

SECOND CARNEGIE INQUIRY INTO POVERTY
AND DEVELOPMENT IN SOUTHERN AFRICA

Aspects of the social effects of
Mseleni joint disease
by
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ASPECTS OF THE SOCIAL EFFECTS OF MSELENI JOINT DISEASE

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INTRODUCTION - BACKGROUND TO THE AREA

Geography and Terrain

Mseleni is the name of a small underground river which emerges and runs a few kilometres before entering the western limb of Lake Sibhayi, the largest natural freshwater lake in South Africa. It is situated in the north-east corner of KwaZulu some 50 km south of the Mozambique border. The area is a flat coastal plain stretching from the Ubombo mountains, 50 km west of Mseleni, to the sea 20 km east of Mseleni. Along the foothills of the Ubombo mountains runs the Pongola river with its flood plain and red soil. This changes to a white sand 20 km west of Mseleni and it is in this sandy strip that the vast majority of people with Mseleni Joint Disease (M.J.D.) are found. The area has thick natural thornbush in some parts and elsewhere a more open grassland with ilala palms.

People

The people of the area are Zulus, though moving north to the Mozambique border they merge with the Tonga (Tembe-Tonga) tribe which also continues in southern Mozambique.

Dwelling Pattern

The people live in the traditional Zulu pattern of scattered homesteads, with some areas more populated than others but no villages. Most houses are either "beehive" or "wattle and daub". A few have corrugated roofs. Concrete block built houses are uncommon.

Social Organisation

The area is divided into communities falling under separate chiefs. Each chief has a number of headmen (izinduna) who oversee perhaps 100 homes. Tribal courts are held by the chiefs and various categories of offenders tried. Polygamy is common. The women are largely occupied with the menial tasks of collecting water and wood, hoeing in the fields, cooking, washing, etc. Men

look after the cattle and goats, plough with oxen, build and make ilala beer. The woman is thus very much the "bearer of burdens" in the society.

Economy

The three elements of the economy are self sufficiency, gathering and cash economy. (Fig. 1.). The relative importance of each varies according to many factors. In years of poor harvest, gathering becomes relatively more important. In the case of those people who are disabled or elderly and unable to perform the work involved in self sufficiency and gathering, cash economy becomes more important.

(i) Self Sufficiency

The traditional "slash and burn" shifting cultivation has largely given way to repeated utilisation of the same plots. Maize, peanuts and cassava are widely grown, while those with gardens near a river or lake also grow sweet potatoes, amadumbi, cabbage, spinach, tomatoes and pumpkins. Cultivation is done by hand or by ox plough. Production is very poor due to lack of nutrients in the soil, very little use of fertiliser and frequent drought. Cattle and goats are kept mainly as a reservoir of wealth. Milking is done by a few families. Animals are slaughtered for special feasts or when capital is required. They are also used in the payment of ilobola (bride price) prior to marriage.

(ii) Gathering

Numerous wild fruits/nuts and leaf vegetables (imifino) are used and are fairly abundant. Grass is collected for thatching and wood for burning or building. Ilala palm, grass and reeds are also collected for making mats, baskets, etc. The sap of ilala is collected for use as a beer. Water is collected from a river, lake or well by the women and girls and carried home in 25 litre containers (25kg carried on the head). Dead wood is collected by the women in the forest and carried in bundles on the head.

(iii) Cash economy/Industry

There are no industries and very few work opportunities in the area. Apart from the hospitals, schools and stores the only significant employers are the forestry plantations at Manzengwenya and Mbazwana. Some boys are employed by other families as cattle or goat herds and a few girls as "nannies". Brewing and selling home-made beer and production of ilala baskets or grass mats also brings a little income.

TRI-PHASE RURAL ECONOMIES

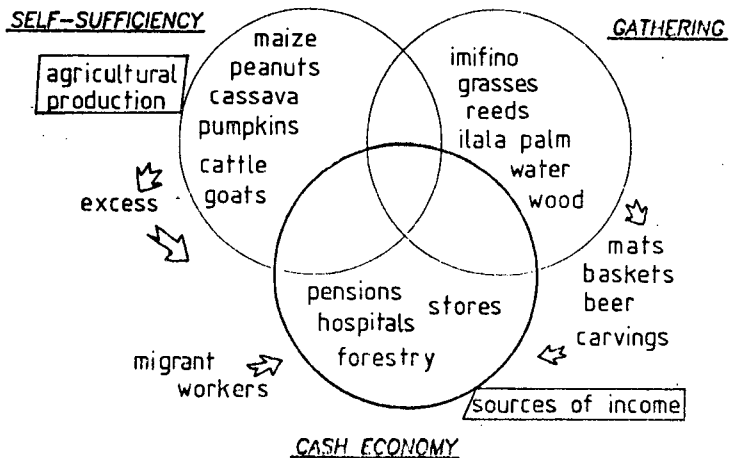


Figure 1. Showing the three elements of the economy, (after G.P. Lind)

Many men and some women are migrant labourers particularly in Empangeni and Durban and some of these send regular amounts home. Others come home once a year and bring some cash then.

The third source of cash income is from pensions/disability grants.

Schooling

There are many primary schools and a few secondary or high schools. Almost all suffer from a shortage of trained teachers and of classrooms.

Health Provision/Social Services

Two KwaZulu hospitals, Mseleni in the Ubombo district and Manguzi in the Ingwavuma district to the north, serve the area and both have mobile and resident clinics serving the more distant areas.

Access to the hospitals can be difficult due to long distances, poor roads and poor communications.

There is no social worker based in the area. The only social worker at present available is based in Ingwavuma and covers both Ubombo and Ingwavuma districts.

There is a branch office of the Ingwavuma magistracy at Manguzi but those in the Ubombo ward must visit the Ubombo office (65 km from Mseleni).

MSELENI JOINT DISEASE

History

The disease was first described in medical circles in 1970.¹ Elderly residents say that when they were younger there was no M.J.D. They pinpoint the beginning of the disease to the 1940's.

Features

M.J.D. is a crippling multi-joint disease of unknown cause resembling dysplasia epiphysialis multiplex. The hip joints are the most important joints affected. The first symptom is pain, then follows progressive stiffness and limitation of movement. Pain is however always a major feature of the disease. In early or mild cases patients walk with a limp, then use sticks, and in very severe cases may be unable to walk at all. The severity of the disease has been graded according to walking ability - good, limp, 1 stick, 2 sticks, crawl, immobile.

Distribution

M.J.D. occurs in the sandy coastal strip shown on the map. (Fig. 2.). The disease is most prevalent around Mseleni and in the areas to the north

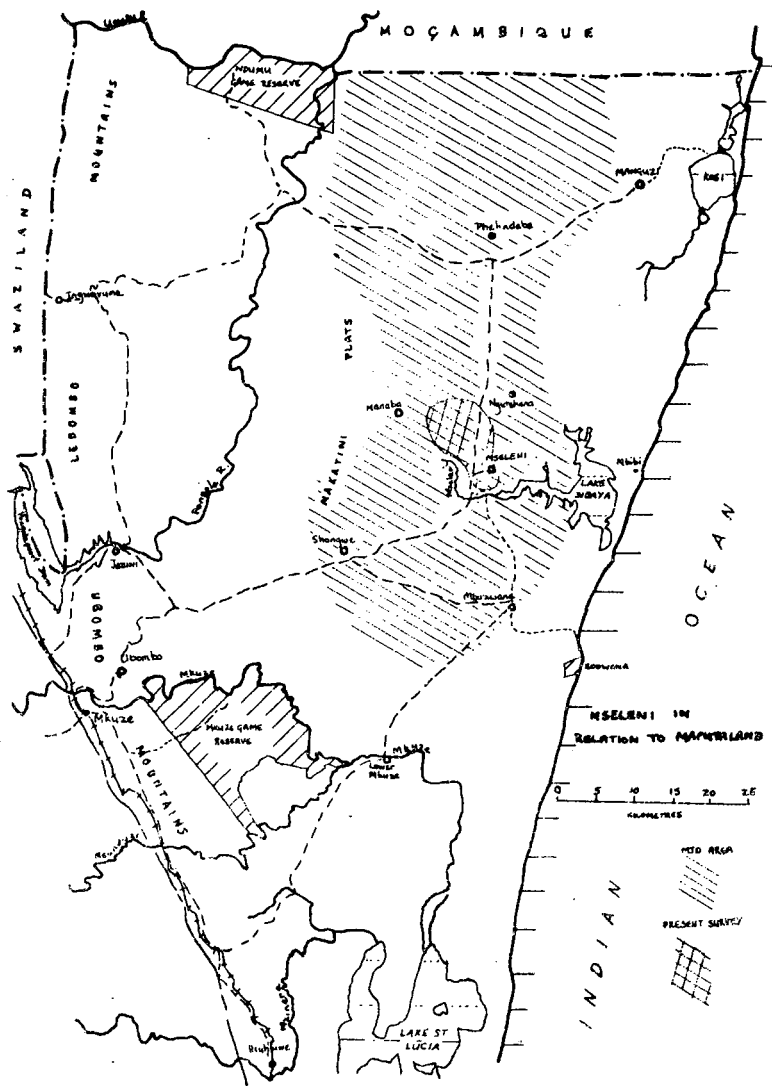


Figure 2. Map of Maputaland showing major communications, rivers and lakes. The area in which Mseleni Joint Disease (M.J.D.) is found is shown as is the region in which the current survey was undertaken.

as shown. Fewer cases appear near the Pongola river, and those living on the coastal dunes east of Lake Sibhayi do not appear to have the disease at all.

Cause

The cause of M.J.D. is unknown. A genetic cause is thought to be unlikely. Theories among the local people include bewitchment and D.D.T. spraying for malaria control. (This was first used around the time of the appearance of the disease - and is still in use.) Current research work is focussed on the possibility of a nutritional cause including a trace element deficiency.²

PRESENT SURVEY

In 1982 the National Council for the Care of Cripples in S.A. proposed an involvement with M.J.D. sufferers both in research into cause and in the help of patients. To achieve the second of these two objectives it was decided to fund an investigation into the social effects of the disease. Previous surveys³⁻⁷ by the Medical Research Council were primarily involved with the epidemiology and possible aetiology of the disease, though the study by Yach and Botha⁸ also highlighted some of the social problems, namely pensions and schooling.

The aim of the survey was to:

1. investigate the problem of sufferers obtaining pensions,
2. assess the effect of M.J.D. on schooling,
3. evaluate the need for surgery for M.J.D. patients,
4. determine the impact of the disease on the ability of M.J.D. sufferers to perform daily tasks, e.g. collect water and wood.

The purpose of the survey was essentially a practical one - that:

1. those found not to be in receipt of a pension should be helped to apply,
2. the problem of those not in school should be brought to the attention of the educational authorities, and possibly sponsorship sought to help those in particular need,
3. facts be provided for consideration by the health authorities of the need for an orthopaedic centre/service for M.J.D. sufferers, and
4. priorities be established for water and agricultural services in the area.

METHOD

The National Council for the Care of Cripples in S.A. provided a vehicle (Land Cruiser) and salary for a driver/field worker. The physiotherapist at

Mseleni Hospital and Health Assistant also assisted with the survey.

Questionnaires were prepared - one for each household with details of people, ages, occupations, those away, income and livestock, huts, as well as proximity to water, wood, store and schools. (Figs. 3. and 4.)

A second questionnaire was prepared for each person with M.J.D. and also for each old person (females over 60, males over 65) with details of degree of disability, ability to perform daily tasks and whether or not they receive a pension or have a reference book. Suitability for surgery was also assessed by the physiotherapist. (Fig. 5.)

Three areas with a known high prevalence of M.J.D. were selected. (KwaMlamula, Bangizwe, KwaJobe.) These were areas previously surveyed by Fellingham et al in 1970. Every home was visited and questionnaires completed.

RESULTS

1. General

274 homes were visited and questionnaires completed. For analysis a 50% sample (alternate homes) was taken. 137 people suffering from M.J.D. were found in the 138 homes analysed. Of these, 51 also qualified for old age pension. Another 28 who qualified for old age pension but did not have M.J.D. were found.

2. Population Statistics

The sample population was 815 people resident and 234 people away (called migrants). The average number of people per household was 5.9. 90 households (65%) had one or more resident M.J.D. sufferers. (These were classified as M.J.D. households.) The overall incidence of M.J.D. was 16.8% of the population.

Fig. 6. shows the age and sex distribution of people with M.J.D. It is apparent that women constitute by far the largest number of sufferers, the overall ratio being 5:1.

44% of women over 20 years, and 58% of women over 30 years had M.J.D. Fig. 7. shows the age distribution of females with and without M.J.D. 63% of M.J.D. sufferers are below old age pensionable age.

Fig. 8. shows that the incidence of the disease in females increases progressively with age, exceeding 50% for 40 year olds and reaching 85% at age 70.

Figs. 9. and 10. show the age distribution of people in M.J.D. and non-M.J.D. households. The much higher proportion of old people in M.J.D. households is shown. Since a high proportion of these old people are also M.J.D. sufferers

Figure 3. Household Questionnaire form used in the present survey.

MSELENI JOINT DISEASE - HOUSEHOLD QUESTIONNAIRE

1. Area: 2. Household No: 3. Survey No:
 4. Interviewer: 5. Date:
 6. List of Persons Living in Household Now:

	NAME	SEX	AGE	HAS MJD?	HAS PENSION DISAB. O.A.	DOES? See Guide
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						
11.						
12.						
13.						
14.						
15.						
16.						
17.						
18.						

7. List of Persons Belonging to Household who are away.

	NAME	SEX	AGE	WHERE AT?	REASON?	IF WORKING SENDS MONEY HOME? HOW MUCH?
1.						
2.						
3.						

this places a considerable burden on the younger people in these households. Thus the impact of M.J.D. is not simply on the individual sufferers but on the entire household.

The overall shortage of males over 20 is apparent for both M.J.D. and non-M.J.D. households. This can partly be explained by the high level of migrancy (see Fig. 11.). It is however also noticeable from Fig. 11. that a fair number of migrants under 30 are female. Some of the younger migrants are employed locally as goat or cattle herds or "nannies". This may prejudice their schooling.

3. Poverty/Pensions

Table 1.

Poverty as assessed by cash income and livestock showing the effect of pension income.

		LIVESTOCK	CASH INCOME	BOTH	NEITHER
PENSIONS EXCLUDED	M.J.D. Households %	19	10	17	54
	Non-M.J.D. Households %	10	40	12	37
PENSIONS INCLUDED	M.J.D. Households %	8	40	28	24
	Non-M.J.D. Households %	6	48	17	29

Table 1. shows the percentage of households with livestock, cash income, both of these and neither of these. Those with neither are considered totally destitute. Excluding pensions 54% of homes with M.J.D. are totally destitute and 37% of non-M.J.D. households. Even with pensions included 24% of M.J.D. households are still destitute and 29% of non-M.J.D. households. 73% of M.J.D. households have no cash income except pensions.

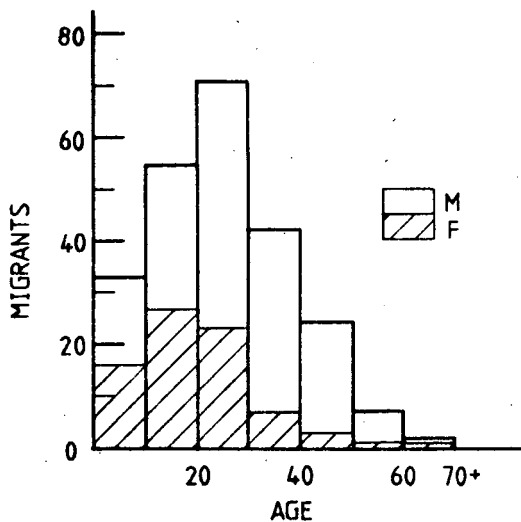


Figure 11. People away from their households for reasons of employment, schooling, visits of long duration and health are shown in this chart. A fairly significant number of women are employed away from their households.

Table 2.

Sources of cash income - all households for a 2 month period.

Total pension income	R6713	66%
Income from migrant workers	R2144	21%
Locally generated income	R1396	13%
Total	R10253	100%

The sources of regular cash income for the community are shown in Table 2. The high dependence on pension income contrasts with the low level of income generated in the area. If all those entitled to pensions actually received them, the total income for 2 months would double (from R10253 to R20322) and 83% of cash income would come from pensions, bringing cash income to virtually all M.J.D. households.

The per capita income is R75 per annum. If pensions are excluded this figure is only R26 per annum. However if all those who qualify for pensions received them it would rise to R150 per annum.

4. Problems of daily living

Distances to water and wood supplies and stores are given in Fig. 12. 60% of households are more than 1 hour round trip to water, whereas very few households are far from wood. Nearly half the households are 2 hours or more round trip from the store.

Table 3.

Performance of daily tasks by women.

People performing tasks	OLD AGE (over 60)		DISABLED (under 60)	
	Non-M.J.D.	M.J.D.	M.J.D. - limp or better	M.J.D. - 1 stick or worse
Water collection %	24	7	83	17
Wood gathering %	47	27	96	47
Cooking %	53	52	100	75

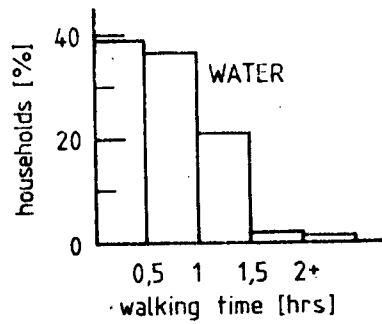
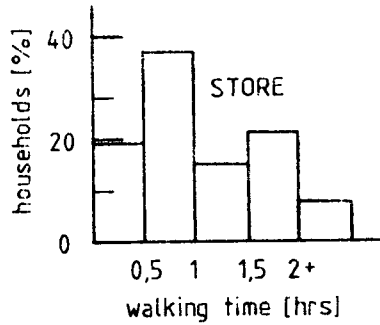
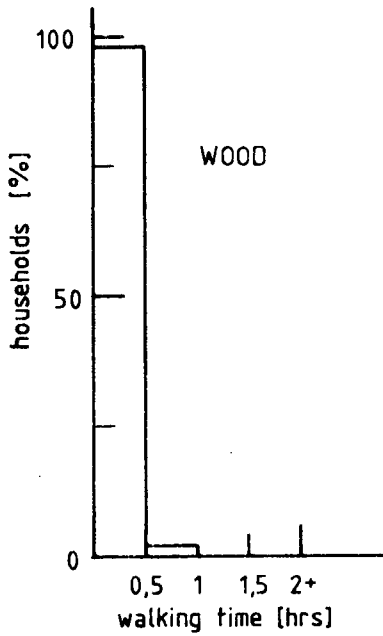


Figure 12.

Distance assessed by a one way trip to a store, to collect wood and to fetch water is shown. The most serious problem is the long distance to water supplies.

Table 3. shows the percentage of women in different categories who indicated that they performed various tasks as shown. Comparison of the two old age columns indicates that M.J.D. sufferers are less able to collect water or gather wood than non-M.J.D. This shows that M.J.D. exacerbates the problems faced by the elderly. The survey indicated that a number of people in this category had to pay for water and wood collection. This was particularly true of old M.J.D. sufferers living alone.


Comparison of the younger M.J.D. sufferers (below 60) shows that whereas in milder or early cases women still perform daily tasks, once the disease has progressed to the stage where one stick is required, this ability is severely limited. It was noted that $\frac{3}{5}$ of the M.J.D. sufferers under 60 were already in the 1 stick or worse category. A similar proportion of these younger M.J.D. sufferers collect water and gather wood as old age pensioners who do not have M.J.D.


5. Housing

The types and number of dwellings in each household was noted in the questionnaire. Values (called housing units) were assigned to each type of house as follows:

 = 1

 = 1

 = 2 (thatch)

 = 3 (corrugated roof)

These values were intended to reflect the number of rooms available and the cost of construction in terms of money or labour.

A comparison was made between households with neither cash income nor livestock (totally destitute) and households receiving pensions. The number of people per housing unit in a pension household was 1.43. The number of people per housing unit in a destitute household was 1.97. The difference between these values was shown to be statistically significant at the 0.1% level.

This again highlights the importance of pension income in the community.

6. Problems of Schooling

All children aged 6-18 whether at home or not were included in the schooling survey. In addition older children still at school were included.

62% of children surveyed in non-M.J.D. households were found to be in school compared to only 41% of children in M.J.D. households. The distribution of children from sub A (first year) to standard 10 is shown in Fig. 13. for both M.J.D. and non-M.J.D. households. The average age per standard is also shown.

Fig. 14. shows the distance of schools from home. It can be seen that whereas 80% of households are within an hour's walk of the lower primary school, 50% of households are more than 2 hours' walk from higher primary and secondary schools. 50% of children in higher primary or secondary schools must therefore either spend 4 hours or more walking to and from school each day, or board nearer school. In either case their ability to help with tasks in the home is considerably lessened. The household may be very dependent on these children for doing tasks and this may partly explain the low numbers who progress to the higher classes. To send an older child to school may therefore not only be a financial sacrifice but also limit further the already limited ability of the household unit to cope with tasks of daily living.

Cost of schooling (including school clothes, books, fees) is estimated to be at least R40 for first year, R120 for standard 5, R180 for standard 9. This should be compared to the present per capita income of R75 per annum.

7. Problems of Pensions

Table 4.

Summary of Pension Position.

	NUMBER ENTITLED	NUMBER WHO RECEIVE	% OF ENTITLED WHO RECEIVE
M.J.D. ONLY	86	19	22%
OLD AGE ONLY	28	16	57%
M.J.D. AND OLD AGE	51	32	62%

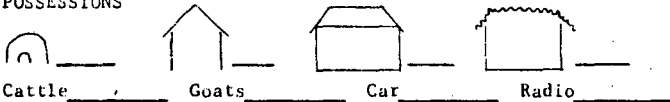
20% of the population are entitled to pensions but only 8% actually receive (40% of those entitled).

Figure 4. Household Questionnaire form continued.

8. SCHOOL AGE CHILDREN

	NAME	SEX	AGE	HAS PASSED STD?	IN STD?	IF NOT IN SCHOOL GIVE REASON
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						

9. POSSESSIONS



10. How much money came into the home in past 2 months? (Specify months _____)

a. Pensions _____ b. Workers living at home? _____
 c. Workers living away? _____ Other? _____

11. Collect water from: Well? Lake? Pan? River? Other? _____

12. Distance to water 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

13. Distance to collect wood 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

14. Distance to store they use 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

15. Distance to school L.P. 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

H.P. 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

Sec. 0- $\frac{1}{2}$ hr $\frac{1}{2}$ hr-1hr 1-1 $\frac{1}{2}$ hrs 1 $\frac{1}{2}$ hrs-2hrs 2hrs+

Figure 5. Questionnaire used to assess the extent of disability and problems faced by M.J.D. sufferers and the elderly.

MSELENI JOINT DISEASE: PATIENTS/ELDERLY QUESTIONNAIRE

1. AREA: 2. HOUSEHOLD NO: 3. SURVEY NO:
4. INTERVIEWER: 5. DATE:
6. NAME: 7. SEX: 8. AGE:
9. JOINT PROBLEMS:
- HIP (L)
 (R) + = MILD PAIN - OCCASIONAL
 KNEES (L) ++ = MODERATE PAIN - MOST OF TIME
 (R) +++ = SEVERE PAIN - ALL TIME
 ANKLES
 SPINE
 UPPER LIMBS
10. Is pain - Better after taking pills?
 - Pills do not help?
 - Worse day or night?
11. Which troubles you most - Pain?
 - Difficulty in moving?
12. Which of the following tasks do you do most days?
 a) Collect water? Yes _____ No _____
 If no, who collects water - Child? Age _____
 - Daughter-in-law? _____
 - Pays someone? How much? _____
 b) Collects Wood? Yes _____ No _____
 If no, who collects wood - Child? Age _____
 - Daughter-in-law? _____
 - Pays someone? How much? _____
 c) Prepares food? Yes _____ No _____
 If no, who prepares food - Child? Age _____
 - Daughter-in-law? _____
 - Pays someone? How much? _____
13. Walking ability: Good Limps 1 Stick 2 Sticks Crawls Immobile
14. Would benefit from surgical help? What?
15. Would be willing for surgical help? At Cape Town?
 At Ladysmith?
 At Mseleni?
16. Qualifies for pension? - Old Age
 - Disability
17. Receives pension? Yes _____ No _____ Used to, but now now _____
 If no - Pension applied for? Yes _____ No _____
 If no - Has reference book? Yes _____ No _____
 If no - Ref. Book applied for? Yes _____ No _____
 If no - Has Birth Certificate? Yes _____ No _____

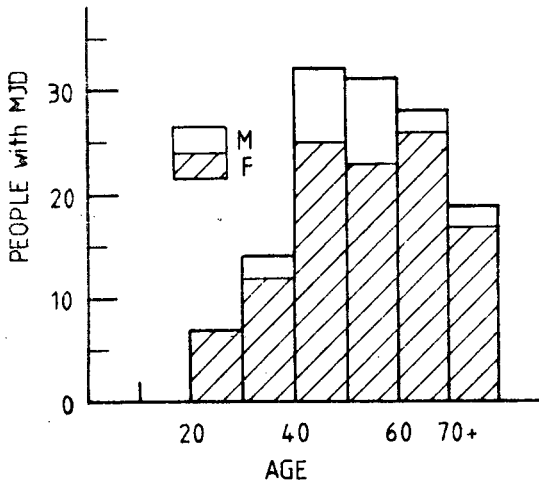


Figure 6. Age distribution of M.J.D. for both sexes.
 Women are afflicted more than men (in a ratio of 5:1).

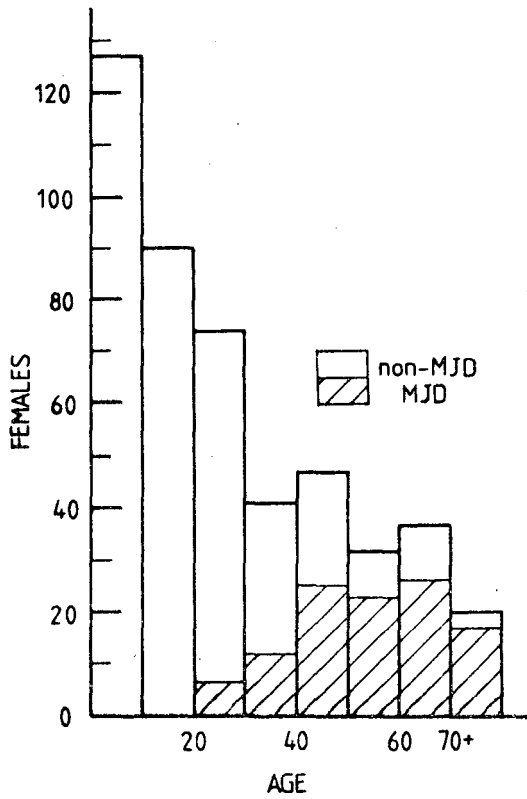


Figure 7. Age distribution of females resident in all households showing the distribution of M.J.D. cases.

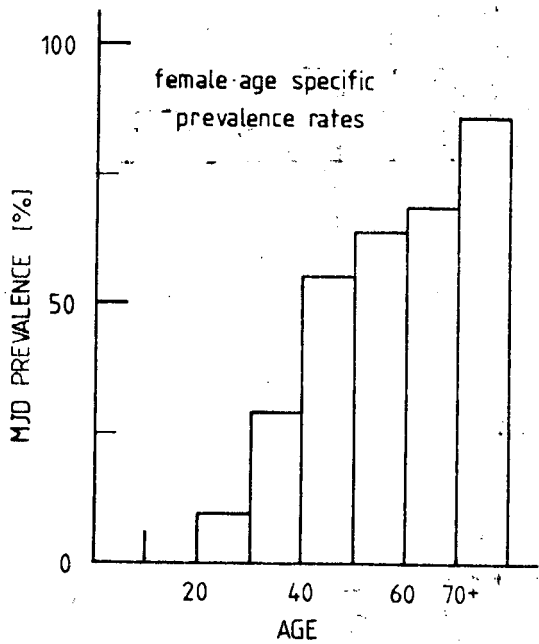


Figure 8. Increased prevalence of M.J.D. in females with age.

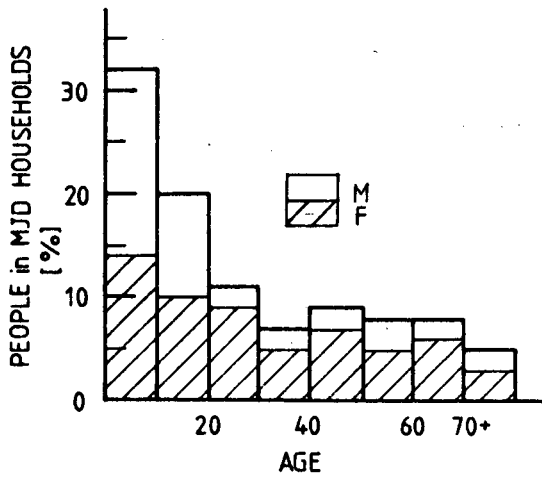


Figure 9. Age distribution of people resident in M.J.D. households.

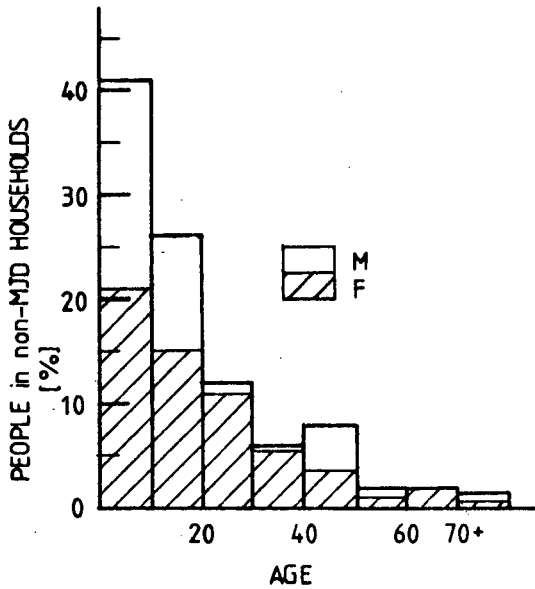


Figure 10. Age distributions of people resident in non-M.J.D. households. The higher proportion of older people in M.J.D. households is evident.

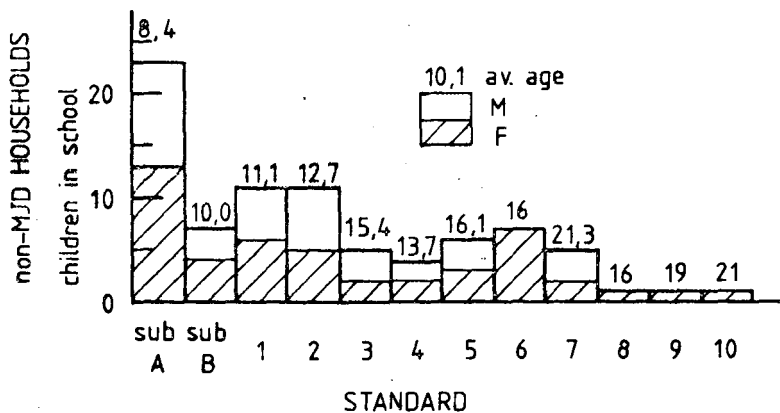
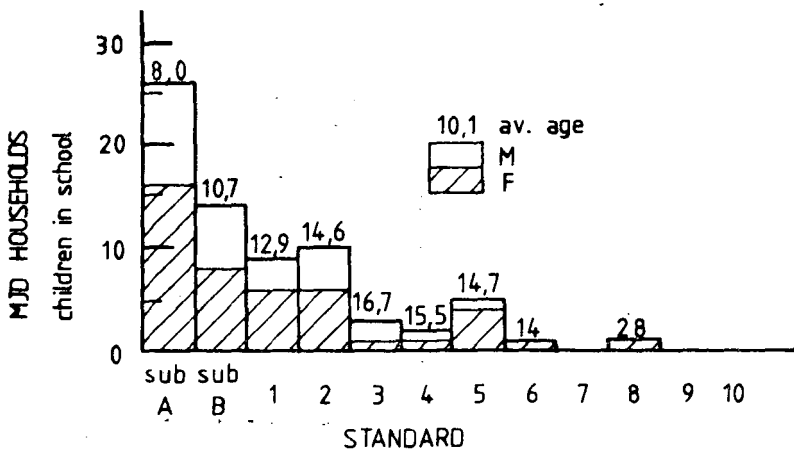


Figure 13.

The distribution of children from M.J.D. households and non-M.J.D. households who are in school according to educational standard. The average age of children in each standard is given. 41% of children in M.J.D. households are in school compared to 62% in non-M.J.D. households.

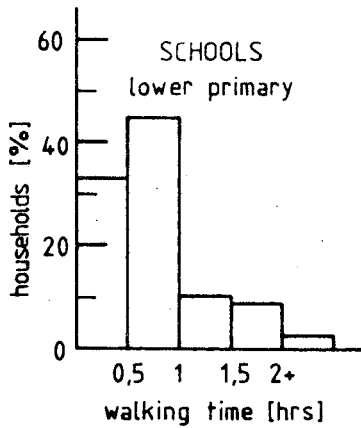
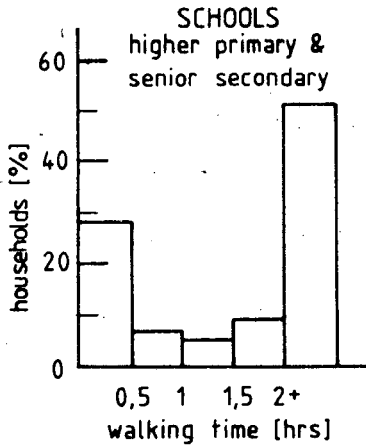


Figure 14. Difficulties in schooling - distances. Distance as assessed by time for a one way trip is shown. The problem for higher primary and secondary school children is clear.

52% of pensions entitled are disability pensions. 48% of pensions entitled are old age pensions.

Not only do many who are entitled not receive pensions, even those who apply may have a considerable delay before receiving their pension. Of those who applied for reference books in May 1983, some received them in January 1984. Others were still waiting. No-one who applied for a pension in April 1983 had received a pension by February 1984.

The total pension bill for the area affected by M.J.D. (in a population of 60,000 with 5% affected - Yach and Botha⁸), if all those entitled received pensions, would be R6 million per annum (R4m old age and R2m disability). The amount of pensions currently paid out is calculated to be R2,8m per annum (R2,4m old age and R0,4m disability). Thus a further sum of R3,2m is required per annum.

8. Surgical Needs See Fig. 15.

Of 138 patients assessed by a physiotherapist 69 needed a total of 117 major joint operations. A further 26 patients were assessed as too early and may need surgery later. If this is projected to the estimated 3000 cases it means \pm 1500 patients need \pm 2500 major joint operations at present. To estimate the cost of this in medical and support services is impossible. The logistical problems at present are immense - patients must go far away from home for a prolonged period and many are not willing to do so. The most reasonable approach would be to establish an orthopaedic centre in the area. This would involve additional large capital expenditure. To do 2500 cases in 10 years would mean 5 major operations per week and an extra 40 beds to the hospital.

A recent assessment of 22 cases who have had major surgery, mostly hip replacements, in the past 4 years showed that they had all benefitted from the surgery, particularly in pain relief, but also in improved mobility in many cases. Some have been able to resume household tasks which were impossible to perform before the operation.

FUTURE AND RECOMMENDATIONS

Social Services

The present "social work" services are done by medical staff and untrained people. This is clearly unsatisfactory and contributes to the delays and problems in communication. The need for resident trained social work staff is apparent.

The distance to the Ubombo magistrate's office (65 km from Mseleni) is also a considerable problem. A branch office at Mseleni is required.

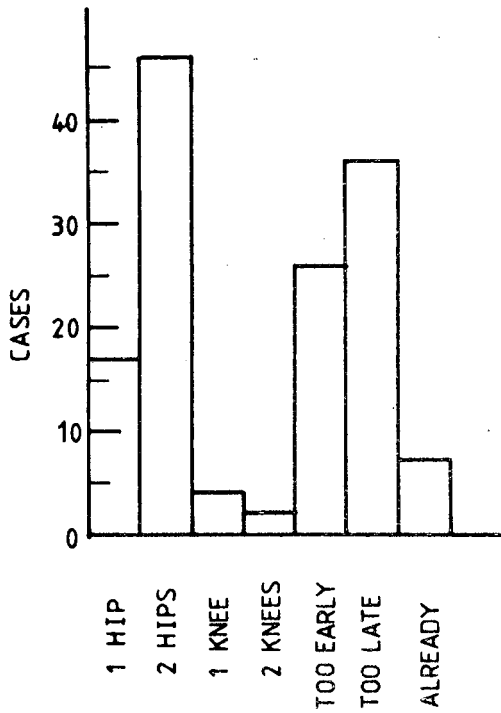


Figure 15. Chart showing 138 M.J.D. patients classified by a physiotherapist according to surgical need.

In addition to social workers it is felt that a person or preferably persons who can work in the field with the community is greatly needed. This could be through the National Council for the Care of Cripples in S.A. With no communications and very poor public transport even the provision of a pension does not enable all sufferers to cope. This is particularly true for people who live alone or have no fit adult members of the family able to attend to their needs. A field worker with the Cripples Care Association is currently assisting in the following areas - the entire arduous process of reference book and pension applications, transport for M.J.D. sufferers, famine relief, housing problems. He has also gained considerable insight into the communities and their problems, which has been a help in further planning. At least one more field worker and vehicle is needed at present as the area is so large.

Pensions/Grants

The extra R3,2 million per annum must be provided by the Government without prejudicing other essential health services.

The processing of applications should also be streamlined to reduce the present considerable delays.

Approximately 140 people have been helped to apply for reference books/pensions so far by the field workers. This must be continued to cover other areas.

Water

It is ironic that within a few kilometers of the largest natural fresh water lake in South Africa (Lake Sibhayi), people have to walk for one to two hours to reach their nearest well or other water source. Limited well-sinking efforts by Mseleni Mission staff have shown the ease of sinking wells, but the difficulty of finding water in this sandy area. The wells project is continuing but it needs hydrological expertise and government support to have any real impact in the needy areas. The possibility of pumping water from Lake Sibhayi to these needy areas also requires investigation.

Employment

At present only 13% of cash income is generated locally. Viable opportunities for employment should be investigated and initiated with government support. The retention of employed adults in this area would contribute considerably to social stability. The need for local infrastructure to serve the communities is also apparent. Banking, post office and electricity services in the area are non-existent and transport services are very limited. Before any significant development can take place in the area these services must be provided.

Medical Care

The need for an orthopaedic centre has been shown. This would need a combined approach between the KwaZulu Department of Health, the National Council for the Care of Cripples in S.A. and a University orthopaedic department.

Schooling

The provision of pensions for all deserving cases should improve the schooling levels. It is felt however that this will never be satisfactory until truly free schooling with free provision of books and supplies comes into being.

Some form of transport for distant communities is also greatly needed so that children can reach Higher Primary and Secondary schools.

CONCLUSION

The above figures and discussion detail some of the social problems presented by M.J.D. However only when one has lived in the area does the size and severity of the problem begin to become apparent. Pensions clearly help people to survive but do not alleviate the continual pain and frustrations of disability. Yet, because of the remoteness of the area and the fact that the people have no means to express their need, it is easy for society as a whole to view M.J.D. as a fascinating epidemiological phenomenon, rather than as a deep human problem affecting 3000 sufferers and their families.

We have tried to make the facts clear. We believe the time for a major co-ordinated response to these facts has come.

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Quoting (in context) from these preliminary papers with due acknowledgement is of course allowed, but for permission to reprint any material, or for further information about the Inquiry, please write to:

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