

House-to-house survey of disabilities in rural communities in the north of the West Bank

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مسح من بيت لبيت لحالات العجز في المجتمعات الريفية في شمال الضفة الغربية
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الخلاصة: أجرى الباحثان هذا المسح للتعرف على معدل انتشار العجز، وخصائصه وحالاته، واحتياجات المصابين به، في المجتمعات الريفية في شمال الضفة الغربية، فتحريا 10 147 أسرة بواسطة مسح عرضي، ووجدوا أن معدل الانتشار 1.7% (806 أشخاص مصابون بالعجز)، وكان أكثرها شيوعاً العجز البدني (34.0%)، ثم العجز النفسي (15.9%)، ثم العجز عن الكلام (11.4%). وكان السبب الأكبر الذي أفادت به الأسر هو الوراثة (30.5%)، وزواج الأقارب 50.8%. أما المشكلات الرئيسية فقد كانت الأحوال الاقتصادية، وكانت هي العائق الرئيسي الذي يحول دون تلقي الرعاية؛ وهكذا كان 44.3% منهم فقط يتلقى نوعاً من الرعاية. كما كان التكامل بين الأنشطة التثقيفية والعمل والأنشطة الاجتماعية منخفضة. وكانت الاحتياجات الملحة هي الرعاية الطبية، وأجهزة الدعم، وخدمات التعليم والعلاج الطبيعي (الفيزيائي) وخدمات التأهيل.

ABSTRACT To identify the prevalence of disability and characteristics, conditions and needs of those with disabilities in rural communities in the north of the West Bank, 10 147 families were screened in a cross-sectional survey. Prevalence was 1.7% (806 persons with disabilities). Physical (34.0%), mental (15.9%) and speech (11.4%) disabilities were the commonest. The major cause as perceived by the families was heredity (30.5%): parental consanguinity was 50.8%. Economic conditions were the major problem for 41.1%, and the main barrier to receiving care: only 49.3% were receiving some kind of care. Integration in educational, work and social activities was low. Pressing needs included medical care, support equipment, and educational, physiotherapy and rehabilitation services.

Enquête porte-à-porte sur les incapacités dans les populations rurales du nord de la Cisjordanie

RÉSUMÉ Afin d'établir la prévalence de l'incapacité et de répertorier les caractéristiques, la situation et les besoins des personnes atteintes d'incapacités dans les populations rurales du nord de la Cisjordanie, une enquête transversale a été réalisée au cours de laquelle 10 147 familles ont été étudiées. La prévalence était de 1,7 % (806 personnes présentant des incapacités). Les incapacités physiques (34,0 %), mentales (15,9 %) et d'élocution (11,4 %) étaient les plus courantes. La cause majeure, du point de vue des familles, était l'hérédité (30,5 %) : le taux de consanguinité parentale était de 50,8 %. La situation économique était le principal problème pour 41,1 % des personnes interrogées et elle constituait le principal obstacle à l'obtention de soins : 49,3 % d'entre elles seulement recevaient des soins sous une forme ou une autre. La participation à des activités éducatives, professionnelles ou sociales était faible. Il existait des besoins urgents en termes de soins médicaux, d'appareillage et de services éducatifs, de kinésithérapie et de réadaptation.

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Introduction

There is a lack of accessibility to basic and rehabilitation services in low-income countries [1]. It is believed that only 3% of those who need rehabilitation in these countries receive any meaningful services [2]. Estimating the burden of disabilities is an essential step for planning appropriate rehabilitation programmes.

As in other countries in the region, there is underreporting of disabilities in the Occupied Palestinian Territory [3,4]. The Palestinian census in 1997 estimated the prevalence of disability at 1.8%. The highest rate, 2.3%, was in Qalqilia and Tulkarm districts in the north of the West Bank [5].

The social and economic consequences of the West Bank separation wall built by Israel on the people living in areas through which the barrier passes are intense [6,7]. Tulkarm and Qalqilia districts are among those significantly affected. Some of the villages there are totally encircled by the barrier, and only people issued special permits are allowed to move in and out through gates that only open at specific times of the day under Israeli surveillance. In addition, the numerous checkpoints are jeopardizing the capacity of the local population to access health care. This particularly affects marginalized and vulnerable groups. In such circumstances, people with disabilities are the most marginalized. It has become extremely difficult for those living in the rural communities to access rehabilitation and health services centralized in urban areas. Therefore, a community-based rehabilitation (CBR) approach reaching the disabled in their localities is crucial.

In response to this situation, a local nongovernmental organization, the Union of Health Care Committees, implemented CBR in the area between 2005 and 2006. The programme extended its services to

persons with disabilities living in 27 villages affected by the separation wall in Tulkarm and Qalqilia districts.

This paper reports on a survey conducted in late 2005 in these rural communities [8]. The aim was to identify persons with disabilities and provide data on their characteristics and conditions as well as the problems they face and their needs. The data were needed to plan and implement the CBR programme in the 2 districts.

Methods

The survey method is a widely used tool for estimating the burden of disabilities and for collecting data about the conditions and needs of people with disability [9–11]. A cross-sectional survey was conducted over the 2-month period August–September 2005 to collect the data. The population of the area studied was 48 516, about 18% of the total population of the 2 districts, and 2% of the total population of the West Bank [12]. The whole population of the 27 communities was studied. The number of families surveyed was 10 147.

A household questionnaire was used to collect data in 2 phases. The tool was based on World Health Organization (WHO) guidelines [13] and had been modified and used earlier by the Palestinian National Rehabilitation Committee in surveying disabilities in other districts [14–16]. In the first visit, 13 trained CBR field workers visited all the families in the targeted areas to collect data about the sociodemographic and economic conditions and screened them for possible disabilities.

A second visit was conducted only for those families which had a person with disabilities: a professional health team (including physician, orthopaedist, neurologist, audio therapist, and physiotherapy and re-

Table 1 Distribution of disabilities according to sex, age and prevalence in Tulikarm and Qalqilia districts

Type of disability	Sex						Age (years)												Total								
	Male			Female			< 6				6-18				19-45				46-60				> 60			T	P
	No.	%	R	No.	%	R	No.	%	R	No.	%	R	No.	%	R	No.	%	R	No.	%	R	No.	%	R	C		
Physical	172	62.7	34.0	102	37.2	34.0	35	12.8	34.7	80	29.1	28.2	88	32.1	32.6	29	10.6	38.7	42	15.4	55.3	274	34.0	0.56			
Mental	94	73.4	18.6	34	26.6	11.3	10	7.8	9.9	35	27.3	12.3	62	48.4	23.0	16	12.5	21.3	5	3.9	6.6	128	15.9	0.26			
Speech	49	53.2	9.7	43	46.7	14.4	20	21.7	19.8	52	56.5	18.3	17	18.5	6.3	1	1.0	1.3	2	2.2	2.6	92	11.4	0.19			
Visual	52	59.0	10.3	36	40.9	12.0	10	11.4	9.9	30	34.0	10.6	23	26.1	8.5	14	15.9	18.7	11	12.5	14.5	88	10.9	0.18			
Hearing	47	69.1	9.3	21	30.9	7.0	7	12.3	6.9	27	39.7	9.5	22	32.4	8.1	7	10.3	9.3	5	7.3	6.6	68	8.4	0.14			
Learning	33	55.0	6.5	27	45.0	9.0	4	6.6	4.0	31	51.5	10.9	24	40.0	8.9	1	1.7	1.3	0	0.0	0.0	60	7.4	0.12			
Multiple	34	58.6	6.7	24	41.4	8.0	6	10.3	5.9	22	37.9	7.7	24	41.4	8.9	2	3.4	2.7	4	6.9	5.3	58	7.2	0.12			
Missing	24	70.6	4.7	10	29.4	3.3	9	26.4	8.9	7	20.6	2.5	9	26.4	3.3	4	11.8	5.3	5	14.7	6.6	34	4.2	0.07			
Other	1	25.0	0.2	3	75.0	1.0	0	0.0	0.0	0	0.0	0.0	1	25.0	0.4	1	25.0	1.3	2	50.0	2.6	4	0.5	0.01			
Total	506	62.8	100.0	300	37.2	100.0	101	12.5	100.0	284	35.3	100.0	270	33.5	100.0	75	9.3	100.0	76	9.4	100.0	806	100.0	1.70			

$\chi^2 = 16.78$; $P = 0.032$

$\chi^2 = 115.37$; $P < 0.001$

R = row percentage; C = column percentage; T = percentage of the type of disability within the total disability cases; P = prevalence of each type of disability per 100 population in the study area.

habilitation, speech and artificial limb specialist, as required) examined the person with disability and identified the type and cause of the disability and services needed. Village councils and volunteers from all the local communities were mobilized to support and facilitate the work of the team. All the families living in the targeted villages were approached during the data collection period. However, about 3% were either not willing to participate or not available at the time of the survey.

The data were entered and analysed using *SPSS*, version 13. $P < 0.05$ was considered significant.

Results

Characteristics of those with disabilities

Mean age was 26 years [standard deviation (SD) = 21]. Children ≤ 18 years comprised 47.8% of the total cases (Table 1). Significantly more males (62.8%) than females (37.2%) had disability ($P = 0.032$). The mean duration of disability was 12 (SD = 12) years. About one-third of those with disability were totally dependent on others to perform daily activities (eating, dressing, hygiene) and just over one-fifth used support equipment e.g. splints, wheelchairs, crutches, walkers, hearing support devices and glasses (Table 2).

Physical disability, 34.0% of the cases, was the most prevalent type, (Table 1), followed by mental 15.9%, speech 11.4% and visual 10.9%. For 34 cases (4.2%) the type of disability was not identified as the team was not allowed to enter one of the villages during the second phase of the study.

Table 2 Characteristics of persons with disabilities in Tulkarm and Qalqilia districts

Variable	No.	%
<i>Use of support equipment</i>		
No	397	49.3
Yes	156	19.4
Does not need	253	31.3
<i>Performs everyday activities (eating, dressing, hygiene)</i>		
Self-dependent	285	35.3
Needs some help	258	32.1
Dependent	263	32.6
<i>Integration into community</i>		
Participating in community activities always/sometimes	487	60.4
School enrolment (6–18 years)	163	58.8
Playing normally ^a (6–18 years)	137	48.8
Employment status (> 18 years)	81	19.2
<i>Residence</i>		
Home or with relative	795	97.0
Institution	11	1.4
<i>Main care-giver</i>		
Mother	388	48.2
Other family member	52	6.4
Other persons	103	12.8
Does not need	263	32.6
<i>Service provider (for those currently receiving care)</i>		
Local NGO	246	48.5
Public sector	145	35.9
International institution	13	3.2
Other	50	12.4

With regard to level of integration of into the community, 69.0% of the persons with disabilities participated always or sometimes in family activities and 60.4% in social activities (Table 2). Only 58.8% of the children aged 6–18 years were enrolled in school and only 19.2% of those over 18 years had a job or income on a regular basis (Table 2).

The main problems facing those with disabilities were economic 41.1%, followed by social 30.6%, medical 6.5% (related to availability of/accessibility to adequate health care services) and psychological 4.7%.

Table 2 Characteristics of persons with disabilities in Tulkarm and Qalqilia districts (concluded)

Variable	No.	%
<i>Type of service provided (for those currently receiving care)</i>		
Medical	213	52.7
Educational	63	15.6
Rehabilitation	58	14.3
Physiotherapy	44	11.0
Other ^b	26	6.4
<i>Type of service required</i>		
Medical	254	31.5
Support equipment ^c	145	18.0
Speech therapy	114	14.2
Rehabilitation	73	9.1
Physiotherapy	73	9.1
Referral to institutional care	70	8.7
Prostheses	22	2.7
Psychiatric care	19	2.3
Social care	15	1.8
Modifying living environment	8	1.0
Occupational care	6	0.8

Mean duration of disability = 12 (standard deviation = 12.1) years.

^aAt time of survey or as youngsters.

^bIncluding social and psychological.

^cIncluding splints, wheelchairs, crutches, walkers, hearing support devices and glasses.

NGO = nongovernmental organization.

Characteristics of the families

In those families which had a person with disability, fathers (8.0 years education) were generally more educated than mothers (4.4 years) (Table 3). Illiteracy among mothers (25.4%) was twice that among fathers 12.0%. Degree of consanguinity in the parents was high: 39.0% were first degree (first cousins) and 11.8% second degree relatives (other than cousins) (Table 3).

Those with disability lived in crowded situations: average family size was 6.7 persons, living in relatively small houses, average 3 rooms per house (2.2 persons per room). The families had relatively harsh economic conditions, only 7.2% rated their income as good (quantitative data of family

Table 3 Family characteristics and conditions of persons with disabilities in Tulkarm and Qalqilia districts

Characteristic	Value
Average family size	6.7
Average no. rooms/house	3.0
Parents' mean age (years)	
Father	45.2
Mother	41.6
Parents' mean years of education	
Father	8.0
Mother	4.4
Parents' degree of consanguinity (%)	
First (cousins)	39.0
Second (other relatives)	11.8
> 1 person with disability in family (%)	32.5
Parents' job status (%)	
Father working	61.7
Mother working	5.0
No. persons working in family (%)	
0	37.8
1	54.5
≥ 2	7.7
Family economic situation (%)	
Bad	27.5
Fair	57.4
Good	7.2

income were not collected; the participants were asked how they rated their family income in comparison with the average Palestinian family income) (Table 3): 38.3% of the fathers were unemployed; in comparison, only 5.0% of the mothers were employed. In 37.8% of the families no-one was working and 54.5% had only 1 person working (Table 3).

Prevalence and causes of disability as perceived by families

In the surveyed communities, a total of 806 persons were identified with disabilities, an estimated prevalence of 1.7%. The cause of disability was reported by 728 families. The main cause as they themselves perceived

was heredity (30.5%) in connection with consanguineous marriages; 26.2% attributed the disability to complications of illness, 6.3% to medical errors, 4.4% to falling accidents, 2.7% to the Intifada (casualties of conflict), 2.6% to work accidents, 2.3% to sociocultural beliefs (e.g. cultural myths and beliefs related to superstition, jinn, evil spirits, magic, etc.), 2.2% to traffic accidents and 1.0% to age.

Care status and needs

About 97% of those with disabilities resided at home: only 1.4% were looked after at special institutions (Table 2). Mothers (48.2%) bore the major responsibility in taking care of those with disabilities.

Families reported a lack of services provided: only 49.3% of those with disabilities were receiving some kind of care (mainly medical) at the time of the survey. Local nongovernmental institutions (48.5%) were the main provider of services received (Table 2).

However, 507 families (about 63%) said that they did not receive the care required. The reasons they cited included: 44.5% economic, 11.4% nonavailability of services, 10.5% lack of knowledge about services, 4.9% transportation difficulties, 2.8% lack of time and 1.8% provider refused to provide care.

According to the assessment carried out by the survey team, the needs of those with disabilities are illustrated in Table 2. These included: 31.5% medical care, 18.0% support equipment, 14.2% speech therapy. In only 0.7% of cases no support was required and 0.1% needed a job. Besides the specialized care necessary for treating the disability, medical care included basic health care (of increased importance due to the decrease in the accessibility to health care centres after the construction of the separation wall).

Discussion

The disability rate estimated through the household survey in 27 villages in the north of the West Bank was 1.7%, which is similar to the national level [5] and consistent with other surveys conducted in the mid-1990s in other districts of the West Bank [14–16]. Except for hearing disability, the prevalence rates of the different types of disability in the studied communities were consistent with national estimates [5]. The figure is, however, lower than the overall rate for both districts estimated at 2.3% in 1997 [5]. This may be because the survey area in our study was totally rural, and the prevalence of disability is expected to be higher in urban areas.

There were significant differences in the type of disability among different age groups. Children (< 18 years) comprised about half the cases (47.8%), which is not surprising since more than 46% of the Palestinian population is under 15 years old [12]. This necessitates a special focus of CBR programmes on children to cover specific educational, social and rehabilitation needs of this age group.

The prevalence of all kinds of disability was greater in males than females. These findings correspond to the 1997 population census, males 60.6%, females 39.4% [5]. The difference may be related to the higher risk of exposure of males to traffic and work accidents, and higher conflict casualties among males according to national statistics [17], in addition to social factors such as underreporting of female disabilities [5].

An inadequate level of integration into society of those with disability was illustrated. It is known that people with disability have less access to education, jobs, and social services including sport and recreation, especially in countries such as the Occupied Palestinian Territory which have inadequate

infrastructure. Therefore, attention should be given to integration into society, and equal opportunities for education and employment should be made available. The unemployment rate in the Occupied Palestinian Territory was 23.5% in 2005 [12], whereas only 19.2% of those in our study of working age were employed.

Consanguineous marriages are noticeably prevalent in many of the neighbouring countries in the region [4]. However, in the Occupied Palestinian Territory the phenomenon is much greater; 45.2% of marriages in 2004 were to a first cousin or other relative [12]. In this survey the figure was 50.8% for the parents, and about 36% of the disabilities were attributed to congenital factors. Although this may support an association between consanguinity and congenital disorders, to ascertain the relationship in this case, further analysis is required of families with and without disabilities in the same community. Nevertheless, raising community awareness on consanguinity and its consequences on well-being is extremely important.

The sharp decrease in the number of Palestinian workers in Israel, the denial of access to agricultural lands in the areas where the barrier was built and the restrictions on the movements of goods and products have led to a deterioration in the economic situation of people living in the rural communities we studied [18]. According to our findings, the economic conditions of the families with disabilities can be characterized as difficult, and this was cited as the main problem facing those with disabilities and the major barrier to receiving care. In addition, the figures for crowding are higher than the average Palestinian family size (5.8 in 2007) [12]. In a country lacking proper social security mechanisms, those with disabilities and their families are especially disadvantaged.

One deficiency in the available care system for the people with disability is illustrated in the type of services provided: the focus was mainly on medical care, with much less attention paid to psychosocial and rehabilitation services. The voluntary sector, with the support of international aid, has assumed a crucial role in providing care for those with disabilities. However, given the change in policy of the international aid community following the January 2006 elections and the forming of new government, the sustainability of these efforts is uncertain.

It is evident that those with disability suffer from lack of appropriate services, low socioeconomic conditions and marginalization in the dominant political context.

While there is a need for comprehensive CBR programmes complemented by an adequate level of institutional care to respond to the needs of those with disabilities, it is also important to support and empower the families taking care of them.

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