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Social Costs and Unmet Needs of Stroke Patients and their Carers - Preliminary Results

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Abstract

Assisting an individual with stroke has significant impact on the caregiver's life. The objectives of the present study are to examine the financial, emotional, physical and social impact of assisting an individual with stroke, as well as whether the individual's and the caregiver's needs are covered by the community. Twenty-two caregivers filled out a modified 167-item questionnaire originally created by "Associazione per la Lotta all' Ictus Cerebralle (A.L.I.Ce.)" (2009) for individuals with stroke in Italy. Reports of general deterioration of the caregivers' quality of life reached 44%. Overall services provided by the hospital were reported as sufficient for the 12%, whereas services provided by the rehabilitation centers were reported as sufficient by 16%. We concluded that important burden is inflicted to caregivers as related to all aspects of their everyday life.

Keywords: CVA, caregiver, care needs, social impact

Introduction

Assisting an individual with stroke can have significant impact on the caregiver's life, yet is seldom mentioned in literature. There are physical, psychosocial and educational support needs of stroke caregivers that remain unmet, but are critical for the recovery of the stroke survivor. Such lack of support has the potential to lead to the caregivers' psychological and physical health compromise (Camak, 2015). In addition, the financial costs of hospitalisation and rehabilitation are rarely covered by the community, and insufficient training as a caregiver might impose additional burdens (Fattore et al., 2012· Hafsteinsdóttir, Vergunst, Lindeman, & Schuurmans, 2011). In other studies, rehabilitation unmet needs were reported by both healthcare professionals treating stroke survivors, as well as older people with stroke (Vincent et al., 2007). Research has also focused not only on the individual's living conditions before the incident, type of stroke and caregiver burden, but also on provided social support. All these factors can influence the quality of life of stroke survivors and their caregivers (Savini et al., 2015).

Research suggests that caregivers' and stroke survivors' perceived quality of life are interdependent (Atteih et al., 2015). Physical and emotional exhaustion have been reported in more recent studies (Olivier, Phillips, & Roy, 2017). Fatigue, anxiety and depression are common among stroke caregivers (Atteih et al., 2015; Grant et al., 2004). Depression and general psychological distress are frequent among members of families of stroke survivors, and they often lead to further need of assistance and healthcare support (Haley, Roth, Hovater, & Clay, 2015; Worrall et al., 2016). Depressive symptoms were also linked to perceived low quality of free time, and perceived low mastery of assistance (Pendergrass et al., 2017). In addition, assistance-related burden can impact caregivers' quality of life, particularly as far as mental health is concerned (Morimoto, Schreiner, & Asano, 2003). That said, difficulties experienced when assisting a survivor, or

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handling their cognitive and emotional changes have been observed from the first month after the incident. Caregivers also feel that they don't have enough time to address all of their duties (Grant et al., 2004). Finally, significant levels of dissatisfaction with community and hospital services are reported (Atteih et al., 2015).

In addition, the caregivers' quality of life is associated with the expenses of the stroke survivors' rehabilitation (Savini et al., 2014). Married individuals who suffered a stroke reported better quality of life, compared to divorced individuals. Hence, a strong support network, including a caregiver can significantly contribute to the stroke survivors' rehabilitation process (Foster et al., 2012), albeit social life reportedly deteriorates after the incident (Tsioupinaki, Serdari, Kouki, Mouza, & Proios, 2017). One interesting finding from this work, which examined quality of communication from the caregivers' perspective, was that people with stroke-induced communication deficits were experiencing as many limitations as people with dementia. These included, social life and interaction, speech and memory problems, trouble in performing daily activities and in making decisions, nervousness, poor self-confidence and negative attitude. However, overall quality of communication was more positively assessed by the caregivers of stroke survivors. Additionally, participating in family activities was associated with less changes in relationships, and less feelings of disappointment or nervousness. Finally, alienation, and negative reports of perceived outcome were linked to speech problems (Tsioupinaki, Serdari, Kouki, Mouza, & Proios, 2017).

Suppporting and educating caregivers might help reduce the cost of assisting a patient (Patel, Knapp, Evans, Perez, & Kalra, 2004), but this is a need unmet in many families of stroke survivors. For instance, families with stroke survivors do not receive enough information about aetiology, medication, prevention of recurrence, support groups and emotional problems thoughout the rehabilitation process (Low, Kersen, Ashburn, George, & McLellan, 2003; Tooth & Hoffmann, 2004). In addition, complex issues such as functional outcome, and vocational and social reintegration are rarely covered in discussions with professionals (Low, Kersen, Ashburn, George, & McLellan, 2003).

The spouses of survivors, were most likely to assume the role of the caregiver. Lower mental health was reported for caregivers of more disabled stroke survivors (Clark et al., 2004). Other studies suggest that partners of young stroke survivors can also be impacted by the incident and go through changes as related to their role in the relationship. Also, couples encountered difficulties making sense of the incident (Quinn, Murray, & Malone, 2014). In addition, caregivers often are forced to alter their work schedule, even resign or retire to take care of the stroke survivor. Full or part-time caregivers were often employed to carry out assistance-related tasks as well (Ko, Aycock, & Clark, 2007). Other studies have focused on the children of stroke survivors as informal caregivers. Taking on the caregiving role can influence daughters' physical and emotional quality of life, as well as affect the parent-child relationship (Bastawrous, Gignac, Kapral, & Cameron, 2014).

The objectives of the present study is to examine the financial, emotional, physical and social impact of assisting an individual with stroke, and whether the individual's and the caregiver's needs are covered by the community. In this study, we used the Italian A.L.I.Ce. questionnaire. This work presents preliminary results for the purpose of stimulating further discussion on the topic.

Methods

Participants

Twenty-five caregivers (19 women), aged from 23 to 80 (Mean: 55, SD: 13.99) were recruited from the broader region of Northern Greece. Out of the 25 participants, 11 were university graduates, 6 graduated from senior high school, and the other 8 participants' education level was junior high, or lower. Sixteen of the caregivers were assisting a male stroke survivor, while nine were assisting a female stroke survivor. Fourteen participants were spouses, 9 were sons/daughters, and one was the mother of the individual with stroke.

Stimuli and Procedure

For the translation of the questionnaire, five Greek speaking individuals were asked to examine each question and report the linguistic compliance to the Greek language. Two Greek speaking but Italian trained neurologists working in two independent rehabilitation centers in the area did the back-translation for each of the 167 questions. The participants filled out thetranslated questionnaire originally created by A.L.I.Ce. (2009). Items were divided in five sections, including general information about the participant, and his/her health condition, the participants' quality of life, and the quality of services provided by the community, as well as health-related expenses after stroke.

To elaborate, in the first section, items included information about the participants' demographics (age, social status, occupation, where and with whom they live, education level, post-stroke changes in occupation). This section also investigated the type of stroke, coexisting cardiovascular and orthopedic problems, and, finally, functional outcome of the participants (i.e., *"Can the stroke survivor walk?"*). The second section included information about the informal caregiver, such as demographic characteristics (age, social status, occupation, where and with whom they live, education level, and post-stroke changes in occupation). This section also examined the type of relationship between the caregiver and the stroke survivor, which family members share responsibility for looking after the survivor, as well as changes in occupation due to their caretaking duties . Other items of this section refer to provision of services by the community, such as the procedure of disability ratification, and provision of disability subsidy or pension (e.g., *"Will the stroke survivor receive/Is the stroke survivor receiving disability subsidy or disability pension?"*). Everyday activities are also investigated, as related to supervision, direct care and outdoor activities, as well as the impact of these activities on the caregivers' health (i.e., assistance-related health problems and medication).

The third section involves the healthcare services that have been used by the families. Hiring of home assistance personel, as well as professional caregivers, nurses and cleaning staff is investigated in this section. This section examines how frequently the caregivers use the aforementioned services, the quality of the provided services, and their monthly cost. In the fourth section, the rehabilitation process and service provision by hospitals, rehabilitation centers, and healthcare professionals is discussed (e.g., *"Do you believe you received enough information about medication from the hospital?"*). In addition, this section includes a scale that measures the assistance burden on the caregiver (e.g., *"How frequently do you feel irritated when you assist your relative?"*; Zarit, Reever, & Bach-Peterson, 1980). Finally, the fifth section addresses the quality of physical and emotional health of the informal caregiver. The participants filled out the 167-item questionnaire. Participants originated from regions of the Northern Greece, and were recruited through the day care units of rehabilitation centers. Inclusion criteria included the existence of only one CVA, 6 to 12 months prior to participation, and high rating (≥3) in Modified Rankin Scale. Regarding informed consent, we included a consent form, in which all important details concerning the study were given.

Results

The mean total cost of rehabilitation was 9716.67€; four (16%) of the participants received financial assistance from the National Health Institute for supporting an individual with stroke, and disability subsidy was provided only to one participant, while disability pension was provided to three (mean earnings reaching 486.67€/month).

Out of the total sample, 9 stroke survivors (36%) were able to function unsupervised, 10 (40%) could be left alone only for a short period of time, and 6 (24%) of the stroke survivors were not able to function unsupervised. Participants dedicated 5.16 hours a day for direct care, 11.2 hours for supervision, and 2.4 hours for outdoor activities with the stroke survivor. Mean distance between caregiver and the person with stroke was 6.67 km. The majority (88%) were living with the individual they were assisting, 2 (8%) were living in a different place but in the same region, and one (4%) in another place and region. The majority (68%) had taken up the caregiving of the stroke survivor on their own. However, 32% was sharing the responsibilities of caregiving with a family member. Twenty percent of those were sharing responsibilities with a sibling, 8% with a parent, 8% with other people. The use of professional caregivers reached 16%, and the overall use of healthcare professionals at home reached 32%. The mean cost of a professional caregiver was 162.50€/month.

Eight percent of caregivers had to leave their employment and find a new one in order to meet the demands of caregiving, and 8% forcefully retired, whereas 12% reduced their working schedule, and 12% forcefully left their job. However, the majority (84%) of participants reported no change of their jobs' setings due to caregiving. One participant had to select more than one answers, reporting changing jobs, reducing schedule, and finally retiring.

Reports of general deterioration of the caregivers' quality of life reached 44%. More elaborately, 52% of the participants reported not having enough sleep, 36% gained weight, and 12% had been hospitalized. Also, participants experienced fatigue (56%), depression (12%), need of psychiatric help (12%), and frequent exhaustion of physical/emotional resources (55%). Pain following physical exhaustion restricted participants' everyday activities in a total of 12%. Emotional exhaustion resulted to low concentration for 36% of the participants.

Overall services provided by the hospital were reported as sufficient for the 12% of the participants, whereas the services provided by the rehabilitation centers were reported as sufficient by a similar percentage (16%). Healthcare professionals were reported as such by the 16%, general physicians were reported as having provided sufficient support by the 8%, and speciallized doctors were reported as sufficiently providing services by the 16% of the caregivers. Ninety-six percent of the caregivers had not been informed by the doctor about the risk of stroke, before the incidence of it.

As far as information about support groups is concerned, 12% received adequate information from the hospital, 20% from the rehabilitation center, 12% from healthcare professionals, 4% from general practitioners, and 24% from specialized doctors. Provision of rehabilitation sessions by the hospital was evaluated positively by the 40% of participants, as well as rehabilitation sessions provided by the rehabilitation center (40%). For the healthcare professionals, the percentage reached 20%. Specialized doctors were evaluated the highest (48%). Information and support for affective disorders aster stroke was provided by the hospital to 20% of the participants, and by the rehabilitation center to 44%. Healthcare professionals provided adequate support to the 16%, while 56% of the participants reported adequate support from specialized doctors.

Twenty-four percent of the participants received enough information about recurrence of stroke by the hospital, 28% by the rehabilitation center, 12% by a healthcare professional, 12% by general practioners, and 56% by a specialized doctor. Information about medication was adequately provided by the hospital for 24% and by the general practitioners to 8% of the caregivers. Finally, specialized doctors provided information about medication to 64% of the participants.

Discussion

The present findings imply that important burden is inflicted to caregivers as related to all aspects of their everyday life, with physical and emotional restrictions, need of psychological support, and financial burdens that are only partially covered by the community. Taking care of a stroke survivor has previously been reported as having emotional impact on a person, leading to significant psychological distress (Haley, Roth, Hovater, & Clay, 2015; Olivier, Phillips, & Roy, 2017). Interestingly, we also found that only a relatively low percentage of caregivers reported depression, a finding that is not consistent with previous studies, such as that of Worrall et al. (2016).

Services provided during the hospital stay for the stroke survivor were evaluated as sufficient as those provided by the rehabilitation centers. Information about recurrence, medication, affective disorders, and support groups was only partially provided by the several infrastructures and professionals that participate in rehabilitation and treatment of stroke. Informartion was not adequatley provided even before the incidence of stroke, rendering the caregivers and individuals unaware of the need of stroke prevention (Low, Kersen, Ashburn, George, & McLellan, 2003; Tooth & Hoffmann, 2004).

Reported total healthcare costs are comparable to those reported in the study of Fattore et al. (2012). In the Italian study, mean healthcare costs accounted for 11.747€, while in our preliminary findings, healthcare cost was 9716.67€. Contrary to previous literature citing that caregivers consider the stroke survivor dependent and unable to function on his/her own (Hallé, Duhamel, & Le Dorze, 2011), the majority of the caregivers believe that the stroke survivor could be left alone, for at least a short period of time.

The present findings should be interpreted with caution due to the small sample size that does not allow conclusions about the burden of social cost and unmet needs of stroke survivors should not be drawn. On the other hand these findings do correspond very well with the Italian findings and the Greek data serves as a lesson for the struggles, decisions and more interestingly the questions that need to be addressed when clinical researchers examine the overall burden of stroke. Future research will further examine the caregivers' perspective, thus contributing to more effective interventions and better quality of services. It is our hope that a 2- and/or 3-year follow-up might enrich findings with a more dynamic view of the association between the stroke survivors' functional outcome and the psychosocial and emotional state of the caregiver in Greece. This work lends itself to a cross-cultural comparison between Italy and Greece and the quite prevalent problem of social cost and unmet needs of survivors of stroke and their caregivers. As reported in Forster et al. (2012), strategies including caregivers in th rehabilitation process and planned follow-up have the potential to boost the stroke survivors' emotional state and contribute to overall progress. The need of a follow-up is highlighted in research (McCullagh, Brigstocke, Donaldson & Kalra, 2005) demonstrating that caregivers' quality of life did not improve with time, contrary to the stroke survivors' quality of life, which was increasingly improving. The present study illustrates the struggles, decisions and can address questions important to address when examining the burden of stroke, such as which are the most suitable strategies for including caregivers in the rehabilitation process and how to plan effective follow-up examinations.

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References

Atteih, S., Mellon, L., Hall, P., Brewer, L., Horgan, F., Williams, D., & Hickey, A. (2015). Implications of stroke for caregiver outcomes: findings from the ASPIRE-S study. *International journal of stroke, 10*(6), 918-923.

Bastawrous, M., Gignac, M. A., Kapral, M. K., & Cameron, J. I. (2014). Daughters Providing Poststroke Care: Perspectives on the Parent–Child Relationship and Well-Being. *Qualitative health research, 24*(11), 1527-1539.

Camak, D. J. (2015). Addressing the burden of stroke caregivers: a literature review. *Journal of clinical nursing*, *24*(17-18), 2376-2382.

Clark, P. C., Dunbar, S. B., Shields, C. G., Viswanathan, B., Aycock, D. M., & Wolf, S. L. (2004). Influence of stroke survivor characteristics and family conflict surrounding recovery on caregivers' mental and physical health. *Nursing Research, 53*(6), 406-413.

Fattore, G., Torbica, A., Susi, A., Giovanni, A., Benelli, G., Gozzo, M., & Toso, V. (2012). The social and economic burden of stroke survivors in Italy: a prospective, incidence-based, multicentre cost of illness study. *BMC Neurology*, *12*(1), 1.

Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J. J., & Young, J. (2012). *Information provision for stroke patients and their caregivers*. The Cochrane Library. doi: 10.1002/14651858.CD001919.pub3.

Grant, J. S., Glandon, G. L., Elliott, T. R., Giger, J. N., & Weaver, M. (2004). Caregiving problems and feelings experienced by family caregivers of stroke survivors the first month after discharge. *International Journal of Rehabilitation Research, 27*(2), 105-111.

Hafsteinsdóttir, T. B., Vergunst, M., Lindeman, E., & Schuurmans, M. (2011). Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. *Patient education and counseling*, *85*(1), 14-25.

Haley, W. E., Roth, D. L., Hovater, M., & Clay, O. J. (2015). Long-term impact of stroke on family caregiver well-being A population-based case-control study. *Neurology*, *84*(13), 1323-1329.

Hallé, M. C., Duhamel, F., & Le Dorze, G. (2011). The daughter–mother relationship in the presence of aphasia: How daughters view changes over the first year poststroke. *Qualitative health research*, *21*(4), 549-562.

Ko, J. Y., Aycock, D. M., & Clark, P. C. (2007). A comparison of working versus nonworking family caregivers of stroke survivors. *Journal of Neuroscience Nursing, 39*(4), 217-225.

Low, J. T. S., Kersen, P., Ashburn, A., George, S., & McLellan, D. L. (2003). A study to evaluate the met and unmet needs of members belonging to Young Stroke groups affiliated with the Stroke Association. *Disability and rehabilitation*, *25*(18), 1052-1056.

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke*, *36*(10), 2181-2186.

Morimoto, T., Schreiner, A. S., & Asano, H. (2003). Caregiver burden and health related quality of life among Japanese stroke caregivers. *Age and Ageing, 32*(2), 218-223.

Olivier, C. L., Phillips, J., & Roy, D. E. (2017). To be or not to be? A caregiver's question: the lived experience of a stroke family during the first 18 months poststroke. *Scandinavian Journal of Caring Sciences*. ISO 690

Patel, A., Knapp, M., Evans, A., Perez, I., & Kalra, L. (2004). Training care givers of stroke patients: economic evaluation. *BMJ, 328*(7448), 1102.

Pendergrass, A., Hautzinger, M., Elliott, T. R., Schilling, O., Becker, C., & Pfeiffer, K. (2017). Family caregiver adjustment and stroke survivor impairment: A path analytic model. *Rehabilitation Psychology, 62*(2), 81.

Pezzella, F. R., & Reale, N. (2009). *I costi sociali e i bisogni assistenziali dei malati di ictus cerebrale.* Roma: A.L.I.Ce.

Quinn, K., Murray, C. D., & Malone, C. (2014). The experience of couples when one partner has a stroke at a young age: an interpretative phenomenological analysis. *Disability and rehabilitation, 36*(20), 1670-1678.

Savini, S., Buck, H. G., Dickson, V. V., Simeone, S., Pucciarelli, G., Fida, R., Matarese, M., Alvaro, R., & Vellone, E. (2015). Quality of life in stroke survivor–caregiver dyads: a new conceptual framework and longitudinal study protocol. *Journal of advanced nursing*, *71*(3), 676-687.

Tooth, L., & Hoffmann, T. (2004). Patient perceptions of the quality of information provided in a hospital stroke rehabilitation unit. *The British Journal of Occupational Therapy*, *67*(3), 111-117.

Tsioupinaki E., Serdari A., Kouki E.P., Mouza E., Proios H. (2017). Quality of Communication in the Rehabilitation of Persons with Stroke and/or Dementia: The Caregivers Perspective. *Νευρολογία*, *26*(1), 43-50.

Vincent, C., Deaudelin, I., Robichaud, L., Rousseau, J., Viscogliosi, C., Talbot, L. R., & Desrosiers, J. (2007). Rehabilitation needs for older adults with stroke living at home: perceptions of four populations. *BMC geriatrics, 7*(1), 20.

Worrall, L., Ryan, B., Hudson, K., Kneebone, I., Simmons-Mackie, N., Khan, A., Hoffmann, T., Power, E., Togher, L., & Rose, M. (2016). Reducing the psychosocial impact of aphasia on mood and quality of life in people with aphasia and the impact of caregiving in family members through the Aphasia Action Success Knowledge (Aphasia ASK) program: study protocol for a randomized controlled trial. *Trials*, *17*(1), 153.

Zarit, S. H., Reever, K. E., Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *Gerontologist, 20*(6): 649-655.