Normal Pressure Hydrocephalus:

A treatable but often not treated disease

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Background

Normal pressure hydrocephalus (NPH) is a brain disorder, which affects mainly people above the age of 65. NPH prevalence is over 5% in elderly [1]. Moreover, it is also estimated that 5% to 10% of patients with dementia, including Alzheimer's disease, are actually effected by NPH [2,3]. Given NPH is an age related disorder, the number of NPH cases is expected to grow as the population ages.

NPH is characterized by the accumulation of excess cerebrospinal fluid (CSF) in the brain's ventricles, which are fluid-filled chambers. As brain ventricles enlarge with excess CSF, they can damage nearby brain tissue, leading to difficulty walking, problems with thinking and reasoning (dementia), and loss of bladder control and which often leads to dependence of help in daily activities, a higher risk of falls and an earlier transition to nursing homes [4,5].

The causes of NPH can be several and are poorly understood but may be due to cerebral vessel disease. In most cases, the causes cannot be treated and no medication exists, however, NPH patients can be effectively treated with shunt surgery, which involves placing a tube into the brain to drain the excess fluid. The high success rate of this clinical intervention is diminished by delayed diagnosis and treatment. So far only a small proportion of NPH patients receives timely and adequate treatment, a large proportion does not even get any.

Despite the fact that NPH is a growing public health problem among the ageing population there is a lack of population-based studies to map the economic impact of NPH across healthcare systems and the economic benefits of timely and adequate treatment. However, the sparse evidence available suggests that treating individuals older than 65 years of age can lower healthcare provider costs and be cost effective [6,7].

This study aimed to identify unmet needs and key issues throughout the course of the disease, which prevent NPH patient to receive adequate and timely treatment.

Methods

This study aiming at an inventory of patients' needs along the development of their disease for people with the condition 'Normal Pressure Hydrocephalus', in order to identify the key issues for improvement and formulate policy recommendations accordingly. The needs and key issues from a patient perspective during different disease stages has been collected through patient journey mapping, as part of a service design methodology. The service design methodology followed an iterative approach (various stakeholder consultations) to define usual care and an optimised scenario which was further substantiated by a literature review. The relation between identified needs and issues and various care aspects were discussed: both from a work floor and a healthcare system perspective. Accordingly, possible solutions were suggested and discussed among the stakeholders for mutual agreement.

The Care pathway: Treatment Gaps and Unmet Needs

MIS- (OR DELAYS IN) DETECTION/DIAGNOSIS. This problem could be characterised as a wrong routing of the patient, resulting in an inefficient use of experience and techniques, which are available at specialised clinics and professionals. Consequently, many patients do not have access to appropriate NPH care.

NO TIMELY TREATMENT. Without early diagnosis and appropriate treatment, NPH results in preventable walking problems, incontinence and dementia leading to a greater dependency on care and hospitalisation and an avoidable earlier death. Patients who receive treatment remain much longer independent [8–10].

INADEQUATE TREATMENT FOLLOW UP. Early detection of shunt insufficiency or shunt complication after intervention is needed in order to reduce the negative effects of complications. The same applies to NPH patients without shunt intervention to anticipate deterioration at the earliest moment possible.

INFORMATION GAP. This information gap contributes to the aforementioned treatment gaps as well as that the necessary multidisciplinary collaboration and appropriate referrals is severely hindered. The limited access, sharing and use of information poses also problems for the patient, family and informal caregivers in the different disease stages. Finding relevant information at the early onset of the problems related to NPH reduce anxiety and uncertainty. Information is essential for self-management and patient/family education. Also communication and information sharing is a key aspect of peer support and shared decision-making [11].

"I was treated 10 years for Parkinson´s Disease before somebody told me I do have Normal pressure hydrocephalus."

"My doctors told me, I have to live with my walking problems, there is no treatment. Then I read the article in the newspaper about Normal Pressure Hydrocephalus and I recognized myself. After getting treatment, I can participate at my social life again.."

"The radiologist told me this is brain atrophy. When I showed it to a NPH-specialist, he told me it is very likely NPH. After testing and treatment I got back to almost normal life."

" Patients with NPH costs too much time in my office, it is not worthwhile for my budget to occupy with this disease."

Recommendations

RAISE AWARENESS of normal pressure hydrocephalus through information and education of relevant healthcare professionals such as GPs, neurologist, radiologists, urologists and supporting disciplines

PROVIDE ADEQUATE ACCESS TO QUALITY OF NPH CARE, it is necessary that a sufficient number of specialised care teams are available in each European country and/or region. Typically consisting of a neurosurgeon, neurologist, geriatrician, radiologist, and urologist as well as supporting disciplines such as a specialised nurse and physiotherapist. This team should maintain a good interaction with primary and social care professionals in which the GP and geriatrician have an important role. Finally, given the effectiveness of available treatment, timely shunt surgery should be promoted and adequately reimbursed to ensure all NPH patients having access to the most optimal quality of care.

EMPOWER PATIENT AND INFORMAL CAREGIVERS such as family, friends and neighbours through the facilitation of virtual care networks. This could be established by an easy accessible digital platform where relevant information can be exchanged between patients, formal and informal carers. Such a care network should also be connected with the GP and specialised NPH centers.

Conclusions

Normal Pressure Hydrocephalus is a treatable but often not treated disease, resulting in unnecessary and avoidable disease burden for both the patient and his loved ones as well as for the healthcare system. The actions required for closing this treatment gap are straightforward but need the support from all stakeholders involved at a regional, national and European level: including the endorsement of governments and responsible authorities.

References:

1. Jaraj D, et al. Prevalence of idiopathic normal-pressure hydrocephalus. 2014. Neurology; 2. Clarfield AM. The Reversible Dementias: Do They Reverse? 1998. Annals of Internal Medicine; 3. BECK JC. Dementia in the Elderly: The Silent Epidemic. Annals of Internal Medicine. 1982. American College of Physicians; 4. Fisher CM. Hydrocephalus as a cause of disturbances of gait in the elderly. 1982. Neurology [Internet]; 5. Relkin N, et al. Diagnosing Idiopathic Normal-pressure Hydrocephalus. 2005. Neurosurgery; 6. Tullberg M, et al. Shunt surgery in iNPH patients is cost-effective – a cost-utility analysis in the Western Sweden setting. 2015. Fluids and Barriers of the CNS; 7. Kameda M, et al. Cost-effectiveness analysis of shunt surgery for idiopathic normal pressure hydrocephalus based on the SINPHONI and SINPHONI-2 trials. 2017. Acta Neurochirurgica; 8. Peterson KA, et al. The effect of shunt surgery on neuropsychological performance in normal pressure hydrocephalus: a systematic review and meta-analysis. 2016. Journal of Neurology; 9. McGirt MJ, et al. Diagnosis, Treatment, and Analysis of Long-term Outcomes in Idiopathic Normal-Pressure Hydrocephalus. 2005. Neurosurgery; 10. Caruso R, et al. Idiopathic normal-pressure hydrocephalus in adults: Result of shunting correlated with clinical findings in 18 patients and review of the literature. 1997. Neurosurgical Review; 11. Coulter A, Collins A. MAKING SHARED DECISION-MAKING A REALITY No decision about me, without me. 2011. The King's Fund.

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The cost effectiveness of addressing treatment gap in Normal Pressure Hydrocephalus patient population

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Background

Normal pressure hydrocephalus (NPH) is a treatable but underdiagnosed condition. The number of diagnosed patients will probably increase in the future which may challenge allocation of resources to secure long term benefits of the shunt surgery. Shunt surgery is successful in most patients and it is reported that more than 85% of operated patients improved their health related quality of life (HRQOL), almost to the same level as found in the normal population [1]. However, there is very limited evidence of the cost-effectiveness of treatment for iNPH [1-4] and no data are available on the socio economic impact of delivering timely and adequate NPH treatment in Europe.

Methods

We calculated the cost effectiveness of delivering shunt surgery to NPH prevalent patients with 65 years old or more in Germany (about 34,000) patients. The model compared two alternatives, current care (25% of NPH patients receiving shunt [4]) vs. target care (90% of NPH patients receiving shunt). The model (see figure 1) looked at health care costs (diagnosis, shunt intervention and follow up care, i.e. visits, hospitalisation, nursing care) from the public health insurance perspective. Effectiveness outcomes were also considered (in terms of lives saved and quality adjusted life years, QALYs). Cost effectiveness is reported as cost to be invested/QALYs (quality-adjusted-life-years) gained (incremental cost effectiveness ratio [ICERs]). The modelling covered different timeline of treatment (5, 10, 15 years as lifetime). Epidemiological data [5-7] as well as survival [8], quality of life [9] and economic [10-11] data were sourced from the literature, and expert were asked their opinion when evidence was not available (e.g. shunt success rate, use of resources, unit costs for specialist visits).

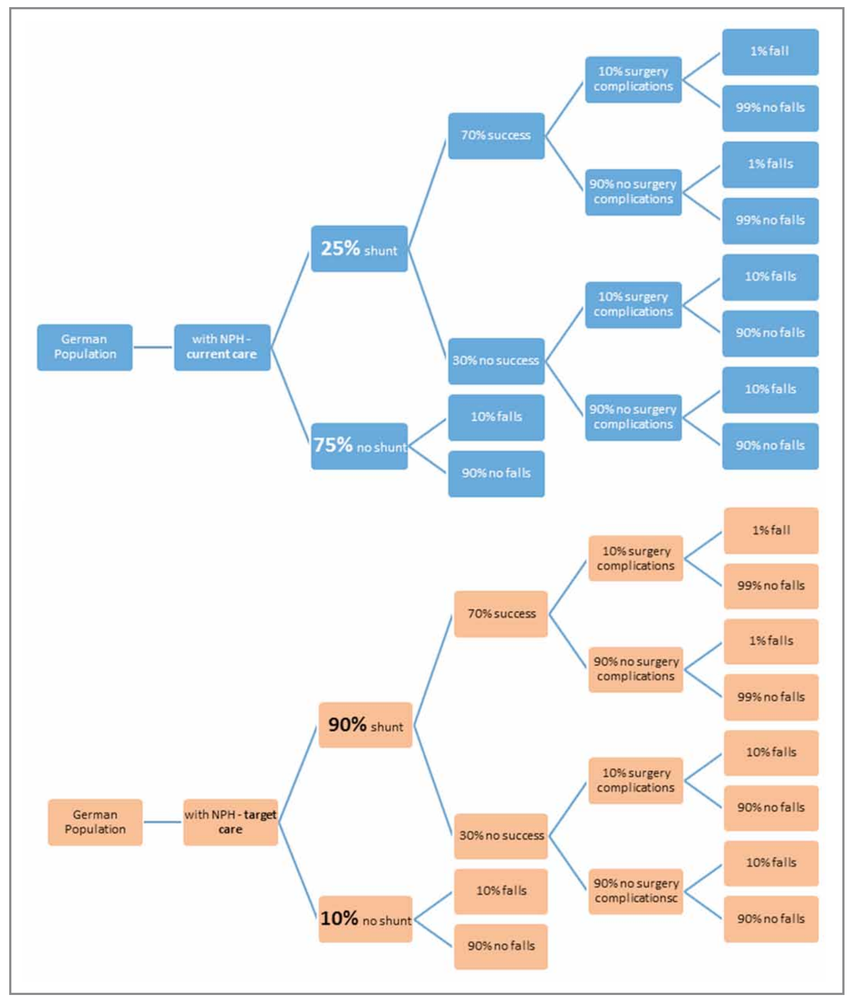

Figure 1: Decision tree

Results

Delivering shunt surgery was more costly and the economic costs increased at longer term for the increased longevity of the NPH patients and their prolonged access to long term care (figure 2). Effectiveness data showed gain in QALYs and lives saved at all time points. Overall shunt surgery proved to be cost-effective across time (5-10-15 years) in terms of both cost per life saved (27,900 -111,000 -247,000 Euros) and cost per QALY (10,200 - 22,000 - 35,100 Euros).

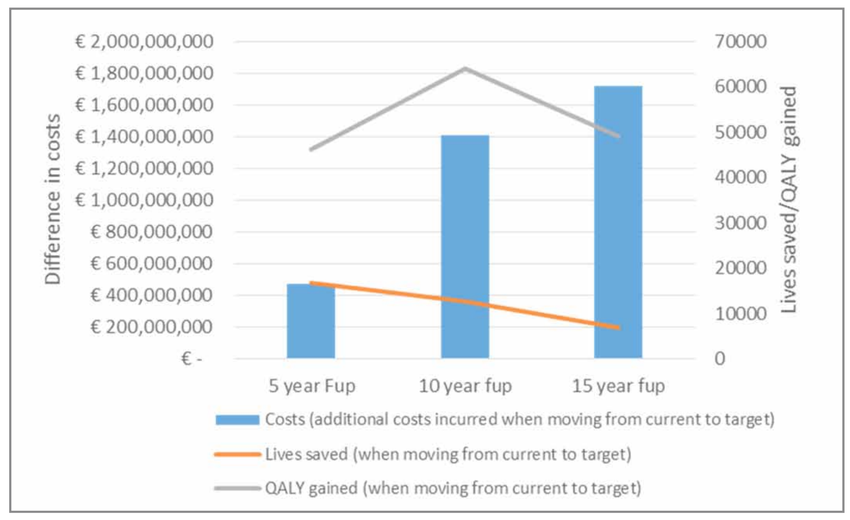

Figure 2: Difference in cost and effectiveness indicators when shifting to target NPH model of care

Conclusions

From the preliminary result of the model, it can be concluded that shunt treatment in iNPH is cost-effective. The estimated average ICER of £10,000-35,000 Euros per gained QALY is below the UK National Institute for Health and Care Excellence (NICE) acceptance level of £20,000 for cost-effective interventions.

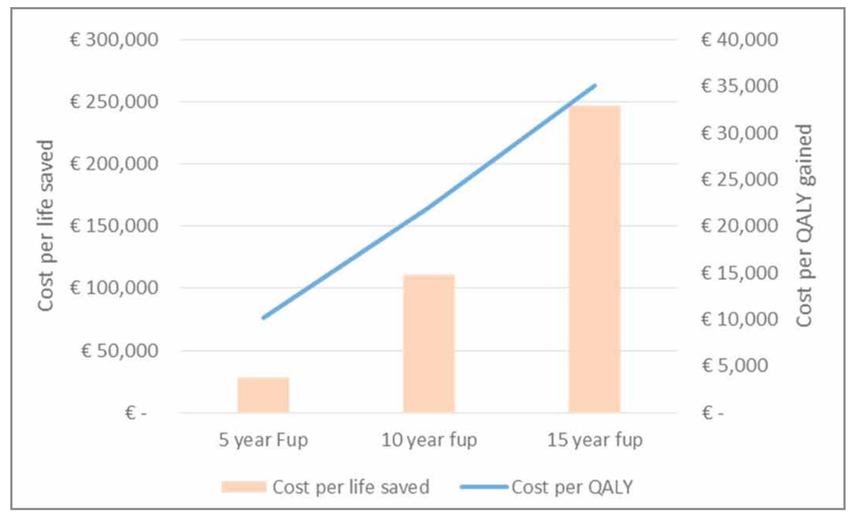

Figure 3: Difference in cost and effectiveness indicators when shifting to target NPH model of care

References:

1.Tullberg M, et al. Shunt surgery in iNPH patients is cost-effective – a cost-utility analysis in the Western Sweden setting. 2015. Fluids and Barriers of the CNS.
2.Kameda M et al. Cost-effectiveness analysis of shunt surgery for idiopathic normal pressure hydrocephalus based on the SINPHONI and SINPHONI-2 trials. 2017. Acta Neurochir (Wien).
3.Unterberg A. The Differential Diagnosis and Treatment of Normal-Pressure Hydrocephalus. 2012. Deutsches Ärzteblatt International.
4.Williams MA, et al. Influence of shunt surgery on healthcare expenditures of elderly fee-for-service Medicare beneficiaries with hydrocephalus. 2007. Journal of neurosurgery.
5.World Bank Data. http://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS?name_desc=false
6.Kiefer M, Unterberg A. The differential diagnosis and treatment of normal-pressure hydrocephalus. 2012. Dtsch Arztebl Int.
7.Picascia M, et al. A review of cognitive impairment and differential diagnosis in idiopathic normal pressure hydrocephalus. 2015. Functional Neurology.
8.Jarai D. Epidemiology of Normal Pressure Hydrocephalus. 2016. University of Gothenburg PhD thesis.
9.Larsen HI. Comorbidity and vascular risk factors associated with idiopathic normal pressure hydrocephalus:The INPH-CRasH Study. 2016. Umeå University Medical Dissertations.
10. DRG list in Germany. 2016
11. Alles über Pflegestufe 0, 1, 2 & 3 (Stand: 2016) https://www.jedermann-gruppe.de/pflegestufen-1-2-3/

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