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Low Income and Stroke Rehabilitation: A Tale of Two Clients

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Low Income and Stroke Rehabilitation: A Tale of Two Clients

Comments

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Stroke is a leading cause of neurological disability among adults, and there is evidence that health disparities exist along the stroke continuum. People living with low income have a higher stroke incidence (Cesaroni, Agabiti, Forastiere, & Perucci, 2009), higher stroke fatality (Kapral et al., 2012), and lower functional recovery (Chen et al., 2015). Living in a low-income neighborhood also leads to poorer participation poststroke, even after adjustments for health and level of disability (Egan et al., 2015). Despite our general knowledge of the association between income and poststroke disability in developed countries, there is little in the occupational therapy literature to support our understanding of how low income can influence stroke survivors' participation in personally valued occupations.

The objective of this paper is to provide a theoretical and practical understanding of these challenges with re-engagement in personally valued occupations following stroke, as well as to make recommendations to guide practice. First, we review the current understanding of the impact of low income on the experience of rehabilitation and on later participation in the community. Second, we present two theoretical approaches to understanding the impact of income: social determinants of health and intersectionality. We then present the stories of two low-income stroke survivors who were treated on an inpatient stroke rehabilitation unit. These stories serve to illustrate how the experiences of rehabilitation can differ based on social location and how an intersectionality approach can improve a rehabilitation team's appreciation of the potential impact of a person's unique context. Finally, we discuss the clinical implications and make recommendations for future research.

The Impact of Low Income on the Experience of Rehabilitation

Low income can create barriers to access to and full engagement in stroke rehabilitation, as well as to later participation in valued occupations. For example, low-income stroke survivors without private health insurance in the United States have difficulty accessing poststroke rehabilitation (Ostwald, Godwin, Cheong, & Cron, 2009). In Canada, despite the presence of universal health care, living in low-income neighborhoods is associated with being admitted to hospitals with fewer stroke patients and with less opportunities for practitioners to develop stroke expertise (Saposnik et al., 2008). Canadian lower-income patients are also less likely to get ideal poststroke follow-up care (Huang et al., 2013).

After hospital discharge, living in a low-income situation can impact access to further rehabilitation services and can create challenges in obtaining transportation, health products and equipment, assistance with personal care (Ganesh, King-Shier, Manns, Hill, & Campbell, 2017), and medication (Campbell et al., 2014), all of which support the ability to participate in meaningful occupations.

Social Determinants of Health or Intersectionality: Two Approaches

Occupational therapists have long recognized the influence of low income on engagement in rehabilitation and participation in personally valued occupations (Kielhofner & Barret, 1998). In the health professions, income is most commonly viewed from the perspective of social determinants of health. Income is seen, along with other determinants, such as education, social class, housing, race, and employment, as having an important potential impact on health (Mikkonen & Raphael, 2010). While social determinants of health are considered within larger socio-political systems, they are generally regarded as isolated categories potentially affecting health (Hankivsky & Christoffersen, 2008). That is, determinants are often seen generically, such that individuals experience the impact of low income in a similar way.

Intersectionality is another approach for considering the influence of income on health outcomes. This approach extends our understanding of social determinants by attending to the interactions and the

compound impacts of other social locations that could contribute to poorer outcomes. An intersectionality approach accounts for the complexities and variations in peoples' experiences of participation. For example, a stroke survivor with low income, who is also an immigrant and a woman, may face challenges different from those faced by immigrant men or non-immigrant women. An intersectionality approach then captures the potential impact of power and privilege in the larger context of the political, social, and economic structure (McGibbon & McPherson, 2011). This provides a more holistic understanding of the impact of low income; it enhances consideration of the client's personal context and guides us not to overlook the needs of clients who, because of a combination of factors, may be at particular risk for poor outcomes without additional support during rehabilitation and transition back into the community.

We present two case stories to illustrate how low income, viewed either as a social determinant of health or as an intersectionality of social locations, may affect the experience and potential outcome of rehabilitation differently. Further, we show how a rehabilitation team's limited appreciation of context reduced their client centeredness. These case stories arose during the pilot testing of methods to better understand the experiences of low income occupational therapy clients who were receiving stroke rehabilitation services in Ontario, Canada. The unit team identified two clients of one stroke rehabilitation unit who had incomes below the government defined regional annual low income cutoff (approximately \$16,375 [USD]). These two participants were recruited at the same time, and both had similar levels of function poststroke. For example, on discharge, both ambulated with walkers, used bathroom safety equipment, and required supervision when showering.

Data was collected using semi-structured interviews with the stroke survivors and their care partners, occupational therapists, and social workers. The interviews focused on the participants' perceptions of the impact of income on rehabilitation and the transition home. Medical charts were reviewed for demographic data, poststroke function, discharge planning, and entries related to income. The research ethics boards of the rehabilitation facility and the researchers' university provided ethics review.

A Short Illustration of Two Cases

Mr. Burke: Back from the brink. At the time of his stroke, Mr. Burke [all names are pseudonyms], a 76-year-old retiree, lived alone in a mobile home. He had recently received an eviction notice from the management of his trailer park for failure to pay his rent. Mr. Burke's financial difficulties were recent and resulted from poor investments. He had been estranged from his children for over 10 years. While in the hospital, two of his daughters reconnected with him and became his main care partners. His social network also included several friends from a local service club.

Mr. Burke spent 6 weeks on the inpatient stroke rehabilitation unit, with the plan of discharge to a noninstitutional setting. During his stay, the team recognized that Mr. Burke could not return to his home because of the eviction and that he had insufficient funds to relocate to an apartment or retirement home. A municipally subsidized assisted living facility was suggested, but these had long waiting lists. To position him as a higher priority on the waiting list for the subsidized facility, the social worker recommended that Mr. Burke be discharged to a homeless shelter. His daughters refused this discharge plan and, subsequently, the social worker assisted Mr. Burke to apply for the subsidized facility and worked to improve his position on the waiting list. Following a complex process of establishing eligibility, Mr. Burke was offered a place in this facility.

With regard to equipment, the unit social worker assisted Mr. Burke with the application for a municipal funding program to assist him with his co-payment on a needed walker. The bathroom equipment he required was available at the subsidized assisted living facility. In addition, Mr. Burke was able, through his service club, to get funding for an orthosis that was not covered by provincial or municipal programs. He knew the application procedure well, since as a club member he had previously participated in funding equipment for others.

Mr. Burke reported no concern regarding his ability to pay for medication, because, as a senior citizen, he was already enrolled in the provincial government's drug benefit program that covered the cost of his prescriptions.

The rehabilitation team had applied for the municipal adapted transportation service. However, following one challenging attempt at using it, Mr. Burke's family and friends decided that they would provide transportation to appointments and outings.

At his request, Mr. Burke's daughters took charge of all of the paperwork and financial decision-making and attended all daytime meetings with the social worker to help with completion of application forms for housing and equipment. They also took care of selling his mobile home and settling his debts. Both Mr. Burke and his daughters noted that his financial position was now better than it had been before his stroke, as the rehabilitation team and his daughters had helped him reorganize his finances and obtain affordable housing.

Though circumstances initially looked daunting, by the time he was discharged from the stroke rehabilitation unit, Mr. Burke had come "back from the brink" of homelessness and its associated negative effects on health and participation. Through his reconnection with his daughters, he navigated toward discharge to a difficult-to-obtain unit in a publically subsidized assisted living facility. Mr. Burke's age made obtaining necessary medications affordable, and he was further supported by his social network, who provided additional equipment and transportation to social outings.

Mrs. Douard: Out into the unknown. Mrs. Douard was a 56-year-old woman who had immigrated to Canada from the Caribbean over 10 years ago. At the time of the stroke, she was living with her daughter and grandchildren, and she was responsible for most of the family's household chores. She was not working outside of the home, and her only source of revenue was a small pension of approximately \$500 (USD) per month from her late husband. Following 6 weeks on the inpatient stroke rehabilitation unit, the discharge plan was to return home with her family.

The social worker assisted Mrs. Douard with applying for municipal funding to cover the costs of recommended bathroom equipment and to pay for the portion of the walker that was not covered by the province's mobility equipment funding program. The application process was complicated because Mrs. Douard's daughter was unable to attend daytime meetings at the hospital, as she worked long hours. Mrs. Douard's 20-year-old granddaughter, who had little previous experience with the health care system, acted as the primary family contact with the treatment team. Mrs. Douard's application was eventually approved for funding assistance for the walker; however, at discharge, she had not been approved for funding for the bathroom equipment.

Prior to her stroke, Mrs. Douard had not had a family doctor to monitor her health and provide access to other medical specialists and health professionals. During hospitalization following her stroke, she was newly diagnosed with medication-dependent diabetes. Although hospitalized patients receive prescription drugs through universal provincial health plans, Mrs. Douard had no coverage for medication following discharge. Having no drug plan, she was concerned about her ability to afford

medication on her limited pension. The team informed Mrs. Douard that she could apply for funding assistance through the provincial Disability Support Program (which funds some of the essential medications for people with very low incomes who are under 65 years of age). However, the team did not provide direct assistance with the complex application procedures. Mrs. Douard was unsure regarding the application process and whether she would qualify. Her inability to pay for medication had not been identified as a concern in interviews with the occupational therapist or social worker, and it was not mentioned by any health care provider in the medical chart notes.

The rehabilitation team prepared an application for Mrs. Douard for the municipal adapted transportation service. Aware of the limitations of this service, she was worried that she would not be able to return to her prestroke family responsibilities. She was concerned that her routine of grocery shopping would become a struggle, now that she was using a walker and had no funds for a taxi and no social network from which to draw.

Mrs. Douard's story could be titled "Out into the unknown." On the surface, her situation appeared to be somewhat better than Mr. Burke's. She had a home to return to and would be living with family members. While her post discharge needs were broadly addressed as per normal unit practice, nothing was specifically done to ensure that she would be able to obtain medication or equipment following discharge. That is, no one on the team made certain that the complex paperwork was completed and submitted prior to discharge, nor did anyone follow up to determine if she had successfully obtained the necessary entitlements. It appeared that they assumed that Mrs. Douard could effectively follow up on these, either independently or with the help of her family. However, there was no indication that she or her family members would be able to do this. Further, it was unclear if her occupations in the family could be managed, given transportation and other difficulties. Mrs. Douard had unwittingly been sent "out into the unknown" without certainty of the necessary supports to foster her health or participation in valued occupations.

The Experience of Rehabilitation Using an Intersectionality Approach

The stories of Mrs. Douard and Mr. Burke illustrate that low income, seen simply as a social determinant, is too broad a category to provide a sufficient appreciation of the potential impact on health and participation in valued occupations. Both stroke survivors were disadvantaged in terms of the social determinant of income. However, the impact of this income on their lives varied substantially. Intersecting social locations, specifically language and newcomer status, age, family situation, and social network, can be seen as having had important effects on the ultimate outcomes of their individual experiences of stroke rehabilitation and potential for future health maintenance and participation in meaningful occupations. Although specifics of these cases were related to the Canadian health care system context, the broader implications can be relevant to occupational therapy clients in other health care systems.

Unlike Mr. Burke, who spoke English, Mrs. Douard's language discordance may have affected her ability to access services and to have her concerns understood (i.e., affording medication). When language discordance exists between the patient and the treatment team members, it may be difficult to discuss the concerns that go beyond functional skills and equipment needs (Taylor & Jones, 2014).

Furthermore, while Mr. Burke was born in Canada, Mrs. Douard had only recently arrived in the country, and her knowledge of the general health care and social service systems may not have been as developed. For example, she may not have thought it possible to ask for help to complete the application forms for funding assistance for her medication. Newcomer status may make people less aware of the

social processes of care and potentially less likely to criticize them, particularly if it could result in immigration problems for themselves or their family members.

Younger age can also increase vulnerability because of age-related eligibility criteria for access to community services (Sadler, Daniel, Wolfe, & McKeivitt, 2014). While Ontario residents 65 years of age and older, like Mr. Burke, have their essential prescription medications covered through universal provincial health insurance, younger adult residents, such as Mrs. Douard, do not. Medication coverage is available for younger adult residents through the provincial Disability Support Program; however, significant difficulties exist in accessing this program (Income Security Advocacy Centre [ISAC], 2011).

Family situation is known to have an impact on engagement in everyday occupations poststroke. These cases illustrate how different families may require different types of help in supporting a family member who has experienced a stroke. Mrs. Douard and her family's limited experience navigating the social service and health care system, and their lack of a family advocate who could meet the social worker during business hours, further complicated the application process for equipment and medication funding assistance. Mr. Burke, on the other hand, was well-supported by middle-aged daughters who could navigate the system. Wider social networks were also a factor. Mrs. Douard did not have social supports beyond her family. Mr. Burke's social network extended outside of his family. Through his service club he had access to extra equipment, and his friends provided transportation to outings.

Practice Considerations: Seeing the Big Picture

To help ensure that people can remain well and engaged in valued occupations after discharge from rehabilitation services, we suggest that occupational therapists be sensitive to intersecting social locations and how these can interact with low income to create unique challenges. These complex individual situations may require occupational therapists to ensure interventions adequately target needs. By anticipating the post discharge reality and by broadening their roles beyond function and individual social determinants, occupational therapists can keep clients from being discharged "out into the unknown," as was Mrs. Douard. Broadening "beyond function" implies evaluating, for example, not only financial or medication management skills in the clinical setting, but also the adequacy of current income to meet health needs and support participation.

Occupational therapists may need to counter a tendency to view clients through a normalizing lens. That is, they may assume that their clients, like them, have adequate incomes to address basic needs. Through this lens, occupational therapists may not fully appreciate the impact of low income on all aspects of daily life (Van Herk, Smith, & Andrew, 2011). Indeed, it is not unusual for occupational therapists to recommend everyday activities (such as meeting friends for coffee) that may seem quite reasonable but actually may be impossible for their clients to afford (Capponi, 1997). Further, they may assign responsibilities to families without investigating their ability and willingness to provide navigation and advocacy through the health and social service systems (Jellema et al., 2016), or even to provide physical assistance.

Occupational therapists can appreciate that addressing each unique client using an intersectionality, rather than a generic social determinant approach, is a more client-centered strategy; however, it may require more one-on-one therapy time. For example, when providing services to people with whom we do not share a language, we will need to spend more time listening for concerns and asking supplemental questions to ensure a good understanding of the situation. Further, providing direct assistance with access to entitlements may be a particularly powerful way to promote health and valued

occupations among low-income patients. We should not forget that resource seeking is a vital and valuable occupation (Aldrich, Rudman, & Dickie, 2017).

Research Recommendations

Future research is needed to further our understanding of how low income, in addition to identified social locations, such as language and newcomer status, age, family situation, and social network, can be addressed by health systems so that stroke survivors experience optimal recovery and occupational disadvantages can be reduced.

Research is recommended to address two specific questions. First, does using an intersectionality approach help occupational therapists identify clients who may need adapted services to help mitigate against income-related barriers to rehabilitation and participation? Second, do services designed to help clients obtain entitlements and related goods and services lead to better outcomes?

To date, health professionals have mainly considered the potential association between low income as a social determinant and occupation. Using a more holistic approach, that is, an intersectionality approach, could lead the way to more client-centered practice and an increased sensitivity to situations where patients may face certain hurdles when engaging in occupational therapy.

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