KNOWLEDGE AND ATTITUDES OF THE SOUTH AFRICAN PUBLIC WITH REGARD TO CONGENITAL AND INHERITED DISORDERS

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OPSOMMING

'n Gemeenskapsgesentreerde genetiese diens is in 1975 onder die Afdeling Genetiese Dienste van die Departement van Gesondheid en Welsyn begin. 'n Reeks kennis- en houdingstudies is deur die RGN onderneem om 'n basislyn van publieke bewustheid van genetiese toestande te bepaal en om enige veranderinge, wat moontlik aan die voorligtings programme van die Afdeling Genetiese Dienste toegeskryf kan word, te monitor.

'n Dramatiese verbetering in die kennis en houdings in die Blanke bevolkingsgroep na drie jaar kan waarskynlik aan die programme van die afdeling toegeskryf word. Die hoeveelheid blootstelling van Indiërs, Kleurlinge en Swartes aan die voorligtingsprogramme was geag te min te wees ten tye van die ondersoek om enige verandering te bepaal.

Voor blootstelling aan voorligtingsprogramme het omtrent 30% van die Blanke ouers met geaffekteerde kinders niemand oor die risiko vir verdere kinders geraadpleeg nie. Drie jaar later het die syfer na 7% gedaal — wat 'n oortuigende indikasie van 'n verandering in kennis is. Opvolgstudies word onderneem om die invloed van voorligtingsprogramme op ander bevolkingsgroepe te bepaal.

Die aanvanklike en opvolgstudies het almal getoon dat al die groepe graag meer kennis oor kongenitale en oorerflike afwykings wil bekom. Swartes en Kleurlinge het die grootste belangstelling getoon.

Daar is ook gevind dat radio en/of televisieprogramme, tydskrifte en koerante baie effektief is om 'n algemene kennis van genetiese afwykings en die beskikbare dienste te kweek.

INTRODUCTION

In the U.S.A. and most European countries the establishment of community based genetic services has emerged only within the last decade[1]. There has been a tendency for the relevant government departments to assume partial or complete responsibility for these services[2]. In South Africa such a community based genetic service under direction of the Genetic Services Division of the Department of Health and Welfare was conceptualised in 1971 and put into operation in 1975[3].

Education and training comprises a major component in the organisational and operational structure of the Genetic Services Division since no educational material on congenital and hereditary disorders for the public or health personnel was available at the time of inception of this division. Furthermore, there was little evidence of a general awareness of the subject prior to 1975.

Since 1975 several surveys on knowledge and attitudes of the public have been conducted by the Human Sciences Research Council (HSRC) at the request of the Genetic Services Division (see table 1). The purpose was to establish a base line of public awareness about genetic disorders and to monitor any change in knowledge and attitudes in subsequent years which might reflect the impact of genetic services.

It was also felt that assessment of the knowledge and attitude status of the public would give some indication of the expected background of potential counsellees. This is shown to be a determining component in the genetic counselling encounter[4].

An analysis of a pilot knowledge and attitude study of White women in 1975[5] confirmed the anticipated lack of awareness of genetic disorders and the general misconception of the public regarding causes, prevention possibilities, and value of counselling for genetic disorders. Above all the need for further information and facilities for genetic services were clearly indicated[6].

This paper examines the results of the 1975 and subsequent surveys in as far as they are comparable.

A brief outline of the nature and scope of the educational and training programmes is given to which the results of the knowledge and attitude studies could possibly relate.

EDUCATION AND TRAINING PROGRAMMES

The objectives of the education and training programmes are to:

* create an awareness amongst the public and health professionals; and
* assist with the training of health professionals.

Education and training are facilitated by lectures and courses on human genetics for health professionals and lay groups and the production of educational material for various target groups.

The first brochures on genetic disorders were issued in 1975 and thereafter the number has steadily increased so that at the time of writing (1982) thirteen titles were available. Two posters for the public and four for health professionals were released on a limited scale in 1980. Caution was exercised not to create excessive awareness such that the service facilities would not be able to cope with the increased demand.

TABLE 1 Knowledge and attitude studies completed

Survey number	Year of survey	HSRC Report number	Population group	N	Respondents	Topic
1	1975	S-N-103, 1977	Whites	2 500	Women	General
2	1977	S-N-145, 1979	Coloureds	2 000	Women	General
3	1977	S-N-145, 1979	Indians	2 000	Women	General
4	1978	S-N-147, 1979	Whites	2 356	Men and Women	General
5	1979	S-N-204, 1980	Blacks	1385	Women	General
6	1980	S-N-223, 1980	Whites	1 719	Men and Women	Down Syndrome and Neural Tube Defects

Sixteen educational films were purchased from overseas, while one film *Genetic Disorders* was locally produced. These films were available from 1978 on a loan basis to any institution concerned with the training of health personnel. The local film was shown on the national television network in 1979. Since then regular programmes or interviews on genetic defects averaging approximately three exposures per year have appeared on television in which various experts in this field were involved.

On the national broadcasting services, interviews or programmes on some or other aspect of genetics or congenital handicaps have increased over the last five years to approximately twenty exposures in 1981. These exposures were the result of participation of various organisations, parents or individual experts in radio or television programmes.

On average, approximately fifty lectures have been given by head office personnel of the Genetic Services Division every year since 1975 to various groups of health personnel in training, including clinicians.

Since 1975 an annual two-week course on human genetics has been presented by the Genetic Services Division for nurses, including genetics nurses and nursing tutors, as well as other health personnel. On average twenty-five to thirty course participants have been catered for every year. In 1981, however, the course facilities were extended to accommodate sixty to seventy participants. In addition to this course, several short courses of one or two days duration are held in the regions on an alternating basis.

TABLE 2 R.S.A. population 1980*

Population Group	Urban	Non-urban	Total
Blacks	6 479 660	10 444 100	16 923 760
Whites	4 002 000	526 100	4 528 100
Coloureds	2 002 300	610 480	2 729 007
Asians	743 820	77 500	821 320

* Department of Statistics, Republic of South Africa. Preliminary Results of 5% systematic sample of the 1982 census. Includes Black National States (self governing).

METHOD (HSRC-surveys)

The findings of the surveys on knowledge and attitudes towards genetic disorders which are discussed here (see table 1), were obtained in the course of multipurpose surveys conducted by the Human Sciences Research Council

Information on the knowledge and attitudes of Whites, Coloureds and Indians was obtained by means of pre-structured questionnaires in the years listed in table 1. In each survey the sample was as far as possible representative of the national population of persons above the age of 15 years. Analyses were done in terms of the following variables: language, educational levels, age, sex, income, residential area, province and marital status.

According to the latest (1980) census figures the R.S.A. population comprises the four main subpopulation groups shown in table 2.

Because of planned campaigns by Genetic Services for 1979 and 1980 on Down syndrome and neural tube defects respectively, the knowledge and attitude survey conducted in those years related to these disorders only. All the other surveys dealt with knowledge and attitudes towards genetic defects in general.

For the survey amongst Blacks (survey No. 5) a different strategy was followed. Questionnaires were completed during interviews conducted by family planning motivators. Analyses were done in terms of the following variables: health region, area of residence, province, ethnic group, age, marital status, home language and educational level.

Certain limitations preclude the comparison of the different surveys in all respects. In the multipurpose surveys elaborate questionnaires were employed and only a limited number of questions on genetic disorders were permitted. Cultural differences precluded the use of identical questions for Whites and Blacks. Experience gained in the initial surveys dictated the nature and scope of questions in the subsequent surveys. Therefore the various surveys can only be compared with regard to some questions. The remaining data is nevertheless grouped in main categories for individual consideration.

In all the surveys, respondents were asked whether, to the best of their knowledge, they had had children with congenital or hereditary disorders, and if so, whether they were concerned about the risk of recurrence.

FINDINGS

Knowledge and attitudes with regard to agents which are considered dangerous to the fetus in utero to the extent that a congenital defect could result are given in table 3.

The degree of knowledge of genetic disorders, or *genetic counselling* where it was specifically asked, is depicted in table 4.

In table 5 the medium through which knowledge on genetic disorders was obtained is shown.

Parents of affected children expressed concern about the risk of recurrence and various sources were consulted in this regard as shown in tables 6 and 7.

Advice given to *affected* parents and the actual action taken (Blacks only) with regard to further children is summarised in table 8.

Interest expressed in obtaining further information on genetic disorders is shown in table 9.

Only in the 1980 survey amongst Whites was knowledge of services provided by the Department of Health and Welfare, addressed (table 10).

DISCUSSION

Agents affecting the fetus

In general the Whites were to some extent aware in 1975 of the dangerous factors for an unborn child with the majority indicating unprescribed drugs, consanguinity and German measles as the more dangerous factors. Advanced maternal age, drinking of alcohol and smoking were regarded as less dangerous (table 3).

In the survey amongst Indians (1977) the ability to distinguish between harmful and non-harmful factors for an unborn child is not evident. Aeroplane travel, dancing, eye strain and, quite rightly, drinking of alcohol and smoking, were considered relatively important whereas consanguinity, advanced maternal age, X-rays and German measles were considered less important.

The awareness profile could be attributed to the cultural background of this population group. For example, it is known that abstention from alcohol and consanguinity is commonly an accepted norm among certain Indian groups.

It can only be assumed that the educational programmes possibly had not reached this population group as a whole by 1977, or that exposure time to these programmes had still been inadequate to justify any conclusion as to the effect of the programmes.

A degree of awareness of factors dangerous for an unborn child seemed to prevail in the Coloured community (1977). For example consanguinity, the drinking of alcohol, German measles, advanced maternal age, and patent medicines were considered dangerous. The extent of this awareness was, however, clouded by the relatively high value attached to non-harmful factors such as aeroplane travel, dancing and eye strain.

Since the beginning of their existance, Coloureds had been in constant contact with Whites and they had much stronger cultural ties with Whites compared with the Indian and Black populations. This could account for the similar tendency of awareness for the harmful factors as compared to the survey amongst Whites (1975).

Amongst the Blacks (1979) there again seemed to be an awareness of some harmful factors for the unborn child, especially German measles, alcohol, smoking and ad-

TABLE 3 Agents considered very dangerous to fetus in utero — Percentage *Yes* responses

Agent	Whites 1975	Indians 1977	Coloureds 1977	Blacks 1979
Aeroplane travel	6	37	44	—
Patent medicine	69	64	85	79
German measels	97	66	90	63
X-rays	51	17	33	27
Alcohol	41	59	79	52
Smoking cigarettes	29	42	57	56
Smoking dagga	—	—	—	76
Malnutrition	—	—	—	84
See a frog or dancing	4	36	28	35
Eye strain	3	23	37	—
Mothers older than 35	17	26	41	31
Consanguinity	68	25	80	—
The will or act of God, ancestors or witch doctor	—	—	—	47

TABLE 4 Knowledge of genetic counselling or genetic disorders

Subject	Whites (1978) % Yes responses	Whites (1980) % Yes responses	Whites (1979) % Yes responses
Has knowledge of genetic counselling	50		33
Has "heard" of genetic counselling			45
Knows of genetic nurse who can help with genetic counselling	34		
Has seen a film or television programme on genetic disorders	22		
Knows of spina bifida		15	
Knows of Down syndrome		65	
Is aware of prenatal diagnosis of some genetic disorders		50	47

TABLE 5 Medium through which knowledge on genetic disorders was obtained — percentage *Yes* responses

Medium	Whites (1975) General	Indians (1977) General	Coloured (1977) General	Whites (1980) Down syndrome only	Whites (1980) Spina bifida only	Blacks (1979) General
Magazines	74	14	38			33
Newspapers	43	25	44			33
Newspapers and Magazines				16	23	
Brochures or pamphlets	26	11	26			24
Doctors books	50	14	29			14
Other books	35	19	34			
Films	18	19	22			
Radio	57	17	30			
Radio and/or television				9	7	53
Lectures or talks	32	17	34	6	6	32
Friends or family				35	27	
Other				20	14	

TABLE 6 Percentage parents with affected children and degree of concern for risk of recurrence

	Whites (1975)	Indians (1977)	Coloureds (1977)	Whites (1978)	Blacks (1979)
Parents with affected children	4,3	2,5	4,5	2,4	11,7
Concerned about risks of recurrence	—	—	—	62,5	54,9

vanced maternal age. However, considerable value is also attached to less delitarious factors such as malnutrition, dancing and the role of supernatural powers, or the fact that it *just happens*. In the latter case 54% yes responses were recorded.

Knowledge of genetic counselling

According to table 4, approximately 50% of Whites (1978 and 1980) had *some* conception of what genetic counselling is, including that some genetic disorders are diagnosable prenatally.

It is notable also that 50% of Whites (1980) were aware of genetic services provided by the Department of Health and Welfare (table 10).

A substantial percentage of Blacks (1979) (33%, indicated that they had knowledge of genetic counselling, and 45% had *heard* of it (table 4). However, it transpired that only a small number of respondents had a real conception of what genetic counselling entails, since there were indications that with the translation of the questions it may have been confused with the concept of *family planning* or *medical counselling*. A surprising 47% of the respondents were aware that there are disorders which are diagnosable before birth.

In general there is obviously ample scope for creating awareness of genetic services in the population as a whole with emphasis on Indians, Coloureds and Blacks. From all the individual reports on the findings of the respective surveys it appears that awareness and knowledge of genetic disorders and available services were directly related to the educational level of the respondents.

Awareness through the media

In 1975, magazines and the radio were the most important media for Whites (table 5). Newspapers were the most important medium for Indians (1977) and Coloureds (1977). A significant number of persons, except Indians (1977), obtained their knowledge from brochures or pamphlets, which can largely be attributed to the education programmes of the Genetic Services Division.

More Black women (1979) obtained information about congenital and hereditary disorders through *radio and/or television programmes* than through any other communication media. It would appear that mass media such as magazines, newspapers, radio and TV are appropriate for creating a general awareness of genetic disorders and the corresponding services.

Who *affected* parents turn to

Except for the respondents in the survey for Blacks (1979), the percentage of parents with *affected* children more or less corresponds with what would be expected.

In Whites (1978) and Blacks (1980) only 63% and 55% of *affected* parents respectively were concerned about the risk of recurrence. This attitude in the Blacks (1979) could probably be related to the high percentage (49%) of the Black public (1979) who consider a super-natural power a *dangerous* agent to the fetus in utero, or that a birth defect *just happens* (table 5).

In 1975 and the follow-up survey amongst Whites in 1978 a marked difference in persons consulted with regard to the risk of recurrence is seen (table 7). The 27% who consulted nobody in 1975 dropped to 7% in 1978. Whereas only 1% of parents consulted a genetic counsellor in 1975, 42% consulted a genetic counsellor in 1978.

TABLE 7 Parents of affected children consulted the following sources with regard to risk of recurrence — percentage *Yes* responses

Source	Whites (1975)	Indians (1977)	Coloureds (1977)	Whites (1978)	Blacks (1979)
Nobody	27	29	30	7	25
A medical doctor	60	47	47	86	10
Witch doctor					2
Genetic counsellor	1	8	9	42	
Genetic nurse				14	
Doctor or nurse and genetic counsellor	12,5	5	9		
Health visitor				5	
A nurse					8
Social worker or minister				4	2
Other				23	
Friend					3

TABLE 8 Advice given to *affected* parents with regard to further children

Possible actions	Whites (1975) %	Indians (1977) %	Coloureds (1977) %	Blacks (1979) %
Sterilisation to prevent further births	13	25	8	*Action taken* 4
No further children — without sterilisation	9	9	8	4
Must decide one self but realise risk of recurrence	11	14	29	4) decides on
Parents reassured of no further risk	56	43	52	5) further children
Parents have already decided against further children	9			
Conflicting opinions	1			
Prenatal diagnosis when pregnant	1			
Other unspecified		14	3	9

The fact that there was a significant percentage increase of parents who consulted a medical doctor, from 60% in 1975 to 86% in 1978, clearly indicates the responsibility of this category of health personnel and the role they can play if they are to help fill the need for genetic counselling. A knowledge and attitude study amongst medical personnel in 1975 revealed areas in which knowledge of medical genetics was incomplete[8].

Amongst the Indians and Coloureds, an alarming 29% and 30% respectively consulted nobody which is similar to the responses recorded for Whites in 1975. Hopefully this situation will be shown to have changed in future surveys. A medical doctor was consulted in only 47% of cases, and a genetic counsellor in 8% and 9% of cases respectively.

Advice received

Advice given to *affected* parents with regard to further children varied in the different surveys from sterilisation to prevent further births (8-25%) to re-assurance of no further risk (approximately 50% in all the surveys).

The percentage of *affected* parents advised to opt for sterilisation to prevent a recurrence of an affected child is considered exceptionally high, especially among the Indians, in view of reproduction options currently known which in only rare cases include sterilisation (table 8).

The advice advocated is reflected in the actual action taken in the case of Blacks (1979) where the 4% of parents (mothers) who underwent sterilisation is relatively high compared with the percentage of parents who took other action.

It is notable that a high percentage of *affected* parents were reassured of no further risk for recurrence whereas a much higher percentage of parents with a risk of recurrence would be expected.

Desire for more knowledge

In the surveys amongst Whites (1975), Indians (1977), Coloureds (1977) and Blacks (1979), 70% — 90% of respondents indicated that they would like to know more about *genetic* defects (table 9).

In a comparable study on knowledge and attitudes of various population groups towards hereditary diseases in the East Block countries, Gahse and Kranhold also found that all groups professed a marked desire to acquire more knowledge or to extend their information[9].

As many as 27% of the Indians (1977) were not interested in genetic defects or considered further information on genetic defects unnecessary although, as shown in table 3, this group was not fully aware of the agents which place the fetus at risk.

TABLE 9 Degree of interest expressed in information on *genetic* defects

Degree of interest expressed	Whites (1975) %	Indians (1977) %	Coloureds (1977) %	Blacks (1979) %
Would like to know more because it had occurred in the family	6	3	9	21
	80	73	90	90
Would like to know more because it can happen to anyone	74	70	81	69
Not interested	13	24	7	7
	20	27	9	10
Know enough, further information not necessary	7	3	2	3

TABLE 10 Knowledge of services provided by Department of Health and Welfare

Service	Whites (1980) % Yes responses	
	Men	Women
Nutritional services	70	70
Family Planning services	95	96
Genetic services	44	53
Dental services	76	77

Among the Whites (1975), 20% of the respondents were not interested in genetic defects (table 9). In contrast the Blacks and Coloureds have shown the greatest interest in further information concerning congenital and/or hereditary disorders.

CONCLUSION

Although no claim can be made that the different surveys are comparable in all respects, certain tendencies regarding knowledge and attitudes of the public towards congenital and genetic disorders are indicated.

As the educational programmes were initiated only in 1975, the surveys amongst Indians and Coloureds in 1977 may have been too premature to draw reliable conclusions regarding the effect of these programmes in these population groups. Initially no specific effort was made to reach these groups as such and for all practical purposes the surveys amongst Indians and Coloureds in 1977 may be regarded as pre-exposure surveys. The action taken by *affected* parents in the Indian (1977), Coloured (1977) and Black (1979) populations supports the supposition.

The survey amongst Whites in 1975 may be considered the pre-exposure survey. In general the Whites were reasonably informed in 1975 of congenital and hereditary disorders and where to obtain the necessary services.

A dramatic improvement of the situation was seen after three years (1978), which could probably be attributed to the education and training programmes of the Genetic Services Division.

In a survey of the general health knowledge of first year university students at a South African University, Slayen found a lack of basic education concerning those aspects of health for which the respondents should be personally responsible (8). There was a definite indication that the students were not learning enough about health at school, at home or from other available sources. Slayen comments that *health education should take place during the formative years in a disciplined manner in which every individual has to acquire the same standard of expertise and knowledge as he or she is expected in other subjects.*

Considering that health is a vital component for the quality of life of the individual and community, it is surprising that so little about health is taught at school.

Apart from acquiring knowledge about health in a formal manner at school level, the need for a major awareness programme for all population groups outside the school setting is indicated. In such campaigns the use of various mass media would be appropriate.

In general, considerable interest in obtaining further information on genetic defects is expressed in all the populations surveyed — the Coloureds and Blacks more than any of the other populations.

Although the Genetic Services of the Department of Health and Welfare were least known compared with the Family Planning, Dental and Nutritional Services of the Department, as many as 50% of the White population (1980) was aware of this service.

It is hoped that future surveys will confirm some of the trends in knowledge of and attitudes towards congenital and hereditary disorders and will confirm the effect of the educational programmes of the Department of Health and Welfare.

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