

# Psychosocial outcome after stroke and traumatic brain injury

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## Knowledge valorization

This part of the thesis will translate this thesis' research findings to its value for society and specific target groups, to forms of innovation, and how to disseminate these findings.

### Societal relevance

The burden of stroke and traumatic brain injury (TBI) on society are reported to be very high<sup>1,2</sup>. Stroke is one of the most disabling chronic conditions with an estimated 80 million stroke survivors worldwide of which numbers are expected to rise in the future because of the ageing population and improved acute care<sup>3-5</sup>. The incidence of TBI worldwide is estimated to be 50 million people per year and is expected to increase because of the fall-related injuries in the ageing population in high-income countries and the rise of motor vehicles in low and middle-income countries<sup>6</sup>. This thesis' studies primarily focused on community-dwelling persons, as the majority of persons with stroke and TBI are discharged home from the hospital and inpatient rehabilitation<sup>7-11</sup>, of whom good recovery is expected as they are 'walking and talking' when discharged. Moreover, non-residential care and individual responsibility is promoted by healthcare policies and supported by the restructured financing system of healthcare since 2015<sup>12</sup>. While we expect community-dwelling persons with brain injury to recover over time psychosocially, we also showed that a significant percentage of community-dwelling persons with stroke and TBI experience psychosocial problems which may last into the long term. Affected psychosocial domains concerned cognitive problems in daily life, emotional functioning and participation. Moreover, levels of societal participation (such as work, sports, and contact with others) was shown to be affected by emotional and cognitive symptoms. While attention for psychosocial problems is integral to inpatient and residential services, our findings show that it is critical to pay appropriate attention to psychosocial symptoms of community-dwelling persons with brain injury.

Appropriate attention for psychosocial symptoms of community-dwelling persons with brain injury includes, next to specialized (rehabilitation) services, designing adequate primary healthcare services. We showed that providing primary care-based and nurse-led aftercare is beneficial for emotional well-being. Psychosocial support is provided by active identification of psychosocial symptoms and personalized low-intensity intervention. Moreover, aftercare actively reaching out to persons with brain injury after hospital discharge can lead to improved self-management skills and problem-solving behavior<sup>14</sup>. Increasing self-sustainability through self-management aligns with current policies promoting individual responsibility<sup>12,13</sup> and recent trends of positive health defined as: 'the ability to adapt and to self-manage, in the face of social, physical and emotional challenges'<sup>14</sup>. Moreover, the observed reassurance effect by aftercare can lead to prevention of persistent symptoms and consequently, in retaining or increasing societal participation levels. As the incidence of brain injury is expected to rise

in the future, the need for aftercare will increase concurrently. We showed that providing aftercare to the community-dwelling population is of low associated costs and therefore feasible to be provided to the increasingly large brain population. Moreover, healthcare costs did not increase as a consequence of aftercare which thereby did not lead to increased societal costs. In sum, our findings substantiate that aftercare contributes to the alleviation of the impact of brain injury on society.

### **Relevance to persons with brain injury and caregivers**

Findings of this thesis' studies are particularly relevant to persons with brain injury living in the community. Whereas good recovery is expected when discharged home, we showed that significant proportions of community-dwelling persons with brain injury experience persisting psychosocial symptoms. We used patient-reported outcome measures, such as subjective levels of participation (i.e. experienced restrictions), which directly reflect a person's functioning. These findings contribute to raising awareness of the psychosocial problems people might experience at home, which remain frequently unrecognized because they are not visible to the human eye and considered 'hidden'<sup>15</sup>. Awareness can be created in persons with brain injury and their caregivers directly, when they are informed of the possible psychosocial symptoms and recovery in order to improve participation at hospital discharge.

Moreover, information gained on the long-term psychosocial outcomes could be used in public campaigns to raise awareness and inform the general public of the psychosocial consequences of brain injury. Raised awareness and literacy manages possible maladaptive illness cognitions in case an individual suffers brain injury<sup>16</sup>. Maladaptive illness cognitions are related to worse outcomes and include negative expectations or beliefs about recovery, such as that any impairment resulting from brain injury is chronic<sup>16</sup>. Increased awareness of brain injury and its consequences in the general public can also indirectly benefit individuals with brain injury, as this way, their social environment would be better able to provide support through empathizing with the psychosocial consequences and impact of brain injury<sup>17</sup>.

The findings regarding the aftercare facility are relevant to persons with brain injury because of the active outreach<sup>17</sup>. It is critical to actively reach out, as community-dwelling persons with brain injury often feel abandoned and marginalized by healthcare services<sup>13,17</sup>. Marginalization by services is a consequence of service passivity and inadequate information provision<sup>13</sup>, which are addressed by aftercare by providing active outreach through screening, personalized support and referral when needed. We did not study these factors independently, but we are confident that the provided elements are relevant to the community-dwelling brain injury population and contributed to the observed increased emotional well-being as a result of aftercare. Emotional well-being increased on group level which indicates that the large proportion of the brain injury population benefits from aftercare. More specifically, beneficial

effects were observed on group level and in a well-functioning group, but one can imagine aftercare is even more critical and beneficial for persons with more severe symptomatology. It seems feasible, from cost-effectiveness perspective, to provide aftercare to larger and other types of brain injury populations, as it was shown to be a cost-effective addition to usual care. For example, the comparable nurse-led aftercare intervention of Moulaert et al. (2016)<sup>18</sup> provided to a cardiac arrest population, showed to be cost-effective as well.

Moreover, caregivers can benefit directly from the findings of this thesis' studies. Caregivers are crucial in the home situation and if aware of the 'hidden' psychosocial consequences, better able to provide and anticipate the needed care. Caregivers are also routinely invited to aftercare and while not studied, providing screening of possible experienced problems, psycho-education and emotional support are relevant to caregivers as well and therefore likely to be beneficial. For example, increased knowledge would contribute to their understanding of brain injury and the management of the (emotional) burden of caregiving<sup>19,20</sup>. Moreover, increased understanding of, for example, cognitive problems in daily life, might benefit the caregivers' relationship with the relative or partner with brain injury<sup>20</sup>.

### **Relevance to healthcare professionals**

In general, gained perspectives on psychosocial outcomes and personal attention are not only relevant to neuropsychologists<sup>21</sup>, but also to other (medical) professions such as neurologists, rehabilitation specialists, psychologists working in mental health care and nurses. Recovery in participation levels and associated factors are relevant to all professions as it concerns the key outcome after brain injury<sup>22</sup> and increased psychosocial knowledge would facilitate interdisciplinary working. Furthermore, the longitudinal perspectives gained throughout this thesis' studies can be integrated into education of the nurses providing aftercare. With knowledge of factors associated with participation levels, they can anticipate possible decreased outcomes over time and provide timely intervention. Findings in the evaluation of aftercare also showed that personal attention through counseling can effectively decrease anxiety symptoms, interpreted to reflect insecurities and worrying thoughts. In support, extra attention through spelling out details of treatment and managing expectations contribute to adherence and problem resolution<sup>23</sup>. Apparently, by providing and leaving room for extra attention to an individual leads to increased emotional well-being and would vote for stepping away from strictly protocolized working.

In the design of aftercare as part of Primary Care Plus (PC+), all persons with stroke are invited at hospital discharge to visit aftercare. Next to this route, persons can be referred to aftercare by the general practitioner (GP), but it appeared that this route was only used occasionally. Findings should encourage GPs to refer more frequently to aftercare because of its benefits and needed attention for psychosocial symptoms because of brain injury. Recently, our research

group, the Brain Injury Center Limburg (Expertisecentrum Hersenletsel Limburg) developed a flow diagram which assists the GP in recognizing long-term problems after brain injury and refer for further support, such as the primary care-based aftercare as we evaluated<sup>24</sup>. Moreover, 'keuzewijzers' were developed in which the available rehabilitation, health care and social support for people with brain injury is offered from a patient perspective.

### **Relevance to policymakers**

Findings regarding psychosocial symptomatology in the community-dwelling population substantiate the necessity of aftercare from the (neuro)psychological perspective. These findings, together with aftercare being considered a cost-effective addition to current services, are essential in informing policymakers. Healthcare policies, and thus policymakers, should aim for effective and efficient service delivery which is, in the end, needed to improve the well-being of the population<sup>25</sup>. More specific, efficiency of service delivery is promoted through the stepped-care model design of aftercare and by integrating low-intensity interventions in primary health care, (emotional) well-being is increased and possibly further healthcare service use can be prevented. The efficiency of the flow of patients from the hospital to visiting the aftercare facility can be improved. It became apparent that a large proportion of persons eligible for invitation, did not actually visit stroke aftercare. A large part of the appointments were cancelled, but an equally large proportion of persons were not invited. The organizational complexity, including multiple stakeholders, are likely to play a part in this observation. In general, the efficiency of aftercare delivery would benefit from a clear and straightforward organizational structure, which contributes to the optimization of communication, logistical procedures of aftercare and the continuum of care.

It must be noted that the dissemination of generated information by academics to policymakers is a complex process and frequently ineffective because of a translation deficit<sup>26,27</sup>. We communicated research findings to healthcare policymakers of aftercare with a factsheet by which findings were applied to clinical practice. Alternatively, it has been suggested to include policymakers early in the research process to overcome translation deficits<sup>26</sup>. Intermediaries called knowledge brokers, could also effectively bridge the policy gap between academics and policymakers<sup>27</sup>.

### **Activities and products**

Stroke aftercare was evaluated in the first year of implementation in Primary Care Plus (PC+). Making use of a factsheet, findings were communicated to the clinicians and policymakers of stroke aftercare, contributing to further development of its services. Currently, stroke aftercare is part of usual care in the region of Maastricht-Heuvelland, the Netherlands. Moreover, also based on our findings, a proposal has been submitted to health insurers, which advocates for expanding stroke aftercare to brain injury aftercare. Our findings also gave rise to the

evaluation of stroke aftercare with equal aims but differently organized. , Next to secondary prevention, general practice nurses in the region of Weert, the Netherlands, essentially provide the same elements as the studied stroke aftercare intervention in order to increase psychosocial functioning of patients and caregivers.

Findings from the studies in this thesis have been, and will be, particularly disseminated through publication in international peer-reviewed journals and international scientific congresses. Research results have also been presented at symposia with clinical audiences (such as Kennisnetwerk CVA) and transdisciplinary in the field of neurology. A summary of the findings has been sent to the participants in the COmplaints, HEalthcARE Needs and cosTs (COHERENT) cohort study. National dissemination of knowledge benefits daily clinical practice, and overcomes or streamlines regional differences in available healthcare services<sup>28</sup>. Dissemination of knowledge internationally can benefit global quality improvement of stroke care, mostly benefiting low-resource regions<sup>29</sup>.

### **Innovation and implementation**

PC+, and stroke aftercare, are on itself, innovations in health care. PC+ is part of 'Blue Care' in the region of Maastricht Heuvelland, which is one of the nine pioneer sites to perform innovative healthcare as designated by the ministry of Health, Welfare and Sport, and initiated by primary care organization Zorg in Ontwikkeling (ZIO), Maastricht University Medical Center (MUMC+), health insurer VGZ and patient advocacy association Burgerkracht Limburg<sup>30</sup>. Innovative healthcare aims to improve health and experience with healthcare at lower associated costs<sup>30,31</sup>, and its aim is, to some extent, supported by our findings of the aftercare evaluation.

Stroke aftercare in PC+ currently concerns usual care in the region of Maastricht-Heuvelland, the Netherlands. While this aftercare model is region-specific, findings from our studies can be generalized to other initiatives in the country and possibly internationally. As healthcare organization varies regionally<sup>28</sup>, it is important to align with existing initiatives and the implementation context such as organizational structures<sup>32</sup>. Aftercare should be the first step of contact along with low-associated costs to ensure cost-effectivity and therefore suited to the primary healthcare setting. Screening, psychoeducation, counselling and referral are considered elementary, and could be provided in different settings as well. Three examples of innovation and implementation are discussed. Firstly, based on our findings, a study is currently being conducted in the region of Amsterdam, the Netherlands, in which screening for cognitive and emotional problems, and self-management support is added to the neurology outpatient clinic for stroke patients. Second, general-practice nurses could also perform aftercare as they are primary care-based and therefore can provide accessible care. Moreover, they are already involved in secondary prevention programs after stroke in certain regions

of the Netherlands. They are also capable to provide aftercare with the elements aimed at psychosocial symptoms after brain injury, if adequately trained to ensure (neuropsychological) expertise. Third and lastly, aftercare can be integrated into the brain injury care pathway by case-management. One point of contact is desired by persons with brain injury but is currently missing from healthcare services<sup>13,17</sup>, and is one of the major advantages of case-management. Case-management has shown beneficial effects in persons with dementia<sup>33</sup> and could be considered in brain injury healthcare as well. Currently, the Brain Injury Centre Limburg (Expertisecentrum Hersenletsel Limburg), is evaluating feasibility and (cost-) effectiveness of case-management for people with brain injury which consists of monitoring, identification and assessment of needs, psychoeducation, practical and emotional support, referral and care coordination. This project is funded by the Dutch Ministry of Health, Welfare and performed in cooperation with Windesheim University of Applied Sciences. Findings of this pragmatic randomized controlled trial are expected in 2022.

While we evaluated aftercare specific to the stroke population, longitudinal perspectives on psychosocial outcomes after TBI and stroke showed comparable outcomes across brain injuries, which support and validate uniform recommendations for aftercare. As psychosocial problems are frequent, we should aim for nationwide and uniform provision of aftercare aimed at psychosocial outcomes for community-dwelling persons with brain injury. Similar to regional differences, each country has its own healthcare system and aftercare should be arranged accordingly. Initiatives do exist, such as the six month review (6MR) in the United Kingdom<sup>34</sup>, but should receive more attention and should be studied more in depth to substantiate the implementation of brain injury aftercare aimed at psychosocial outcomes worldwide.

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## Appendices

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