

Quality of life - Ageing and Down syndrome

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Abstract — This article, based on pilot qualitative research, examines the quality of life of people with Down syndrome who are in the upper age bracket (45-70 years). Through use of a questionnaire, the current life experience and interests of a small group of individuals are noted, along with some of their perceptions concerning their past and present, including their views on the ageing process. Recommendations are made particularly in relation to the need to recognise the principles of variability, perception and choice, while providing support to encourage dignified and active lifestyles.

Keywords — Down syndrome, ageing, quality of life, perception, choices.

Introduction

Quality of life measures lend themselves to newer research methodologies, particularly in the initial or developmental phases of research. In this study, concerned with ageing amongst persons with intellectual disability, particularly Down syndrome, considerable use is made of narrative and analysis of qualitative aspects of performance. We wanted to gain some idea of how individuals respond to questions about ageing, and assess whether there is much variability or clarity of viewpoint. We were also interested in areas where few or no comments were made as these may shed light on people's ability to express issues about ageing.

Down syndrome is a particularly pertinent area in which to examine ageing. Not only is it generally conceded that people with Down syndrome age earlier than most people, the additional chromosome 21 associated as it is with potential triggers for dementia, for example, Alzheimer disease, suggests that it is possible to examine in a magnified way ageing in the context of psychological and sociological factors. Already Brown (2000) has noted the earlier decline of leisure activity in persons with Down syndrome compared with others with intellectual disability. It is suggested that this decline may begin around the mid-twenties. Yet it seems appropriate to start examining ageing and Down syndrome in terms of ageing around 45 years of age, a

notion that is fairly well accepted within the research community (see Janicki & Wisniewski, 1985).

Quality of life has been portrayed as a developing model or models within the field of developmental and intellectual disability (see Goode, 1994 & Rinwick *et al*, 1996). In this context, it is essentially a sociological and psychological construct. Initially there were considerable disagreements about the nature of quality of life (Wolfensberger, 1994 and Taylor, 1994) and a number of issues still have to be resolved (Hatton, 1998). However, there has been a growing consensus in the last few years, both in terms of the definition and the constructs involved (Brown, 1997). For example, in terms of definition, the notion of wellbeing in a variety of domains is well accepted.

Felce and Perry (1997) have indicated five areas of wellbeing:

- Physical Wellbeing
- Material Wellbeing
- Social Wellbeing
- Emotional Wellbeing
- Productive Wellbeing

Further, definitions include the notion of discrepancies between what an individual wants and what an individual has. Quality of life involves personal perception, and although this is regarded by some as a subjective component, it is increasingly being recognised that such commen-

tary is susceptible to measurement and constructs such as validity and reliability can be assessed (Cummins, 1997). But for most people in this area of quality of life both objective and subjective (or as we would prefer to call it, perceptual) components are important. Within the definition is the notion that quality of life is the extent to which an individual has increasing control over his/her environment (Brown, Bayer & MacFarlane, 1989).

Brown *et al* (1992, 1994) have also argued that quality of life is lifespan in orientation. Thus the quality of life model enables us to view disability from a new perspective. Elsewhere it has been argued (Brown, 1997) that we must recognize that, though transition points in lifestyle are important, there is a need to see the individual's life as a developing array of complex perceptions which establish varying needs over the lifespan. Many of these needs are social and psychological. Thus, although there are units set up to look at ageing and disability, and this is important, unless the personnel recognize how the needs of ageing adults change over the lifespan, we are likely to underestimate or incorrectly estimate the types of support, care and interaction people need to sustain older age within a framework of positive wellbeing.

Issues of personal choice are also important. The individual's continuing opportunity for empowering her or himself within the environment is critical (Raphael, 1997). The nature of quality of life, then, is on the one hand a sociological construct looking at the way environment impacts on the individual, and a psychological construct in that its interest lies in the way the individual perceives aspects of his/her environment. Thus issues of empowerment, choice and self-image within the different aspects of environment (see Bronfenbrenner, 1979) contribute to a complex interaction of variables over the lifespan.

Ageing and Down syndrome

Lifespan has increased markedly for persons with Down syndrome. In 1900 life expectancy was around 9-11 years. It is now above 50 years with 1:10 living to 70 years of age (Baird & Sadovnick, 1987). In the western world there are more persons with Down syndrome who are in their mid-teens or older than there are children with Down syndrome (Extrapolated from data reported by, amongst others, Steele, 1996). As the relative prevalence of Down syndrome at birth lessens, and as life expectancy increases this most common of the intellectual disability conditions will then be most commonly represented amongst the elderly. This shift in chronological age has not been clearly recognised by the professional community.

In this study, we are interested in looking at quality of life of a group of people with developmental disabilities, and particularly those with Down syndrome over the age of 45 years. Because of their age many of them will have lived in institutions, and what is to be said about them may not necessarily apply to new cohorts that are now in young adulthood. Suffice it to say that it is critically important that we

attempt to relate what people perceive, and what they need within the context of their previous lifestyles.

Although the extra chromosome in Down syndrome leads to extra gene dosage and means persons with Down syndrome are likely to be susceptible to some biochemical negatives, e.g. amyloid precursor protein which is associated with Alzheimer's disease (Wishart, 1996), this should not blind us to the interactive nature of intervention and environment, and the possibility that change in quality of life may influence wellbeing in such a manner that predispositions are barricaded by environmental factors. Elsewhere Brown (1993) has suggested this may be true of leisure time activities which, if encouraged early in the lifespan, may lessen the potential of later life negative effects in persons with Down syndrome.

Assessment techniques

In this study the Brown and Bayer Rehabilitation Questionnaire: *A Personal Guide to the Individual's Quality of Life* was employed. It has been used extensively in Canada where the authors obtained protocols from over 1,000 interviews (including persons with Down syndrome) over a 6 year period, following individuals through part of their rehabilitation process, including individuals who had choice over the types of intervention that took place. The questionnaire has also been employed with individuals over the age of 55 years. It has been used clinically and in research, including ageing research (see Hogg & Lambe, 1997) in Canada, Australia and the United Kingdom.

The questionnaire has 10 different areas and full instructions are given in the manual, along with some indications of reliability, which Brown & Bayer (1992) found surprisingly high, varying in terms of coefficients from 0.5 to 0.9.

In the present study, further content was added to specifically explore aspects of older life (see below). Part of this had been previously trialed with a small group of individuals with intellectual disability, including those with Down syndrome.

Presenting the questionnaire

Obviously, the language of the questionnaire is important. We believe it is critical that the questions are used as only a guide but the person presenting the questionnaire orally must have considerable interview skills, must be able to grasp quickly the language level at which the person is speaking and utilise the individual's own terminology in order to elicit answers.

It is important that the individuals are interviewed on their own. We frequently found that staff or family members, when present, corrected the individual. We were interested in the individual's current recollections on a particular date and time and their perception of these events!

New questionnaire content

Gillies and James (1994) argued that there is important therapeutic value in reminiscence. If one accepts that recollection or reminiscence can influence self-esteem (Biggs 1993), increase life satisfaction, and reduce depression in the elderly (Hardison, 1994), then such effects are likely to be more, rather than less, critical for people who are ageing with intellectual disabilities because of their already lowered functioning level. However, this has not always been the view and contrary evidence exists (see Middleton & Buchanan, 1993). Brown, Bayer and Brown (1992) have demonstrated in a quality of life study that self-esteem or self-image is very low in many adults with intellectual disability, and life satisfactions are often very limited. A finding also reported amongst persons who are aged and intellectually disabled. New quality of life programs attempt to enhance self-image in the belief (and there is supportive evidence - Brown, Bayer & Brown, 1992) that performance is improved.

Reminiscence lends itself to qualitative and narrative exploration. Like quality of life measures, it must include measurement of personal perception. For example, Angrosino (1994) notes that life history can be used as a method of ethnographic research in study of disempowered persons and this includes people with intellectual disabilities. The additional questions reflected the above comments.

Pilot research

Initially the revised quality of life questionnaire was used on a group of persons (N=5) at least 45 years of age (most in sixties) with intellectual disability but not necessarily with Down syndrome. The following comments, or conclusions, were noted.

1. There were difficulties for people remembering events.
2. Individuals expressed a desire to be allowed to go to bed when they wanted to.
3. Their comments were often conformist, e.g. "I do what I am told."
4. They noted the importance of contact with relatives, (such as mother or sister).
5. They often noted there were no other social contacts which could be regarded as friendships.
6. Where individuals were living in group homes in the community or other residences, they felt that outings into the community depended on staff time and where staff wished to go.

Home living
Things you do
Your health
Your family and friends
You and your family
Self Image
Leisure Time
Employment
You and the law
Help you need

Table 1. Brown and Bayer (1992) Quality of life questionnaires: Areas of assessment

7. Belongings were meagre. For example, one individual noted he had a radio, wallet, after-shave lotion, a hammer, a toolbox and two pairs of glasses.
8. There was an absence of pets, a concern expressed by those who wanted pets.
9. Individuals often thought themselves as middle aged.
10. Recollections of the past were associated with adventures in childhood, e.g. climbing the roof and still would like to do so, or e.g. there was reference to the police finding him in the gutter when he was a child waiting for his mother. There were comments concerning distaste of the institution where they had lived, with recollections of pranks, such as pushing people out of bed. One individual stated that doctors would not let him leave because he had epilepsy.
11. Memory seemed limited. "I used to remember a lot, but I can't remember much. I sit down and take things easy."
12. There was little concept of age or change with age, e.g. "I cannot change."
13. There was little concept about what the individual might do when they become older, e.g. "I don't know, I am here for a certain time."
14. Concepts of retirement related to lack of activity and interaction were noted, e.g. "retire from work and sit at home and do nothing."
15. Death was seen as inevitable, e.g. "I know it is something you can't help. We were having a lot here the year before last, some nice friendly people." To the question what do you feel about dying?, one individual noted "I cannot stop it."
16. Changes in appearance with age were sometimes noted, e.g. "the look on my face."

In terms of future activities, responses were sparse, such as "I've got to take it easy now, as the doctor has told me to go easy." When asked about friends, individuals indicated they had few and they noted their absence, such as family members who died. They sometimes noted the importance of a relative - "I hope she (mother) lives a long time." They could sometimes remember activities that they carried out earlier, such as milking cows. Individuals sometimes claimed that they currently worried a lot and in terms of use of spare time, statements like "I like someone with me", "I don't have as many friends" or statements relating to former involvement and present absence, such as "I used to like sports." Being taken out a lot seemed important. In terms of activities, talking to people was often noted. Disappointment and happiness were also recorded.

Down syndrome - Results

So far we have interviewed only a small group of persons with Down syndrome (N=7) all above the age of 45 years. Two vignettes from this group follow:

Vignette 1

Male aged 50 with Down syndrome

He carries out most activities of personal hygiene and is expected and carries out, through management, house cleaning, washing dishes, personal laundry. Planning menus, cooking meals and budgeting were included in his activities. This participant believed that he was able to make, and keep, friends. He participates in leisure activities but needs help to make appointments. This individual also said he is getting older, but that he can play cricket and goes to work. Of his former life, he said "I remember the institution but I don't think about it now" but he did remember individuals from the past and he misses them sometimes. Again, he believes he can live to a good age and mentioned 100. He is 50 and said that people would retire when they are old and he is not retired. He was able to list a group of friends including a girlfriend. This individual indicated that he helps to sort out other people's problems. The individual still saw himself as getting better in all areas, except looking after his medications, making friends, and getting along with others. These are the same. He had no plans for the future. He likes doing woodwork, also bowling, cricket, watching TV and shopping. The main change from when he was younger is that he has lost a bit of hair. He does not worry about things in the past. He does indicate that he needs emotional support. He notes that life is a bit better now - "I can do my own things." He believes it can get better still, but is not sure how. This individual wants a bigger house, he likes things nice and clean but does not like people barging into his room. He has no locks on his bedroom door. He feels safe in his neighbourhood and talks to his local neighbours. Being close to a corner store is important. He is treated like an adult and has things to do by himself and has a key to the front door. He looks after his own basic hygiene needs. He believes he is old but he could do things he used to do and he thinks about living on the farm with Mum, in the past.

Vignette 2

Female aged 52 with Down syndrome

This woman felt she had lots of room, but she did not like the large number of people, which got her down. She was concerned her place was cold in the morning, and people come into her room without knocking. She likes dogs and pats them and she likes her neighbours, who she likes to talk to and is close to a corner store. She likes to deal with her own hygiene, has not many friends, goes out to town by bus. At 52 she sees herself as young, although the oldest in the house. She does not remember the olden days, but Mum does. She recognizes that she dies when she is old. She would not live as long as 100, or 80, she would stay the same, but when she was old she said she would sit down and not move. She does not want to do that if she can help it. If her mother died she would be scared. She listed people as friends - her fiancée, her housemate, and her neighbour. She goes out with friends when they ask her. In terms of what she looked like when she was younger, she said "I

cannot remember when I was young. I used to have long hair. I saw a photo of myself". She does not worry about things in the past as she cannot remember them now. She does have current worries about current events. Again, she indicated she needs help with these worries but sometimes just goes for a walk. Her life now is better than when she was young and better than those she lives with. She did not know what it would be like in the future.

The total findings must be regarded as preliminary though consistent with the pilot survey.

1. Several individuals did not seem to have a clear understanding of concepts of ageing and dying.
2. Most of the individuals appeared happy with their circumstances.
3. Some wished to change their residential accommodation.
4. Individuals may know to whom they go to seek help, but have little concept of individuals coming to them for assistance or help.
5. Frequently individuals have no family.
6. There was some indication that music was important.
7. Activities chosen were often simple, such as colouring in, painting books, feeding ducks, visiting shopping centres.
8. Individuals were worried they might lose things.
9. Some noted the smallness of their accommodation.
10. Participants seemed proud that they maintained their own bedroom. Expressions of "clean" and "comfortable" were noted.
11. Privacy was a concern within the home or residence - the right to be alone and only interrupted by formal request.
12. Location of accommodation was important, e.g. "it is near the beach" or "it is near a corner store."
13. Personal trophies won in various recreational activities were seen as important items.
14. They commented on whether they were treated as a child or an adult.
15. Joining in community activities were seen important for some individuals.
16. Individuals within their late 40s and 50s sometimes saw themselves as young.
17. Individuals believed that once they become old they will have to move to an institution.
18. Retirement was seen as when one is too tired.
19. Personal safety in local communities was seen as critical. Even so, individuals stated they did not go out after dark.
20. Being happy was noted.
21. Being treated like an adult was recognised as important.

Discussion

The pilot and later data are discussed together for they largely support each other - the later results confirming and amplifying the former. Most of the individuals were in their 50's, but one was 70 years of age. Most of the individuals lived with other people with disabilities but often within the community. A number were quite active in terms of leisure pursuits at a simple level, such as walking, watching television, and in some cases mowing the lawn. Other activities, which were liked, included painting pictures and drawing. Several expected to live very much longer. Some noted they did not remember much about the past, although sometimes there were notations, particularly in relation to activities with their mother, and their early home life. Individuals sometimes stated that they have forgotten the past, did not commonly indicate worries about the past but did indicate worries about the present. Elsewhere, Brown & Bullitt (1998) comment on the issues of mental imagery amongst older people with intellectual disabilities. They suggest amongst persons with Down syndrome imagery is often vivid, but they did note instances where imagery appeared to be absent or lost with age. This may be an issue of some importance and like much of the narrative reported here, underline the need to encourage individuals to keep active not just in terms of physical activities, but also with reference to mental imagery and problem solving.

Some of the individuals were reasonably active - others seemed to have little or no activities, or relied on other people to stimulate them, such as inviting them out or including them in activities. Having said this, most individuals claimed that they were happy. This is common in a large number of quality of life studies for around 70% of people claim to be happy. In our view this is not generally a useful predictor for wellbeing in most instances. Privacy was seen as important and concern was expressed when there was a number of people around. Privacy in their bedroom was often ignored, and they perceived themselves as requiring more time alone. Several of the individuals did not regard themselves as old, but most appeared to have little idea about dying or death, although the absence of relatives, again generally mother, seemed important.

Individuals may be responsible for vacuuming their own room, helping with dishes and doing their own laundry. Supports for such activities, i.e. a carer, may be noted by the individual.

We recorded notations about friends and friendships. Frequency, and the times of meetings were often vague and unclear. It is interesting that sometimes the idea of living to an old age was associated with individuals who have some interest in leisure and recreation events. Physical activity, such as cricket, may be included in people's comments over this time. Frequently leisure time activities occurred when the individual was accompanied by a carer. Individuals often looked as though they were enjoying life.

Although we have only seen a small group of people with Down syndrome, to this point, and the study is in its early stages, a number of tentative conclusions may be drawn:

1. Lifestyle, perceptions of life, and responsiveness to events are highly varied. The social and psychological attributes associated with an individual cannot be classified in any particular fashion. Individualisation and individual needs are varied and need to be taken into account in relation to levels of observed functioning, while seriously attempting to meet the individual's choices. This is consistent with other quality of life studies for people in younger age groups.
2. Most individuals regard themselves as happy although this should not necessarily be taken to mean satisfaction with an environment.
3. Some individuals refer to early life, particularly with their mother, and early childhood experiences, but also individuals may claim they remember nothing about the past and certainly not about their worries.
4. Issues of the presence or absence of mental imagery and its possible relationship to reminiscences are important in this context.
5. Freedom of choice, and the ability to move around the community seem important and are often noted in relation to changes in life from previous times. Yet most individuals see themselves as constant. Except for minor attributes they do not perceive themselves as changing over the years. It is life experience which changes and is seen to improve.
6. Cleanliness of where they live, privacy, having their own room, keeping things tidy, all seem important and many wish to be active in these areas.
7. Although the individuals can carry out a wide range of activities to support their own needs, particularly around their personal matters, support is still needed from carers but this may be at a distance, i.e. regular and intensive care is not needed for the individuals we have spoken to so far, although support of certain activities, such as buying clothes or going to carers in emergencies, may be important.
8. Most individuals know how to get help for themselves, but do not seem to know much about providing help to others. We had one instance where providing help to others and giving support was clearly noted.

This article is of an exploratory nature and underscores some of the psychological and social issues which are likely to emerge as people with Down syndrome age. Further exploration is necessary both within qualitative and quantitative frameworks in order to provide families or personnel with appropriate information concerning environments within social, psychological and physical contexts. The importance of such work lies in recognising and applying aspects of quality of life and wellbeing and ensuring that personnel are aware, sensitive and pro-active in recognising the importance of perception and choice of the people they support and that the support is consistent, as far as possible, with expressed needs of the individual.

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References

- Angrosino, M.V. (1994). On the bus with Vonnice-Lee - explorations in life history and metaphors. *Journal of Contemporary Ethnography*, 23, (1) 14-28.
- Baird, P.A. & Sadovnik, P.D. (1987). Life expectancy in Down syndrome. *Journal of Paediatrics*, 110, 849-54.
- Biggs, S. (1993). *Understanding Ageing: Images, Attitudes and Professional Practice*. Buckingham, UK: Open University Press.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge, MA: Harvard University Press.
- Brown, R.I. (1997). *Quality of Life for People with Disabilities: Models, Research and Practice*. Cheltenham: Stanley Thornes.
- Brown, R.I. (2000). Learning from quality of life models. In M.P. Janicki and E.F. Ansellow (Eds.). *Community Supports for Ageing Adults with Life Long Disabilities*. Brooks.
- Brown, R.I. & Bayer, M. B. (1992). *Rehabilitation Questionnaire and Manual: A Personal Guide to the Individual's Quality of Life*. Toronto: Captus Press.
- Brown, R.I., Bayer, I., & Brown, R.I. (1992). *Empowerment and Developmental Handicaps: Choices and Quality of Life*. Toronto, Ontario, Captus Press and London: Chapman and Hall.
- Brown, R.I., Bayer, M.B. & MacFarlane, C. (1989). *Rehabilitation Programmes: Performance and Quality of Life of Adults with Developmental Handicaps*. Toronto, Ontario: Locus.
- Brown, R.I., Brown, P. M., & Bayer, M. B. (1994). A Quality of Life Model: New challenges arising from a six year study. In D. Goode (Ed.). *Quality of Life for Persons with Disabilities, International Perspectives and Issues*. Cambridge, MA: Brookline Books. pp 39-56.
- Brown, R.I. & Rees, T. (1996). The evaluator's role in developing quality services. In R. McConkey (Ed.) *Innovations in Evaluating Services for People with Intellectual Disabilities*. Lancashire: Lisieux Hall. pp 149-166.
- Brown, R.I. & Bullitis, E. (1998). Images of consciousness and Down syndrome. *Proceedings of the 1st Biennial Scientific Conference on Down Syndrome*. Down Syndrome in the 21st Century, Vancouver.
- Cummins, R.A. (1997). Assessing Quality of Life. In R. Brown (Ed.) *Quality of Life for People with Disabilities: Models, Research and Practice*. Cheltenham: Stanley Thornes. pp 116-150.
- Felce, D. & Perry, J. (1997). Quality of life: the scope of the term and its breadth of measurement. In Roy I. Brown (Ed.) *Quality of Life for People with Disabilities: Models, Research and Practice*. Cheltenham: Stanley Thornes. pp 56-71.
- Gillies, C. & James, A. (1994). *Reminiscence Work with Old People*. London: Chapman & Hall.
- Goode, D.A. (Ed.). (1994). *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. Cambridge, MA: Brookline.
- Hardison, M.G. (1994). Pictorial Paradox - reminiscence therapy for nursing home elderly. *Public Health Reports*, 109(2), 178-179.
- Hatton, C. (1998). Whose quality of life is it anyway?: Some problems with the emerging quality of life consensus. *Mental Retardation*, 36, 104-115.
- Hogg, J. & Lambe, L. (1997). An ecological perspective on the quality of life of people with intellectual disabilities as they age. In R.I. Brown (Ed.) *Quality of Life for People with Disabilities: Models, Research and Practice*. Cheltenham: Stanley Thornes. pp 201-227.
- Janicki, M.P. & Wisniewski, H.M. (Eds) (1985). *Ageing and Developmental Disabilities - Issues and Approaches*. Baltimore: Brookes.
- Middleton, D. & Buchanan, K. (1993). Is reminiscence working?: Accounting for the therapeutic benefits of reminiscence work with older people. *Journal of Aging Studies*, 7(3), 321-333.
- Raphael, D. (1997). Quality of life in persons with developmental disabilities: Five issues concerning its nature and measurement. *Journal on Developmental Disabilities*, 5(2), 44-66.
- Renwick, R., Brown, I. & Nagler, M. (1996). *Quality of Life in Health Promotion and Rehabilitation: Conceptual Approaches, Issues and Applications*. Thousand Oaks, CA: Sage.
- Steele, J. (1996). Epidemiology: Incidence, prevalence and size of the Down Syndrome population. In B. Stratford & P. Gunn (Eds.) *New Approaches to Down Syndrome*. London: Cassell. pp 45-72.
- Taylor, S.J. (1994). In support of research on quality of life, but against QOL. In D. Goode (Ed.) *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. Cambridge, MA: Brookline.
- Wishart, J.G. (1996). Avoidant learning styles and cognitive development in young children. In B. Stratford & P. Gunn (Eds.) *New Approaches to Down Syndrome*. London: Cassell. pp 173-205.
- Wolfensberger, W. (1994). Let's hang up 'Quality of Life' as a hopeless term. In D. Goode (Ed.). *Quality of Life for Persons with Disabilities: International Perspectives and Issues*. Cambridge, MA: Brookline.