

ANGELA MOLNOS

OUR RESPONSES
TO A DEADLY VIRUS

The Group-Analytic Approach



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The Institute of Group Analysis
and The Group-Analytic Society
(London)

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A.M.

ABBREVIATIONS

AGIPAD	Asociación Guipuzcoana Investigación Prevención Abuso Drogas, San Sebastian, Spain
AIDS	acquired immune deficiency syndrome
ARC	AIDS-related complex
AZT	azidothymidine or zidovudine (antiviral drug)
BAC	British Association for Counselling
BSE	bovine spongiform encephalopathy
FAIDS	feline AIDS
FTLV	feline T-lymphotropic lentivirus
GA	group analysis or group analyst
GAS	Group-Analytic Society (London)
HIV	human immunodeficiency virus: name given by the International Committee on the Taxonomy of Viruses, May 1986
HIV+	HIV-positive test result; also the person whose blood test shows the antibodies indicative of the HIV infection. It does not mean that the person has AIDS
HIV-1	is the initial isolate, which is epidemic in Central Africa, Haiti, Western Europe and the United States

HIV-2	is the second subtype, more recently identified and found in a few West African countries such as Guinea-Bissau and Gambia and sporadically in Europe and some parts of South America
HTLV-III	human T-cell lymphotropic virus: first name given to HIV by the American researchers Popovic, M., Sarngadharan, M. G., Gallo, R. C. (Bethesda, Maryland) in May 1984.
IGA	Institute of Group Analysis (London)
IV	intravenous: it can mean drug users who inject drugs directly into their veins.
KS	Kaposi's sarcoma
LAV	lymphadenopathy-associated virus: first name given to HIV by the French researchers Barré-Sinoussi, F., Chermann, J. C., Montagnier, L. (Paris) in May 1983.
PCP	pneumocystis carinii pneumonia
PWA	person (people) with AIDS
SAIDS	simian AIDS
SIDA	syndrome d'immunodéficit acquis (AIDS in French); síndrome de inmunodeficiencia adquirida (AIDS in Spanish)
SIV	simian immunodeficiency virus
STD	sexually transmitted disease
STLV	simian T-lymphotropic virus
THT	Terrence Higgins Trust
VD	venereal disease
WHO	World Health Organization (Geneva)

PREFACE

Dr Terry E. Lear

President of the Group-Analytic Society (London)

An English folk story tells of a stranger who finds himself isolated and fearful in an empty cottage at night. He is startled, and, as though his fright had taken on a huge form, he is pursued by it down a moonlit lane. He pauses, breathless. 'That was a good race we had', he hears, and, unwilling to take a good look at what it is beside him, in reply he says, 'Yes, and we shall have another just as soon as I catch my breath'.

There is a hint of humour in the story which could be helpful, though no human conversation nor understanding emerge to assist him, only the contemplation of his own dread.

Instead of flight, Dr Angela Molnos and the other participants sought something better through group events in a one-day workshop. Overall they found moving, worthwhile experiences and bits of understanding in the brief opportunity which they share with readers through the detailed account in the second part of this book.

The author had ideas to test. One was that the shame of having the HIV infection, or an association with such a

person, or of being unable to cope with feelings of disgust and rejection, together with reactions of anger or withdrawal, could be explored by analogous experience in the quasi-laboratory situation of a workshop. It was in the so-called 'non-fishbowl' event that this idea came home to people and surprised most.

Another idea was that if the method of group-analytic psychotherapy is relevant to locate, contain and understand to some extent such feelings in experiential workshop groups, then it could have wider applications in the AIDS crisis. This proposal gained much affirmation in subsequent evaluation.

Sex talk in the groups was thought to express a longing for renewal of life as a defence against the hovering threat of death conjured by the AIDS talk. Such close encounters of participants do promise deeply satisfying intimacy between group members, which may give birth to new ideas in a safe process without physical contact or ugly consequences.

In New Orleans, a medical student showed me round the bustling floors of the Charity Hospital. I left with two impressions—one of many patients dying of AIDS, and the other a picture of rows and rows of newborn babies on the top floor.

I joined a session in a groupwork conference having AIDS as the theme. I recall a small group: among other members, the spouse of a patient, a nurse who worked in an AIDS ward, a gay therapist who, attempting to come to terms with the death of some of his AIDS patients, was concerned with burn-out, a psychiatrist who treated AIDS cases complicated by dementia, and a prison officer who reported the violent behaviour of others against prisoners with AIDS. Reading this report, I was reminded of my own experience in that New Orleans group, namely the struggle to identify the nature of my own involvement with AIDS. It wasn't the reiteration of 'everyone's involved with AIDS', but the dawning awareness that I was involved with the members of that group.

The author wrote several books based on original research in East Africa. They became textbooks for planners and

policymakers in the search for a deeper understanding of social and cultural values and attitudes and their relevance to modern economic development. Among other qualifications, she is a group analyst and a social psychologist and has first-hand experience in working with those who give pre- and post-test HIV counselling and attend to AIDS patients. Despite this wealth of experience, her account reveals the courage, determination and painstaking work that was necessary to see the Workshop through. Care was the watchword—care that is, with planning, taking the context into consideration, with recruiting trained staff, with the composition of the experiential groups and with gathering after-reflections of participants for evaluation.

I am grateful to the author and participants who have assisted me to achieve more understanding by means of this account of a pioneering workshop. I believe that others, in particular those who plan similar projects, would find this book invaluable.

Northampton, England, February 1989



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FOREWORD

Dr Deirdre Cunningham

Director of Public Health, Parkside Health Authority

AIDS and HIV infection constitute a comparatively new public health problem, and Dr Molnos' thorough and illuminating book documents and explains many features of the responses to it. But in some respects AIDS and HIV infection merely highlight areas in which the needs of particular groups and individuals, be they patients, staff or others, have been overlooked or treated insensitively. As one who has been heavily involved in developing and evaluating health services for HIV infection in the United Kingdom, I am aware of the immense importance of looking at aspects of our services which we have previously not challenged. Unless we pay attention to staff' and patients' attitudes and perceptions, both covert and overt, we are bound to fail. Experience reported from the United States, Canada, continental Europe and the United Kingdom all indicate that whatever policies are developed and finally agreed for the delivery of health care, they always will be implemented unevenly due to differences in staff attitudes. Unless we allow and help staff to recognize, express and deal with their feelings and unless we reflect these feelings in

sensitive policies, we will have ineffectual services and patients will suffer, along with the staff.

As a group analyst, Dr Molnos is unusual in that she has a particular interest in the social and psychological problems connected with HIV infection and the AIDS epidemic. After a distinguished, long and varied career in several countries, she has brought her wisdom and experience to this field. Many have written about prejudice and stigma in relation to people with AIDS, but her viewpoint is uniquely group analytic.

In the first part of the book she analyses the disturbance that HIV/AIDS causes in society and in the individual and shows how it can activate the destructive power of groups, if nothing is done to stem these effects. The logical conclusion is that group analysis should be applied to conducting staff support groups. The second part of the book is devoted to documenting experiences from a workshop the author convened in London in December 1987. Those who have talked to people with HIV infection or AIDS or their close associates or carers will recognize as familiar many of the quotations and feelings expressed.

The third and final part of the book, the synthesis, entitled 'Looking towards the future', is what the book is all about for those of us concerned with delivering effective health services. Juxtaposed with the recommendations made by participants at the experiential workshop, here we read the author's views of what group analysts have to offer. Finally, we learn about Dr Molnos' demonstrably successful application of her theory to the practice of conducting staff support groups. Her work with a group of health advisers has been extremely impressive. Its success is assessed by herself, confirmed by the participants and, what is more, can be measured also in terms which cost-conscious managers would find convincing, such as reduced staff sickness, absence and turnover and hence increased cost-effectiveness of the service. Finally, her approach has significantly contributed to reducing those boundary problems, detrimental to staff and

patients, which are very evident in many areas of delivery of care to this particular group of patients.

The author's obvious interest in and insights into the issues surrounding HIV and AIDS, together with her experience in applying group-analytic principles successfully to running staff support groups, provide an introduction for the reader that will whet the appetite. This book should convince both individual carers and their managers that group analysis has much to offer and can produce tangible results. I hope that one effect of Dr Molnos' book will be to interest people in a wider application of group-analytic staff support techniques within the Health Service.

London, April 1989

THE AIDS PANDEMIC

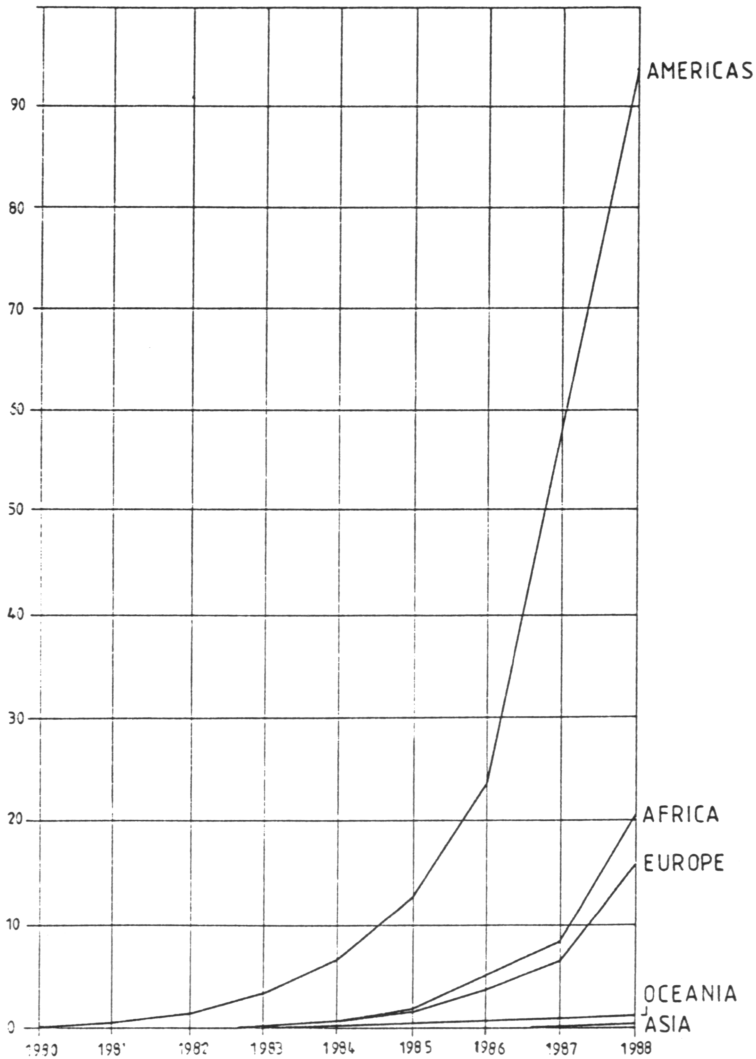


Figure 1. Number of AIDS cases in thousands reported to the World Health Organization year by year. Although these figures are low compared with other health problems, they increase steadily at an exponential rate. This trend is clearest in the Americas, where reporting approaches 90% of the presumed total. Under-reporting of AIDS cases is still a problem in many other parts of the world.

INTRODUCTION

The spread of AIDS world-wide is one of the impending disasters of immense proportions that threaten our life on earth. While public awareness, like a nervously held torch, periodically focuses on it, only quickly to withdraw and cast light on some other less disturbing public health issue, the reported cases of AIDS increase steadily at a mind-boggling exponential rate. Neither a cure nor a vaccine are in sight. To be ready to meet the advancing AIDS pandemic (Koch, 1987) we need every bit of up-to-date knowledge science can offer, but more than that, we need to become aware of unconscious processes that hamper our ability to cope at all levels.

This book addresses a wide range of professionals as well as the general reader who is keen to reflect upon the ways in which our shared unconscious seems to react to the spread of the HIV infection, which is just one of the life-threatening phenomena of our age. Specifically, it has been written with the carers in mind, and for them. It intends to speak to all those who are involved in HIV/AIDS-related programmes and especially those who are in direct patient contact. Hope-

2 INTRODUCTION

fully it will encourage them to explore and try to understand the nature and source of their own responses as well as those of the groups within which they work. At present those attending to HIV-positive people and AIDS patients are under great stress and often suffer psychosomatic illnesses and burn-out. Many of them abandon the field. Their invaluable expertise, gained through costly training, great personal dedication and sacrifice, is lost. New staff have to be recruited and trained.

It is also hoped that this volume will help many group analysts, psychodynamically orientated psychotherapists and counsellors to realize how much their skills are needed in this field and also prompt them to inform themselves about the virological and medical complexities of the condition called AIDS and to keep abreast with developments. That knowledge will enable them to assist and support primary care workers in their emotionally and professionally demanding work.

The global threat posed by HIV infection and AIDS becomes even more, not less, worrying when we look at the problem on the level of the individual, the group or the country. Each case of HIV infection demands the personal attention of workers from virtually every section of the caring professions: health advisers, doctors, nurses, specialist consultants—such as dermatologists, gastro-enterologists, heart and lung specialists, rheumatologists, neurologists, psychiatrists, radiotherapists—as well as nutritionists, physiotherapists, dentists, occupational therapists, social workers, home visitors, community workers, often also counsellors, psychologists, psychotherapists, priests and even those working outside the caring professions—legal advisers, the person at the dole office and so on. This list has to be extended to include the friends and relatives of the person with AIDS. Due to the complex nature of the condition and the enormous and deep anxieties connected with AIDS, the infected person requires a series of different inter-

ventions at any of the various stages and constant support far over and above normal medical care.

If all those thousands diagnosed seropositive and those who will develop AIDS in this country are to be given proper care, by the end of the century every person who works in any of the caring professions will have to be familiar with the nature of the infection, be versed in up-to-date patient management and be able to respond adequately to the social and psychological needs of those affected. This universal requirement in a civilized society will put a tremendous emotional stress on hundreds of thousands of carers. Millions of us will be affected one way or the other by what has been aptly termed the 'ultimate challenge' (Kübler-Ross, 1987).

* * *

At the core of this book are the participants who attended the workshop 'Group Responses to the AIDS Crisis' on 5 December 1987. The sum total of their personal and professional experiences, their practical and scientific knowledge covers all the treacherous intricacies of the HIV/AIDS field. Together they stand for all those who in ever-growing numbers care for patients living with AIDS and dying from it, for health advisers and others who do pre-test counselling, help HIV-positive persons and give care to people with AIDS, for doctors who find it hard to admit to emotional stress and for administrators and managers of HIV/AIDS-related programmes. This book is not just about one workshop, but about the extreme anxieties, emotions and wild associations AIDS generates in groups and the mental and institutional confusion it causes. The one-day workshop at the Institute of Group Analysis may be viewed both as holding a mirror to the above processes and as a possible example to follow.

In writing this book, I also hoped to make a contribution to the group-analytic understanding of the phenomena that

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have surrounded the threat of AIDS in this country up to the end of the 1980s and might continue recurring under the same or similar conditions of collective anxiety.

* * *

I divided this book into three parts:

The first part sets out the wider frame of reference—the various aspects of the AIDS epidemic, the nature of the HIV infection, how it affects individuals and groups. Group analysis, its essence and its relevance to dealing with HIV/AIDS-related problems are introduced.

The second part of this volume, which has been brought into focus in the Preface, attempts to convey the workshop participants' very personal, yet universal responses to HIV/AIDS. It also describes in detail the preparations and mechanics of the workshop, together with its step-by-step evaluation.

The third part, which has been emphasized in the Foreword, points to the future. The application of group-analytic principles, especially to conducting staff support groups for carers of AIDS patients and those who do HIV test counselling, is discussed and documented. A chapter on 'Strange phenomena' gives concrete examples of the confusion created by HIV/AIDS and also illustrates how in the future collective anxieties might move from AIDS towards other areas.

There are two illustrations in the book. Figure 1, entitled 'The AIDS Pandemic', highlights the magnitude of the potential threat; figure 2, at the end of the text, symbolizes the small group conducted along group-analytic lines as the place where overstressed carers can share their anxieties and find deep understanding, tolerance and support.

This book contains a variety of material: not only factual accounts and overviews, theoretical expositions by myself and reports of my own personal experiences, but also analyses, summaries of specialist addresses and workshop sessions by various contributors, working documents and so on. The distinct styles have been maintained deliberately, and it