

Thalassemia Patients' Situation During the Israeli Reinvasion of the West Bank

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Introduction

The current situation in Palestine has severely affected every aspect of Palestinian society. One of the main sectors affected is the health sector. In this brief report, the status of a very specific and vulnerable group of patients will be described—patients suffering from Beta Thalassemia Major.

Beta Thalassemia Major is an inherited blood disease (hemoglobinopathy). It is also known as Cooley's anemia or Mediterranean anemia. The amount of hemoglobin (Hb) that the body can produce is reduced (usually less than 8 gm/dl compared to the normal range, mean=12 g/dl), resulting in anemia. Thalassemia major is the most severe form and requires continuous, specific, and expensive medical care. The main treatment for this disease is blood transfusions in addition to drug therapy. Currently, most thalassemia patients receive blood transfusions (red blood cells) every 3–4 weeks to keep the hemoglobin within the normal range. This transfusion, in combination with the chelator drug, Desferrioxamine (Desferal[®]), must be administered to rid the body from excess iron resulting from repeated transfusions. Both are vital for the survival, well being, and reduction of complications.

Current statistics estimate 700 thalassemia patients in Palestine. In the West Bank, there are 461 registered patients. Two organizations, the Thalassemia Patients' Friends Society (TPFS) – Palestine and the Falastine al-Mustaqbal or Palestine Avenir Foundation (PAF), work with this group of patients and their families. These two organizations more or less serve the same group of patients.

Both organizations reported that they have been trying their best to coordinate the transport of patients to hospitals during the recent Israeli incursions. This report was compiled from telephone interviews with key personnel from each organization.

Situation During the Reinvasion

As the invasions occurred at different times, and some communities experienced more severe closures even before the invasions, events in each district were unique. In Ramallah, Israeli soldiers entered the TPFS central office on April 11; office equipment, walls, and furniture were destroyed. Two of the senior managers who work in the central office at TPFS-Ramallah were taken prisoners—the main coordinator, who was the link between the patients, the Red Cross or Red Crescent services, and the hospitals where blood transfusions take place, and the chairperson of the society who was sent to al-

Nakab prison. One of the TPFS volunteers took responsibility for these two in order to get patients to the hospitals.

In Qalquilia, the TPFS office was destroyed. At this time, there is no contact with Jenin. The nurse who works in Jenin hospital and is a resident of the Jenin refugee camp cannot be located. Communication with key persons as well as patients was cut off due to the curfews and destruction of phone lines and /or electricity in many areas.

❖ **Ramallah:**

- During the 23-day Israeli incursion, many patients who live in the nearby villages could not get to the hospital for their scheduled blood transfusions.
- A Ramallah nurse who was specifically trained by TPFS to monitor and deal with the thalassemia cases could not reach the Ramallah hospital. She was visiting her family in Ramoon village just before the invasion into Ramallah and could not return home even when the curfew was lifted for a few hours. She lost touch with many patients.
- During the first week, two patients had to be transported to a Jerusalem hospital since there was no access to the Ramallah hospital, which was under siege as well as overcrowded with injured patients and martyr bodies. Getting these patients to Jerusalem involved contacting several humanitarian organizations, including the Red Cross and obtaining a special permit from the Israeli government so the soldiers would allow the ambulance with these patients to cross Kalandia checkpoint. At that time, it was almost impossible to transport patients by the ambulance even if they had permits!
- Of 18 patients who live in the villages surrounding Ramallah and served by the PAF, 14 were transported to Jerusalem (al-Maqassed hospital) since they could not get into Ramallah. The person who we interviewed indicated that when the ambulances were not able to pick up the patients, he personally took them to the hospital, as he had a Jerusalem ID.
- Every time the curfew was lifted, 2–3 children who lived in central Ramallah were taken to the hospital for blood transfusions. Since the invasion started in Ramallah, 30 patients were able to get their blood at Ramallah hospital. For some, special arrangement with the Red Crescent ambulances had to be made so they could be picked up from their villages. Several times the Red Cross also attempted to help, but found it too dangerous for them to reach certain areas.
- Families of the young patients who made it to the hospital reported that their children were very pale and tired throughout the period. Some of them continue to be 1–2 weeks late for their regular blood transfusion. Their hemoglobin levels were between 7–7.5 g/dl as they arrived at the hospital, where it had earlier been maintained at 9.5 to 10 g/dl.
- The nurse indicated several problems at this time:
 1. Patients should receive fresh blood. The only blood available at the Ramallah hospital was donated from Tunisia and Jordan and was more than 10 days old. When a patient does not get fresh blood, another transfusion is required sooner than the regular 3–4 week interval. If the reoccupation and curfews continue, there will be severe problems of transporting these patients more frequently to the hospitals for blood transfusions.

2. Blood transfusions have to be administered slowly through a special filter in order to be safe and effective for the patients' bodies needs. The untrained nurses had no choice but to increase the rate of transfusion so that the patients would be able to finish and go home before the curfew began again. Normal time for a transfusion is 3.5 to 4 hours and the curfew was lifted for only 2 to 3 hours.
 3. Ramallah hospital is running short of filters, as well as Desferal[®] vials. At the time of this report was compiled, patients had not contacted anyone to indicate that they finished their supply of medication.
- At this time, one cannot be sure of the long-term implications on the health of these patients resulting from the above-mentioned problems.
 - One patient, 9-year-old M.T. from Beit-Ur village, had splenectomy surgery a few days before the invasion. Several efforts were made to get him to Ramallah hospital for his check up and blood transfusion. No one, including the Red Cross and Red Crescent, was able to contact his family to see how he was recovering. The patient also has a thalassemic brother, and both are four weeks late for their blood transfusions at this time. A doctor from the Jerusalem area is trying her best to coordinate with some humanitarian organization to bring them to Jerusalem as soon as possible.

❖ **Tulkarem:**

- The nurse in Tulkarem who lives in Kufr Sour, a village between Tulkarem and Qalquilia districts, has not been able to reach the hospital in Tulkarem. Days before the March 29 Israeli incursion into Tulkarem City, at least seven patients from surrounding areas were prohibited from entering Tulkarem to go to the hospital, due to the strict siege around the area. During the first two weeks of the incursion, the number of patients late for their blood transfusion was multiplying without anyone being able to help.
- After the tanks left the center of the city, many of the patients, with the cooperation people in the community donating blood, were able to get their transfusions, even though they were 10–14 days late.
- One patient, 8-year-old A.S., was scheduled to have a splenectomy, and was taking blood transfusions on a weekly basis; no one knows how he was managing.
- One TPFS patients, 9-year-old A.T. from Kufr Aboush, a village in Tulkarem district, had to walk with her father 3 km from her village through the road blocks to reach an area where a Red Crescent ambulance could pick her up to take her to the Tulkarem hospital. Special arrangements and permits allowed this ambulance to get to the village to take her to the hospital. As she arrived late that morning to get her blood, there was no one to take them back home. They had to sleep at the hospital and wait for the ambulance to go to the blockade the next day where they were dropped off and had to walk the 3 km to their village. Her blood Hb was less than 7 g/dl, and she was only one week late for her blood transfusion. If this situation continues, one can be sure that she will not make it through the same scenario for another blood transfusion!! This is only one case that was reported at this time. Other examples will definitely be found once the military forces withdraw from the occupied areas.

❖ **Qalquilia:**

- It is also difficult to contact patients in Qalquilia. The Qalquilia hospital was out of reach for many. By chance, one patient was able to get to the local UNRWA hospital for refugees for his blood transfusion. Arrangements were made for TPFS to pay the UNRWA hospital for blood transfusions for any thalassemia patients able to reach them, even though the hospital is not equipped with the proper blood filters, needles, or sufficient blood bags.
- The Qalquilia TPFS branch office was among the offices blown up in the area. The equipment and patient files have all been destroyed.

❖ **Jenin:**

- It was reported that Jenin, with 108 thalassemia patients requiring blood transfusions, has the second largest number of thalassemia patients in the West Bank after Hebron. Both the PAF and TPFS organizations lost contact with patients and their families during the invasion of Jenin, which began on April 2 and ended 21 days later.
- Up to the completion of this report, [April 22], telephone lines and electricity have been out of order. Details of what is happening with these patients could not be identified. PAF indicated that they have been unsuccessful in reaching a family with four thalassemic children in Beir al-Basha village, who were 10 days late in getting a transfusion. There were fears that their Hb blood levels may be as low as 5–5.50 g/dl, if they did not get their transfusion.

❖ **Nablus:**

- No one from Nablus area could be contacted at the time of writing this report.
- TPFS indicated that nine patients were due for their blood transfusions the first week and a half of the Nablus invasion, which began on the evening of April 3 and continued until April 21. A doctor from the Nablus area told one of the TPFS volunteers that even if patients made it to the hospital, there would be a problem transporting blood. The blood bank is located at the Rafida Hospital and patients go to the al-Watani hospital, which is located across town. With the strict Israeli curfew, it sometimes took 4–5 hours, rather than the usual 10 minutes, to get the blood to the al-Watani hospital for any operation. Special arrangements had to be made to make sure that the blood is available before the thalassemia patient's arrival.
- PAF indicated that they had to transport 25 patients from Nablus-area villages in the northern West Bank to the Jericho Government Hospital in the south for their blood transfusions, since no one was allowed into Nablus City, which has 95 thalassemia patients.

❖ **Toubas**

Toubas was one of those areas that witnessed severe siege conditions around it even before the invasion, which lasted from April 2 to April 20. There were no specialized units available to deal with thalassemia cases or any severe cases. A doctor in the area had to arrange for the 12 patients in his area, some two weeks late for their transfusions, to meet at a special location in order to be taken to the only hospital accessible at that time, Jericho Government hospital, a 6-hour trip through side roads and barricades. They

had no choice in getting their blood transfusion, and the doctor did not want to risk waiting for the siege to be lifted or sending one patient at a time.

❖ **Hebron, Bethlehem and Jericho** did not report any problem up to the completion of this report.

Last Words

Thalassemia patients and their families come mostly from the low socio-economic class. This by itself will be a crisis to the patients, as their families are barely providing basic daily food. In addition, they are more susceptible to infections, which is another problem in such situations where they cannot be monitored on a regular basis. The hard work that was put into bringing up the Hb levels for many patients so they can grow “normally” has been affected. Thorough blood tests will have to be done when the siege is over to evaluate the health of these children. Both organizations, TPFS and PAF, help such families with getting their drugs and food packages when possible in normal times. One can only imagine the mental state that the patients and their families are undergoing in the current situation!
