, moral dilemmas, fears and frustrations which they experience in their disrupted and fragmented lives, but you will also be helping people rediscover personal capabilities, gain confidence and consider new possibilities for living. You will be helping people on difficult journeys move from the way things are, to the way things could be – helping them transform their social and personal realities as they try to understand and give meaning to their lives.

This might sound at first like a rather overwhelming task. As refugees of civil war and political exile, making sense of all that has happened to us on our journey is painful and bewildering; so much has been lost or left behind. However, as a health and outreach worker using participatory methods, you can help people see that even with all this anguish there is also much courage, strength, and dignity in who we were, and who we are. Our roots are strong, and our values, traditions, relationships, and sense of community are still very much a part of us. They have sustained us and have helped us come this far.

Through your work you will help people rediscover and value these strengths. Your support and understanding will nurture the natural capacities within individuals to think, imagine, explore, care, make decisions and act – enabling them to re-examine, re-build and transform their lives. You are thus an important part of an active process which is about change – your work can create opportunities for hope in people and in our communities.

You are well equipped to face this challenge because of your own experiences, knowledge and compassion. Value these and use them often for they will serve you well, as you begin the next segment of your own journey. For

as you do this work of helping others reshape their lives and restore their well-being, the experience is sure to transform your own.

In the end, the hope is for other voices in our communities to join with yours and speak with new awareness about the issues that affect their health. The goal, as you nudge people toward this new understanding, is that they might begin to consider what needs to change, plan what to do and how to do it, take action themselves and assess the results. In building on the strengths in our communities, finding new ideas, trying them out and modifying them in the light of this experience, people can work together to plan health promotion programs based on their own reflections. As this happens, you will be helping to move people toward sexual health and well-being in the context of their daily lives, their relationships, and their community.

And, as we tell and live the stories which are our lives, we learn to understand and value what it is to be human, in ourselves and others, and to care of one another on our journey through life together.

EPILOGUE

Now that you have read the **Many Voices** handbook and have a sense of how the approach looks in practice, I would like to reflect on the meaning of doing the work and its significance in a wider context. More specifically, I will discuss its contributions to intervention science, and its implications for thinking about ethnographic representation and anthropology's future project.

6.1   Contributions to intervention science

Assessing the significance or success of such a work is a difficult task, given that it is very much a work in progress. Its original goals were to produce a resource for HIV prevention which would enable the generation of community-based HIV/AIDS prevention programs; to explore representational issues relating to how we communicate our research evidence; and through the process of doing this work, contribute to the thinking about intervention science and what is needed to do this work well. Did it meet these goals? Certainly, it produced a resource which can be used by communities as they seek to develop HIV prevention programs. And clearly, it wrestled with issues of representation and offers an experimental approach to translating our research evidence into practise. Through these achievements, it advances a model from lessons learned of what we *think* is needed to do successful intervention work. It demonstrates an approach which uses a broader evidence base, including both

scientific and experiential evidence in the form of people's stories; it incorporates a broader understanding of the relationship between risk, vulnerability and responsibility; it involves the community in the design, implementation and evaluation of interventions; it espouses equitable research partnerships; and it uses a research process which is dialogical and participatory, with narrative stories as a tool for generating dialogue. As this model is implemented and evaluated, it will inevitably produce its own lessons learned. The voices of others – community members, health workers, and other social researchers – will help us learn what contribution it has made to intervention science.

In a bigger context, this highlights again the need for us to find ways of communicating our research evidence to others, of sharing our experiences in health and development work to support those doing similar work. It is vital to those striving to make a difference – whether these are social researchers, community leaders, and smaller non-governmental organisations working at the grass-roots level, or government, university, corporate and larger non-governmental organisations working in partnership at a more macro-level – that we build on and disseminate the knowledge we generate with our work and contribute to the thinking of intervention science. I hope the lessons learned [1], and the important lessons yet to be learned with the *Many Voices* project, in a small way, will do this.

6.2   The meaning of the work in *Many Voices*

Thinking about the meaning of the work in *Many Voices* is also a very complex undertaking because it can be viewed from a variety of perspectives. So, I will reflect on the question of meaning by looking at the product of the research, the *Many Voices in Dialogue* handbook, through an anthropological lens and view it as a multi-vocal

symbol – that is, for the variety of meanings it might embody for different people in different contexts.

In a material sense, the handbook is a practical and useful product of research, but in the context of intervention science, it symbolizes a partnership between researchers, community participants, funding agencies, and non-government organizations. It signals an approach to looking at research that acknowledges the necessity of partnerships and is open to looking for new ways to meet the challenges facing individuals, communities, researchers and funders. It represents an attempt at breaking down barriers, creating questions, and stimulating dialogue which will help us move forward and learn together as partners in research, and human beings in a wider social project.

To community members, the handbook could symbolize many things – from hope for a way to help their communities, to a tangible show of support and understanding from outsiders. I hope that it symbolizes possibilities for working together to overcome dispiriting life situations that have been difficult to change. The question of what the project means to the community is one I hope to explore in the evaluation phase.

To the researchers, however, it is much more than just a handbook. It symbolizes an opportunity to be involved in work that has the potential to make a difference. It symbolizes an approach to life and work that is about caring, compassion, understanding, learning and hope. It is also about valuing individuals and their capacity for enduring, surviving, and imagining better futures. This is an openness of being that recognizes ourselves in other individuals, and acknowledges the social implications of our common humanity. Thus, to me, the handbook symbolizes a search

for a way to practice our work – an ethical anthropology – a kind of work which

expresses this way of being, supports individuals who share a fragile space, and

through coming to know these people as individuals, contributes to our understanding

of what it means to be human, and brings about a wider social discourse on how we

want to live.

It is in this wider context that I would now like to place the work of *Many Voices*,

and focus the discussion on what I see as anthropology's project, particularly as this

relates to ethnography, in the coming years. Central to this project of what could be

called moral ethnography are two of the two themes embodied in the Many Voices

project which I have just described – understanding what it means to be human and

generating a unique social discourse on what kind of world we want to live in. I will

ground this discussion in the work of a number of contemporary writers and

philosophers and show how their thinking might inform and support our discipline's

search for relevance and revitalization at the turn of the 21st century.

6.3   Ethnography's changing project

The ideas underlying the *Many Voices* project – those relating to intervention

science, the strategy of stories, the experimentation with ethnography, and praxis-

oriented anthropology (all discussed earlier in the Prologue) – in part reflect the post-

modern de-constructive influences which have affected anthropology over the last

fifteen to twenty years. This generalized shift away from the modernist paradigm has

influenced thinking across many other disciplines as well and can be seen in literary

theory, cultural studies, psychology, history, sociology and philosophy, often blurring

the boundaries among all of us [2]. The turn from modernism has changed thinking

about such things as objectivity, rationality, truth, and ethical principles, and moved inquiry from an objective search for the 'really real' to more nuanced interpretive meaning-making. It has shifted the academic gaze from looking at the way things are, to the way they might be, and helped us see privileged structures of hierarchy, power and knowledge. This re-visioning has engendered a profoundly different way of looking at our rapidly changing world and has caused us look for new relevance in our work – what Wallman (1997) has called an 'appropriate anthropology'.

But post-modernist sensibilities are not the only influences behind the *Many Voices* handbook. My thinking about the handbook specifically, and what it represents in a larger context, has also been affected by a number of contemporary moral philosophers and writers [3], whose ideas resonate with where I instinctively see our work going. Their thinking is reflected in the themes which run throughout the handbook and thesis, and I will draw attention to the more central aspects here.

Of the contemporary philosophers, the ideas of Richard Rorty (1989), mentioned briefly in the Prologue, and a number of feminist philosophers, including moral theorists including Jaggar (1992) and Benhabib (1992) are particularly relevant. In a general sense, their thinking embraces an openness to possibilities, a sensitivity to the contexts in which people live and an understanding about the contingencies that affect our lives. Their philosophical stances engender caring, compassion, and hope, and focus attention on the creativity, capability, agency and intrinsic value of individual selves, while reminding us of the inescapable necessity and significance of our social relationships. On a practical level, their thinking urges us to engage with humility and respect the lives of others. It illuminates our common humanity and gives us cause to reflect on, and have conversations about, the fundamental questions of how we should

carry out our lives.

This brings us to an interesting place in our search for relevance. If our work is informed by post-modern influences, an ethic of kindness and community, an understanding and appreciation of our common humanity, and awareness of our moral responsibilities, we will be doing ethical research. This is a kind of practise that works toward a better world and helps us understand the larger questions about what it means to be human. It thoughtfully considers and responds to the questions posed earlier: 'for whom?'; 'about whom?'; 'by whom?'; and 'by what method?'. However, the question 'for what ends?' is still not completely answered. There remains a bigger purpose for why we do what we do, and this relates to the second theme of what I consider to be our future project.

A reading of Jaggar (1992) helped me think about this. As a contemporary moral theorist, she is concerned with understanding individual moral reasoning and contextualizing what are often difficult ethical decisions. However, while she acknowledges the importance of understanding particular situations in their particular contexts, she struggles with the need to move from individual moral reasoning to social consensus about moral issues – the ethicist's problem of getting from description to prescription.

I see in anthropology a parallel need to move from description of individual experience toward a social discourse on human issues. We can describe and analyse with our research in order to understand, but then what do we do with this knowledge? Again, 'for what ends?' On one level, we can, and do, apply it to real world problems. We are also concerned with representing in it ways that help people think about what this knowledge might mean to them as individuals – revealing possibilities and

deepening their understanding of our common humanity. However, there could be

another project for our work which raises it to another level: we could articulate it in a

social context, promoting moral conversations that speak to questions of 'what kind of

world do we want to live in?'

Should this be our business? Robert Bellah and colleagues (1985) offer an

argument as to why it should.

> "Each generation, no matter how much it learns from
> tradition or how much it is aware that...it cannot forget its
> founders, must still create a new social science for new
> realities." (:297)

In *Habits of the Heart*, Bellah et al suggest that social science needs to return to

its roots and close association with moral philosophy. At one time, before

professionalization and separation of academic disciplines, there were few disciplinary

boundaries and social science was actually taught as moral philosophy [4]. As a result,

social researchers looked, among other things, for moral and political meaning in what

they studied, and their work was debated and criticized in the public sphere. With

specialization, general social debate about scholarly ideas left the public arena and

became the privileged knowledge of intellectuals, debated behind narrowly defined

academic walls. This withdrawal by scholars from the public sphere, the authors feel, is

an abdication of our public responsibility as social scientists. They say today's realities

call for a re-invention of social science as public philosophy – a philosophical social

science which transcends disciplinary boundaries, particularly those which exist

between the social sciences and the humanities. Such a social science, they suggest,

would "hold up a mirror to society ... make connections that are not obvious...[and] ask

difficult questions" (:301). Our inquiry would probe the philosophical, historical and social aspects of what we study and provide ethical reflection on the evidence, since research "does not exist in a moral vacuum" (:302) and analysis of evidence and moral reasoning operate simultaneously. As public philosophers, then, we would bring our 'scholarly stories' to public consciousness for criticism and engagement in public in dialogue [5].

I see this role of public philosopher as a fundamental part of anthropology's project for the future. If our work and knowledge remain in the academy, we cannot influence social and personal change – and we have important things to say. Our work can give voice to those living on the margins of society, silenced by powerlessness and inequality; it can teach us fundamental lessons about ourselves and of human nature; it can break down walls and create bonds of understanding by showing us how 'under the cloak' we are all the same; it can offer hope by opening us to possibilities and showing us the creative, imaginative and enduring nature of individuals; it can build community by showing us, even as we strive to express our individuality, that we need each other. This is the essence of what Jean Vanier (1998) has called 'becoming human' [6].

So if we accept this role, how do we then begin moral conversations? The recent writing of Denzin (1998) suggests a way, and brings us back to issues of representation and the ethnographic project of the future – the work of moral ethnography.

"Interpretive ethnographic writing in the twenty-first century will move closer to a sacred and critically informed discourse about the moral, human universe ... a new ethics of inquiry." (:xvii)

In his book, *Interpretive Ethnography*, Denzin discusses ethnography's future in a rapidly changing post-modern and post-colonial world, with its blurred boundaries and identities, globalized economies, and borderless flow of people, currency, technology and information. Such shifting and unpredictable realities create challenges to traditional ways of thinking about truth, knowledge, self and community.

This historical moment, Denzin says, requires a new mode of research [7] and a discourse based on a feminist, communitarian moral ethic [8], which sees "dialogical communication [as] the basis of the moral community" (:274). He believes ethnography can be indispensable to this project, and describes what he calls ethnography's "sixth moment" – a socially responsible ethnographic journalism [9] which connects people and their personal concerns, involves readers as active participants, raises public and private awareness, promotes discussion and civic discourse about values, choices and what defines a meaningful life, and moves people to action.

Such an undertaking would require alternative and experimental forms of ethnographic writing, some of which have been mentioned earlier, such as evocative narratives of the self, poetics, performance texts, plays, and ethnographic fictions. Ethnographers, guided by the norms and values of a communitarian ethic, would tell 'moral tales' grounded in the experience of individuals, "... stories people tell one another as they attempt to make sense of the epiphanies or existential turning-point moments in their lives ..." (:xvii). As storytellers, they would "awaken [people's] moral sensibilities" (:xxi), engage them in social dialogue and critique, and move them to action [10] . Ethnography seen this way would become "the moral discourse of the contemporary world" (:xvi) and become a form of 'moral practice'.

Denzin's re-visioning of ethnographic writing clearly supports the argument for

ethnography's future project as public philosophy, and its potential for raising individual

consciousness and promoting moral conversations.

This takes us to a place of relevance and revitalization at the turn of the 21st

century. Through moral ethnography, we can give voice to those 'moral tales' which

help us understand ourselves and our fellow human beings, connecting our local 'moral

worlds' with webs of understanding, compassion and caring. And with particular

attention to how we represent our work, we can bring the voices of others to the public

arena so that they can stimulate and take part in moral conversations about what kind

of society we want.

I would like to think the *Many Voices* handbook is an example of moral

ethnographic writing involving a particular local world. It is guided by and embodies the

values and norms of an ethic of kindness which respects and values individual

experience and acknowledges our common humanity. It works to build bridges of

understanding and support disadvantaged people struggling with difficult situations. It

works to undo structures of hierarchy and power by privileging the stories of individuals

living on the margins of society and creating a place where their voices can be heard.

As part of a participatory process, their 'moral tales' will enter a public space within their

communities, generating new dialogue – moral conversations which will move people to

new understandings about their own lives and those with whom they live. These

conversations may move to a wider public arena as the handbook is read by other

researchers, social service agencies, foundations, and government officials.

6.3   Our human project

Ultimately, however, generating moral conversations is important in an even

larger context. The idea of bringing voices together in a spirit of community to examine, reflect on, question and respond to issues produced by rapidly changing realities is not just a matter for a local project, or even an ethnographic project: it is part of a profoundly human project.

It is a project which involves our basic conceptions about who we are as individuals, and about how we want to live with others as human beings. Our world is in crisis – fractured, wounded and disrupted by such things as poverty, sickness, alienation, violence, and oppression. In the west, our lives are largely driven by individualism and exclusion – qualities that keep us distant from those in need and prevent us from becoming fully human [11]. Somehow we must come to a balance between honouring the autonomy and creative consciousness of the individual and seeking a commitment to the common good. We must somehow find a way to re-awaken people to our shared humanity and an openness to others, so we can work together to find solutions to the suffering, injustice and inequality experienced by our fellow humans and make the world a better place.

Is this a utopian view? Most certainly. People often criticize these "... foolish, so-called utopian ways of the one in their midst who befriends a beggar" (Vanier 1998:71). But this is not just a naive generosity, a wish to 'do good'; it is an enduring faith in humanity and our collective strength, wisdom, experience, compassion and imagination. It is a belief that there are answers to be found when people come together "in the way of the heart" (Vanier 1998:88) [12].

Clearly, in today's reality, we are faced with seemingly insurmountable problems and many issues which probably cannot be solved. However, we can still search for solutions, and I believe that if we are going to find them, they will be in the 'moral

conversations' we have with others in the spirit of community (a common-unity). It brings us to a hard place where there are difficult questions, but when I share this vulnerable space with others, such as people from the Horn of Africa communities or more recently, with those on a PAR project team in Uganda [13], there is a profound sense of communion, respect, and possibility.

One travels to these local moral worlds fearful and uncertain of how to be, as Vanier says, "...at sea with no horizon, in unknown territory without a map" (:80). They are worlds stripped of the familiar, the safe, and the predictable – worlds where there can be no assumptions. If one comes together with strangers, in a state of openness, free of our individualism and protective pretensions, there is a wondrous and profound realization of a common humanity and shared purpose, a connecting in the "way of the heart". This connectedness is transforming, humbling, and fills one with feelings of love and respect – a sense of pure relatedness approaching what feels like the spiritual.

This is a world where the artificial boundaries between academic and professional disciplines, individuals, families, communities, and nations are set aside and we all enter a new place of learning. In this place there is no privileged knowledge, no established ways of knowing, no last word. Instead, we hear many voices and many words – what Gergen (1998:xii) calls "the inspiration of the incomplete", an indeterminacy which is an essential catalyst for the creation of new knowledge. As we listen and talk together, joined in moral conversations about deeply human issues, we bring to one another and to our life situations a different sense of the world that offers new possibilities for seeing, being and journeying together. Creating opportunities for this to happen is our human project.

I see the work related to *Many Voices* as part of this human project. In a

humble way, it is an attempt to engage individuals, including yourself, in moral

conversations about how we want to live and what kind of society we want. The people

from the Horn of Africa who have shared their stories have given us a valuable gift, an

opportunity for us to deepen our understanding about others, our selves and our

shared humanity in the context of our communities and our larger society. As we

reflect on and have conversations about what this means, I hope we will move forward

together in a spirit of caring and community and celebrate the possibilities this

experience brings.

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ENDNOTES

1.   The initial lessons learned from doing this work are perhaps more useful to me as a novice researcher, than as ground-breaking lessons for intervention science. These initial lessons include learning first hand about: the fact that such projects are long-term, time consuming, and cannot be rushed; the issue of contested knowledge (for examples see prologue endnote 32); obstacles to full participation include time, funding, and human resource constrairts; the problems involved with using an existing data base (also discussed in the prologue); the importance of knowing yourself as an ethnographic writer; the importance of being grounded by strong guiding principles with work that is a moving target; the importance of being able to take risks and step out of what you know – making yourself vulnerable; the importance of having faith in the process; the joy of working with the unknown and with others committed to the same ends.

2.   In intervention work, blurring of boundaries is particularly important. Some approaches involve interdisciplinary, multidisciplinary, or transdisciplinary teams of researchers working together to solve health and development problems, with each discipline working from its own perspective on a common problem. More recently Albrecht et al (1996) have expanded this idea and suggested the use of *transcontextual teams*, which include people from non-academic contexts,such as communities, governmental, non-governmental and corporate organisations. Transcontextual teams represent a true blurring of boundaries both within and beyond the walls of academia.

Transcontextual teams have been used by Dr. Dennis Willms and colleagues in what are termed *conceptual events*. These are carefully organized discussions where participants pool their individual understandings of a problem in order to work out a mutually agreed upon explanation. The distinguishing feature of these events is the use of personal narratives – stories – to uncover the hidden logic behind people's responses to health risks. The discussions which follow are rich in possibilities for developing healing scenarios, as participants merge scientific and lay explanations to develop new knowledge. This will form the oasis of personally and culturally compelling health promotion initiatives. See Willms et al (1995) for an example.

3.   Some of these I have already referred to in the Prologue, but they include the contemporary philosophers Rorty (1989), Habermas (1990) and Merleau-Ponty (1962), with their interests in discourse, communication and language; feminist philosophers with their focus on communitarian ethics, which emphasize values of care, kindness, and interdependence (see Hekman 1995); and contemporary moral theorists such as Jaggar (1992), Benhabib (1992), who discuss a more humanistically transformed ethics sensitive to the social and personal contexts within which people make moral decisions, and the need for moral discourse; contemporary medical anthropologists influenced by critical theory and phenomenology such as Good (1994), Kleinman (1995), Farmer (1992), Csordas (1994), with their interests in existential, aesthetic, and relational aspects of human experience, and aims of understanding moral reasoning and the experience of suffering.

4.   Moral philosophy was taught originally to integrate the learning in other subjects such as literature, arts, science, and religion, and extract lessons for living a good life from them. However, late in the nineteenth century, emphasis on sciences and business transformed the unified, ethics-oriented education of the past into one of specialization and professionalism.

5.   Bellah's discussion is founded, in part, on his concern that the professional social sciences have uncritically embraced a 'scientific' perspective to justify and authenticate their inquiry, and as a result, have lost their original humanistic roots. This is true in anthropology to a certain extent, but I think we have retained more of our humanistic sensitivities – certainly we have undergone a major rethinking of our objectivist leanings in light of the post-modern critique. Nevertheless, I think Bellah's argument that we need to transcend academic and disciplinary boundaries in our research and bring our work to a debate in the public arena is still valid and extremely important. See endnote 2 above.

6.   Jean Vanier (1998), in his CBC Massey Lectures entitled "Becoming Human", spoke of his vision for creating common good. It involves many of the qualities just discussed – openness, trust, understanding and compassion – a 'spirit of inclusion', which shows us new ways of living. This is a deeply human vision, and one which our own work can both embody and serve.
    Susan Smith (Smith, Willms with Johnson 1997) also talks about the meaning of being human in the context of participatory action research. In her discussion, becoming human involves discovering and forming our spirituality – a "wonder and [an] understanding of being connected to all living entities" (:225) This occurs through an 'holistic knowing' which includes attention to and integration of six ways of knowing: the rational - our capacity to think, analyze and use logic; the creative - our capacity to imagine, remember and create; the heart - our capacity to feel; the body - our capacity to sense and act; dreams - our capacity to know through the subconscious; and the spirit - our life force and capacity to be.

7.   Denzin's discussion, like Bellah's, is rooted in sociology and clearly aimed against modernist influences in social science research, particularly in ethnography. He spends a great deal of time refuting the positivist arguments for realist ethnography and against interpretive ethnography, something that has become a rather time-worn debate in anthropology. However, he takes this debate forward, suggesting as I have, that ethnography has a bigger project which can stimulate public moral discourse. Denzin's focus is on civic transformation aimed at promoting democracy, but his basic proposal for ethnography's project is valuable and important.

8.   The general concepts of a communitarian moral ethic, with its emphasis on solidarity, care, community, dialogue, and context was described briefly earlier. Denzin compares the utilitarian, modernist ethical model to its challenger, the feminist communitarian model and discusses how each of these influences research, ideas of the individual and community.

9.   Denzin, like Bellah, goes back to the historical roots of his discipline, where journalism and ethnography were both were thought of as forms of democratic social practice. Over time, their paths separated – ethnography preoccupied with becoming a respectable form of research, and journalism turning to the news business. Denzin believes ethnography has much to learn from public journalism, in particular, its focus on "the epiphanal, the problematic, and the link between private troubles and larger, public issues ..." (:279), and its protection of the public good. I would argue that most journalism still has little to do with ethnography, and is basically oriented to selling the news. However, some in-depth documentary journalism can be very powerful, and from a representational perspective, I think there are valuable lessons there for ethnographic practice trying to communicate deeply human issues and stir people to action.

10.   Vanier (1993:90) has this to say about the power of telling stories: stories "reveal truths and ... awaken hearts. Stories seem to awaken new energies of love; they tell us great truths in simple, personal terms ... stories have a strange power of attraction. When we tell stories, we touch hearts. If we talk about theories or speak about ideas, the mind may assimilate them but the heart remains untouched."

11.   Vanier (1993) in his book *Becoming Human* talks about how we exclude others we perceive as weak or needy, in the interest of maintaining our own power, privilege and positive self-image. This is why we ignore beggars or turn away from people with disabilities. Doing this keeps us from acknowledging our common humanity – something many people feel is dangerous because it involves "moving into a certain insecurity" (:49). He says we also fail to acknowledge our common humanity when we privilege the rights, power and needs of the individual over the social group, to the disadvantage of both.
         Gergen (1998:xv-xvi) also speaks about these issues and the need for conversations to move out of disciplinary boundaries into society. While he is speaking about the implications of constructive therapies (whose parallels with ethnography were described in the Prologue) to provoke 'deliberations on cultural life', I think these words apply equally to anthropology's future project   :

> "...this work raises questions of the most profound variety, a way in
> which it subtly begins to shift our very conceptions of who we are as
> human selves. Central to the modernist tradition is the presumption of
> the individual mind as the fundamental atom of society. It is the
> individual's capacity for independent thought upon which our democratic
> institutions are based; it is on the basis of the individual's capacity to
> love that we trust our institutions of intimacy; and it is the individual's
> capacity for free agency that forms the foundation for our conceptions of
> moral responsibility. Yet as the dialogues...unfold, we find the
> presumption of independent, self-contained individuals increasingly
> problematic. To construct an intelligible world essentially requires
> relationship; indeed, out of relationship emerges the very intelligibility of
> the individual self. In effect, the fundamental material out of which
> society emerges, from which institutions of democracy, intimacy, and
> moral responsibility derive, is that of relational process".

12.   "The way of the heart" is a way of thinking, being and entering into relationships that shows us our common humanity and causes us to be more fully human. It "... permits us to be vulnerable with others, not to fear them but to listen to them in all their fears, needs, and hopes ... It permits us to accept others just as they are ..." (Vanier 1998:88) "The heart is the place where we meet others, suffer, and rejoice with them. It is the place where we can identify and be in solidarity with them ...The heart is the place of our "oneness" with others" (:86). Thus, rather than 'doing good' it is more about being open and vulnerable to others in order to receive the life that they can offer.

13.   This refers to my recent experience with team members of a participatory action research project in Uganda this summer. Susan Smith (Smith, Willms with Johnson 1997) writes about this kind of experience – see pages 198-200; 216-219.

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