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Access to rehabilitation services: a 'fair go' for individuals living with a dementia

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Access to rehabilitation services: a 'fair go' for individuals living with a dementia

Abstract

Similar to other Western countries, approximately nine per cent of Australians aged over 65 are living with a dementia and for those aged over 85 the prevalence rate rises to up to 30 per cent. As the ageing population increases, the prevalence of dementia will increase (Guideline Adaptation Committee, 2016). It is doubtless an important healthcare issue. In the past 10 years, since the Australian Government published its first National Framework for Action on Dementia and the nomination of dementia as a National Health Priority, dementia care has achieved never imagined improvements. Dementiaspecific research and educational initiatives by the Dementia Collaborative Research Centres and Dementia Training Study Centres achieved unprecedented hope for consumers, family carers and clinicians about the new opportunities to improve the wellbeing and quality of life of individuals living with a dementia, and their family carers.

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Editorial: Access to Rehabilitation Services: A 'fair go' for individuals living with a dementia

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Access to Rehabilitation Services: A 'fair go' for individuals living with a dementia

Introduction

Similar to other Western countries, approximately nine per cent of Australians aged over 65 are living with a dementia and for those aged over 85 the prevalence rate rises to up to 30 per cent. As the ageing population increases the prevalence of dementia will increase (Guideline Adaptation Committee, 2016). It is doubtless an important healthcare issue. In the past ten years, since the Australian Government published its first National Framework for Action on Dementia and the nomination of dementia as a National Health Priority, dementia care has achieved never imagined improvements. Dementia specific research and educational initiatives by the Dementia Collaborative Research Centres and Dementia Training Study Centres achieved unprecedented hope for consumers, family carers and clinicians about the new opportunities to improve the well-being and quality of life of individuals living with a dementia and family carers.

Lay perceptions about dementia and attitudes towards caring for those living with a dementia have also improved in all communities. Having said this, there is still much work to be undertaken to further improve the daily lives and care experiences of individuals living with a dementia, family carers and practitioners who provide dementia care (Isbel & Jamieson, 2016). One area where a bold change could be made is to adopt a more explicit rehabilitative model of dementia care. Over ten years ago the eminent dementia care researcher, Professor Mary Marshall, dedicated a text to the rehabilitative approach in dementia care (Marshall, 2004). Today, this approach remains on the periphery of best practice and is mainly part of innovative models of dementia care rather than integrated into the everyday practices of aged care or rehabilitation services. The purpose of this editorial is to outline what the Australasian Rehabilitation Nurses' Association (ARNA) could offer individuals living with a dementia, family carers and dementia care.

Evidence to support rehabilitation approaches in dementia care

We know that, rehabilitation outcomes for individuals are determined by a range of external factors, including the experience and knowledge of rehabilitation clinicians, policies and funding models. This is particularly true for individuals living with a dementia who are more susceptible than other population groups to the effects of external factors. It is sad to say, but regularly individuals living with a dementia face negative attitudes about their potential to benefit from rehabilitation services. An access equity issue exists and individuals living with a dementia are denied services. This is despite evidence which clearly demonstrates that individuals living with a dementia experience positive rehabilitation outcomes. We do not have to search far to locate systematic reviews demonstrating the positive effects of rehabilitation interventions for individuals living with a dementia and family carers. The type of rehabilitation interventions reported included, cognitive 'brain training' activities, physical activity programmes, assistive technologies, modifying physical care environments, personalised 'real-life goal setting', psychosocial/ psychological interventions, a telephone support line, problem solving activities and family carer education.

Do policies support the implementation of a rehabilitation model for dementia care?

Policies supporting the implementation of rehabilitation in dementia care are uncommon. One troubling example is the Australian Commonwealth Government Transitional Aged Care (TAC) programme (Department of Health, 2015). TAC funds short term care to optimise the functioning and independence of older people after a hospital admission when they would otherwise be eligible for re-location into residential accommodation. The TAC programme can prevent re-location into residential accommodation after a hospital admission but also requires clients commence planning of longterm care needs. The Aged Care Assessment Teams (ACATs) are the gatekeepers for this service through an assessment to determine eligibility for the TAC programme. Rehabilitation clinicians also contribute to the TAC programme because their referral of individuals to TAC is required to trigger the ACAT assessment. The contribution made by rehabilitation clinicians to enabling individuals living with a dementia to achieve their rehabilitation goals could be enhanced by increasing the number of referrals they make to ACAT. For this to happen, rehabilitation clinicians need to adopt a more positive attitude about how well individuals living with a dementia can meet their rehabilitation goals.

One way to achieve this change, is for rehabilitation clinicians to expand their everyday practice to include dementia specific rehabilitation interventions. Unfortunately, the TAC guidelines do not actively support an expansion of their expertise to dementia care. Rather, caution is implied when reference is made to referring individuals living with a dementia to ACAT because 'the cognitive abilities of a person with dementia may fluctuate from day to day and so the extent of the person's dementia may not be evident at the initial assessment'. Conversely, we need to acknowledge that hospital environments are disabling and cause negative consequences for individuals living with a dementia. Given the opportunity, individuals living with a dementia will show great improvements in their rehabilitation outcomes post-discharge when the disabling effects of the hospital are eliminated. Rehabilitation clinicians could contribute more to dementia care by demonstrating of transformation of attitudes and make more referrals to TAC for individuals living with a dementia.

Non-physical outcome measures

In Australia, the current emphasis on the Functional Independence Measurement (FIM) (Australian Rehabilitation Outcomes Centre, 2016) for funding rehabilitation services is intrinsically discriminatory for individuals living with a dementia because the main focus of the FIM is physical health outcomes. The FIM has no meaningful inclusion of psychological health and cognitive outcomes. This omission is neglectful for individuals living with a dementia since we know that their psychological health is inextricably linked to the promotion of independence and functional capacity. Ignoring these non-physical outcome measures results in funding of services which simply address physical health problems. TAC guidelines themselves mention the value of implementing cognitive therapies for individuals living with a dementia but we see little of this in practice. Implementation of cognitive therapies remain limited to 'demonstration sites' or small-scale research. These gaps in the outcome measure need to be addressed to ensure rehabilitation services including cognitive and psychological health interventions can be funded.

Goal orientated care

An alternative way to measure outcomes (and fund services) is to deliver a rehabilitation service focused on goal orientated care. This approach works well for individuals living with a dementia. Within a goal orientated approach, clients (including the support of the family carers as necessary) develop their own goals. In a goal orientated service the effectiveness of rehabilitation interventions are measured by achievement of individualised goals. One practical tool, known as the goal attainment scale (GAS), developed in the UK and demonstrated by the authors (Aged and Dementia Health Education and Research 2016) describes working with clients to develop their individualised goals. The GAS tool includes a scoring system which is individualised for clients but can also be easily used by service providers to measure the effectiveness of rehabilitation interventions. The implementation of the GAS tool creates wins for individuals living with a dementia who are enabled individualised goals and clinicians who can objectively measure non-physical health outcomes.

Where to from here?

In Australia and the USA, the competencies models for rehabilitation nursing provide clear explanations about how rehabilitation nurses can work in partnership with clients, family carers and all members of the healthcare multi-disciplinary team to deliver effective rehabilitation nursing (Association of Rehabilitation Nurses, 2014; Australian Rehabilitation Nurses' Association, 2004). These rehabilitation models could be applied in dementia care. In Australia, however, an inherent challenge exists in Government guidelines, such as the TAC programme, which authorises practitioners to use their judgement about whether an individual living with a dementia will benefit from a rehabilitation service without first trialling the intervention. Where else, in a healthcare world driven by the need to deliver evidence healthcare, would we see a policy authorising practitioners to use their judgement for a specific population group. Clearly, in Australia, individuals living with a dementia experience discrimination within rehabilitation services. ARNA has the potential to challenge this inequality by promoting and facilitating the use of its competencies across rehabilitation services.

ARNA could also contribute to this reversal of fortune by advocating for a rehabilitation approach to be adopted within dementia care. Occupational therapists attempted to address this issue within their profession and undertook a survey to explain current barriers for occupational therapists delivering effective dementia care (Bennett, Shand & Liddle, 2011; McGrath & O'Callaghan, 2014). They found an over-emphasis on assessment, rather than implementation of interventions, was preventing occupational therapists from contributing more positively to the lives of individuals living with a dementia and family carers. Reflecting on the documentation within healthcare services and service accreditation processes it would be no surprise if a survey of rehabilitation nursing also found a similar lack of focus on implementation of interventions. The occupational therapy survey stopped short of seeking out solutions. An ARNA survey could add questions to generate ideas to implement rehabilitation interventions within dementia care.

There is a long way to go before we achieve a 'fair go' in rehabilitation for individuals living with a dementia. This editorial addressed issues in hospital and community settings but there is also a role for ARNA to lobby policy makers for an extension of rehabilitation into residential accommodation. There is unequivocal evidence about the positive effects of rehabilitation on the physical and psychological health of individuals living with a dementia in residential accommodation. We need

more investment from clinicians, service providers and policy makers to increase the presence of rehabilitation care for individuals living with a dementia across all care settings. There is evidence and tools demonstrating how to implement rehabilitation interventions in dementia care. Now we need innovative strategies to achieve implementation of these so we can contribute to the well-being and quality of life of individuals living with a dementia and family carers.

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