

Experiences of persons with physical disabilities regarding rehabilitation services: A systematic review

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Abstract

Introduction: Rehabilitation has been found to improve the integration of persons with disabilities into the society. For rehabilitation to be effective, there is a need to seek patients' perceptions of the services rendered to them. Incorporating these perceptions in the rehabilitation process of patients is one of the ways that recognises patients' involvement in rehabilitation. The most common identified persons with physical disabilities' experiences that have been explored are: accessibility of rehabilitation services, interaction of service providers with patients, provision of information related to disability and rehabilitation. This review aims at highlighting the experiences of persons with physical disabilities regarding rehabilitation services as it relates to different studies.

Methods: This review involved a search of studies published from January 2000 to February 2010. The electronic search was done in CINAHL, COCHRANE, EBSCOHOST, MEDLINE and SCIENCE DIRECT databases. Articles were reviewed using the Critical Appraisal Skills Programme (CASP) and the Central for Evidence-Based Social Services Critical Thinking Tools and seven articles are included in the review.

Results and Discussion: Seven articles met the inclusion criteria: one cross-sectional and six qualitative studies. Most studies revealed that patients experienced challenges regarding rehabilitation services. These included but were not restricted to unavailability and inaccessible rehabilitation services. Other difficulties were identified in relation to the interaction of patients with service providers (inadequate communication between service providers and patients and ineffectual attitudes of service providers towards their patients) and poor information dissemination.

Conclusions and implications for practice: The review discusses the different number of experiences of persons with physical disabilities. The studies included in this review indicated that rehabilitation services for persons with physical disabilities remain challenged with regards to provision of necessary information related to these services and their accessibility. Rehabilitation challenges identified can be solved when there is a considerate investment to address these challenges by policy makers and rehabilitation management.

Key words: Patients' experiences, persons with physical disability, rehabilitation services, systematic review.

Introduction

Rehabilitation is a concept that aims at enabling persons with physical disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. In addition to this, rehabilitation contributes to patients' sense of autonomy, self-worth, and social participation. However, when patients' experiences are not adequately identified, patients receive less than optimal assistance. It is with this reason that

client-centeredness emerged as an important principle for delivering health and rehabilitation services. Patients and their families need to be involved in providing ideals related to the services provided to them within the client-centeredness principle. The most common identified experiences reported in literature are, but not limited to: accessibility to rehabilitation services, interaction of service providers with their patients, involvement of patients and their families in their rehabilitation,

information/knowledge dissemination (Booth & Kendall, 2007; Martensson & Dahlin-Ivanoff, 2006 ; Leith, Phillips & Sample, 2004; Kroll & Neri, 2003; Neri & Kroll, 2003; Tod, Lacey & McNeil, 2002). In assisting persons with physical disabilities to achieve their functional independence, there is a need to plan and implement rehabilitation programmes and services that address their experienced problems/needs.

As aforementioned, accessibility to health/rehabilitation services amongst others is one of the different ways persons with physical disabilities have experienced as highlighted in literature (Booth & Kendall, 2007; Neri & Kroll, 2003; Tod, et al., 2002). Accessibility to rehabilitation is a key component, that successively meets the needs of PWDs when catering for a potentially large number of PWDs in a community. The United Nations approved rules recognise accessibility as a way that facilitates persons with disabilities to utilize any services available for them on an equal basis like people without disabilities.

Accessibility include; right of entry of physical environment, transportation, right to use information and communication and other facilities and services provided to the public both in urban and rural areas. Accessibility of services like rehabilitation has continually been a challenge to persons with physical disabilities (Booth & Kendall, 2007; Neri & Kroll, 2003; Tod et al., 2002). Once these patients with physical disabilities are discharged from any form of rehabilitation, they tend to lack information and access to community services. Patients have indicated that they are hindered to attend rehabilitation mainly due to difficulties in accessing means of transport (Booth & Kendall, 2007) and lack of information related to rehabilitation services. Barriers related to rehabilitation accessibility encountered by cardiac patients in South Yorkshire Coalfield include waiting for a long period for rehabilitation services due to limited service capacity (Tod et al., 2002). Patients with physical disabilities in the USA and the Netherlands encountered problems while accessing rehabilitation services, such as travelling long distances due to absence of these services within their vicinity (Booth & Kendall, 2007). In addition, inaccessibility to rehabilitation buildings/areas such as unavailability of ramps in facility areas or rooms, narrow doorways and

cramped waiting and examination rooms is reported. In some cases, patients are able to access health services however they receive services which are of poor quality due to inadequate services. Information that relates to patients' condition and treatment is also another aspect that is crucial to patients however, unavailable to them.

Availability of information regarding rehabilitation and disability is one of the other greatest needs reported by patients (Martensson & Dahlin-Ivanoff, 2006). However, the availability of information to patients is less fulfilled in rehabilitation domain. The provision of disability information/knowledge in practice has been reported to improve on the health/rehabilitation professional practice, guidance and education. However, the lack of information among patients is reported (Darrah, Magil-Evans & Adkins, 2002; Tod et al., 2002; Kroll & Neri, 2003) and this is due to lack of more informed/educated health/rehabilitation professionals in disability related issues (Leith et al., 2004; Martensson & Dahlin-Ivanoff, 2004).

Different ways have been put forward in solving the dearth of information and these include: the implementation of programmes and central information centres that are accessible by patients and their families (Kroll & Neri, 2003; Darrah et al., 2002). Leith et al (2004) attributed the lack of information to limited training skills among service providers. Which might also result to ineffectual attitudes on the service providers towards patients.

The ineffectual attitudes of service providers towards patients have been reported in this review (Tod et al., 2002), this also affects their relationship. Contrary, Darrah et al (2002) reported that patients and their families expressed that the service providers were caring and supportive across all service areas. Client-centeredness was one of the approaches recognised to improve the service provider's relationships with patients (Martensson & Dahlin-Ivanoff, 2004). Patients' experiences and knowledge are recognised by therapists like occupational therapists within the client-centeredness approach. The interaction and improvement of communication skills between patients with service providers within the client-centeredness approach is recognised (Martensson & Dahlin-Ivanoff, 2004).

Communication in rehabilitation service provision is one of the component in client-centeredness approach. With this approach both patients and service providers interact and share ideals, challenges and difficulties. Communication was reported to be inadequate between patients, families and their service providers (Darrah et al., 2002; Tod et al., 2002). This affected the patients, in a way that they were unable to get opportunities to share their needs and challenges encountered during rehabilitation. Seeking patients' perceptive in order to incorporate their views prior to planning and delivering of rehabilitation services is important. Therefore, the purpose of this systematic review is to highlight the different experiences of persons with physical disabilities regarding rehabilitation services as it relates to different studies.

Methods

Search strategy

A computer search was conducted on different databases at the University of the Western Cape (UWC) library. The following databases were searched; CINAHL, COCHRANE, EBSCOHOST, MEDLINE and SCIENCE DIRECT. MeSH and key terms used: persons with physical disabilities, clients'/patients' experiences, rehabilitation services and rehabilitation service delivery/provision.

The abstracts of the studies were assessed using the P: Problem, I: Intervention, C: Comparison with intervention and O: Outcomes of interest (PICO) system and Sackett's level of evidence hierarchy system.

The total sum score of PICO (4) and of the Sackett's level of evidence hierarchy system (5) with a full text accessed (1) provided the final score (10) of each abstract that was included in the current study. This process facilitated the refining of a researchable and answerable question hence finally having an effective search of the evidence. The abstracts which scored 5 and above out of 10 PICO and Sackett score were included in the study. The articles which scored 4 and less out of 10, and studies conducted in geriatrics, paediatrics and psychiatrics were excluded.

The present review is based on the information attained from peer reviewed published articles. The title and abstracts of the articles included in this study

were screened by two independent reviewers.

Search results

Using the search terms, 847 hits were retrieved from the mentioned databases but, only 63 abstracts were retained. These articles were selected using the following criteria: article needed to be published in a science journal, not a geriatric, paediatric or psychiatric abstract, published between January 2000 and January 2010. The 63 abstracts were assessed using the PICO and the Sackett's level scores, 46 abstracts were excluded because they scored 4 and less out of 10. The remaining 17 articles were subjected to the methodological quality assessment.

Methodological quality assessment

The review was followed by grouping the selected articles following the nature of the methodology followed to conduct the study. The 17 selected articles were then grouped into 3 categories namely; Quasi-experimental (3 articles), qualitative (11 articles), and cross-sectional studies (3 articles). The Centre for Evidence-Based Social Services Critical Thinking Tools were used to score the Quasi-experimental and qualitative articles for the methodological quality. The score of these tools had a scale ranging from 1-13. The first two questions of the tools are screening questions which determine whether the reviewer would continue with the review. This assists the researcher/reviewer to determine if the article is worth to be included or excluded. If the screening questions are positive, the reviewer continues with the process. However, if the screening questions are negative, the trustworthiness of the study/article is questionable providing less chances of applying the findings of the study in practice or in making decisions of clients. Articles would be included in the study if they scored highly and moderately, 8-13/13 and 6-7/13 respectively. If the score was poor with 1-5/13, the article would be excluded. 6 qualitative articles out of the 11 were selected for this review. The 5 qualitative and all the 3 quasi-experimental articles were excluded as they had a poor score.

The Critical Appraisal Skills Programme tool namely; cohort was used to assess the cross-sectional studies. This tool has proved to enable researchers in developing skills that assists them in finding and making sense of the research evidence. The tool

comprises of 12 questions, but the first two questions are screening questions and these two questions assist the reviewer to find out the worthiness of continuing with the other 10 questions. The first two questions of this tool are used to screen the article and are not part of the overall scoring of the article. When using this tool, articles that scored 8-10/10 were viewed to have a high score, 5-7/10 a moderate score and 1-4/10 a poor score. The 3 cross-sectional studies were assessed and only 1 was retained as the others 2 scored too low. The final number of articles used in this review was 7; 6 qualitative and 1 cross-sectional study.

Results

The sample size of the participants included in this study ranged between 20-137. The different methods used to collect the data included; questionnaires and data gathering instruments for quantitative data. Semi-structured interviews, in-depth interviews and focus group discussions were utilised to gather the qualitative data. Referring to 7

studies included in this review related to the experiences of persons with physical disabilities, the cross-section study reported on the challenges patients encountered while interacting with their service providers (Darrah et al., 2002). While Martensson and Dahlin-Ivanoff (2006); Leith et al (2004); Kroll and Neri (2003) reported on how patients were less informed regarding disability and rehabilitation services. The other 3 qualitative studies meanwhile, reported on the challenges experienced by patients while accessing rehabilitation services/facilities (Neri & Kroll, 2007; Tod et al., 2002; Booth & Kendall, 2007).

In summary, as indicated in Table 1, the articles included in this review report that the participants who took part in the studies experienced challenges with regards to rehabilitation services. The table below summarises the description of the articles included in this study.

Table 1: Description of studies included in this study

Authors	Study design	Tools	Country	Population	Outcome measured	Result
Booth, S & Kendall, M. (2007)	Qualitative study	In-depth interviews.	Australia	40 individuals with Spinal Cord Injury who participated in the transitional rehabilitation. Ages not indicated.	Accessing rehabilitation services in the community (Transitional rehabilitation).	Provided inequitable services.
Darrah et al., (2002)	Quantitative study	Demographic and satisfaction questionnaire	Canada	88 participants, 49 adolescents (13-15 years) and 39 young adults (19-23) and their families. Ages not indicated	Interaction of service providers with patients and information/education related to disability	Communication difficulties were experienced in all service areas. Information was difficult to provide and receive.
Kroll, T & Neri, M.T. (2003)	Qualitative study	Semi-structured interviews	United States of America	30 people with cerebral palsy, multiple sclerosis or spinal cord injuries, 16 women and 14 men. With a mean age of 44.8 years.	Disability specific knowledge	Lack of disability specific knowledge and insufficient communication

Leith et al., (2004)	Qualitative study	Focus group discussions	United States of America	21 persons with Traumatic Brain Injury. Ages not indicated.	Information and education related to Traumatic Brain Injury and Traumatic Brain Injury services	Lack of information and education related to Traumatic Brain Injury and its services
Martensson, L & Dahlin-Ivanoff, S. (2006)	Qualitative study	Focus group discussions	Sweden	24 individuals with chronic pain with the mean age of 7.6 years.	Knowledge and information about disability	Participants needed to be more informed about disability and rehabilitation services available for them
Neri, M.T & Kroll, T. (2003)	Qualitative study	Semi-structured, in-depth interviews.	United States of America	30 participants with spinal cord injury, cerebral palsy or multiple sclerosis(ranged between 18-65 years)	Access to rehabilitation services	Inappropriate (delayed) services affected the participants accessibility.
Tod et al., (2002)	Qualitative study	Individual and group discussions.	United Kingdom	20 post-myocardial infarction patients, 4 women and 16 men (ranged between 43-76 years) and 15 staff.	Access to cardiac rehabilitation service and information regarding the availability of these services.	Limitation of services and capacity resulted in absence of cardiac rehabilitation services. Unavailability of information about available services for patients.

Discussion

This review explored and summarised the available literature relating to the experiences of persons with physical disabilities regarding the provision of rehabilitation services. The main areas focused on by the articles included in the review can be divided into three main sections: accessibility of rehabilitation services, interaction of service providers/health professionals with patients, and information and knowledge dissemination related to patients conditions and treatment. Each category is discussed in detail below.

Accessibility of services

For rehabilitation to be effective, it is reported that the accessibility of rehabilitation services is important. However, inaccessibility of rehabilitation/health services have been reported in the studies included in this review (Tod et al., 2002; Neri & Kroll, 2003;

Booth & Kendall, 2007). Tod et al (2002) reported that patients in South Yorkshire Coalfield in the United Kingdom experienced challenges when accessing rehabilitation services. These challenges included delayed and limited services which prevented the provision of appropriate services. In some instances, the rehabilitation personnel are prevented from offering accessible and appropriate range of services due to limited resources (Tod et al., 2002). Another problem that might cause inaccessibility of rehabilitation services is related to lack of funding of services and service providers that lead to inequitable service provision (Booth & Kendall, 2007).

The following is recommended by different studies in addressing the inaccessibility of services, seeking patients' perceptions is one of the approaches of monitoring the quality of services amongst others.

Neri and Kroll (2003), suggested the implementation of appropriate and timely access services was a solution to embark on the problems that patients encounter while accessing rehabilitation services in the USA. This was recommended due to the fact that patients encountered challenges of long waiting lists due to a deluge number of persons with disabilities needing services which do not correspond to the service providers' capacity. Due to the deluge number of patients needing to be attended too, service providers have difficulties in sparing time to educate patients on their disabilities and rehabilitation.

Provision of information

The provision of information by service providers needed by patients is among the needs identified by patients in different studies (Martensson & Dahlin-Ivanoff, 2006; Tod et al., 2002), however, it is the least fulfilled need in rehabilitation. The information needed by patients relates to the nature of their conditions and treatment, available health/rehabilitation and supportive services available for them. The lack of information provision among persons with physical disabilities might impact on their rehabilitation outcomes. A study by Darrah et al (2002) which evaluated the perceptions of cerebral palsy patients and their families regarding service delivery, reported that the information regarding the services available for them was only disseminated through different networks. While the families and patients which were not belonging to any network missed out the information because they didn't know the existence of these networks and lacked access. Information related to patients' disability was also not provided to them and their families.

Ways of disseminating information that can be accessed by all patients and their families is reported (Darrah et al., 2002; Kroll & Neri, 2003). These include but not limited to: a central information centre in the patients community that provides updated and accurate information that is accessible to all patients and their families (Darrah et al., 2002). The implementation of programmes that provide patients with all the information they need in their vicinity, in order for them to access the information they need that is not provided by service providers during their rehabilitation is also recommended (Kroll & Neri, 2003). Leith et al (2004) reported that service

providers are not adequately skilled enough to provide the necessary information needed by the patients regarding rehabilitation services and their disability.

There is a need to provide training to health and rehabilitation professionals to improve on their knowledge and skills at their workplaces (Neri & Kroll, 2003; Leith et al., 2004; Martensson & Dahlin-Ivanoff, 2006) in order to educate patients. The time for service providers is more dedicated to the workload and invest less time to provide patients with the necessary information (Martensson & Dahlin-Ivanoff, 2006). In some instances, service providers feel disrupted from their activities when they have to invest time to talk and interact with patients.

Interaction of service providers with patients

Rehabilitation is observed to be essential in the lives of persons with physical disabilities, and their interaction with their service providers plays a big role in improving their quality of life. When interacting with service providers, patients are able to communicate, share and express their ideals, challenges and needs to them (Martensson & Dahlin-Ivanoff, 2006). Through the interaction of service providers with patients, the treatment goals, interactional difficulties and challenges are presented and strategies of dealing with these challenges are sought. However, if there is lack of communication, patients feel ignored (Darrah et al., 2002), ill treated and rejected (Martensson & Dahlin-Ivanoff, 2006). In a study conducted in Canada, patients and their families encountered communication difficulties because service providers used complex terminologies while talking to patients (Darrah et al., 2002).

In a study conducted in the UK, Tod et al (2002) reported that patients encountered language barriers while communicating to service providers. Patients who were unable to express themselves in English encountered difficulties in communicating to their service providers. Studies have reported that poor/lack of communication might be due to personnel inadequacy, increased workload, hence service providers concentrate/focus only on treating patients (Kroll & Neri, 2003). Client-centeredness is recommended as a method of improving the interaction of service providers with patients during

rehabilitation. Client-centeredness allows decision-making between patients and service providers during rehabilitation and patients are able to express their ideals and needs regarding rehabilitation and their conditions.

Conclusion

The experiences of persons with physical disabilities regarding rehabilitation services has been investigated in terms of accessibility of these services, provision of information and interaction of service providers with patients. 3 studies which reported on accessibility revealed that patients experienced inaccessible rehabilitation services due to limited resources. The other 3 which reported on provision of information and knowledge regarding patients' disability and rehabilitation indicated the need for health and rehabilitation professionals to provide patients with appropriate information that is also easily available for them. As well as one article which reported the lack of interaction between patients and the service providers. Recommendation for improvement are also indicated in this review. To address these challenges, the reorganization of rehabilitation services would improve or maintain the quality of services rendered to patients. Not all the problems raised by the patients can immediately be addressed, but expressing their views of rehabilitation service provision assists on improving the quality of services. The review concludes that, rehabilitation services need to be accorded more attention to address challenges experienced by patients.

Implications for practice

Rehabilitation challenges identified can be solved when there is a considerable investment to address the mentioned challenges by policy makers and rehabilitation management. Health professionals as well as physiotherapists need to understand the need of interacting with their patients, allowing patients to express their needs and challenges. The

review indicates the need of training among rehabilitation professionals in order to improve their practice skills on disability related issues. This can be achieved by the management of rehabilitation sectors supporting continued education and providing time for service providers to attend workshops, seminars and any other employees' online workshops and seminars. It is through the dissemination of information that patients can access information about the services available for them. Researchers in this domain need to conduct studies in Africa and not all in the developed countries.

References

1. Booth, S., & Kendall, M. (2007). Benefits and challenges of providing transitional rehabilitation services to people with spinal cord injury from regional, rural and remote areas. *Australian Journal Rural Health*, 15, 172-178.
2. Darrah, J., Magil-Evans, J., & Adkins, R. (2002). How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery. *Disability and Rehabilitation*, 24(10), 542-549.
3. Kroll, T., & Neri, M. T. (2003). Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis and spinal cord injury. *Disability and Rehabilitation*, 25(29), 1106-1114.
4. Leith, H. L., Phillips, L., & Sample, P. L. (2004). Exploring the service needs and experiences of persons with Traumatic Head Injury (TBI) and their families: the South Carolina experiences. *Brain Injury*, 18(12), 1191-1208.
5. Martensson, L., & Dahllin-Ivanoff, S. (2006). Experiences of a primary health care rehabilitation programme. A focus group study of persons with chronic pain. *Disability and Rehabilitation*, 28(16), 985-995.
6. Neri, M. T., & Kroll, T. (2003). Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disability and Rehabilitation*, 25(2), 85-96.
7. Tod, A. M., Lacey, A. E., & McNeill, F. (2002). "I'm still waiting.....": barriers to accessing cardiac rehabilitation services. *Journal of Advanced Nursing*, 40(4), 421-431.