Ageing with an intellectual disability: support issues in rural localities

Stuart Wark1,2, Rafat Hussain1, Helen Edwards3
1CRN for Mental Health and Well-Being, University of New England, 2The Ascent Group, 3School of Education, University of New England

Introduction

Improvements to both medical diagnosis and subsequent access to appropriate services has seen a dramatic increase in the life expectancy of a person with an intellectual disability. Even with severe disabilities, individuals are able to live into not just adulthood but chronological old age. For people with Down Syndrome, the increase in life expectancy in the past one hundred years has been remarkable. Both Australian and overseas studies have shown that, at the start of the 20th Century, a person with Down Syndrome had a life expectancy of approximately ten years. By the 21st Century, it had increased to nearly sixty. While the increasing life expectancy of people with intellectual disabilities has been clearly identified for the past few decades, significant problems are emerging in delivery of services to this cohort of people both in Australia and elsewhere around the world. The ageing of people with intellectual disabilities is a relatively new issue to arise within the community services sector, and as such, the policy frameworks and support structures in Australia are still relatively immature. There is a paucity of information and a lack of government policy guidelines specifically for people with an intellectual disability who are ageing. However, it is known that people with intellectual disabilities already experience a higher number of health care issues than the mainstream population, that these existing health needs are often not appropriately addressed and treated, and that ageing is then often associated with a further increase in care needs. Further, individuals with intellectual disabilities encounter significant inequality in accessing health care and support services, even before the secondary factors of ageing start to emerge. A report commissioned by the New South Wales Department of Family and Community Services in 2011 recommended significant changes to the structures of drop-in and in-home support for people with intellectual disabilities. It noted that the funding for these services was not flexible enough to meet the needs associated with ageing, with a 47% rise in average needed hours of support occurring by the time a person with an intellectual disability reaches 60 years of age. It also identified that travel costs to attend both generic and specialist medical appointments are taking up an increased proportion of accommodation support funding as the individual with an intellectual disability ages.

While some work is occurring with respect to specifically supporting this group with their emerging health needs, there is little known about how the ageing process has flow-on impacts upon the carers, family and friends of the individual. In particular, there is limited understanding of the financial, social and emotional issues facing the families, co-residents and services supporting a person ageing with an intellectual disability. Many ageing people continue to look after their adult children who have a disability and to act as their person responsible even if the individual has a specialist accommodation placement. There are emerging issues for families such as the need for home modifications to support ongoing community living, while there are new problems arising as people with disabilities are now consistently outliving their parents. As such, there is a need for the wider family unit, friends and service providers to consider and plan carefully for what will happen following either the death or incapacity of one or both carer parents. However, it is reported that comprehensive planning by the family is rare, and there is an element of resistance to the process. The point at which ageing parents either die, or become incapable of continuing to look after their adult child, will usually occur when the person with the disability is in middle-age and/or starting to age him/herself. The brothers and sisters of adults with intellectual disabilities then may experience problems with maintaining care for their sibling following the death of the primary caregiver.

Many of the health care and family support issues are magnified in rural areas as a consequence of factors including lower socio-economic status, reduced access to housing and public transport, and limited health and allied services. The base funding of accommodation support programs in rural
areas of New South Wales appears problematic, with one study showing that block funded drop-in service models in rural areas received an average of $235,528 per annum which was just 53% of their metropolitan counterpart’s $437,248.19 In one of the few studies that specifically examined rural issues for people with intellectual disability, Hussain and Edwards interviewed rurally based ageing carers of people with an intellectual disability.18 This research noted the inadequate or restricted access to appropriate activities and specialist services in rural areas, as well as very limited future planning. According to Grant22, many ageing parents struggle to make final decisions about what will happen when they die, particularly in situations where options are limited as evident in rural localities, and that future planning is a particularly stressful issue for families.

The objective of the current paper is to identify the impact that ageing with an intellectual disability has upon the wider network of family, co-residents and service providers. The geographic focus of the study is on rural areas of New South Wales.

Method
This research builds upon the work of Hussain and Edwards18 who interviewed rurally based ageing carers for people with intellectual disabilities. The focus of this paper is on gaining information from rural disability support workers who are employed to assist individuals ageing with an intellectual disability. The geographical base for this study, the state of NSW, covers an area of 800 642 square kilometres.23 The study concentrated on those areas classified as rural, regional and remote by the Australian Standard Geographical Classification—Remoteness Areas system.24 This included all areas of the state except for the four major cities of Sydney, Newcastle, Wollongong and Gosford. This sector had an approximate population of 1.6m.25

As a consequence of the large geographic area, the face-to-face qualitative personal interview process as used by Hussain and Edwards18 was not considered to be viable. A structured questionnaire model was also deemed not to be optimal as the participants may be restricted in their ability to appropriately describe their experience of ageing with an intellectual disability. The Delphi Technique was selected for use in the project as it was considered the most appropriate method to gather a diverse range of information from a large geographic base.26 The Delphi Technique provides all participants with an opportunity to make unique observations and contributions, before establishing group consensus positions on issues of key importance through a process of successive survey rounds.27

A three-round Delphi process was undertaken for this study comprising 31 participants. In round one, all the study participants were asked an open question:

What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?

All participants provided individual responses to this question. Responses were collated into alphabetical order for the second round of the study, with the exception of any issues that were conceptually identical. Each of the participants were requested to identify any additional issues that they may have thought of subsequently to completing the first round, and to nominate if they disagreed with any items on the collated list. The third and final round of the project involved the information gathered in stages one and two being again collated alphabetically as separate items. Each participant was asked to nominate the importance of each of the items using a seven-point Likert scale.

In order to determine the group’s levels of importance for each item in the final list of identified issues the data was analysed using measures of central tendency including mean, median and mode.28 It was determined prior to commencement that a mean score of greater than 4.5 would be required for an item in order for it to be considered ‘important’. As a secondary mechanism, it was also considered that the median and mode scores for each item was required to be a minimum of 5 on the 7-point Likert scale for importance to be attributed to the item. A position of group consensus for an item was determined through levels of dispersion including standard deviation and coefficient of variation.29
Group consensus was considered to occur for an item when the coefficient of variation fell between 0 and 0.5, and when the standard deviation for the item was equal to 1.0 or less.

Following this process of determining importance and consensus, a thematic analysis was conducted on the list of items considered important and for which group consensus was reached. The purpose of this analysis was to identify any key themes that may recur throughout the list of individual items. More details on this process have been previously described.

It is worth noting that the Delphi methodology utilised in this study was time consuming and labour intensive. However, it proved to be a very effective mechanism to successfully gain information and knowledge from a wide range of individuals covering geographically diverse locations. It is a model that appears to be a successful fit for rurally focused research projects.

**Demographics**

The participant group of 31 was composed of 26 females and 5 males. This high proportion of female participants is in line with the demographics of the disability workforce. The respondents were from fourteen different non-government disability organisations situated in nine state government regions designated as being predominantly rural. There was a wide range of experience, with some participants having worked in the disability field for less than a year while others exceeded three decades of employment. The average participant age was 47 years, with 30 of the 31 respondents having completed a post-school accredited disability training course.

**Results**

There were a total of 25 different issues identified by the participants. An analysis of the data showed that all 25 items were considered to be important by the Delphi Panel, and consensus was also deemed to have been achieved. In Appendix A, all 25 issues are listed in descending order of mean scores, where an overlap in many of the categories can be noted. The wording of the items is exactly as presented by the participants.

When the thematic analysis of the responses was performed, this identified any recurring or consistent areas of concern. This analysis revealed a number of key concepts as outlined below. These themes included issues relating to:

- **Ageing Parents**: all the participants identified the theme of parent/s ageing concurrently with the person with the intellectual disability. This theme included generic issues such as “Ageing parents”, which was considered the third most important item overall. There were some other more specific items like “Family concern about future planning as the person with the disability may outlive the parents” which was among the top five issues listed.

- **Access to Services**: The ability of the family to link up with appropriate services was seen as a major issue of concern. A number of specific issues were seen as problematic including “Access to respite” which was ranked by the panel as the second most important item, and also “Lack of information for families to source services”.

- **Increasing Care Needs**: There were a number of different issues associated with the effect increasing health care needs has upon family and friends. The participants identified both direct and indirect items that pertained to increasing care needs, including “Concerns about person’s ongoing and increasing care needs”, “Communication problems” and “Coping with increased support needs”. These were all rated in the top 10 most important items, as well as “Need for major home renovations (e.g. stairs, ramps, rails etc)”.

- **Understanding and Coping with Ageing**: This theme included a number of items that were associated with a lack of understanding of the ageing process by family and friends. “Understanding and separating behavioural issues from physical/mental health issues” was ranked in the top five issues.
Other key concerns included, “Household members reducing the person’s level of independence by attempting to ‘help’ by doing everything for them” and “Fellow residents not understanding what is going on (why the person has changed or moved)”.

**Discussion**

The issues raised by the participants were complex, overlapping and multilayered with regard to the individual, the role of families, and service providers and the impact ageing of people with disabilities has upon their families and friends. These issues are discussed below with reference to the four specific thematic areas identified in the analysis.

**Ageing parents**

One of the key themes identified by the participants pertains to issues associated with ageing carers. The primary problem in this theme appears to be a growing inability to continue to provide care. The concerns appear not to be centred on the needs of the carer, but instead relate to what will happen in the future once they cannot continue to provide the same levels of personal support. Previous research\textsuperscript{9,18} argues that the need for future planning is vital for adults with intellectual disability, as both the ageing carers and service providers have to prepare the individual for a major change in daily living, at the same time as the person may be starting to experience their own decrease in functional levels. A crisis situation, in which the parents of a person with a disability are suddenly no longer able to look after their child, presents accommodation services and their staff with a very difficult scenario. The person is often suffering from grief associated with the loss of a parent, as well as being disorientated after being moved from their familiar family home.\textsuperscript{35} The wider extended family is also busy with various legal requirements following the death of a person, and as a result the needs of their sibling with a disability can be overlooked at this point. This situation leaves the disability workers, who may have limited or no prior experience with the individual, as the main point of support. It is considered that proper and comprehensive planning by ageing parents prior to a crisis occurring is imperative if people with disabilities are to successfully transition into a new living environment.\textsuperscript{36} The results of current survey indicate that there is a clear recognition of the need for effective and efficient future planning for people ageing with an intellectual disability. In recent years, the Commonwealth and State governments have implemented some support around future planning\textsuperscript{37}, however the lack of appropriate tools was identified in 2011 as a key priority area in a NSW Government commissioned report.\textsuperscript{15} It would appear that current processes are not adequately addressing the concerns of the family members in rural areas, and that a more effective system is required.

**Access to services**

The participants in the study noted a lack of information and access to available community services, with this problem reflecting the ongoing lack of local health and ageing resources in rural areas for the mainstream population\textsuperscript{38}, let alone disability specific options. Rural residents generally have significantly less access to both general practitioners and allied health professionals, whilst experiencing higher levels of mortality and morbidity that their metropolitan counterparts.\textsuperscript{39} Therefore, even if rural families do plan ahead, the capacity and ability of both government and service providers to respond in an appropriate and timely manner is uncertain.\textsuperscript{40} It is recognised that geographic location has a great impact upon the availability of intellectual disability services in Australia\textsuperscript{41}, and this problem is further magnified by the lack of access to mainstream ageing support options. In particular, there remains a substantial gap between the needs of the individual and the available resources in rural areas. There are very limited opportunities for planned transition into supported accommodation for people with intellectual disabilities, with an eventual crisis often being the catalyst for a placement. In this environment, it is not surprising that a lack of resources was identified as a key impediment to successful ageing of people with intellectual disabilities, but the flow-on effects to family members and other residents is explored more in the next section on Increasing Care Needs.
Increasing care needs

The impact of ageing upon the individual with an intellectual disability has been subject to some exploration in recent years, however in this study the participants related to the impact that ageing had upon fellow residents and friends. In New South Wales, there is no formal process for review of government funding for organisations to support the changing needs of people ageing with intellectual disabilities, with the situation then further complicated by the fact that the individual is often deemed ineligible for separate aged care assistance due to their existing disability support funding. This limitation has a natural consequence of reducing the level of service available for other residents. If the overall level of funding does not change, but the minimum required level of staffing for one person increases, it is inevitable that there must be a reduction in services elsewhere. This issue is particularly relevant for disability services operating under a block grant model of funding to support a group of people. This situation can translate to a fellow resident’s quality of life programs being reduced in order to meet the care needs of the person who is ageing. Resources and staff time are reallocated internally within the service, with some clients receiving less support hours than desired, in order for the organisation to appropriately meet the increasing needs of another resident. At the same time, the individual who is ageing will also experience a reduction in his/her own quality of life programs, if the primary focus of service shifts to instead meet his/her new personal or health care needs.

Understanding and coping with ageing

It is well established that a person with dementia will experience an increase in care needs associated with a decline in memory and intellectual functioning. However, these impairments can also have an emotional impact upon carers, friends and co-residents. A decrease in daily capacity to function can result in a separation from family and a loss of long-standing friendships. The person’s family, friends and the other residents within the house can be impacted by symptoms of grief, both in terms of the loss of friendship with a long term companion who may have dementia, and also through knowledge and possible fear of the individual’s impending death. In some situations, individuals with an intellectual disability may have been cohabitating with the same people for many decades and any physical changes to one resident may have a flow-on emotional impact upon the other housemates. This issue is reflected more widely in the item “Friends experiencing depression themselves due to worry about their own mortality”.

The current study identified a number of key issues relating to this lack of understanding of ageing such as the item “Fellow residents not understanding what is going on (why the person has changed or moved)”. Parents, disability support staff and even mainstream age care providers often have limited experience or knowledge of ageing issues for people with intellectual disability, with information packages and training opportunities relevant to ageing with an intellectual disability generally not yet well developed nor widely available in Australia. If the carers and disability staff are not able to provide the people they support with accurate and relevant information, either through lack of availability or their own limited knowledge, the individual with a disability and his/her family will struggle to understand and cope with aspects of the ageing process.

Recommendations

Increasing funding is often seen as the universal panacea to resolve all issues. Certainly additional capacity within the disability sector is highly desirable and would assist to address some of the issues pertaining to increasing health care needs and access to appropriate services in rural areas. However, two of the key themes identified in this project related to ‘a lack of family and carer knowledge of the ageing process for people with intellectual disability’, and of ‘future planning processes’. While the need for supplementary funding will remain ongoing, it would appear that some cost-effective steps could occur to address the information barriers evident in this rural population.

A greater level of interaction between the ageing and disability providers may help to address aspects of these knowledge problems. Mainstream ageing information packages and resources could be readily
translated or linked more fully for carers and the disability sector. This would provide a means of ensuring families and friends have a greater understanding of the generic processes of ageing, and how to cope with changes as they occur. Through such a re-utilisation of existing materials developed for mainstream ageing services, staff would be able to provide individuals and their families with pertinent information on the topic. In rural areas, collaboration and cooperation between existing ageing services, disability providers and allied health professionals with respect to joint community and staff training opportunities is another mechanism through which the sharing of key knowledge could be maximised.47

One of the main issues that arose in the study related to ageing carers and the need to appropriately plan for the future. As noted previously in the discussion, there are currently resources to assist in future planning, but families are either unaware of their existence or are unable to access them easily.1 A collaborative approach would help to assist both the aged care and disability providers in rural areas to more successfully support both individuals and their families, but it would require coordination at a national level for it to be effective across large geographic areas.

Five key cost effective recommendations were developed to attempt to redress the current problems for people ageing with an intellectual disability in rural areas.

Key Recommendation 1—Translating Existing Aged Care Resources
That relevant existing mainstream ageing resources be translated and adapted specifically for the disability sector to ensure that both paid and unpaid carers have a better baseline understanding of the ageing process.

Key Recommendation 2—Future Planning
That the relevant industry bodies and disability organisations make representations to state and commonwealth governments to obtain funding for groups such as Carers Australia to conduct and widely publicise further workshops across rural areas for families to assist them in future planning.

Key Recommendation 3—Joint Training Agenda
That the major industry peak bodies including National Disability Services (NDS), Leading Age Services Australia (LASA) and Aged & Community Services Australia (ASCA) develop a joint training agenda pertaining to ageing with an intellectual disability to address common educational needs.

Key Recommendation 4—Greater Collaboration
That aged care and disability service providers who are located in close proximity in rural areas collaborate with respect to shared attendance at relevant sessions of their respective training, and to provide joint community education programs.

Key Recommendation 5—Better Networking
That rural disability organisations be proactive in establishing better networking models with local specialists such as medical practitioners, allied health professionals and pharmacists as a mechanism to raise awareness and understanding of the issues associated with people with an intellectual disability who are ageing.

Conclusion
Reports into the health and personal care needs of ageing people with an intellectual disability usually focus upon the individual, however, his/her increasing support requirements can also negatively affect co-residents, family and friendship groups. The current government policy framework does not readily meet the expectations of individuals, their families and disability support organisations to provide appropriately what is necessary. While additional funding is undoubtedly necessary, some of the

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1 Links to some existing on-line future planning resources are provided at the end of this article.
identified areas of concern may be successfully addressed through collaboration and cooperation in rural areas.

**Author note**
The authors have no conflicts of interest to declare.

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**Resources**
While no specific endorsement is made by the authors in relation to any of these sites, some potentially useful on-line resources for families with respect to Future Planning include:


Other hard copy resources are available in the various states and territories across Australia.

**References**


30 Boyatzis, R. *Transforming qualitative information: Thematic analysis and code development.* (Sage, 1998).


44 Bleechmore, K. *A history of challenges and achievements.* (The Ascent Group, 2010).

45 Dowse, L., McDermott, S. & Watson, S. Ageing with a lifelong disability student project final report. (University of New South Wales, Sydney, 2009).


Table 1  Mean, Median, Mode, Standard Deviation (SD) and Coefficient of Variation (V)

What do you think are the main issues facing the families and friends (including co-residents) of someone with an intellectual disability who is ageing?

<table>
<thead>
<tr>
<th>No</th>
<th>Issue</th>
<th>Mean</th>
<th>Median</th>
<th>Mode</th>
<th>SD</th>
<th>V</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Access to appropriate facilities to assist people with higher care needs</td>
<td>6.54</td>
<td>7.00</td>
<td>7.00</td>
<td>0.51</td>
<td>0.08</td>
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<td>2</td>
<td>Access to respite</td>
<td>6.46</td>
<td>7.00</td>
<td>7.00</td>
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<td>0.10</td>
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<td>Ageing parents</td>
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<td>7.00</td>
<td>7.00</td>
<td>0.65</td>
<td>0.10</td>
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<td>4</td>
<td>Family concern about future planning as the person with the disability may outlive the parents</td>
<td>6.46</td>
<td>7.00</td>
<td>7.00</td>
<td>0.76</td>
<td>0.12</td>
</tr>
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<td>5</td>
<td>Understanding and separating behavioural issues from physical/mental health issues</td>
<td>6.38</td>
<td>6.00</td>
<td>6.00</td>
<td>0.70</td>
<td>0.11</td>
</tr>
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<td>6</td>
<td>Coping with increased support needs</td>
<td>6.31</td>
<td>6.00</td>
<td>6.00</td>
<td>0.74</td>
<td>0.12</td>
</tr>
<tr>
<td>7</td>
<td>Financial security and ongoing financial management</td>
<td>6.31</td>
<td>6.00</td>
<td>6.00</td>
<td>0.68</td>
<td>0.11</td>
</tr>
<tr>
<td>8</td>
<td>Concerns about person’s ongoing and increasing care needs</td>
<td>6.19</td>
<td>6.00</td>
<td>6.00</td>
<td>0.69</td>
<td>0.11</td>
</tr>
<tr>
<td>9</td>
<td>Clients with lower needs miss out due to an increased focus on person who is ageing</td>
<td>5.96</td>
<td>6.00</td>
<td>7.00</td>
<td>1.00</td>
<td>0.17</td>
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<td>10</td>
<td>Communication problems</td>
<td>5.96</td>
<td>6.00</td>
<td>6.00</td>
<td>0.77</td>
<td>0.13</td>
</tr>
<tr>
<td>11</td>
<td>Friends experiencing depression themselves due to worry about their own mortality</td>
<td>5.88</td>
<td>6.00</td>
<td>6.00</td>
<td>0.99</td>
<td>0.17</td>
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<tr>
<td>12</td>
<td>The need for greater advocacy by the families to gain additional funding as support needs increase</td>
<td>5.85</td>
<td>6.00</td>
<td>6.00</td>
<td>0.83</td>
<td>0.14</td>
</tr>
<tr>
<td>13</td>
<td>Impact upon closeness of relationship (affected by dementia)</td>
<td>5.73</td>
<td>6.00</td>
<td>6.00</td>
<td>0.83</td>
<td>0.14</td>
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<td>14</td>
<td>Legal issues (e.g. making a will or power of attorney)</td>
<td>5.73</td>
<td>6.00</td>
<td>6.00</td>
<td>0.96</td>
<td>0.17</td>
</tr>
<tr>
<td>15</td>
<td>Fellow residents not understanding what is going on (why the person has changed or moved)</td>
<td>5.69</td>
<td>6.00</td>
<td>6.00</td>
<td>0.93</td>
<td>0.16</td>
</tr>
<tr>
<td>16</td>
<td>Need for major home renovations (e.g. changing stairs to ramps, rails in bathrooms, etc)</td>
<td>5.65</td>
<td>6.00</td>
<td>5.00</td>
<td>0.98</td>
<td>0.17</td>
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<td>17</td>
<td>Residing within a complex with other people with disabilities compounds personal problems for those who are ageing</td>
<td>5.65</td>
<td>6.00</td>
<td>6.00</td>
<td>0.85</td>
<td>0.15</td>
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<tr>
<td>18</td>
<td>Lack of patience (everyone wants everything done right now!)</td>
<td>5.62</td>
<td>5.50</td>
<td>5.00</td>
<td>0.70</td>
<td>0.12</td>
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<tr>
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<td>Household members reducing the person’s level of independence by attempting to ‘help’ by doing everything for them</td>
<td>5.62</td>
<td>5.50</td>
<td>5.00</td>
<td>0.90</td>
<td>0.16</td>
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<td>20</td>
<td>Increased pressure on families to provide ongoing advocacy</td>
<td>5.54</td>
<td>6.00</td>
<td>6.00</td>
<td>0.90</td>
<td>0.16</td>
</tr>
<tr>
<td>21</td>
<td>Lack of information for families to source services</td>
<td>5.54</td>
<td>6.00</td>
<td>6.00</td>
<td>0.81</td>
<td>0.15</td>
</tr>
<tr>
<td>22</td>
<td>Pressure on friends to cope with changing personality and skills</td>
<td>5.54</td>
<td>6.00</td>
<td>6.00</td>
<td>0.76</td>
<td>0.14</td>
</tr>
<tr>
<td>23</td>
<td>Frustration</td>
<td>5.46</td>
<td>6.00</td>
<td>6.00</td>
<td>0.95</td>
<td>0.17</td>
</tr>
<tr>
<td>24</td>
<td>Increased reliance upon staff to facilitate family contact (primarily through phone)</td>
<td>5.42</td>
<td>5.00</td>
<td>5.00</td>
<td>0.76</td>
<td>0.14</td>
</tr>
<tr>
<td>25</td>
<td>Lack of acceptance of the ageing process</td>
<td>5.31</td>
<td>5.00</td>
<td>5.00</td>
<td>0.68</td>
<td>0.13</td>
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