The Nature of Stressors Experienced by People with an Intellectual Disability

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Abstract

There is no systematic empirical research base on stress perceived by people with an intellectual disability. This is somewhat surprising considering the changes in philosophy and service delivery models across the western world that have resulted in people with an intellectual disability having to be at the forefront of massive attitudinal shifts within society. In this study, administration of the Lifestress Inventory to 459 people with a mild or moderate intellectual disability and to a reference group of university students revealed that people with a disability reported experiencing an average of 8.57 stressors in a list of 31 stressors, while students reported experiencing an average of 12.02 of these same stressors. When the ratings for the individual stressors were examined, however, it was clear that whilst the disabled group experienced fewer stressors, they tended to assign higher impact values (on a scale from 1 to 4) to the stressors they did experience ($p < .001$). Comparisons between the nature of stressors reported by both groups revealed that students reported significantly more occasions where they were not coping and more general worries, while people with an intellectual disability reported slightly more stress from negative interpersonal relationships. Achieving a clearer picture of the stressors impinging upon the lives of people with an intellectual disability is a critical factor in the design of appropriate programs of interventions.

Introduction

The Nature of Stressors Experienced by People with an Intellectual Disability

A recent trend, evident in the stress literature, involves a change in focus from stress at an individual difference level, to an examination of the construct within groups (Eckenrode and Bolger, 1995). This approach assumes that individuals within some fairly homogenous groups may share common cognitive stress themes such as 'inept at everything' or 'cannot control even the little things' and that these themes may be a feature of both the minor hassles and major life events that they experience. This thematic approach to stress appears particularly relevant in groups that share similar environments or lifestyles. It allows researchers to build models of perceived threats and vulnerabilities that are particularly relevant to such groups.

An example of this approach is the construction, and preliminary validation, of a questionnaire measuring stress for HIV positive homosexual men (Nott & Vedhara, 1995). This group-specific stress scale is entitled the Gay Affect and Life Events Scale and taps five event factors and five stress factors, some overlapping with commonly found elements of stress scales (social support and coping) and some factors specific to people with a terminal illness. Similarly, Horesh et al., (1995) measured stress in a group of adolescent girls with anorexia and found stressors commonly reported in the literature as well as problems more unique to the group such as major negative events that involved parents and family members.

The enduring features of stress, which appear to be common to many people and groups, seem to involve such elements as general worry or anxiety, inadequacies in coping, and difficulties with personal resources and relationships (Martin, Kazarin, & Breiter, 1995). The stress unique to groups appears to have many different manifestations. Apart from those already listed, other examples include housing conditions and employment status for migrants (Jerusalem, 1993), and student misbehaviour and professional identification issues for teachers (Boyle, Borg, Falzon, & Baglioni, 1995).

People with a mild or moderate intellectual disability represent a group within society in which subjective stress has yet to be systematically researched. This is despite the fact that people with an intellectual disability as a group are increasingly facing educational mainstreaming (Schalock, 1985), open or supported employment (Schalock & Kiernan, 1990), and deinstitutionalisation (Emerson & Hatton, 1996). This western-world policy and philosophy shift away from segregated, sheltered, 'special' services offers people with an intellectual disability more choices and new responsibilities (Parmenter, Cummins, Shaddock, & Stancliffe, 1993). However, such major life adjustments frequently require individuals to be imaginative, independent, flexible, ambitious and welcoming of change. For many people with intellectual disabilities, this may contrast markedly with their past experience and introduce new demands and pressures. It would be reasonable to assume that such people are experiencing considerable stress.

Whether this group has a normal experience of stress has been moot. Early beliefs in the existence of a special susceptibility to stress and frustration because of a disability were challenged by Nucci and Reiss (1987) in the first data-based study in this area. They

used controlled stress in a laboratory situation and concluded from the results that people with an intellectual disability react to stress much like everyone else. The authors also concluded that there was no support for the hypothesis that intellectual disability is associated with any special deficiencies in coping with stress. Similar findings were reported by Zetlin (1993) who used unstructured interviews over a twelve month period. A number of investigators have also examined a related variable, the frustration tolerance of people with an intellectual disability and similarly found little difference from that of non-disabled controls (Angelino & Shedd, 1965; Tebeest & Dickie, 1976). Thus, the idea that people with an intellectual disability readily fall apart when frustrated or stressed seems to be an outdated, invalid, stereotypic conception.

Whether an intellectual disability is itself an ongoing stressor has yet to be empirically addressed. For a disability to be regarded as a stressor it must be perceived and function as a handicap or a disadvantage for the individual that limits or prevents the fulfillment of a role that is normal for them (Knussen & Cunningham, 1988). Thus, it seems likely that some disabilities are never handicaps, some can become handicaps, and some are always handicaps in certain situations but not in others. The relationship between disability and stress is certain to be highly variable.

This study is concerned with the measurement of stress experienced by people with an intellectual disability. It is based upon a broad and widely cited definition of stress as harms, threats, and challenges, the quality and intensity of which depend on the environmental conditions and the personal agendas, resources and vulnerabilities of the person (Lazarus, 1984). A feature of this definition, which makes it well-suited to use in this project, is its transactional emphasis (person by environment) which facilitates the consideration of individual differences in a population such as those with an intellectual disability. Individuals are considered to experience stress when they perceive a threat to their self-esteem or security and are not confident that their coping mechanisms will be able to maintain control (Roe & Gray, 1991). The resultant stress emerges from the combined effects of individual and environmental characteristics, potential stressors, actual stressors, health status, personality characteristics and coping mechanisms (Boyle et al., 1995). The orientation is clearly on the individual and his/her interactions with the environment.

Measurement Issues

Despite the low incidence of empirical research into the nature of stressors perceived by people with an intellectual disability, Lazarus (1984) reported that daily hassles varied with developmental stage and as a function of sociodemographic variables such as education, income, occupation, ethnicity, and culture. Because most people with an intellectual disability vary from the general population on developmental level, education, income and occupation, it is likely that the daily hassles reported by them may include some that are quite different from those commonly reported by non-disabled populations.

On the other hand, consistent with research on other populations previously cited, such people will also experience hassles that are common within the non-disabled population as well. This has been demonstrated in a study of stressors thought to be associated with suicidal tendencies among 44 people with an intellectual disability (Benson and Laman, 1985). Their results revealed a mixture of generic stressors and

those more specific to the circumstances of this group.[1] A different type of measurement issue concerns the response mode. Subjective stress is traditionally measured by self-report questionnaires. While reliability within such measures is frequently a concern for researchers dealing with the general population (Turner & Wheaton, 1995), it is even more of a concern among people with an intellectual disability (Heal & Sigelman, 1995). This means that any self-report scale for this group must be simple in format and content.

The present study aims to show that people with a mild or moderate intellectual disability experience some stressors in common with the non-disabled population and some lifestyle stressors which are unique to them as a group. A sample of convenience, consisting of university students, is included as a comparison group.

Method

Subjects

A total of 459 people with a mild or moderate intellectual disability completed the Lifestress Inventory. The sample consisted of 238 men and 134 women with 87 people omitting to specify gender. A breakdown of age found 87% of the sample was between 20 and 30 years of age. The majority of subjects lived with their parents (56%) and the remainder in residences either with live-in staff or drop-in supervision. Most of the subjects worked in sheltered workshops (68%), with 16% still at school and the remainder at activity therapy centers. The subjects were selected on two criteria: all had been assessed as functioning in the mild or moderate range of intellectual disability (based on agency files) and all exhibited adequate conversational skills (based on staff reports). The group of people fitting these criteria were provided with an explanation of the nature, purpose and requirements of the study. Those people wishing to participate gave their informed consent before starting. Only six people chose not to participate in the study.

A sample comprising people without an intellectual disability was also included in the study as a reference group. It consisted of 135 university students who completed the scale for course credit. The mean age of the group was 21.4 years and 73% were female.

Measure

The Lifestress Inventory is based on lists of stressors compiled by people with an intellectual disability and those who work with them (Bramston et al., 1993). This approach to scale derivation has ensured that the test items are relevant. The inventory was shown to be reliable with a Cronbach Alpha coefficient of .85 for people with an intellectual disability and .80 for students, and an inter-rater reliability of .87 for frequency and .79 for impact scores (Bramston & Bostock, 1994). Acceptable convergent validity was found between Lifestress and the Perceived Stress Scale (Cohen, Kessler, & Gordon, 1995), Daily Hassles Scale (Kanner, Coyne, Schaefer, & Lazarus, 1981) and Daily Stress Inventory (Brantley & Jones, 1989) when used by university students (Bramston, 1994). The factor structure of Lifestress has been found to be clearly

[1] Consequently, any scale that is constructed to reduce stress for this group must be sensitive to the circumstances of people who are intellectually disabled (Bramston, Bostock, & Tehan, 1993).

interpretable with three factors emerging labelled general anxiety, negative interpersonal interactions and a lack of skills and coping behaviours (Bramston & Fogarty, 1995).

Subjects completed the 30 items (Appendix A) using different modes. People with an intellectual disability had the questions read out to them, while the students completed a pencil and paper questionnaire. Each item in the Lifestress Inventory used a two-stage approach to the assessment of stress. Respondents were first asked to indicate whether they had experienced a stressor. If they had not, they selected the response category 0 and moved on to the next item. From this, a frequency score was computed that indicated the range of stressors that a respondent has experienced. The higher the Frequency score, the more stressors experienced. If respondents had experienced a stressor, they used a four-point Likert scale in order to calculate a stress impact score. Respondents selected from Likert points “no stress” (1), “a little stress” (2), “a fair bit of stress”(3), and “a great deal of stress” (4). A visual aid showing a series of buckets empty through to full was also used with the intellectually disabled population to improve understanding of the Likert options.

Procedure

The stress interviews for the disabled were conducted in a private room or on a garden bench within the workplace. Participants were advised that no names would be recorded and that nothing they said would be repeated to any other person. A simple definition of stress was given to them- 'the things that happen in your life which are hard to cope with'. Where necessary, questions were repeated to assist in clarity. After most questions, the participants were asked a clarifying prompt to ensure that there had been no misunderstanding. These prompts generally asked for more information or the name of a person or place, they fitted quite smoothly into the conversation and enabled the participants to expand or clarify what they wanted to say. Any questions which the interviewer felt were partly or wholly misunderstood were scored as such and not used within the analyses.

The Lifestress interviews were shared equally between two interviewers, both aged in their late 30's, one male and one female. Both were experienced clinicians and familiar with the scale. Each interviewer saw approximately half the subjects in each of the establishments. Allocation of subject to interviewer was by chance and none of the subjects were previously known to either of the interviewers. The interviews generally took about 15 minutes each.

Results

Prior to analysis, all variables were examined for accuracy of data entry, missing values, and fit between the distributions and assumptions of multivariate analysis. There were ten items scored as not understood by one or more respondents and these were treated as missing data. Inspection of these items revealed that four subjects had difficulty with item 23 ‘ Have you recently been in a situation where you didn’t know what to do?’ and item 29 ‘Do people think you can’t do many things when you feel you can?’. Both of these items are lengthy and item 29 is relatively complex in both form and concept. Due to the large sample, respondents with missing data were omitted from the analyses.

The data were inspected for response sets and six people with an intellectual disability were found to score 'Yes' on 27 or more of the 33 Lifestress items. These participants were considered to be using a 'yea-saying' response bias and were therefore withdrawn from the analyses. Four people with an intellectual disability and two students scored all 30 Lifestress items as recently occurring in their lives. These six subjects initially appeared to be confounding the results by attempting to appear stressed, however, their impact scores were all within one standard deviation of the group mean, suggesting that although they scored all these events as occurring, they rated most of them as 1 (not stressful). These subjects were therefore included in the study but it should be noted that their impact scores may be a more accurate representation of their stress levels than frequency scores.

Looking first at the frequency scores, people with an intellectual disability reported, on average, 8.57 ± 6.14 stressors compared with a mean of 12.02 ± 6.04 for the student group. Thus, students tended to experience a greater range of stressors. The data were further analysed to see which Lifestress variables caused most stress for people with and without an intellectual disability. This was done in two ways: firstly, by noting the frequency with which various items were endorsed by the two groups; secondly, by calculating the average impact of the stressors that were reported. The impact and frequency data for the two groups are shown in Table 1.

Table 1
Item Mean Impact and Percentage Reporting it as Stressful

	Intellectually Disabled			Students		
Item	M	SD	% Reporting	M	SD	% Reporting
Choice	2.17	1.09	18	1.70	0.92	22
Privacy	2.48	1.12	27	2.17	0.96	39
Argue	2.77	1.10	60	2.31	0.87	67
Treatdf	2.51	1.21	27	1.69	0.92	31
Rights	2.56	1.27	16	1.88	1.07	25
Death	2.85	1.15	54	3.02	0.89	43
Partner	2.25	1.20	27	2.41	1.00	41
Family	2.59	1.10	23	2.17	0.94	27
Listen	2.59	1.05	39	2.21	0.95	35
Quick	2.55	1.07	40	2.50	0.90	77
Instrct	2.30	1.07	22	1.55	0.91	16
Undstyou	2.12	1.06	18	1.80	1.00	22
Bully	2.98	1.07	37	3.35	0.85	25
Interupt	2.75	1.09	51	2.24	0.92	83
Tease	2.95	1.11	47	1.41	0.67	30
Worksup	2.14	1.02	14	1.59	0.80	13
Coerce	2.62	1.10	30	1.98	0.91	48
Fights	2.88	1.12	36	2.75	1.05	61
Expect	2.16	1.04	18	2.07	0.90	72
Help	2.10	1.07	13	2.40	0.97	54
Crowds	2.04	1.15	13	1.68	0.93	74
Helpless	2.42	1.07	41	2.79	0.97	68
Informed	2.31	1.27	29	1.87	0.82	35
Findjob	2.23	1.17	21	2.70	1.00	47
Change	2.18	1.09	18	2.48	1.05	46
Home	2.56	1.11	23	2.03	1.05	30
Intrub	2.50	1.11	20	1.84	0.96	14
Friends	2.42	1.17	31	1.90	1.02	30
Cantdo	2.44	1.12	33	2.03	0.91	28
Like You	2.33	1.29	9	1.41	0.87	13

N.B. The items are shown in Appendix A

It is important to note that an impact score is recorded for an item only if the response is at least '1'. It would not make sense to include the 'not experienced' category ('0') in the impact rating. Looking first at the data for the intellectually disabled group, it can be seen that the mean impact ratings are all between 2.04 and 2.98, indicating that when a stressor was encountered it tended to create some stress. On a 4-point scale, the midpoint was 2.5. Almost half the variables received an impact rating of 2.5 or above for the intellectually disabled group. The variables with the highest impact ratings were Death, Argue, Bully, Interrupt, Tease, and Fights; all representing the negative interpersonal experiences factor identified by Bramston & Fogarty (1995) and Fogarty, Bramston, and Cummins (1996). Frequency ratings indicated similar concerns. The ones that were endorsed by more than 50% of the disabled sample included Argue, Death, and Interrupt; all three rating high on impact as well.

Impact ratings for the students followed a similar pattern, but with only six variables reaching the 2.5 impact mark. These were Death, Quick, Bully, Fights, Helpless, and Findjob. The most stressful were Death, Bully, Fights, and Helpless. The frequency data showed that variables endorsed by more than 50% of the students included Argue, Quick, Interrupt, Fights, Expect, Help, Crowds, and Helpless. Not all of these were high impact variables for the students. Thus, although 83% of students indicated that they had been subjected to interruptions, it was not regarded as a particularly stressful happening. Bullying, on the other hand, although experienced by only 25% of the student sample, was perceived as very stressful when it happened.

These data indicate that although students experienced more stressors, they did not reckon these experiences as stressful as the intellectually disabled group. The mean rating of experienced stressors was 2.23 (SD = .55) for the students and 2.57 (SD = .75) for the disabled group. The difference was significant, $\underline{t}$ (571) = 4.64, $p < .001$. When viewed in this light, the data appear to lead to different conclusions. If one examines only the number of stressors encountered over the six-week period of the study, the students would seem to have experienced greater stress. If, however, one looks at the average ratings given to the stressors that were exerienced, the disabled group emerged as the more stressed group.

In the final stage of data analysis, a single index of stress was obtained by re-scoring the items along the lines suggested by Fogarty, Bramston and Cummins (1996). These authors used Rasch analysis to examine the distances between the categories used in the item response format. They found that the steps between the categories were more even if the 0 and 1 scoring categories were combined. This, in effect, equates the conditions of not having experienced a stressor with that of having experienced it but not perceived it as stressful. A transformation of this kind is in keeping with the general meaning of Lifestress impact scores. To examine differences among the groups in more detail, items were also grouped according to the three factors identified by Bramston and Fogarty (1995) as forming the basis of the Lifestress Inventory. These were: General Worry, Negative Interpersonal Relations, and Coping. Three subscale scores were computed by summing responses on the items corresponding to the factors. The MANOVA routines from SPSS were then used to compare means across the three groups. Pillai's multivariate test for overall differences indicated that there were differences between the groups, $\underline{F}$ (3,467) = 11.82, $\underline{p} < .000$. Means, standard deviations, and univariate F tests are shown in Table 2.

Table 2

Differences Between Students and the Intellectually Disabled on Lifestress Dimensions

	Intellectually Disabled		Students			
Dimension	M	SD	M	SD	F(1,469)	p <
General Worry	2.82	3.88	3.62	3.51	4.36	.05
Neg. Inter. Rel.	6.55	5.76	5.62	3.68	3.02	N.S.
Coping	3.50	4.04	5.04	3.64	14.87	.001

From Table 2 it can be seen that when comparing the groups, the students obtained significantly higher stress scores on the General Worry and the Coping Factors. The difference in means was in the reverse direction for the Negative Interpersonal Relations factor but this difference did not reach significance. It can also be seen that the second and third factors were greater sources of stress for both groups than the General Worry factor. This conforms with the findings of the Rasch analysis in Fogarty et al (1996).

Discussion

The results of this study indicate that, using the Lifestress scale, 8.57 ± 6.1 events can be expected to impinge upon the life of a person with a mild or moderate intellectual disability when recalling stress over recent weeks. Generally, these events or issues are rated between 'a little' and 'a fair bit' stressful. This confirms the 12 months of unstandardised stress interviews reported by Zetlin (1993), and the earlier exploratory research by Bramston and Bostock (1994) that people with an intellectual disability do experience and report stress.

Eight stressors is fewer than the number reported by the student reference group used in this study. However high stress scores for students seem to be a feature of this population, as evidenced by the norms for the Daily Stress Inventory (Brantley & Jones, 1989) and the Perceived Stress Scale (Pbert, Doerfler, & DeCosimo, 1992) which both show students to have higher mean scores than the general population. Thus, the mean stress frequency scores of people with an intellectual disability, like those of other groups within society, are lower than those reported by students and possibly much the same as the general population. Indeed, this pattern has recently been confirmed by Cummins, Baxter, Colquhoun, and Monteath (1996).

When group differences were examined on the factors measured by the Lifestress Inventory, using both simple frequency scores and the re-scaled impact scores, some similarities were found in the items which students and people with an intellectual disability reported as most troublesome. Both samples appeared to find being hit or bullied, the death of a friend or relative and arguing or fighting with someone to be very stressful. This finding confirms intuition that some events are highly stressful for

everyone. However, comparing the lists of most commonly reported stressors, it is clear that some events differentially stress people with and without an intellectual disability.

The group with a disability tended to focus most strongly on negative interpersonal dealings such as arguing, teasing, and being interrupted. These were not only associated with high impact scores (above 3 on a 4 point scale) but also stressed almost half the sample. On the other hand, the students were mostly stressed about not working quickly enough, not finding jobs, being interrupted and not achieving what was expected of them. These concerns reflect the demanding and increasingly competitive lives of university students, while the interpersonal nature of the stressors reported by people with an intellectual disability probably reflects their lifestyle which often entails living in a group hostel, working with many of the same people and then spending weekends and outings within the same group. This confirms Monroe and Peterman's (1988) view that people's way of life almost preordains what will stress them.

A stressor of particular relevance to people with a disability is their disability. The literature suggests that an intellectual disability is neither an inevitable nor a permanent handicap; it is dependent upon the transactions and interactions among a whole range of social, cultural and behavioural factors (Knussen & Cunningham, 1988). Although the stressfulness of a disability was not measured directly in this study, some people clearly appeared to blame their intellectual disability and see it as a stressor in addition to the other hassles and life events that they experienced over time. During the course of the data-gathering interviews, many people with an intellectual disability reported that being seen to be disabled by the general public was a stressful issue for them. Apart from the obvious embarrassment of being stared at or avoided, their disability was also frequently associated with low expectations of them by others. Zetlin (1993) refers to a similar 'worry over how others view them' amongst a group of people with an intellectual disability. Further research into self and other perceptions of an intellectual disability could lead to useful insights into the basis of many of the perceived stressors.

In summary, this paper has established that people with a mild or moderate intellectual disability will report their perceptions of stress and that many of their concerns are similar to those of university students and possibly the general population. However, there is also a group of related stressors involving negative interpersonal relationships which seem to be a particular problem for people with a disability. This is consistent with a large body of literature and confirms this area as a particularly important target for interventions.

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Appendix A The Lifestress Inventory

1 Do you get to choose things that are important to you? (Choice)
2 Do you get enough privacy/time to yourself? (Privacy)
3 Have you heard people you know arguing? (Argue)
4 Do people treat you as though you are different? (Treatdf)
5 Do people respect your rights? (Rights)
6 Has someone you know been seriously ill or died? (Death)
7 Have you been getting on with your partner/girlfriend/boyfriend? (Partner)
8 Do you get on well with your family? (Family)
9 Do people listen to you when you have something to say? (Listen)
10 Do you feel you can't do things properly or quickly enough? (Quick)
11 Can you understand other peoples instructions or directions? (Instrct)
12 Can people understand you? (Unstyou)
13 Does anyone bully or hit you? (Bully)
14 Do people interrupt you when you are busy? (Interupt)
15 Do people tease you or call you names? (Tease)
16 Do you get on well with your supervisor/teacher? (Worksup)
17 Do people make you do things you don't really want to do? (Coerce)
18 Have you had any arguments or fights with anyone? (Fights)
19 Can you do the things people want you to do? (Expect)
20 Can you get enough help when you want or need it? (Help)
21 Have you recently been in any really crowded places? (Crowds)
22 Have you ever been in a difficult situation where you didn't know what to do? (Helpless)
23 Do people around you let you know what's going on? (Informed)
24 Will you always be able to have/find a job? (Findjob)
25 Do you feel confident handling money and counting change? (Change)
26 Do you like living where you live at the moment? (Home)
27 Have you been in trouble lately? (Intrub)
28 Do you have enough friends? (Friends)
29 Do people think you can't do things when you think you can? (Cantdo)
30 Do people like talking to you? (Likeyou)