Fitting disability into practice

Focus on spinal cord injury

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BACKGROUND

People with specialised needs such as spinal cord injury (SCI) may not feature prominently in the caseload of the general practitioner. However, when people with chronic disabilities are aggregated, they constitute a reasonable percentage of consultations. It may be difficult to deliver high quality health care for such complex patients.

OBJECTIVE

We propose a method for integration of health care and prevention activities for patients with SCI in general practice, using tools such as a structured questionnaire, general practice management plans and team care arrangements.

DISCUSSION

Practice structures can efficiently and effectively accommodate people with disabilities. Tools can serve as clinical prompts, help with planning, save time, and be financially rewarding. Importantly, they can anchor a 12 month cycle of preventive health care, allowing systematic monitoring and increasing intensity/coordination of professional input for those identified with greatest needs.

Health surveillance and promotion activities are cornerstones of general practice. Fulfilling these roles adequately within the context of a busy practice may prove challenging.[1] This is compounded in the care of persons with unfamiliar specialised needs.

It is well accepted that self management programs for persons with chronic conditions require collaboration between health providers, and the patient and their family. A shared process is needed to:

- identify health issues
- agree on goals/strategies
- develop a management plan, and
- provide tailored education and follow up to monitor outcomes and treatment adherence.[2]

A systematic approach using structured health assessment questionnaires or checklists has improved health promotion, disease identification, care coordination and outcomes in primary care settings for chronic condition self management,[3] intellectual disability[4] and geriatrics.[5]

Around 300 Australians suffer a traumatic spinal cord injury (SCI) each year, with more than 10 000 people with SCI currently living in the community.[6] In addition, the incidence of nontraumatic SCI (from vascular injury, infection, demyelinating diseases, neoplasm) is estimated to be almost double that for traumatic SCI.[7] Individuals with SCI are at considerably greater risk of health complications, such as urinary tract infection, pseudo-bowel obstruction, pneumonia and pressure sores, leading to more frequent rehospitalisation.[8,9] As life expectancies have increased for people with SCI, they experience correspondingly greater morbidity from secondary conditions.[10]

With this increasing prevalent SCI population, it is likely that many general practices will see patients with SCI. We suggest a practical way to incorporate the care of people with complex needs into your practice process by systematically using existing medical record systems that incorporate recall and reminder systems. We also introduce a questionnaire that aims to streamline patient assessment. It is hoped that this tool will help foster comprehensive chronic disease management in SCI and focus on preventive health strategies in a financially viable and timely way.

Can a person in a wheelchair access your practice?

While wheelchair accessibility to general practice surgeries was not mandatory in the past, current key indicators for The Royal Australian College of General Practitioners (RACGP) Accreditation Standards[11] are based on the *Federal Disability Discrimination Act,* 1992 and legislation regarding the right to access general practices (www.hreoc.gov.au). The indicators are:

Table 1. Making practices wheelchair friendly

Try this exercise:
Walk through your practice (whether in reality or in your mind's eye) and imagine how a person in a wheelchair attending your practice would:
- view the waiting room
- approach the receptionist desk
- find the toilet and use it
- negotiate their way to your room
- occupy space in your room
- have an intimate examination that requires clothing to be removed
- return to pay their bill
- receive recalls
- make an appointment

Are there gaps?
How are you set up to see a person with a disability who has a carer of the opposite gender, gather information for a GPMP and TCA, ensure that information is delivered in an understandable fashion?

- there is wheelchair access to your practice and its facilities (direct observation), or if physical access is limited, your practice provides home or other visits to patients with disabilities (interview)
- there is adequate parking within a reasonable distance from your practice (direct observation)
- Our GP(s) and staff can describe how they facilitate access to your practice for patients with disabilities (interview).

Simple measures can be adopted to make practices more wheelchair friendly. These may include:
- removable ramps to facilitate access to the building
- cut outs in the front desk, and
- low desks for the person to sign documents on (*Table 1*).

For more information on appropriate design for practices being built or undergoing renovations see *Resources*. Many practices may not have height adjustable examination beds or hoists to facilitate transfers, making thorough physical examination and certain procedures difficult. This necessitates special arrangements (such as a home visit) for Pap tests, breast and prostate examinations or routine physical examination.[12] Valuable information can be gained from seeing a person in their own environment, such as home and equipment set up, the person's level of function and coping mechanisms, and the social milieu. For example, consider a SCI patient with recurrent pressure areas. Examining the person without his clothes on at home reveals the extent and severity of pressure areas over both ischial tuberosities, and provides the opportunity to observe his transfers. You notice that he does not adequately lift his torso, resulting in shear forces to the skin over the ischial tuberosities. Furthermore, he experienced urinary leakage during transfers, which is an often undiagnosed contributor to moisture and skin breakdown. Together the GP and the patient can develop a management plan including review of his transfers, investigation of urinary incontinence and management of his pressure areas.

Where to access information

Management of SCI can be challenging as it often requires specialised expertise to manage multiple systems involving neurogenic bladder and bowel, sexual dysfunction, autonomic instability, spasticity, pain, neuromuscular complications, equipment, care and psychological issues. There are also specific complications to SCI that need to be considered. For example, testing for faecal occult blood is unreliable in the presence of haemorrhoids, which occur in the majority of persons with SCI.

Having access to practical, relevant knowledge is the first step in successful management (see *Resources*).

Patient assessment

Given the time limitations of a busy practice, it can be difficult to elicit a comprehensive and systematic history. The Spinal Outreach Service Health Questionnaire (SOS-HQ) aims to identify new problems, prompt preventive care activities, alert to red flags and elicit the relevant information needed to manage ongoing issues. The questions are typical of what spinal specialists would ask in a patient consultation and are versed in lay language. It be completed by the patient, doctor or nurse. The SOS-HQ has been divided into four parts, covering multiple systems (*Table 2*).

The SOS-HQ has been reviewed and revised after feedback from spinal specialists and GPs to ensure good content validity. It has been further validated through trials in over 100 people with SCI in the past year and is

Table 2. Systems covered in the SOS-HQ

Questionnaire 1
- Bladder function
- Bowel function
- Autonomic dysreflexia

Questionnaire 2
- Skin integrity
- Cardiovascular, respiratory and endocrine function

Questionnaire 3
- Neurological function, pain and spasticity
- Musculoskeletal function

Questionnaire 4
- Sexual function
- General health and psychological wellbeing

currently being utilised as a preclinic tool by the Statewide Spinal Outreach Service before rural visits. A nurse completes the SOS-HQ in 30–45 minutes and the information is integrated into the patient's medical records (see *Resources*). Highlighted points are given priority by the spinal specialist during the rural visit, thus ensuring that the patient's primary concerns are addressed. The questionnaire also acts as a springboard for the doctor to discuss personal issues (eg. sexuality) with the patient and tackle red flags, which may otherwise not have been uncovered during the limited time available.

Discussion

Similar stepwise approaches to health promotion, disease prevention and control, utilising tools systematically to gather a comprehensive history, target physical examination and develop a health action plan, have been described to improve outcomes in chronic conditions such as asthma[13] and diabetes.[14] A recent randomised controlled trial has shown many increases in identification of hearing and vision impairments, attention to immunisation status, obesity, women's health screening and increased case finding using a comprehensive health management program in persons with intellectual disability.[4] Undertaking a comprehensive review in a single visit is not practical in patients with SCI, and the time required may be a financial disincentive. The patient with SCI could be reviewed over a 12 month period to complete a cycle of preventive care in a similar fashion to what has already been formalised within Medicare Australia for diabetes.[14] The practice nurse (or Aboriginal health worker) could help to coordinate this process by using the questionnaire to identify patient needs and generate issues which need to be addressed before the consultation, saving time and allowing the patient to consider the issues carefully. The practice nurse can also assist the GP in developing a general practice management plan (GPMP), facilitate communication with other health providers, give vaccinations when due and provide patient education for self management.

Case study

George, 52 years of age, sustained T4 complete paraplegia 25 years ago. He presents to your surgery for the first time with urinary leakage, malodorous urine and feelings of malaise. He manages his bladder with clean, intermittent self catheterisation. He has not had a medical review for many years.

You suspect that George has a urinary tract infection (UTI). You ask him a few quick questions from the bladder section of the SOS-HQ and find out that he has been having recurrent UTIs, many episodes of autonomic dysreflexia and has had some 'grit' in his urine.

You commence an annual cycle of care for his SCI, with the first visit addressing his acute need, and plan the next, longer visit 1 week later. Because he has not had any screening renal tests for 12 months, you organise blood tests, a clean specimen urine microscopy and culture and a renal ultrasound. You give him patient questionnaire 1 of the SOS-HQ, which asks questions on bladder, bowel and autonomic dysreflexia, to fill out at home and bring back for visit two.

Second visit

As requested, George attends 30 minutes before his next appointment with you. For each of these visits, your practice nurse checks over the questionnaire, and undertakes BP, pulse and glucometer checks as needed, and alerts George when it is time for vaccinations.

George then sees you to review the results of his blood, urine and imaging investigations, which confirms a UTI on the background of bladder calculi. You consider solutions to the problems raised, and develop preventive health strategies together.

You commence a GPMP (item 721, $122.40) and one for a TCA (item 723, $96.90), including your nurse, the resource that George uses for his catheters and enemas, the spinal outreach service whose resource on autonomic dysreflexia you give to George, and a urologist for further management of his bladder calculi.

You arrange for George to return in 3 months, giving him questionnaire 2 of the SOS-HQ. You set up a reminder for George to return in 3 months, with his questionnaire. You advise the front desk to charge a Medicare item 44.

Third visit

George receives his reminder and comes back, repeating the process. You review your GPMP (Item 725#, $61.20), following up on the goals and actions decided on the previous visit and adding the gym that George attends as part of his preventive care (and enjoyment!) You arrange a reminder for George to return in 3 months, with questionnaire 3 of the SOS-HQ, and charge Medicare item 36.

Fourth visit

Three months later, you are alerted by the red flag of shoulder pain in questionnaire 3. You refer George to a physiotherapist with experience in SCI. George is eligible to claim a maximum of five allied health Medicare item rebates as he has a GPMP and TCA in place. You change the GPMP and TCA accordingly for that visit, indicating on the bill that there has been a significant change in the patient's clinical condition or care. You give him questionnaire 4 of the SOS-HQ for the last visit.

Fifth visit (1 year from first visit)

You review questionnaire 4 of the SOS-HQ, the GPMP and TCA are complete, and are billed accordingly.

Changes to the Enhanced Primary Care package and the addition of new Medicare Benefits Schedule item numbers (eg. GPMP and team care arrangements) offer GPs improved opportunities and greater flexibility to undertake health assessments and care planning for patients with chronic conditions,[15] and provide suitable remuneration for the time and effort taken to plan and coordinate chronic care plans.

The *Case study* illustrates how the GP and practice team can deliver a cycle of preventive care efficiently. This stepwise approach can be tailored to suit different practices. During the consultation, management goals can be detailed in a systematic manner in the GPMP. A collaborative approach which evokes the patient's own motivation for change, or self efficacy, is key to successful health care and prevention. Furthermore, for preventive activities to remain relevant and for the impetus to continue, reviewing the effect is important.[16]

Conclusion

General practitioners can deliver high quality care to people with complex disabilit and address health prevention activities. This involves good organisation, the utilisation of suitable tools and a practice team. Guidelines and specialised resources can support the development of this process. Judicious use of available Medicare items ensures adequate remuneration for the time taken to coordinate the patient's comprehensive care plan.

Resources

- The SOS-HQ can be obtained free of charge from the NSW Statewide Spinal Outreach Service: telephone 02 9808 9666; www.health.nsw.gov.au/gmct/spinal/resources.html
- Federal Disability Discrimination Act (1992) and legislation regarding the right to access general practices: www.hreoc.gov.au
- MyGeneralPractice provides extensive access to international guidelines (RACGP members): www.racgp.org.au/mygeneralpractice
- Rural practice guidelines (ACCRM members): www.acrrm.org.au/main.asp?NodeID=3638
- Guidelines for preventive activities in general practice (the 'red book'): www.racgp.org.au/guidelines/redbook
- Putting prevention into practice: guidelines for the implementation of prevention in the general practice setting (the 'green book'): www.racgp.org.au/guidelines/greenbook

Specialist resources

- Rural Spinal Cord Injury Project clinical information booklets (including the SOS-HQ): www.health.nsw.gov.au/gmct/spinal/resources.html
- Guidelines for Health Care in People with Intellectual Disability: www.cdds.med.usyd.edu.au/html/PDF/HealthCare_in_People_withID_Guidelines.pdf
- Health Maintenance Plan for Adults with Spinal Cord Injury: telephone Statewide Spinal Outreach Service on 02 9808 9666 for a free copy
- Autonomic Dysreflexia Medical Emergency Card: telephone 02 9808 9666.

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