HOUSING AND LOW VISION REHABILITATION – ACROSS THEORIES, PRACTICES AND EVERYDAY SETTINGS

Turid Borgestrand Øien *

The Danish Building Research Institute, Aalborg University, Denmark

* Corresponding author e-mail: tbo@sbi.aau.dk

Abstract

Objective – The objective of this paper is to open up the 'black box' of low vision rehabilitation related to domestic lighting and to explore a current progress in practice.

Background - Alterations and adjustments of the home or working environment for people with low vision have been based on scientific diagnostics and the level of vision and translated into a level of required lighting. This narrow and technical approach have recently been challenged by rehabilitative initiatives from professional and political stance. The rehabilitation approach embraces the everyday self-reliance of the citizen, where the social and physical contexts play an important role. Since 2015, the Danish municipalities have been required to offer citizens with impaired functioning rehabilitative initiatives that are 'organised and performed in a holistic and interdisciplinary manner'. The methods and theories for handling this in a holistic and interdisciplinary manner have been missing. Consequently, some of the low vision services have developed their own methods to gain a better understanding of the social and physical context of low vision rehabilitation and the citizens' quality of life. In addition, the current practice is adapted along the way.

Methods – Two low vision consultants and their implementation of a recovery-based lighting assessment have been explored by participative observations in home visits and in the light lab, followed by a semi structured interview with the consultants. Drawing on the field of science, technology, and society studies the paper discusses different kinds of knowledge and their role in rehabilitation practices.

Results – By focusing on issues of domestic lighting in relation to everyday activities, the scientific diagnostics were translated to highly contextualised conditions. Different types of knowledge were addressed in the consultations, including tacit knowledge, embodied in the participants and embedded in guidelines, technologies and surroundings. The narratives of the citizen, accompanied with photos and lux measures were used to recreate the settings when moving to the light lab. Based on the specific activity, the consultant demonstrated different lamps and arrangements and was guided by the immediate feedback from the participant when different lamps were compared. The approach by large resemble the person-environment-occupation model, enabling different types of knowledge and the aspect of development over time.

Conclusion – By framing the visual impairment in terms of light and occupation, the consultants enabled a space for discussing challenges and testing possibilities regarding the citizens' physical and social context, and to co-create the most relevant knowledge.

Keywords: *Low vision rehabilitation | interdisciplinary research | housing | STS, co-creation of knowledge*

Background

Since 2015, Danish municipalities have been required to offer citizens with impaired functioning rehabilitative initiatives that are 'organized and performed in a holistic and interdisciplinary manner' [1]. In theory, rehabilitation and recovery-based services embrace the everyday self-reliance of the citizen, where both the social and physical context play an important role. However, low vision services are still largely based on diagnostics: a physical examination of the function of the eyes, which is measured at a distance of three metres in the clinical setting of an optometrist or ophthalmologist and is translated into a level of required lighting or recommended lux value. This narrow and technical approach represents a medical model of understanding, where the impairment is the focus of attention.

New approaches to low vision services are emerging locally, and this paper describes an initiative that argues that a) the need for light is different for different tasks, b) that people have different preferences for light, and different desires and interests, and c) that the role of relatives is critical concerning the success of the implementation of the

recommendations. The services move closer to the everyday lives of the citizens and call for different approaches than the medical model.

The article is based on the initial fieldwork of an ongoing postdoc project on low vision rehabilitation following the vision department at the Centre for Special Education (CSU) in Slagelse and their development-project *Better light for better living* (BLBL).

Theoretical framework and methodology

The work of CSU has been explored through participative observation in eight home visits and seven consultations in the lighting lab, each for one to three hours. The focus has been the situated practice, the consultants' use of methods, and the different types of knowledge at play. In essence, to assess the interaction between consultant, citizen, relatives, and the home environment. The observations have been documented using audio recordings, photos, and field notes. An additional two-hour semi-structured qualitative interview with the visual consultants was conducted to reveal subjective understandings embedded in their practices, technologies, or spatial structures in which they work [2].

BLBL forms an instrumental case for understanding the nature of the development of recovery-based services, explored by the theoretical framework of science, technology and society studies. Knowledge and technologies are understood in their social contexts as shaping and as being shaped by social aspects [3]. This shaping or construction is practised by both human and non-human actors who translate, mediate, and negotiate different objectives and understanding [4]. The different actors are qualified and informed by different knowledge domains, or hinterlands, which work as standardised packages of collective understanding: 'The *hinterland* produces specific more or less routinised realities and statements of those realities' [5]. In the collective understanding, knowledge, technologies, and practices can constitute 'black boxes' where complex conditions are simplified into input and output. The most effective black boxes use *immutable mobile*s, inscriptions keeping their meaning when applied in different contexts: that are 'presentable, readable and combinable with one another' [6]. This applies to mathematical formulas, diagnoses, diagrams, and units.

Better light for better living

BLBL is a three-year method development for a recovery-based lighting assessment for low vision services run by two consultants at CSU. The service focuses on the role of lighting and the citizen's quality of life in everyday activities. During the winter seasons of 2017/18 and 2018/19, 60 citizens participated. Besides an initial visual function questionnaire, the study design includes three steps. 1) In the home environment of the citizen, guided by a narrative interview, the citizen described their challenges and desires, regarding light and vision. Together, the consultant and citizen identified and assessed three activities where they experienced challenges in their home and conducted two visual tests. The consultation was further documented by photos, light measurements, and drawings. Finally, the visual impairments were communicated to the relative by virtual and augmented reality. 2) The citizen and relatives were invited to the lighting lab. The lab included a kitchen-dining area and a living room with a range of different lamps and arrangements available to test the lighting. The consultants and visitors recreated three activities and tested different bulbs, lamps, and arrangements step by step. 3) A home visit was made two to three months after the lighting session to follow up on the process.

The complexity of the everyday

A multitude of different activities were identified through the narrative interviews: to see (your family or oneself in the mirror), to *socialise* (find the way, recognise people, travel, and play sports or games), read (recipes, books, newspapers, letters, instructions, email, subtitles, banknotes, TV programmes, and bus numbers), write (letters, messages, and diaries), do *handicrafts* (draw, sew, knit, and crochet), *locate things* (at home and in public), *prepare and eat food* (measure ingredients, avoid crumbs and food spills or burning food, and avoid toppling a water glass), *do housework* (handle laundry and dishes) and *handle self-care* (personal hygiene and getting dressed). For many elderly individuals, the variety of activities during a day influenced the quality of life because many were housebound. For the represented young individuals, it was also a question of obtaining an education, keeping a job, or forming their future lives. The needs and desires were individual, and the same diagnosis was experienced at different intensities and stages combined with other conditions, and most importantly, they were always in flux and changing. The home environment held different variables: size, organisation, and orientation of space; thresholds; window sizes and locations; interior arrangements; surfaces and finishes (colours and patterns); design, distribution, and position of lamps; and a range of different bulbs and light sources. Finally, to add to the complexity, the citizen's ability to handle the situation and cope with the challenges, involves not just bodily functions but also psychological and social processes.

Mapping different kinds of knowledge

The mapping of the 15 consultations showed a range of different types of knowledge addressed and used in the consultations.

Embodied knowledge

Relating the discussion and assessment of vision to everyday activities, the light, and the home environment, the home visits focused on the contextualised body. In the narrative interview, the impairment was described as a dynamic condition changing between painful days (headache, eye pain, and fatigue) and periods or even seasons when individuals were less affected, influencing their ability to endure or maintain an activity over time. Conditions between seeing and not seeing seemed to be a particularly individual kind of tacit knowledge that is difficult to describe or communicate and that individuals often kept to themselves because it was inconvenient or considered 'their own business'. Due to the light, some preferred stronger light, whereas others favoured twilight and had blurry vision from bright environments, and transitions between light and dark were a challenge. They were increasingly dependent on their interaction with their environments. The more they lost sight, the more they used other senses, but the interaction was also crucial for the residual visual function.

Embedded knowledge

The home visits and laboratory consultations also revealed a range of embedded knowledge or knowledge locked in processes, products, culture, routines, artefacts, or structures [7].

Everyday routines were largely mediated by light, and the participants described the change of seasons, daylight, sunlight, and artificial lighting, and the spatial organisations, thresholds, interior arrangements, textures, surfaces, patterns and colours as enabling or disabling their everyday activities. This knowledge was embedded in their interaction with their environment, and many of the participants were not aware of this embeddedness before the consultation. For the residual vision, the relation between lighting and the home environment was critical. Dark surfaces absorbed the light, a patterned tablecloth or floor covering obscured and disturbed their vision. A given bulb was interrelated with the lamp and its shade and the illuminated environment. A closed metal lampshade centred the light, while a frosted glass pendant illuminated the surroundings. The light source and how it was positioned could be crucial for a visually impaired person to see and work at the kitchen benchtop. In addition, the impaired person's position (e.g. in front of a TV or computer) and the position of a lamp on or over a table were also important. People experienced large differences in the illuminated environment inside and outside, which changed due to season and during the course of a day. Many experienced fewer problems in the summer, but the sun could also be an issue.

Medical knowledge was embedded in the tests and surveys, and physics was employed in the device for measuring light. The narrative touched on values, such as *identity* (baking, reading, participating, and contributing), *moods and emotions from 'not being able'* (feeling bored, annoyed, abandoned, passive, depressed, or less worthy), or *aesthetics* (the design or sentimental value of lamps or arrangements). In the interview, the consultants described cultural values in terms of 'cosiness' or different socio-economical categories affecting the character of the home arrangement. In a Muslim family, the closed curtains allowed the mother to take off her hijab at home. Values concerning impairment ranged from passively accepting the condition as part of ageing to fighting for equality and actively trying to improve everyday living, or a young single mother fighting to be a better mom. This revealed knowledge about the citizen's ability to cope and adapt and to include the social context, asking for help from close relatives or even volunteers.

The low vision consultants had *medical knowledge* of vision and of different types of impairments. They had *practice knowledge* of working with people with low vision, and with other consultants, ophthalmologists, and opticians. Moreover, they had *technical and functional knowledge* about light, light sources, and lamps, which was acquired as part of the BLBL project. They also held *practice knowledge* from working with light, by assessing and finding lighting solutions for people with visual impairments, including knowledge of human- environment interactions and the needs and desires for the home environment.

Explicit knowledge

The explicit or verbally expressed knowledge in the consultation included information about light. Using the spectrometer, the light levels were translated into a digit or a graph of colours that was explained to the participants informing them about light in different ways. This was also seen in the lighting lab in sharing knowledge about the lighting-technology.

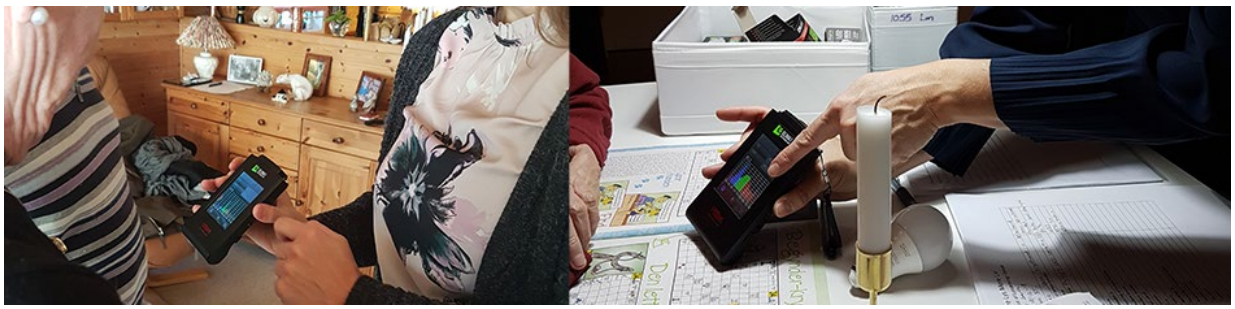

Figure 1. Using the spectrometer to communicate qualities and quantities of different light.

The diagnosis and data concerning the vision, from the optometrist or from CSU's database were also used in the consultations. In some consultations where the conditions were discussed, the consultant provided general knowledge of the disease or the expected development of it. In some cases, general knowledge also involved information about the opportunities for funding or support in the public health system.

Translation and coordination

The consultants performed a range of translations to decontextualise the conditions of the home environment and re-contextualise them in the lighting lab. Translations were contained in the transcriptions of the notes from the narrative interviews, test results, measurements, photos, and drawings. The embedded knowledge of the spectrometer and how it measured the specific lux value is in itself black boxed. However, when used as support for the embodied knowledge of the impaired, the everyday knowledge of the household, and the practice knowledge of the consultant, the explicit and scientific knowledge was contextualised and operationalised. Focusing on activities and how these were enabled or disabled by the interaction of the luminous environment and the vision the procedure of translation included the narrative and descriptions of the embodied experience, the observed occupational performance, and the measured light.

Figure 2. Testing different lighting in the lighting lab.

The sequence of the light lab was an equally important part of the translation process. The information from the narrative interview enabled the consultant to support and guide the citizens and to adjust the different solutions to fit the specific case. The focus on the possibilities allowed the citizens to feel less defensive and more able to engage in the process than if they had been focusing on the limitations. The citizens and relatives were 'taken by the hand' through their own home environment, which was re-contextualised in the lab concerning their own particular activities and challenges, using their body as a point of departure and as an instrument.

In summarising the lab visit, the consultant translated the results by drawing the suggested lamp, and its style and position on a printed photo of the home environment and added a list of specifications to each of the investigated activities. In this way, the assessment went through two rounds of translations: from the home environment to the lab and from the lab back to the home environment.

The citizens were able to compare and experience the difference immediately. They learnt about light and different arrangements. They were qualified and empowered to improve their surroundings, and with assistance from their relatives, they re-contextualised their new knowledge.

Mutable and immutable mobiles

The narrative interview, surveys, measurements, and final list of recommendations represents immutable mobiles that translate and translocate different conditions of the home environment to the laboratory and back again. They form

inscriptions that can be presented, read, and combined without the additional knowledge of the specific context of time or place and are typically used for generalising and producing a scientific outcome across a number of samples.

In contrast, the practice of the low vision consultants demonstrated an open approach with adjustments from case to case and from citizen to citizen that resemble the mutable mobile that is enacted differently at different times and at different geographical locations [8]. The next section will further explore the role of the consultants.

The person-environment-occupation model

During the fieldwork and the later discussions with the consultants, it was clear that their role in interacting with the citizens was central to the outcome of the service. The two consultants had backgrounds as occupational therapists, and the analysis of their hinterland was based on a model used in occupational therapy: the person-environment-occupation (PEO) model. The PEO model has been developed as a practical analytical tool to assist in problem analysis, intervention planning, and evaluation or to communicate occupational therapists' practices [9]. Here, I use the PEO model as a framework for discussing the consultants' approaches in the BLBL compared to a purely medical model approach.

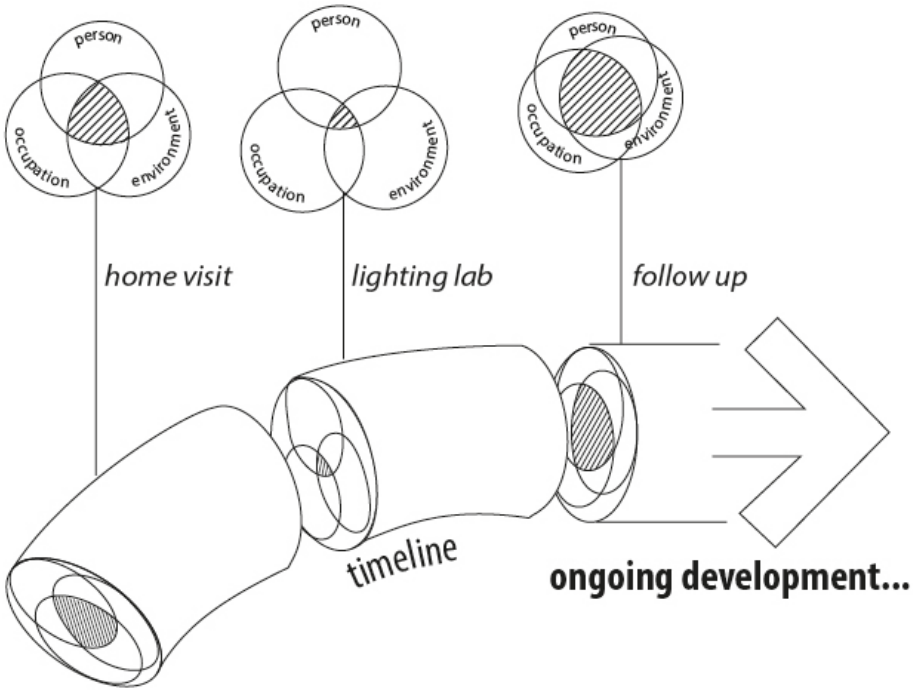

Figure 3. The PEO model, as a refinement of the diagram by Strong et al. [9].

Time and change

In PEO, people, occupations, and environments are understood to be in a dynamic and interdependent relationship. In contrast to the medical model, where the aim is objectivity and truth, the PEO model embraces the 'complexities of daily human experience', including the aspect of development or change over time, such as changes in self-concepts, disability status, environmental constraints, politics, and economics. Opposite the decontextualised and generic diagnosis, the everyday is all about context and specificity. As shown in Figure 3, the series of consultations in BLBL were scheduled over a period when the course of processing the assessments and suggestions was considered an important part of the intervention for the citizen concerning the learning-process and acquiring new knowledge about themselves and their situation.

The elasticity of the PEO model enables interventions that assess the congruence between the parameters in different contexts over time, where the notion of the mutable mobile seems useful. The context- and time-specific scope of BLBL in which the outcome of the service depends on the active participant also calls for a more collaborative approach. After all, citizens are the experts regarding their own lives, bodies, and everyday settings.

Co-creation of knowledge

An essential aspect of the PEO model is that it enables different types of knowledge in the BLBL, above all demonstrated in the open dialogue with the citizens. During the course of the sessions, the consultant supported the citizens concerning their future decisions. The consultant explained and demonstrated technical knowledge of the impairment, light, and illuminated environment and shared practice-based knowledge and experiences from former cases. In this way, they also engaged knowledge from the medical model. However, the consultants stressed an

awareness of their own knowledge and when to use it: 'Due to the medical knowledge, you can say we have it, but we do not apply it too early'. They also described an openness and curiosity about each encounter:

> *We have an idea of the diagnosis and the vision, but we are curious about what it means in relation to light. Two people with AMD [age-related macular degeneration] do not necessarily have the same needs, so we are interested, and very well aware of not getting disturbed of our own pre-existing knowledge.*

This awareness of their a priori knowledge was observed both in the narrative interview and when testing the light in the lab.

The purpose of the narrative interview was to obtain the citizens' own descriptions of their everyday challenges related to light and vision and to identify two to three activities that are central for the further course. Therefore, it was stressed that the choice of activities was the citizen's and not that of the consultants or relatives. In the laboratory, different kinds of knowledge were combined: the citizens embodied knowledge as they tested the light, supplemented by explicit information concerning different technologies and the relational aspect of light and activity. The attentiveness of the citizens was emphasised regarding what they felt or what worked better or worse. As the consultants stressed, these were aspects that they could not predict. Contrary to the medical model approach in which the impaired client is a passive receiver of the authoritarian professional's knowledge and expertise, the co-creation of knowledge depends on an active client. The shifts between different types of knowledge were a way to make explicit knowledge relevant and let the citizens and relatives take part in creating knowledge.

Contextualising low vision rehabilitation

Latour described the theoretical sciences as faster and more immutable than empirical sciences [5]. Following this, the models work as immutable mobiles in the practices of low vision. Whether this is a medical model or a relational and dynamic model, such as the PEO, seems to be crucial because the models enable different aspects. This section will discuss the nature of the different models and how BLBL navigates between them.

Low vision is a concern for public health, and the medical model has been a way to conceptualise and classify diseases, such as in the International Classification of Diseases (ICD) [10], which initially was the standard for keeping track of the major causes of death. The model is deeply embedded in contemporary health systems and structures from diagnostics and paradigms for treatment and support to subsidies and insurances [11]. During the twentieth century, different alternative models have been developed, including a social model shifting the problem of a disease or impairment from the individual to the structures of society that are unable to handle the condition. The bio-psycho-social model has been described as a relational and complex understanding in which a condition is the result of dynamic interactions of body functions and contextual factors. This model is represented in most rehabilitative initiatives and in the International Classification of Function (ICF) [12]. The main use of the ICF has been to handle information and communication among health professionals and has been widely used in professional and political decision-making processes. The preceding procedures for investigation used by the two consultants were based on the ICF; however, the ICF is not in the language of a layperson and does not concern aspects of the citizens' everyday lives: 'Filling out all the different parameters was time-consuming and not very useful, other than to ensure that you got "it all" '. Developments in low vision rehabilitation have largely addressed the multidisciplinary and holistic aspects but only within the health professions concerning devices, training, and education [13-14]. Even though the ICF includes the social and physical environments, it is reduced to an 'enabling' or 'disabling' factor and does not operationally explore the everyday. In addition, the ICF is closely linked to the ICD and the medical model. The classification starts and ends with the impairment, no matter whether the responsibility is put on the individual or society.

By addressing light and activity, the BLBL opens up discussions concerning all of us, not just the visually impaired, and does so in a way that makes sense outside of 'the medical domain'. The two consultants described the medical model as the overall framework for their work because the diagnosis and health structure both determine who receives the service. The bio-psycho-social model is present in the rehabilitative or recovery-based approaches as the overall paradigm for treatment or services, and they use both the medical and bio-psycho-social models in their cooperation and coordination with other health professionals. The BLBL, represents a part of the low vision services in which the encounter with the citizen is operationalised by a more relational and dynamic approach, as described in the PEO model. The model 'embodies the principles of client-centred practice and supports the collaborative working' [9] and is open to other professions working with person-environment relations. The occupational therapists have a special relationship with the occupation, and shared responsibility can be implied by focusing on all three spheres.

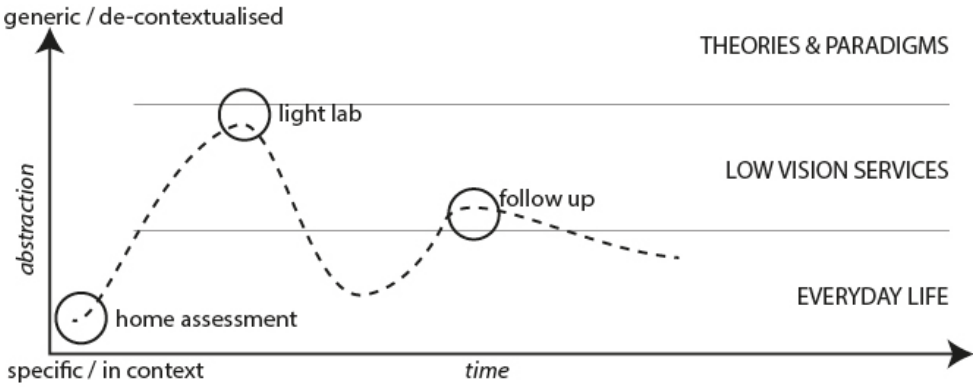

Figure 4. The three consultations navigating between everyday life, practices, and theories.

Figure 4 illustrates this process in which the consultants 'embody and carry a bundle of hinterlands' [3] and are able to navigate and apply the different kinds of knowledge across epistemologies and ontologies.

Conclusion

To open the black box of low vision services and apply 'their own model' to systematically analyse what the consultants see and do [9] has enabled the awareness of the otherwise tacit practice knowledge. Low vision services rely on medical understanding, where the diagnosis or impairment is the point of departure. However, different types of knowledge are coordinated, targeted, and, most importantly, co-created by the citizens and the consultant. By framing the challenges of visual impairment in terms of light and occupation, the consultants enable a space for discussing the challenges and possibilities regarding the citizens' physical – and social context.

The flexibility and elasticity of the PEO model constitute a mutable mobile, an essential characteristic for embracing the complexity of working across theories, practices, and everyday settings.

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References

[1] Børne- og socialministeriet (2017) *Bekendtgørelse af lov om social service.* [Executive Order on Social Services Act]. LBK nr. 988 af 17/08/2017, Retsinformation.
[2] Tamboukou, M. (2015) Narrative phenomena: Entanglements and intra-actions in narrative research. In M. Livholts; M. Tamboukou, *Discourse and narrative methods* (pp. 37-47). London: Sage Publications.
[3] Law, J. (2002) *Aircraft stories.* Duke University Press.
[4] Latour, B.; Woolgar, S. (1979) *Laboratory life: The social construction of scientific facts.* London: Sage.
[5] Law, J. (2004) *After method: Mess in social science research.* Routledge.
[6] Latour, B. (1986) Visualisation and cognition: Drawing things together. *Knowledge and society studies in the sociology of culture past and present*, 6(1), 1-40
[7] Gamble, P.R.; Blackwell, J. (2001) *Knowledge management: A state of the art guide*. Kogan Page Publishers.
[8] De Laet, M.; Mol, A. (2000) The Zimbabwe bush pump: Mechanics of a fluid technology. *Social Studies of Science*, 30(2), 225-263
[9] Strong, S.; Rigby, P.; Stewart, D.; Law, M.; Letts, L.; Cooper, B. (1999) Application of the person-environment-occupation model: A practical tool. *Canadian Journal of Occupational Therapy,* 66(3), 122-133.
[10] World Health Organization (1992) *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.
[11] Bowker, G.C.; Star, S.L. (2000) *Sorting things out: Classification and its consequences.* MIT press.
[12] World Health Organization (2001) *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.
[13] Ryan, B. (2014) Models of low vision care: Past, present and future. *Clinical and Experimental Optometry*, 97(3), 209-213
[14] Markowitz, S.N. (2016) State-of-the-art: Low vision rehabilitation. *Canadian Journal of Ophthalmology*, 51(2), 59-66