

CONFERENCE ABSTRACT

Embedding shared decision-making in a guidance framework - Guidance on the support needs of adults with spinal cord injury

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Introduction: In contrast to the evidence-based medicine ‘pyramid’ of scientific knowledge, the ‘Greek Temple’ model (2017) identifies five pillars. For the guidance topic, randomised controlled trials (experimental knowledge pillar) are unavailable. We used four pillars of knowledge to develop the guidance on support needs for people with spinal cord injury. The aim was to embed contextual and experiential knowledge in a shared decision-making framework, thereby enhancing the potential for integrated supports.

Methods: The guidance topic is complex. Sourcing the multiple pillars of scientific knowledge, the mixed methods included: systematic literature search of peer-reviewed published and grey literature; stakeholder survey; data analysis on support workers; international trends and frameworks to inform the structure of the guidance, stakeholder feedback and peer review of the draft. Essential to guidance development and particularly the decision-making framework was the extensive discussions and use of nominal group techniques with the working party of experts. The experts (practice and lived experience) ensured that experiential, contextual and practice knowledge informed consensus-based decisions.

Results: There are many factors to consider when deciding on the need for support services for a person with a health condition such as spinal cord injury. We ‘unpacked’ all these factors and ‘packed them up’ again into a framework. Three waves identified are: understanding the person, understanding the person’s context, understanding the person’s progress. The guidance provides information, resources and definitions, estimates for the level of support based on body function, assistive technology and other practical matters to further assist decision making.

Discussions: Critical to the decision making and integration of supports for a person is the expert knowledge gained from the lived experience, the fifth pillar (experiential knowledge from consumers and carers) and the fourth pillar expert knowledge (formal and tacit from practice). The decision-making framework provides a structured approach to embed shared decision-making. As the framework uses real world information, it is user friendly for the person, practitioners and decision makers to use.

Conclusions: The guidance acknowledges the person, their family and carers have expert knowledge. Use of the decision-making framework ensures collaboration and shared decision-making. Embedded in the decision-making framework is the need to understand, gain information

from and about the person, their context and progress, looking beyond their neurological level of injury to determine their support needs.

Lessons learned: Sourcing expert and experiential knowledge in real terms can be difficult in terms of time, confidence and group dynamics. Many guidelines are developed with only notional consumer or lived experience input. The working party was involved in lengthy and collaborative discussions which significantly enriched the guidance outcome.

Limitations: Evaluating the impact of the guidance is problematic. Anecdotal evidence has been positive, although impact analysis may assist with future revisions of the guidance.

Suggestions for future research: Of interest for future research is the evaluation of the impact of the guidance. For example examining change (if any) to decision-making on the need for supports, or change to the configuration of supports pre and post use of the guidance in different settings.