People with intellectual disability

Barriers to the provision of good primary care

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The provision of health care to people with intellectual disability is increasingly the role of the general practitioner following the patient's de-institutionalisation. However, the quality of this care is often inadequate.[1-6] There are many contributing reasons for this. People with intellectual disability suffer multiple undiagnosed – or, when diagnosed, inadequately managed conditions. Rates of morbidity and mortality among this group of people is substantially higher than that of the general population.[7,8] A large proportion of the commonly undiagnosed inadequately managed medical conditions are treatable and/or preventable.[3,9,10]

Intellectual disability is often overlooked in medical education and continuing medical education (CME) for GPs.[11-13] Furthermore, rural GPs face additional challenges to successfully participate in CME.[12,13] However, there have been efforts to improve health care to people with intellectual disability.[10,14,15] These include ongoing research focussing on elucidating and understanding health gaps.[16]

Method

Questionnaires were mailed to 300 GPs selected from the 'Yellow Pages online' listing for the Newcastle and Hunter regions (New South Wales) (response rate 14.3%). Sections one and five of the questionnaire had been developed previously.[9,17] We supplemented these with additional sections to assess secondary barriers (those external to the GPs and the result of outside agency policies) to service provision for patients with intellectual disability. Statements were scored on a 6-point Likert scale to measure respondents' agreement with each. We collapsed the top three agreement categories as agreement.

Table 1. Respondents agreeing to individual statements

Statement	Respondents agreeing n (%)	
I would be able to provide better health care for people with intellectual disability if I undertook further education and training in this area	39	(93)
I find that communication difficulties are often barriers to high quality health care with patients with intellectual disability	35	(83)
It is usually easy to gain the complete history of a patient who has intellectual disability (disagree)	34	(81)
Difficulties in obtaining a history significantly affect the quality of health care I am able to provide for people with intellectual disability	34	(81)
I find it harder to provide good quality health care to patients with intellectual disability than nondisabled patients	34	(81)
I am often uncertain of patients' baseline health and behaviour when the patient has intellectual disability	31	(74)
I am adequately trained in intellectual disability (disagree)	31	(74)
I know little about the resources available for people with intellectual disability	30	(72)
I have time to attend a training session on intellectual disability	28	(67)
It is often difficult to know how seriously to take a complaint when the patient has intellectual disability	25	(60)
I find that consultation time restrictions limit the quality of care I provide to people with intellectual disability	25	(60)
Poor communication between GPs and other health professionals often limits the health care provided to people with intellectual disability	25	(60)
It is easier to establish ongoing doctor-patient relationships with nondisabled patients than with patients with intellectual disability	24	(58)
It is often too time consuming to thoroughly examine patients with intellectual disability	24	(56)
I feel I lack experience when dealing with patients with intellectual disability	22	(53)

Results

Of the 300 GPs mailed the questionnaire, we received replies from 14 rural and 29 urban GPs, a response rate of 14%. The barrier nominated by the highest percentage of

Table 2. Percentage of respondents nominating secondary barriers as impacting quality health assessment, quality health management and competence

Secondary barrier	Health assessment	Health management	Competence
Lack of government funding in the area of ID	86	84	88
Lack of awareness in disability services about the role of GPs in providing health care to people with ID	77	77	72
Lack of awareness in the political domain about the role of GPs in providing health care to people with ID	81	84	79
Current political agendas in the area of health	84	81	77
Current political agendas in the area of intellectual disability	81	84	79
Geographical isolation	67	72	67

respondents (93%) pertained to further education and training (*Table 1*). Communication difficulties, and those about gaining history, were also important (*Table 1*).

We investigated differences between barriers identified by rural and urban GPs using the nonparametric Mann-Whitney U test. There was only one significant difference between rural and urban GPs (statement three, p=0.009). We explored whether GPs (regardless of region) thought that secondary, external barriers were creating those identified (*Table 2*). All secondary barriers listed were selected by more than 50% of GPs as impacting on three processes of care (*Table 2*).

Discussion

Our findings support past research.[2,9,17] Communication issues are important primary barriers to the good care of intellectually disabled patients. The single significant finding from 21 statements between rural and urban GPs is likely attributable to chance alone. General practitioners feel external factors contribute to the care they deliver to people with intellectual disabilities, consistently across the domains of health assessment, health management and competence. The very low response rate makes generalisation to other GPs problematic; yet it supports previous trials with better methods.

Implications of this study for general practice

- Both rural and urban GPs encounter barriers to the provision of good health care to people with intellectual disability.
- Communication is the major primary barrier.
- Education and training in communication might lead to solutions.
- These might contribute to improvements in the quality of life for those with intellectual disability.

Conflict of interest: none declared.

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