FISH

FISH (Functional Independence Score in Hemophilia) has been developed as a measure of disability in patients with hemophilia. It is intended to measure what the person with disability actually does, and not what he ought to be able to do, or might be able to do if circumstances were different. It can be used to evaluate change in functional independence over time, or after a therapeutic intervention.

FISH incorporates items that are perceived as important by persons with hemophilia, is performance based, and is relatively safe to perform. The FISH is meant to complement other scores that measure body structure and function such as the clinical joint evaluation score, and the radiological score. We do recognize that there are several activities that are not evaluated by the FISH, and it may be necessary to complement the FISH with other self-rated scores. Its major advantage is that it can be used with illiterate patients, and in different language settings, as it is an objective, performance-based instrument. It has good face validity, content validity, and internal consistency (Cronbach’s alpha of 0.83). It correlates well with other self-rated activities such as the Stanford Health Assessment Questionnaire (HAQ) (0.90), and has a reasonable correlation with the clinical score (-0.68) and radiological score (-0.44).

Any trained therapist or clinician can administer the FISH. It is advised that one reads the complete instructions prior to scoring the activity. It is recommended that one perform the test as instructed, without any modifications. It is also necessary that one score the activity only after observing the subject performing the task. One should not score the item based on the person’s subjective ability.

As the data is still being refined, feedback and suggestions are invited.

LEVELS OF FUNCTION AND THEIR SCORES

4. The subject is able to perform the activity without any difficulty like other healthy peers.

3. The subject is able to perform the activity without aids or assistance, but with slight discomfort. He is unable to perform the activity like his healthy peers.

2. The subject needs partial assistance/ aids/ modified instruments/ modified environment to perform the activity.

1. The subject is unable to perform the activity, or needs complete assistance to perform the activity.
EATING AND GROOMING

Score the lowest of either dressing/grooming for this activity.

(A) EATING

Activity

Serve the meal with appropriate utensils and implements and observe the subject’s ability to mix and lift the food to his mouth using hands or implements.

This activity does not assess the subject’s ability to serve the food on the table or his ability to sit on the floor/chair during meals like other members of his community.

This activity assesses the subject’s ability to gather food from the plate and take it to the mouth. Important aspects to observe in this activity are posture, elbow movement, cascade grasp (if using hands to eat) and the use of aids and adaptations not commonly used by other members in his community.

For those using their hands to mix and eat food, the test may be performed using a bowl of cereal (raw rice) or simulated using ball bearings. A bar of chocolate or a slab of plastercene can be used to assess skills with the knife and fork. (The slab of plastercene needs to be divided at least 5 times) Chopsticks simulation can be done where applicable.

Scoring

Score 4 if the subject:
− has no difficulty in performing the activity.

Score 3 if the subject:
− has to lean over unnaturally to reach his food due to limitation of flexion of the elbow.
− has to take several breaks in between due to pain. The subject is not to be asked if he has pain, but is to be observed to see if he has any discomfort.
− has no difficulty performing the activity with a prosthesis, using implements commonly used in his community.

Score 2 if the subject:
− uses implements that are not commonly used in his community e.g. spoon or a fork in a community where other members use their hands.
− uses modified utensils/implements to feed himself.
− has difficulty feeding himself using a prosthesis, or uses implements that are not commonly used in his community.
− is a right-handed individual, but has to eat with his left hand due to problems with the right upper limb.
Score 1 if the subject:
  – is unable to feed himself.

(B) GROOMING

Grooming includes oral care, hair grooming, washing hands and face. Shaving is optional. It does not include the ability to reach the dressing table or the washbasin. It does not include the subject’s ability to sit on the stool / floor / the surface on which the individual does the grooming.

Activity

The subject can sit/stand to perform the activity.
Place the subject in front of a sink and place a toothbrush and toothpaste, comb and other culturally appropriate instruments on a table close to the subject.
If the subject is able to shave, place the appropriate razor and shaving cream and brush in front of him.

Scoring

Score 4 if:
  – the subject has no difficult in grooming.
  – the child needs assistance only to apply the toothpaste on the brush.

Score 3 if the subject
  – adopts abnormal postures to comb the back of his head / shave / wash his face.
  – experiences pain or discomfort while grooming (as assessed by the observer).
  – takes an unnaturally long time to perform the activity.

Score 2 if the subject
  – is not able to comb hair in all areas of the head - the back / side of the head (is not able to perform the activity completely).
  – requires any modified instrument.
  – is a right-handed individual, but uses the left hand for grooming, due to problems with the right upper limb

Score 1 if the subject
  – is unable to do the activity because of problems with reach.

Score the lowest of either dressing / grooming for this activity.
BATHING

Activity

This activity assesses the ability to wash, soap, and dry different parts of the body – including the perineal region, and feet (except the back). It is essential to assess the reach on both sides of the body, using both hands.

This is a complex activity involving various subtasks and is culturally influenced. It may need to be simulated.

Assess the:
• ability to turn on/off a tap
• ability to lift a mug of water from the floor to above the head
• ability to pick up a 75 gms bar of soap from the floor.
• ability to take the bar of soap to the feet, shin, thigh, perineum, abdomen and nape of the neck

Scoring

Score 4 if the subject:
– has no difficulty in bathing.

Score 3 if the subject:
– adopts unusual postures while bathing e.g. Places feet on a stool to apply soap.
– is in discomfort while performing the activity

Score 2 if:
– the subject requires a shower instead of water from a bucket in a community where the other members use water from a bucket (modified environment); but if others in the community too use the shower, score 4.
– the bathtub or bathroom has to be modified (modified environment.)
– the subject sits on a stool for his bath (modified environment.)
– the subject has to use instruments to reach any part of the body (except the back).
– the subject requires occasional help to bathe and dry the feet, perineum, or any other part of the body, except the back.

Score 1 if:
– the subject requires a bed bath, or is unable to perform most of the activity of bathing/ drying.
DRESSING

This activity assesses the ability to get dressed - wearing a shirt/T-shirt/ vest/ trouser/ dhoti /tie / socks - as appropriate to the culture, and donning and doffing of prosthesis or orthosis, when applicable. This activity does not include ironing clothes or taking clothes from a cupboard. The ability to don the footwear is not tested.

Activity

Place a shirt, T-shirt/vest, trouser, socks, prosthesis/orthosis (if any) in front of the subject. The patient's own clothes may be used to perform the activity if needed.

Scoring

Score 4 if the subject:
- is able to get dressed without discomfort and without assistance.

Score 3 if the subject:
- experiences discomfort during the activity. [Assess the activity using an open shirt with buttons, and a T-shirt or vest].
- takes momentary support from the wall/ table to steady himself while donning his trousers.
- uses adaptive maneuvers to don the shirt due to discomfort.
- takes a long time to put on his shirt/ T-shirt/ vest/ trouser

Score 2 if the subject:
- requires help to wear the trouser.
- requires an aid such as a trouser puller.
- sits to put on his trousers (aid).
- requires considerable amount of support from the wall/ table while donning trousers.
- needs help with his upper buttons (requires partial assistance).
- requires complete help in <50% of the activity, e.g. partial assistance in donning the trouser, but no help required in putting on the shirt. If however, he requires assistance in donning both shirt and trouser, score 1.

Score 1 if the subject
- requires help in >50% of the activity.

If the subject has to sit only to put on/take off his socks- score 4.

Where wearing a necktie is not the norm, do not assess the ability to do so. If other members of the community wear neckties, and the subject does not due to difficulty, do not score the activity as 4. He will need to be scored based on the amount of assistance required.
Examples:

**Figure 1** – This subject scores 3 for the activity of dressing. Compare this to figure 2, and note the way the subject puts the left arm into the sleeve. Unlike the person in figure 2, he does not use the right hand (with the affected elbow) to pick up the shirt from behind the back, prior to directing the left hand into the sleeve. He uses the left hand for the extra maneuvering. Therefore, the activity is to be scored as 3.

**Figure 2** - Normal donning of the shirt – grade 4. Note how he uses both his hands to take the shirt behind the back, and insert the left arm (the unaffected limb) into the sleeves.

**Figure 3** – The subject scores 3 for wearing the trousers, as he is in discomfort while standing on his left leg while attempting to introduce his right leg into the trouser
**CHAIR TRANSFER**

**Activity**

Place a chair with armrests of an appropriate height in front of the subject (i.e. the patient sits comfortably with hips and knees flexed to 95 degrees, with feet on the ground - 18 inch for adults). Ask the subject to appose his palms (as in a Namaste/ prayer posture), get up from the chair, and then sit down.

**Scoring**

Score 4 if the subject:
- has no difficulty in performing the above activity.

Score 3 if the subject:
- leans excessively forward in order to get up.
- sits with one or both knee joints slightly extended, but does not require support to get up.
- uses momentary support of the arm rest while getting up

Score 2 if the subject:
- requires a lot of support from the armrest to get up.
- requires the use of crutches to get up.

Score 1 if the subject:
- is not able to get up from the chair.

**Examples**

**Figure 4** - This subject scores grade 4 (normal sitting and getting up).

**Figure 5** - This subject scores grade 3 as he leans forward to get up
SQUATTING

Activity

This assesses the ability to squat on the floor and rise to an erect posture.

Ask the subject to stand by a scale/wall on which 8-inch and 12-inch heights (6 and 10 inches for children less than 15 years) are marked off. Ask him to oppose his palms (as in a prayer/ Namaste position). Ask him to go down on his haunches to a height of 8 inches (6 inches for children), and then rise to standing. **It is not necessary that both soles be completely on the floor while squatting.** He should squat for duration of at least 5 seconds

This is a provocative test. Hence ask the patient first if he feels able to perform the activity. If he says it is not possible for him to squat, try carefully with support from the side (e.g. with a stool/chair placed on the side), or with one leg extended if needed. If at any point the subject complains of pain, or is reluctant to proceed, the test should be stopped, and the subject scored appropriately.

Scoring

Score 4 if the subject:

- has no difficulty in performing the activity.

If the subject has discomfort while trying to get down to 8 inches (6 inches for children), do not coax him to go lower. Ask him to attempt squatting with one leg in extension.

Score 3 if the subject:

- is able to squat to a height of 8-12 inches (6-10 for children).
- is able to squat to a height of 8 inches, with one leg in extension (6 inches for children).
- is able to squat to a height of 8-12 inches (6-10 for children) using momentary support from the side/floor

If the subject cannot come down to 12 inches (10 inches for children), attempt the activity with support from the side (chair/grab-rail).

Score 2 if the subject:

- is able to squat to a height of 8-12 inches (6-10 for children) with maximum support from a chair/grab-rail.

Score 1 if the subject:

- is not able to squat to a height of 12 inches with support from the side (10 inches for children).

Examples

**Figure 6** – The subject scores grade 1 – as he is unable to squat to a height of 10 inches even with support from the side.
WALKING PATTERN

Activity

Walking is to be assessed over a distance of **10 meters**. There has to be a good heel to toe pattern in the gait, with steps of relatively equal length and cadence. Heel strike should be with knee in full extension. The knee should bend adequately during stance and swing phase. There should not be an obvious limp.

Scoring

Score 4 if the subject – has an apparently normal gait.

Score 3 if the subject
– has a stiff knee gait/ limp. If stance phase in a limb is reduced due to pain – score 3

Score 2 if the subject
– uses a cane/walking stick.
– uses a knee/ankle brace

Score 1 if the subject
– is unable to walk 10 meters.

Examples

**Figure 7** – The subject scores 3 as he is walking with a limp.

**Figure 8** – the subject scores 2 as he requires an aid.
STAIR CLIMBING

Activity

Place the subject in front of a flight of stairs with banisters/side rails. There should be at least 14 steps, each of approximately 8 inches in height. Ask him to climb up and down the stairs slowly. Assessment of the activity on a flight with 4-5 stairs is inadequate.

Scoring

*As this is a provocative test, ask the patient first if he is able to climb the flight of 14 steps. If he says it is not possible, ask him to try to do so with aid from the railings; but if he still says it is not possible, score 1. Do not force the subject to do the activity. The activity should be timed.*

Score 4 if the subject
- is able to climb up/down the stairs without a limp or aid with an alternating stepping pattern. He should be able to climb up/down the steps in less than 9 seconds (in either directions).

Score 3 if the subject
- has a limp/discomfort while climbing the steps. If he uses the rails for occasional minimal support – he should be able to climb up/down the steps within 14 seconds (in either direction).
- climbs up the stairs, taking one step at a time.
- climbs down the stairs, taking one step at a time

Score 2 if the subject
- takes more than 14 seconds to climb up/down the stairs using the aid of the rails or crutches/assistance of a helper (in either direction).

Score 1 if the subject
- is unable to climb 14 steps.

Examples

*Figure 9.* It is important to assess the activity on a stairway with at least 14 steps. Else, the subject may mistakenly be scored 4.

*Figure 10.* The same subject in figure 9, when put in front of 14 steps has a limp, and scores 3.

*Figure 11.* This subject scores 3 when assessed on the small flight of steps. This activity ought to be tested on a stairway with 14 steps – as in figure 12.

*Figure 12.* The same subject in figure 11 needs the aid of the side railings when confronted with 14 steps, could potentially score 2.
RUNNING

Running is to be assessed over a distance of 25 meters for children, and 50 meters for adults (age 15 years and above). There should be periods during which both feet are off the ground.

Scoring

As this is a provocative test, ask the patient first if he feels able to perform the activity. If he says it is not possible for him to run, assess his ability to walk briskly, by asking him to walk the same distance as fast as he can. If at any point the subject complains of pain, or is reluctant to proceed, the test should be stopped, and the subject scored appropriately. Do not force the subject to do the activity.

Score 4 if the subject:
- has no difficulty/discomfort while running.

Score 3 if the subject:
- has pain/discomfort while running.
- is able to run only part of the distance.

Score 2 if the subject:
- is not able to run, but is able to walk briskly (>70 meters/min for children, and >100 meters/minute for adults).

Score 1 if the subject:
- is not able to walk briskly (<70 meters/min for children, and <100 meters/minute for adults).