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Addressing dementia's identity crisis

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Dementia should be understood more as a disability, rather than a disease, with a greater emphasis placed on supporting those who care for people with the condition, according to a new report from the Social Care Workforce Research Unit, part of the Policy Institute, King's College London.

The report's authors call for a revised 'Dementia Strategy' which would invest in strengthening social support for people with dementia, and their families. This, they argue, is all the more urgent given that most current scenarios for supporting people with dementia involve either the transfer of labour to unpaid family carers or the expectation that other people, usually women, will do this work.

The researchers propose that thinking of dementia as a disability would help highlight the importance of reducing poverty and enhancing educational opportunities in prevention. This public health approach appears to hold out the best prospects for reducing risks of dementia. Blaming doctors for not recognising dementia or accusing families of not wishing to become carers are not the most effective responses and can distort funding.

Other proposed measures in the report include helping people with dementia through the greater promotion of intergenerational initiatives and dementia-friendly communities. Part of this would also involve changing the language used about dementia, in order to reduce stigma. The report highlights examples of a 'panic-blame' theme in media coverage of the condition, which presents it in catastrophic terms such as 'worse than death' or through emotionally charged metaphors. Instead, the researchers suggest more needs to be done to provide realistic and credible images of people with dementia, and to not instil fear of the condition and its costs in the general public.

They also argue that some steps taken to address dementia, such as the expansion of memory clinics and the introduction of dementia screening into general practice in England, have been driven by political and professional interests, and are not supported by strong evidence. Indeed, the researchers caution against relying too much on medical solutions, saying: 'a cure … may not be realistic given what we do know about dementia's causes'. They warn that dementia is not yet sufficiently well understood to produce effective medical therapies for it.

Professor Jill Manthorpe, one of the report's authors, said:

'The identity crisis of dementia means that we see it as a disease and so get focused on cure rather than care and support. There needs to be greater join-up between dementia support and social care. Most people supporting people with dementia are not scientists or clinicians but frontline care workers and family members. Investment in their work and in care practices needs to be debated in any new Dementia Strategy, twinned with real public health efforts in prevention.'

More information: The dialectics of dementia: www.kcl.ac.uk/sspp/policy-inst … tics-of-dementia.pdf

Provided by King's College London

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