Exploring the significance of falls in the everyday lives of the older person with haemophilia

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Introduction

People with haemophilia are increasingly enjoying older age, but are known to show signs of haemophilic arthropathy from young adulthood. It has been suggested that they may be at greater risk of falls, at an earlier age, than people within the general population.1 A review, in 2013, of the orthopaedic co-morbidities in the older haemophilic population revealed there have been few published studies which have investigated the risk of falls in people with haemophilia.2 There is a lack of information on the effects of falling on balance, self-confidence and perceptions of the need for modified behaviour.

Methodology

In this pilot study, we used grounded theory methods to explore the significance of falls in the everyday lives of adults with haemophilia. Semi-structured interviews were conducted with ten participants with severe haemophilia [Haemophilia Joint Health Score (HJHS): median 34; IQR 17-49] aged 36-82 years (median 56; IQR 49-66). We utilised the following instruments to ascertain if these standardised falls risk measures were able to identify those at risk of falling.

Modified Falls Efficacy Scale (FES) which measures the level of confidence about completing social and physical activities inside and outside the home without falling, rated between 0 not confident to 10 completely confident,

Berg Balance Scale (BBS) a clinical test that’s observes a person’s static and dynamic balance abilities during 14 functional tasks, and

Timed-Up-And-Go (TUG) which records the time taken to stand, from a standard height chair, walk 3 meters, turn, walk 3 meters back to the chair and sit down.

Results

Due to the exploratory nature of this pilot study, a narrative and descriptive analysis was performed. All participants were fearful of falling in the future and eight had fallen in the previous year. A theme of “slipping away” emerged which was underpinned by three core categories;

Feeling of inevitability
“you know, you reach for something and your legs don’t work like legs should work... it’s a fact of life”
“I have to just think about every step I take that I don’t fall... where I have fallen I have survived it”

Avoidance and behaviour change
“I’ve stopped sailing... I’ve stopped walking”
“because I’m worried about falling I’m a lot more careful outside... avoiding rough terrain... if there is a hill involved it’s no way”
“heavy doors... that kind you have to put your weight against to open, you have to be aware some well-meaning person the other side doesn’t pull the door while your leaning on it... you’re over”

Exclusion
“it’s embarrassing to go into some people’s houses where you can’t take your shoes off because you can’t walk properly... some people I avoid altogether now... I don’t want to get their beautiful clean carpets dirty”
“there are a number of places that I would kind of like to go to, but I don’t feel that I can... I haven’t been shopping for ages”
“I am noticing that more often I am saying to my 7 year old I am really sorry but I can’t give you a fireman’s lift today”
“My wife normally walks ahead... in fact in very high winds I wouldn’t even think about going out of the front door”

The fallers along with the non-fallers were categorised as more than fairly confident in performance of everyday activities (Falls Efficacy Scale) and a low risk for falling (Berg Balance Scale). However, all measures (HJHS, Falls Efficacy Scale, Berg Balance Scale and Timed-Up-And-Go) were worse in the fallers when compared to the non-fallers.

Table 1. Median HJHS, FES, BBS and TUG for fallers and non-fallers.

<table>
<thead>
<tr>
<th></th>
<th>HJHS</th>
<th>FES</th>
<th>BBS</th>
<th>TUG (sec)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fallers (n=8)</td>
<td>40.50</td>
<td>6.65</td>
<td>44.5</td>
<td>10.70</td>
</tr>
<tr>
<td>Non-fallers (n=2)</td>
<td>24.50</td>
<td>9.00</td>
<td>48.0</td>
<td>7.90</td>
</tr>
</tbody>
</table>

FES: 0 = not confident; 5 = fairly confident; 10 = completely confident
BBS: 41-56 = low risk; 21-40 = medium risk; 0-20 = high risk

Conclusions

- Older people with haemophilia
  - are concerned about falling
  - view falling as inevitable
  - avoid activities and modify their behaviour to minimise their fall risk
  - feel excluded from friends and family activities

- Adjustment of risk cut-off levels in current measures may be required to identify older people with haemophilia at risk of falling

- Higher HJHS scores and reduced TUG appear to be associated with a higher risk of falling

References