

# Patients and Sibships

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## 12.1 Patients Source and Status

The Blind Schools Survey encompassed initially pupils and trainees in the blind schools and schools' workshops and incumbents of residential homes. Children on schools' waiting lists and relatives of the affected pupils were later included to ensure a meaningful assessment of the genetic conditions encountered. After the completion of the survey, patients who met the criteria of childhood onset visual impairment were added to the register. Table 14.1 shows a breakdown of the source and status of the cases by region.

Forty cases of the 709 registered in the study did not fulfil the criteria of childhood onset bilateral visual impairment and were excluded, thus leaving 669 patients for inclusion in the analysis. (Table 12.1)

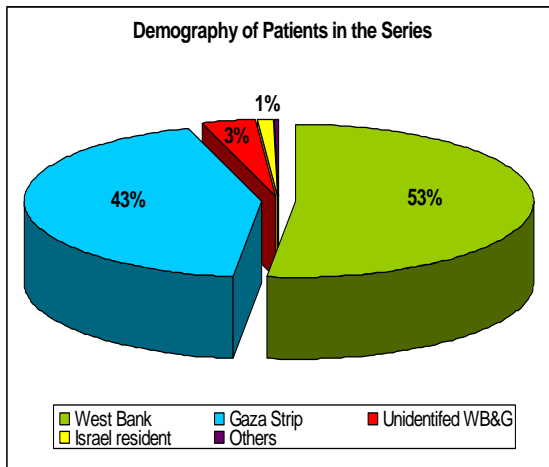
Of the 669 cases who fulfilled the study criteria, 347 originated from the WB and 289 from GS. There are an additional 23 patients who come from either region but their exact location was not possible to ascertain and a further 8 patients had their families living in Israel. (Figure 12. 1)

**Table 12.1 Cases by status and region.**

Status	M	F	Total	M/F	Mean
<b>West Bank</b>					
Pupils	69	60	129	1.1	3 – 19.5 (13)
Workshops	1	8	9	0.1	12 - 40 (2407)
Residents	13	32	45	0.4	2.4 – 60 (27)
Outpatients	61	52	113	1.2	0.6 – 46 (11)
Relatives	26	21	47	1.25	1 – 60 (20)
<b>Gaza Strip</b>					
Pupils	49	33	82	1.5	4.5 - 20 (12)
Workshops	5	9	14	0.5	20 - 27 (23)
Residents	3	5	8	0.6	2.6 - 83 (5)
Outpatients	44	20	64	2	0.7 - 57 (5)
Relatives	63	33	96	2	0.6 - 83 (20)
<b>Both Regions*</b>					
Pupils	119	93	215	1.3	3 – 20 (12.6)
Workshops	6	17	25	0.3	12 – 40 (24.5)
Residents	7	41	48	0.2	2.4 - 83 (27)
Outpatients	122	80	202	1.5	0.6 - 57 (22)
Relatives	89	134	223	0.6	0.6 – 83 (12)

\* Includes 33 cases whose families' live in either regions but exact location is unspecified.

**Figure 12.1 Demography of the 669 cases in the survey with childhood onset visual impairment.**



## 12.2 Age Composition

Children <16 at the date of the completion of the survey formed 62% of the total number; in the WB 58% and 57% in the GS. The proportion of each age cohort in the survey in comparison to the corresponding age cohorts in the general population at the time of the survey is given in Table 12.2 and Figure 12.2.

## 12.3 Gender

There was a preponderance of males in the total series with 396 (55%) males and 275 (45%) females (M:F 1.44:1). (Tables 12.2 and 12.3)

In the West Bank, there are an almost equal proportion of both genders in the WB with 172 (49.5%) males and 175 (50.5%) females (M:F 0.98:1), which equates the ratio in general population.

In the Gaza Strip, there are 176 males and 114 females (M:F 1.54:1). This disparity is observed in all age cohorts but it peaks in the < 5 and 16-20 years. In school age pupils, the gap diminishes to 1:15.

Many of the older females, were recruited from

the training centres' and the school waiting list. The former were essentially female adults working in the workshops, the outpatient cohort and relatives of all above. The training centres were UNRWA Training Centre for the Blind in Gaza and the second was based at blind school in Nablus.

There is a high preponderance of males in the non-hereditary cases in both the WB and GS with a sex ratio of 1.8:1 and 1.5:1 respectively. (See aetiological classifications).

## 12.4 Pedigrees and Sibships

The total number of pedigrees in the series was 391, comprising 458 sibships. (Table 12.4) Nearly two thirds (58%, n=228) of the pedigrees were resident in the WB and one third (34%, n=131) in the GS. There were 24 whose residence was not determined clearly, whether in the WB or the GS, together with 8 pedigrees who lived outside the WB). The percentage of sibships was higher in the WB, forming 56% (n=257) versus 37% in the GS (n=171).

The ratio of pedigrees between the WB/GS is almost identical to that of the population between the two regions at 1.78:1. When the same ratio is applied to sibships and pedigrees, it drops to 1.5:1 for sibships and 1.2:1 for pedigrees (extended genetic families) thus reflecting the larger numbers of sibships and consequently of patients in the GS.

Figure 12.3 demonstrates this graphically but for the purpose of a better visual impact the ratio was reversed using GS/WB ratio outcome. In this figure the first column on the left represents the ratio of GS/WB population, which is 0.56:1. Ratios of pedigrees, sibships and patients are shown in the subsequent columns.

The highest proportion of cases in the series were villagers totalling 269 (40%), followed by town residents 223 (33%) and camps 111 (17%). This, however, does not necessarily imply a refugee status of the individuals. (Table 12.5)

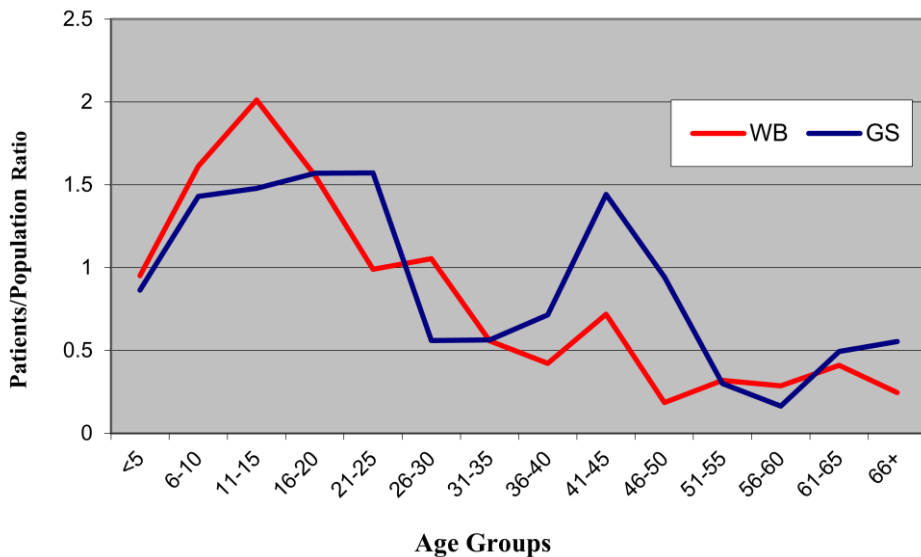
**Table 12.2** Correlation of the survey population with the corresponding cohorts in the general population.

Age Cohorts	West Bank			Gaza Strip			Others			Total		
< 6	63	<b>18.2</b>	<b>16</b>	56	<b>19.4</b>	<b>18</b>	13	<b>39.4</b>	<b>16</b>	132	<b>19.7</b>	<b>16</b>
6 to 10	72	<b>20.7</b>	<b>13</b>	59	<b>20.4</b>	<b>15</b>	8	<b>24.2</b>	<b>14</b>	139	<b>20.8</b>	<b>14</b>
11 to 15	79	<b>22.8</b>	<b>11</b>	49	<b>17</b>	<b>11</b>	6	<b>18.2</b>	<b>11</b>	134	<b>20</b>	<b>11</b>
16 to 20	64	<b>18.4</b>	<b>12</b>	46	<b>16</b>	<b>9.7</b>	2	<b>6</b>	<b>11</b>	112	<b>16.7</b>	<b>11</b>
21 to 25	22	<b>6.3</b>	<b>8.7</b>	30	<b>10.4</b>	<b>8.8</b>	1	<b>3</b>	<b>8.8</b>	53	<b>8</b>	<b>8.8</b>
26 to 30	18	<b>5.2</b>	<b>5</b>	12	<b>4.2</b>	<b>7.4</b>	3	<b>9</b>	<b>5.8</b>	33	<b>5</b>	<b>5.8</b>
31 to 35	4	<b>1.2</b>	<b>3.6</b>	7	<b>2.4</b>	<b>5</b>	0	-	<b>4.1</b>	11	<b>1.6</b>	<b>4</b>
36 to 40	8	<b>2.3</b>	<b>3.4</b>	7	<b>2.4</b>	<b>3</b>	0	-	<b>3.2</b>	15	<b>2.2</b>	<b>3.2</b>
41 to 45	6	<b>1.7</b>	<b>3.2</b>	10	<b>3.5</b>	<b>2.4</b>	0	-	<b>2.9</b>	16	<b>2.4</b>	<b>3</b>
46 to 50	1	<b>0.3</b>	<b>3.1</b>	6	<b>2.1</b>	<b>2.2</b>	0	-	<b>2.8</b>	7	<b>1</b>	<b>2.8</b>
51 to 55	5	<b>1.4</b>	<b>2.7</b>	-	-	<b>2.3</b>	0	-	<b>2.6</b>	5	<b>0.7</b>	<b>2.6</b>
56 to 60	1	<b>0.3</b>	<b>2</b>	1	<b>0.3</b>	<b>2.1</b>	0	-	<b>2</b>	2	<b>0.3</b>	<b>2</b>
61 to 65	1	<b>0.3</b>	<b>1.4</b>	2	<b>0.7</b>	<b>1.4</b>	0	-	<b>1.4</b>	3	<b>0.4</b>	<b>1.4</b>
66+	3	<b>1</b>	<b>3.5</b>	4	<b>1.4</b>	<b>2.5</b>	0	-	<b>3.1</b>	7	<b>1</b>	<b>3</b>
Total	347	<b>100</b>	<b>100</b>	289	<b>100</b>	<b>100</b>	33	<b>100</b>	<b>100</b>	669	<b>100</b>	<b>100</b>

Grouped Cohorts												
<16	214	<b>61.7</b>	<b>42</b>	164	<b>56.7</b>	<b>46</b>	27	<b>81.8</b>	<b>43</b>	405	<b>60.5</b>	<b>43</b>
<18	247	<b>71.2</b>	-	184	<b>63.7</b>	-	19	<b>57.6</b>	-	458	<b>68.4</b>	-
<20 All	278	<b>62.0</b>	<b>52</b>	210	<b>53.3</b>	<b>53</b>	29	<b>48.5</b>	<b>52</b>	517	<b>57.5</b>	<b>52</b>
16+	133	<b>38.3</b>	<b>48</b>	125	<b>43.3</b>	<b>47</b>	6	<b>18.2</b>	<b>48</b>	264	<b>39.5</b>	<b>48</b>

**Figure 12.2** Graphic representation of the correlation between the survey populations with the general population in 5 yearly age-cohorts.



**Table 12.3 M:F ratios by age cohort and region.**

Age	West Bank				Gaza Strip				Total			
	M	F	M:F	Pop. <sup>a</sup>	M	F	M:F	Pop.	M	F	M:F	Pop.
< 5 <sup>a</sup>	27	23	<b>1.2</b>	1.1	31	14	<b>2.2</b>	1.1	68	41	<b>1.6</b>	1.1
5-15	80	70	<b>1.1</b>	1.1	59	50	<b>1.2</b>	1.1	147	127	<b>1.6</b>	1.1
6-18	129	118	<b>1.1</b>	-	113	71	<b>1.6</b>	-	260	198	<b>1.3</b>	-
<16	113	101	<b>1.1</b>	1.1	97	67	<b>1.4</b>	1.1	228	177	<b>1.3</b>	1.1
16-20 <sup>a</sup>	28	26	<b>1.1</b>	1.1	26	8	<b>3.2</b>	1.1	54	35	<b>1.5</b>	1.1
Total	170	177	<b>1</b>	0.88	176	113	<b>1.6</b>	1	367	302	<b>1.2</b>	0.9

Numbers and ages are as at the end of the study. Pop. = M:F ratio in general population.

<sup>a</sup> Population figures are for the < 4 and 15-19 years cohorts can also be applied to the age group as the ratio of 1.1:1 is consistent in all the < 24 years old population.

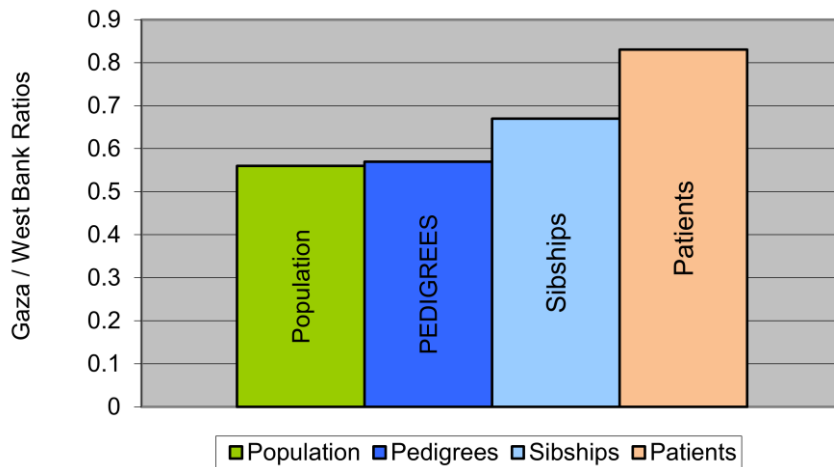
<sup>b</sup> Population ratios are those of the 21+ years old population

**Table 12.4 Pedigrees (extended families), sibships and patients by region.**

Region	Patients		Sibships		Pedigrees	
West Bank	347	<b>52</b>	256	<b>56</b>	228	<b>58</b>
Gaza Strip	289	<b>43</b>	170	<b>37</b>	131	<b>33</b>
Unidentified	23	<b>3.4</b>	24	<b>5</b>	24	<b>6</b>
Israel	9	<b>1.3</b>	8	<b>2</b>	8	<b>2</b>
Total	669	<b>100</b>	458	<b>100</b>	391	<b>100</b>
WB/GS	1,2		1.5		1.75	

Percentages in **bold italic**

**Figure 12.3 Comparison of ratio of the general population in Gaza Strip / West Bank (used as a crude baseline figure) and the ratios of pedigrees, sibships and patients in the total series of 699 cases**



The highest proportion of cases in the series were villagers totalling 269 (40%), followed by town residents 223 (33%) and camps 111 (17%). This, however, does not necessarily imply a refugee status of the individuals. (Table 12.5)

**Table 12.5 Cases by type of residence**

	Nos.	%
Villagers	269	<b>40%</b>
Town	223	<b>33%</b>
Camp	111	<b>17%</b>
N/A	66	<b>10%</b>
Total	669	<b>100</b>

N/A: not available

families were sent to Europe and America for further education.

In the GS, there was one mixed primary school funded by UNRWA which also contained a workshop for older girls. The school was non-residential and children who progressed to secondary education joined the sighted school in the GS. Students from Gaza who joined WB universities resided in residential homes in the WB. The schools in the GS followed the Egyptian curriculum.

For breakdown of schools and institutes refer to appendix A of methodology (Chapter's 10).

## 12.4 Patients by Religious Background

Muslims by birth formed the vast majority of cases (659, 98%), the remaining 10 being Christians. Three of the **elderly** Christians had converted to Christianity at their residential home.

## 12.5 Schools and Institutes

Blind institutes in the WB comprised 3 primary schools for girls funded by local and international charities and 1 school for boys which provided both primary and secondary education and was funded by the Department of Education. The former 3 also accommodated very young boys. The remaining 2 institutions were residential for all disabilities and housed older students in higher education. The primary school in Nablus also contained a workshop for older girls who did not proceed to higher education. All the schools in the WB followed the Jordanian curriculum. Visually impaired boys progressing to university education either stayed at the residential homes in the WB or moved to Jordan. A few children from affluent