Some population survey approaches: Incontinence in Australia

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Some population survey approaches: Incontinence in Australia

Abstract
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Some Population Survey Approaches: Incontinence in Australia

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Australian Health Outcomes Collaboration
2011
Introduction

- These projects are about using a population survey approach to identify estimates of the prevalence of incontinence in Australia and to assess the relative performance of a number of continence and multi-attribute utility instruments. It was also useful in deriving Australian norms for SF-36V2.

- Some important references:
About the study: methods and sample

• Study was recommended by the “Continence Outcomes Measurement Suite Project”, Department of Health & Aged Care (Special Needs and Strategies Section)
• South Australian Health Omnibus Survey is a ‘user-pays’ population health survey
  – April/ June 2004 (13 participating organisations)
  – To examine incontinence in the population
  – To report on 5 key health related quality of life instruments
  – To report population norms for the new SF-36 Version 2
• The study methods:
  – Sampled all locations throughout SA with 1,000+ inhabitants
  – Sampling from ABS collectors’ districts, using a random starting point and every 4th dwelling
  – Response rate: 72%
    • 4,700 households selected, 3015 interviews
  – Weighted data based on probability of selection and 2001 ABS Census to achieve representativeness
About the study: measures included for this study

- **Health status measure:**
  - SF-36 Version 2

- **Incontinence measures:**
  - Urogenital Distress Inventory
  - Incontinence Symptom Severity Index
  - Wexner Faecal Incontinence Scale

- **Health-related quality of life measures:**
  - AQoL (Assessment of Quality of Life)
    - Australian instrument
  - EQ5D
    - Western Europe, with British weights
  - HUI3
    - Canada
  - 15D
    - Finland
  - SF6D
    - USA (SF36 descriptive system) & UK (British weights)
Health status of the sample (SF36V2)

All scales significantly different (Welch’s T, p < 0.05)

USA General population (N=6742)  Australian SA HOS (N=3014)
Health status of the sample (SF36V2)

All scales significantly different (Kruskall-Wallis, p < 0.01), except GH (p = 0.18)
**Urogenital Distress Inventory (UDI 6)**

- **Urogenital Distress Inventory 6 (Short Form)**

*Do you experience and if so how much are you bothered by*

- Frequent urination
- Urine leakage related to the feeling of urgency
- Urine leakage related to physical activity, coughing or sneezing
- Small amounts of urine leakage (drops)
- Difficulty emptying your bladder
- Pain or discomfort in the lower abdominal or genital area

- **The response scale is with a score range from 0-18**

  - Not at all = 0
  - Slightly = 1
  - Moderately = 2
  - Greatly = 3

**What might be some issues with this instrument?**
Incontinence Severity Index

- **How often is urine loss experienced?**
  
  Never = 0
  
  Less than once a month = 1
  
  Once - several times a month = 2
  
  Once - several times a week = 3
  
  Every day and/or night = 4

- **How much urine is lost each time?**
  
  None = 0, A few drops = 1, Small splashes = 2, More = 3

- **Severity Index = (points for frequency) * (points for amount)**
  
  The minimum score is 0 and the maximum score is 12.

How does this index compare with the UDI? What might be some issues with this instrument?
**Urinary incontinence: UDI score distributions & coding**

Classifications based on being bothered in last month:

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No incontinence</td>
</tr>
<tr>
<td>1-3</td>
<td>Slight problem</td>
</tr>
<tr>
<td>4-6</td>
<td>Moderate problem</td>
</tr>
<tr>
<td>7-9</td>
<td>Problem</td>
</tr>
<tr>
<td>10-18</td>
<td>Major problem</td>
</tr>
</tbody>
</table>

None (54%)  Slight (32%)  Moderate (10%)  Problem (3%)  Major problem (2%)
**Wexner Faecal Incontinence Scale**

- Do you leak, have accidents or lose control with solid stool?
- Do you leak, have accidents or lose control with liquid stool?
- Do you leak, have accidents or lose control with gas (flatus or wind)?
- Do you need to wear a pad to protect your underwear from stool?
- Does bowel or stool leakage cause you to alter your lifestyle?

**Response Categories**

0 = Never

1 = Rarely, i.e. less than once in the last four

2 = Sometimes, i.e. less than once a week, but once or more in past four weeks

3 = Often or usually, i.e. less than once a day but once a week or more

4 = Always, i.e. more than once a day or whenever you have a bowel movement

**Minimum score = 0 and Maximum Score = 20**

**What are some issues with this instrument?**
Faecal incontinence: Wexner score distributions & coding

Classifications based on reported episodes in last month:

- 0 episodes = No incontinence (66%)
- 1 episode = Rarely (20%)
- 2-3 episodes = Sometimes (9%)
- Weekly episodes = Weekly (3%)
- Daily episodes = Daily (2%)
Urinary incontinence by severity by gender (UDI)

Statistics:
All cells statistically significant, Sresid >1.96,
$$\chi^2 = 274.84, p <0.01$$
Faecal incontinence by severity by gender (Wexner)

- **Male**
  - **Never**: 69%
  - **Rarely**: 63%
  - **Sometimes**: 21%
  - **Weekly**: 19%
  - **Daily**: 10%

- **Female**
  - **Never**: 63%
  - **Rarely**: 21%
  - **Sometimes**: 8%
  - **Weekly**: 3%
  - **Daily**: 3%

Statistically significant cells: Sresid >1.96, p <0.01
### Utility HRQoL instruments in this study

<table>
<thead>
<tr>
<th>Country</th>
<th>N. Items</th>
<th>N. Scales</th>
<th>Weight</th>
<th>Combination rule</th>
<th>Range *</th>
</tr>
</thead>
<tbody>
<tr>
<td>AQoL</td>
<td>Australia</td>
<td>12</td>
<td>4</td>
<td>TTO</td>
<td>Multiplicative</td>
</tr>
<tr>
<td>EQ5D</td>
<td>Europe/UK</td>
<td>5</td>
<td>5</td>
<td>TTO</td>
<td>Regression</td>
</tr>
<tr>
<td>HUI3</td>
<td>Canada</td>
<td>12</td>
<td>8</td>
<td>VAS/SG</td>
<td>Multiplicative</td>
</tr>
<tr>
<td>15D</td>
<td>Finland</td>
<td>15</td>
<td>15</td>
<td>VAS</td>
<td>Additive</td>
</tr>
<tr>
<td>SF6D</td>
<td>US/UK</td>
<td>12</td>
<td>6</td>
<td>SG</td>
<td>Additive</td>
</tr>
</tbody>
</table>

**Notes:**

1.00 = Full health, 0.00 = Death

Note: as there are many possible health states and not all can be weighted directly (e.g. 245 states for EQ-5D and more for the others) the combination rule refers to the statistical method that is used to infer the remaining utility weights from a sample of health states to those health states not directly assessed. Multiplicative rule is preferred.
### Content of HRQoL instruments

<table>
<thead>
<tr>
<th><strong>Dimensions</strong></th>
<th><strong>HRQoL Elements</strong></th>
<th><strong>Utility instruments</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>AQoL</td>
</tr>
<tr>
<td>Illness</td>
<td>Pain</td>
<td>*</td>
</tr>
<tr>
<td>Independent living</td>
<td>ADLs</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Bodily/Self care</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Safety &amp; security</td>
<td></td>
</tr>
<tr>
<td>Physical ability</td>
<td>Mobility</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Physical ability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Vitality/Fatigue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sensory function</td>
<td>**</td>
</tr>
<tr>
<td></td>
<td>Sexual relationship</td>
<td></td>
</tr>
<tr>
<td>Psychological state</td>
<td>Anxiety/Depression</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Cognitive ability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Emotional fulfillment</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Memory</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Rest/Sleep</td>
<td></td>
</tr>
<tr>
<td>Social interaction</td>
<td>Communication</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Family role</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Intimacy</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Social function</td>
<td>*</td>
</tr>
<tr>
<td></td>
<td>Work satisfaction</td>
<td></td>
</tr>
</tbody>
</table>
Distribution of HRQoL utility scores by instrument

- **AQoL**: Nice even distribution
- **HUI3**: Nice even distribution
- **SF6D**: Most cases 0.80-1.00, Almost none <0.40
- **EQ5D**: Inconsistent distribution
- **15D**: 74% cases >0.90, Almost none <0.50
Effect of urinary incontinence on HRQoL by gender

![Graph showing the effect of urinary incontinence on HRQoL for males and females. The x-axis represents the level of urinary incontinence problem (UDI), ranging from None to Major. The y-axis represents the mean utility (95% CIs). The graph includes data from AQoL, EQ5D, HUI3, 15D, and SF6D.](image-url)
Effect of faecal incontinence on HRQoL by gender

Males

Females

Level of faecal incontinence problem (Wexner)

Mean utility (95% CIs)

Never

Rarely

Sometimes

Weekly

Daily

AQoL

EQ5D

HUI3

15D

SF6D
Utility instruments: Psychometrics

• Reliability (Cronbach $\alpha$):
  – AQoL: 0.81
  – EQ5D: 0.69
  – HUI3: 0.74
  – 15D: 0.84
  – SF6D: 0.77

• Effect Size and Responsiveness

A standardized indicator of the ability of scores on a measures to distinguish between 2 groups – takes into account the mean differences between the groups (Mean 1 – Mean 2) divided by the pooled standard deviation (a measure of variation). Being standardized, effect sizes may be directly compared between different measurement instruments…
Discussion - incontinence

1. This paper presents population-based estimates of the effect of incontinence on leading utility instruments

2. Urinary incontinence:
   - No urinary incontinence symptoms were reported by 68% of males and 40% of females
   - There were significant differences in incontinence severity by gender, with females reporting higher rates and more severe conditions

3. Faecal incontinence:
   - No symptoms reported by 69% of males and 63% of females
   - There were few significant differences between males and females

4. The effect of age (both urinary and faecal):
   - In males, systematic increases until 65 years
   - In females, systematic increases until 45 years
Discussion – effect on quality of life

1. Study compares 5 different HRQoL utility instruments
   – All scores presented on life-death scale (0.00 = death, 1.00 = full life)

2. Scores remarkably consistent:
   – for the AQoL, EQ5D, HUI3 & SF6D very consistent and close
   – 15D scores systematically higher when compared with others

3. The range of scores varied by HRQoL instrument, & type and severity of incontinence:
   – urinary: None = 0.85-0.96; major problem = 0.47-0.77
   – faecal: None = 0.80-0.95; daily = 0.54-0.85

4. Effect size analysis comparing groups with different levels of incontinence:
   – range of average effect sizes: 0.29-0.41 (low to moderate)

5. Suggests that effects of an intervention may depend upon instrument chosen rather than treatment efficacy
   • So choose instruments carefully
Discussion – issues with instrument scores

1. AQoL - no noticeable problems

2. EQ5D:
   - poor data distribution across the range of scores
   - inconsistent values for faecal incontinence for “Sometimes/ Weekly”
   - insensitive to urinary incontinence differences “Slight/ Moderate”
   - the least sensitive instrument

3. HUI3 - no noticeable problems

4. 15D:
   - assigned 74% of cases to top decile (>0.90)
   - assigned 2 cases only to bottom 40% of the utility scale
   - scores higher than any other HRQoL instrument
   - the most sensitive instrument

5. SF6D
   - assigned 57% of cases across the range 0.80-1.00
   - insensitive to females with urinary “problems/ major problems”
   - similar sensitivity to the EQ5D


**Conclusion**

- Urinary incontinence:
  - 32% of males and 60% of females report some symptoms
  - 1% of males and 7% of females report a problem/major problem
- Faecal incontinence:
  - 31% of males and 37% of females report some symptoms
  - 2% of males and 3% of females report this is a daily problem
- Symptoms increase with age
- Incontinence has a moderate effect on HRQoL:
  - on average, those with the worst incontinence conditions obtain HRQoL utility scores 30% worse than those with no symptoms
- HRQoL instruments:
  - four of the instruments (AQoL, EQ5D, HUI3 & SF6D) showed remarkably similar scores and score variations
  - 15D showed higher scores, but was the most sensitive
  - some problems with the scores of the EQ5D & SF6D
  - **preferred instruments would be AQoL & HUI3**
Caveat

- These findings are based on a preliminary analysis of the data and should be treated cautiously.
- These analyses ignore the effects of comorbidities (e.g. other physical or mental health conditions)
- Further analyses may change some of the findings and recommendations
Refining Measures Project

- Hawthorne (2006) found UDI not as good a measure of severity as ISI. Consider the questions concerning severity in UDI...only really taps frequency but not volume whereas ISI examines both dimensions (refer slides 7-8). ISI, however, has no questions concerning type of incontinence (stress, urge, mixed) whereas UDI does cover these elements and these would be useful to include in a short measure for use in clinical practice.

- Some items in UDI do not appear to be directly related to incontinence (e.g. is frequent urination associated with incontinence?/ pain in lower abdominal? – items may relate to other conditions or fluid intake!)

- A better short measure of the symptoms of UI might be to make a blend of these measures.
Refining Measures Project: Wexner

- Wexner scale confounded by flatus. Should flatus (farting) be considered of equal weight to incontinence for solid and/or liquid stool? Current ICS definition excludes flatus. If flatus item is included 35% of the sample report any faecal incontinence symptoms but if flatus is excluded this drops to 8%. So because of the flatus item the Wexner Scale over inflates the reported prevalence of faecal incontinence (this would also make the prevalence of faecal incontinence greater than urinary incontinence which seems inconsistent).

- Should a measure of incontinence symptoms both measure the symptom (incontinence) and the consequence/impact of the symptom (pad use) within the same scale or does this lead to double counting?

- What item might be missing from the Wexner Scale?
Descriptive Statistics: Urinary Incontinence

- **UDI 6***
  Males: n=1203; mean = 6.98; SD=1.85; range 6-22
  Females: n=1714; mean = 8.13; SD=2.72; range 6-24
  * Not at all =1; lowest possible score =6

- **ISI**
  Males: n=1204; mean = 0.24; SD=0.96; range 0-12
  Females: n=1712; mean = 0.98; SD=1.96; range 0-12

- **Internal Consistency**
  UDI = 0.78 (Cronbach’s alpha)
  ISI = 0.83 (Pearson’s – only 2 items)

- **Correlation between ISI and UDI = .72**
Cronbach’s Alpha: UDI

Corrected item-total correlations and Cronbach’s alpha if the Item was deleted for each item of the UDI-6. Cronbach’s Alpha for UDI 6 = .78

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected Item –Total Correlation</th>
<th>Cronbach’s Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>UDI 1 (frequent urination)</td>
<td>.56</td>
<td>.75</td>
</tr>
<tr>
<td>UDI 2 (urgency leakage)</td>
<td>.70</td>
<td>.70</td>
</tr>
<tr>
<td>UDI 3 (stress leakage)</td>
<td>.57</td>
<td>.73</td>
</tr>
<tr>
<td>UDI 4 (leak small amount)</td>
<td>.69</td>
<td>.71</td>
</tr>
<tr>
<td>UDI 5 (emptying bladder)</td>
<td>.37</td>
<td>.78</td>
</tr>
<tr>
<td>UDI 6 (pain lower abdominal)</td>
<td>.32</td>
<td>.79</td>
</tr>
</tbody>
</table>
Rotated Factor Matrix: Urinary Items

Rotated Factor 1 accounted for 53.43% of the variance and Rotated Factor 2 accounted for 13.58%.

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequent urination</td>
<td>0.48</td>
<td>0.49</td>
</tr>
<tr>
<td>Urgency leakage</td>
<td>0.74</td>
<td>0.33</td>
</tr>
<tr>
<td>Stress leakage</td>
<td>0.82</td>
<td>0.09</td>
</tr>
<tr>
<td>Leak small amount</td>
<td>0.85</td>
<td>0.22</td>
</tr>
<tr>
<td>Emptying bladder</td>
<td>0.14</td>
<td>0.76</td>
</tr>
<tr>
<td>Pain lower abdominal</td>
<td>0.09</td>
<td>0.75</td>
</tr>
<tr>
<td>Leakage frequency</td>
<td>0.89</td>
<td>0.16</td>
</tr>
<tr>
<td>Leakage amount</td>
<td>0.89</td>
<td>0.15</td>
</tr>
</tbody>
</table>
Issues

• ISI estimated prevalence of urinary incontinence at 24% overall. By gender, it would be 38% for females and 10% for males.
• UDI-6 estimated prevalence of urinary incontinence at 47%; for females it would be 60% and for males 33%.
• Some items on UDI may be gaining endorsement from conditions other than urinary incontinence. If items on frequency of urination and abdominal pain are removed prevalence drops to = 36% overall and greater case agreement (87%) with ISI. If ‘emptying bladder’ removed = 32%
• ISI produces prevalence estimates more consistent with literature. Factor analysis results would suggest a 5 item scale (RFIS) combining ISI items with 3 items (stress, urge, leak small amount) from UDI (Revised Urinary Incontinence Scale)
Faecal incontinence items included in survey

(Wexner Items)

- In the past 4 weeks: Do you leak, have accidents or lose control with a liquid stool?
- In the past 4 weeks: Do you leak, have accidents or lose control with a solid stool?
- In the past 4 weeks: Do you leak, have accidents or lose control with gas (flatus or wind)?
- In the past 4 weeks: Do you need to wear a pad to protect your underwear from stool?
- In the past 4 weeks: Do bowel or stool leakage cause you to alter your lifestyle?

0=never, 1=rarely, 2=sometimes, 3=often/usually, 4=always
Other faecal items

- In the past 4 weeks: How do you describe your usual bowel pattern? (normal, constipated, diarrhoea, alternating)
- In the past 4 weeks: How many bowel movements do you have in a week? (seven categories)
- In the past 4 weeks: Do you experience an urgent need to have a bowel movement that makes you rush to the toilet?*
- In the past 4 weeks: Do you leak stool if you don’t get to the toilet in time?*
- In the past 4 weeks: Does stool leak so that you have to change your underwear?*

* Response categories as for Wexner Scale
Issues: Endorsement Rates for ‘Never’

![Bar chart showing endorsement rates for 'Never' across different age groups and gender]

Legend:
- Males flatus
- Females flatus
- Males solid
- Females solid

Age Groups:
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+
Corrected item total correlations and Cronbach’s alpha if item deleted (Wexner FCGS)

<table>
<thead>
<tr>
<th>Item</th>
<th>Corrected – Item Total Correlation</th>
<th>Cronbach’s Alpha if Item Deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>X4 (Leak Solid)</td>
<td>0.52</td>
<td>0.46</td>
</tr>
<tr>
<td>X5 (Leak Liquid)</td>
<td>0.53</td>
<td>0.44</td>
</tr>
<tr>
<td>X6 (Leak Gas)</td>
<td>0.25</td>
<td>0.77</td>
</tr>
<tr>
<td>X8 (Wear Pad)</td>
<td>0.39</td>
<td>0.50</td>
</tr>
<tr>
<td>X10 (Alter Lifestyle)</td>
<td>0.42</td>
<td>0.50</td>
</tr>
</tbody>
</table>

Cronbach’s Alpha for Wexner FCGS $r = 0.57$ (unacceptable range, Streiner and Norman 2003)
Rotated factor matrix for the faecal incontinence items X1 – X10

<table>
<thead>
<tr>
<th></th>
<th>Factor</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>X1</td>
<td>Bowel Pattern</td>
<td>0.27</td>
<td>0.59</td>
<td>-0.12</td>
</tr>
<tr>
<td>X2</td>
<td>Bowel Movements</td>
<td>0.08</td>
<td>-0.03</td>
<td>0.95</td>
</tr>
<tr>
<td>X3</td>
<td>Urgency</td>
<td>0.20</td>
<td>0.70</td>
<td>0.33</td>
</tr>
<tr>
<td>X4</td>
<td>Leak Solid</td>
<td>0.71</td>
<td>0.22</td>
<td>0.07</td>
</tr>
<tr>
<td>X5</td>
<td>Leak Liquid</td>
<td>0.75</td>
<td>0.31</td>
<td>0.10</td>
</tr>
<tr>
<td>X6</td>
<td>Leak Gas</td>
<td>0.08</td>
<td>0.74</td>
<td>-0.08</td>
</tr>
<tr>
<td>X7</td>
<td>Leak Stool / Urgency</td>
<td>0.77</td>
<td>0.25</td>
<td>0.06</td>
</tr>
<tr>
<td>X8</td>
<td>Wear Pad</td>
<td>0.71</td>
<td>-0.03</td>
<td>-0.06</td>
</tr>
<tr>
<td>X9</td>
<td>Leak / Change Underwear</td>
<td>0.78</td>
<td>0.18</td>
<td>0.06</td>
</tr>
<tr>
<td>X10</td>
<td>Alter Lifestyle</td>
<td>0.70</td>
<td>0.15</td>
<td>0.09</td>
</tr>
</tbody>
</table>

\[ X4 + X5 + X6 + X8 + X10 = Wexner FCGS \]
**Interpretation**

For the faecal incontinence items, Rotated Factor 1 accounted for 40.06% of the variance, while Rotated Factors 2 and 3 accounted for 10.70% and 10.24% respectively.

Items (leak solid), (leak liquid), (wear pad), and (alter lifestyle) from the Wexner FCGS, plus the (leak stool / urgency) and (leak / change underwear) items, all load heavily on Rotated Factor 1 (weights above 0.50). This appears to represent the common factor of faecal incontinence / soiling.

Items (leak gas), (urgency) and (bowel pattern) load highly on Rotated Factor 2 (weights above 0.50). This seems to reflect a collection of other bowel symptoms like gas, urgency and erratic bowl patterns.

Item (bowel movements) loads only on Rotated Factor 3. This item appears to define this factor almost completely.
**Confounded by Flatus**

Not surprising endorsement rates for liquid and solid stool leakage are low – not common in community.

Endorsement rates for flatus are much higher, but should flatus be counted as incontinence? Excluded in ICS definition.

In the Wexner all items are of equal weight in deriving the total score for incontinence. Is flatus leakage as severe a symptom as liquid or solid leakage?

AIHW 2006 _Incontinence in Australia_ – of the 1099 subjects that endorse any faecal incontinence symptom 892/1099 are only endorsing the flatus item.

Hawthorne 2006 – prevalence including flatus item = 35%; prevalence without flatus item = 8%.

8% figure more consistent with other prevalence estimates.
Revised Faecal Incontinence Scale (RFIS)

The six items that loaded most highly on the faecal incontinence factor were:

- In the past 4 weeks: Do you leak, have accidents or lose control with a liquid stool? (WFCGS)
- In the past 4 weeks: Do you leak, have accidents or lose control with a solid stool? (WFCGS)
- In the past 4 weeks: Do you need to wear a pad to protect your underwear from stool?* (WFCGS)
- In the past 4 weeks: Do bowel or stool leakage cause you to alter your lifestyle? (WFCGS)
- In the past 4 weeks: Do you leak stool if you don’t get to the toilet in time?
- In the past 4 weeks: Does stool leak so that you have to change your underwear?

*The pad question from the Wexner has been criticised as it may related to patient fastidiousness (Vaizey, 1999). This item may be excluded on these grounds and its similarity to the item on soiling (loadings = 0.71 and 0.78 respectively)