

Qualitative Study for the Design of Assistive Technologies for Improving Quality of Life of Visually Impaired

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Abstract. This paper describes an effort to create a conceptual design of an assistive technology that aims to improve quality of life of people with low vision. We carried out a qualitative study including in-depth interviews with people of low vision.

The analysis revealed several key concepts to understand people's lived experiences of low vision including the ambiguity of their self-images and burdens in the interaction with the sighted people. The importance of building 'self-confidence of managing people's appropriate appearances' of low vision was emphasized. We created a conceptual design of a total assistive solution that supported people of low vision to perform each stage of a comprehensive cycle of the arrangement of their appearances. Our challenge continues to enhance a methodology for bridging a gap between qualitative research and the design of user experience.

Keywords: qualitative study, life story, low vision, assistive technology, quality of life.

1 Introduction

This paper describes an initial effort to create a conceptual design of an assistive technology that aims to improve quality of life of people with low vision. We adopted a qualitative study approach to clarify their *felt need*¹ [3] for the assistive technologies through a careful investigation of the *lived experience* [31] of people with low vision.

1.1 Living with Vision Loss

The visual impairment is divided into blindness and low vision. The WHO global report (2012) stated more than 285 million people are visually impaired worldwide, of

¹ Jonathan Bradshaw (1972) distinguished between different types of need: normative need is defined by experts, professionals such as doctors, policy makers; felt need is want, desire or subjective views of need which may or may not become expressed need; expressed need is demand or felt need turned into action [3].

whom 39 million are blind and 246 million have low vision [41]. The majority of visually impaired have low vision, however, low vision is very poorly recognized by the community and its reality is rarely understood. Globally the principal causes of low vision include cataracts, age-related macular degeneration (AMD), and diabetic retinopathy [41]. It may also result from a brain injury, or cancer of the eye.

Low vision is emphasized on an aspect of 'vision that people hold,' rather than that has been lost. It can be defined as 'vision that, even when corrected by optical refractive correction, is not adequate for a person's needs' [20] and is typically appeared as a reduction in visual acuity and/or visual field. The visual performance of person with low vision is not same. There are various types of eye conditions that cause low vision including: central loss of vision, peripheral loss of vision, hazy vision, refractive errors, contraction of visual field, glare sensitivity, adjustment of eye movement, and color blindness. Loss of vision, even partial vision loss, leads significant consequences in various aspects of human life: mobility; communication and accessing to information; personal care such as toileting and dressing; daily living such as eating, cooking, time-keeping, cleaning and shopping; social activities; education; employment; recreational activities; and safety and freedom in everyday life.

On the basis of the WHO International Classification of Impairments, Disabilities, and Handicaps (ICIDH) [38], figure 1 illustrates different levels of vision loss [6]. This scheme describes the consequences of visual diseases and disorders at the level of the organ (e.g. impairment), the person (i.e. disability, reflecting the consequences of impairment), and the person as a social being (i.e. handicap, reflecting interaction with the surroundings). It should be noted that how the organ (e.g. eye) functions does not automatically determine how the person will function in their society.

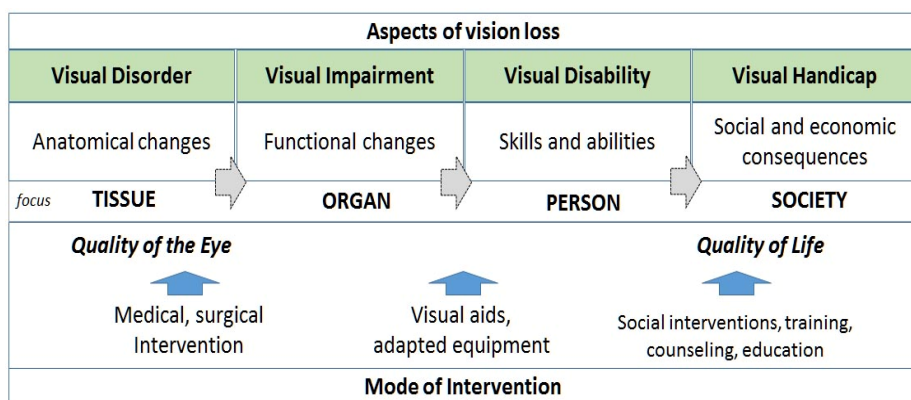


Fig. 1. Aspects of Vision Loss. (adapted from Corn, A.L. & Lusk, K.E., 2010, p.23)

1.2 Quality of Life and WHO ICF

Quality of life (QoL), as a concept, is frequently referred to in literature of various domains [32, 36] such as healthcare, rehabilitation, mental health, and nursing.

However, a definite definition of quality of life has not been obtained yet. For example, Hughes (1995) conducted a comprehensive review of 87 applied research literature, and found more than 40 different definitions of QoL [19].

The World Health Organization (WHO) has defined quality of life as ‘an individual’s perception of their position in life in the context of culture and value system in which they live and in relation to their goals, expectations, standards, and concerns’ [39]. Quality of life has been defined as having both subjective and objective components. The objective component includes aspects of living conditions and social functioning such as employment, leisure, accommodation, and finance. The subjective component is frequently referred to as “well-being” or “life satisfaction.”

Health has been defined in the WHO Constitution (1948) as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’. The functioning of an individual in a specific domain reflects an interaction between the health condition and the contextual: environmental and personal factors (Fig. 2). The WHO’s International Classification of Functioning, Disability, and Health (ICF) is a framework that provides the concepts, definitions, categories and codes for functioning and disability as well as related Environmental and Personal Factors influencing them [40]. Body Functions are the physiological aspects of body systems, while Structures are the anatomical support. Actions executed by individuals are defined as Activities, and involvement in life situations is defined as Participation. Activities may relate to the interplay of multiple functions and structures. For example, essentials of jogging include the combination of orientation, balance, control of voluntary movement, muscle force, mobility of joints, structural support of bones and ligaments as well as Environmental Factors such as well-built pavements [40].

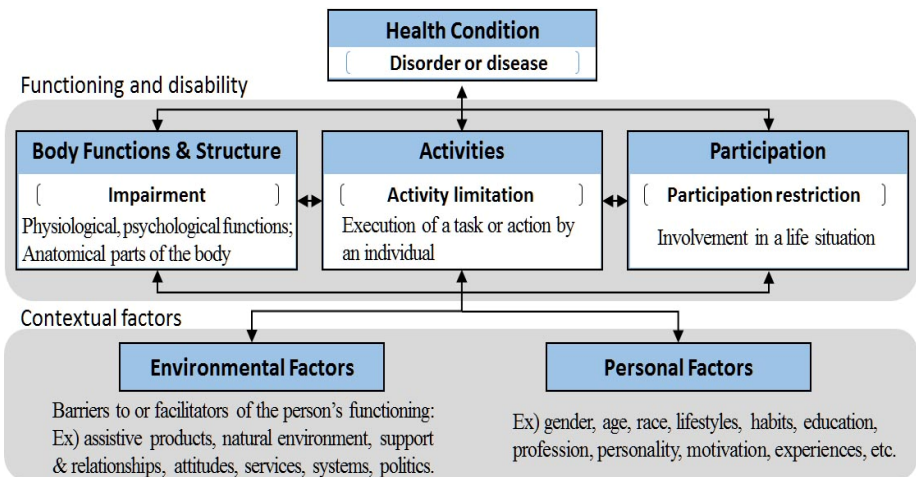


Fig. 2. WHO International Classification of Functioning, Disability and Health (ICF) [40]

1.3 Related Works: Assistive Technologies for Visually Impaired

Assistive device is located as a key component of the Environmental Factors of WHO's ICF. Assistive technology has a potentially important role to play in opening up new opportunities to disabled people and increasing the range of options open to them [17]. Various types of assistive devices and tools including conventional low-vision aids are available for people with visual impairments [1]; for example, spectacle magnifiers, stand magnifiers, large print books, audible kitchen aids, tactile scales, vibrating watches, and electronic vision enhancement systems (EVES). Recently, the wide range of advanced assistive technologies have been developed for visually impaired. Efforts include the use of various digital props, for example, an augmented cane using spatial sensors [34], intelligent way-finders for traveling [14, 26], assisting devices for shopping [24, 25], a head-mounted EVES [4], a remote infrared audible signage [16], robot-assisted navigators for traveling [27] and shopping [13].

Assistive technologies are expected to improve daily functioning of individuals with disabilities, particularly their performance of activities and pursuit of vocational, social, and community interests [29]. Historically, however, the development of assistive devices has tended to be characterized by a technology-centric approach [23]. The design of assistive technology generally did not take account of the types of their visual performances of the particular user class of low vision, instead, most assistive technology was mainly designed for its average population [18].

1.4 Our Approach

One of the most essential outcomes of assistive technology is increased quality of life of visual impairments. In the design of assistive technologies, it's essential to understand the specific needs of people with low vision in more detail, and their attitudes to visual impairment, and obtain an insight into 'hidden agendas' [33] that may not be immediately apparent.

In this paper, we examine *life-world*²[30, 31] of people with low vision and investigate their felt-need as well as 'hidden agendas' for assistive technologies in everyday lives. We consider an integrated approach [22] that combines qualitative study and the design of assistive technologies for low vision. There exists a gulf between the outcome of field research and basis for the design of user experiences [9]. Our challenges involve methodological enhancements to bridge this gap in the research and design.

2 Qualitative Study

In order to carefully understand life-world of people with visually impaired and investigate various aspects of their potential requirements of assistive technologies, we

² "Only in the world of everyday life can a common, communicative, surrounding world be constituted. The world of everyday life is consequently man's fundamental and paramount reality." (Alfred Schutz and Thomas Luckmann, 1973).

adopted multiple qualitative research methods [8] that included structured interviews, semi-structured interviews [15], participant observation [35], and questionnaires. The triangulation of methods and data [7, 11] was taken into account.

The study started in Tokyo metropolitan area in 2010, with cooperation of a school for the blind and an association for supporting people with visually impaired. The participants were identified through the snowball sampling, a technique for gathering participants through the identification of initial subjects who can provide an escalating set of potential contacts by taking advantages of their social networks. This method is often used because the population under investigation is 'hidden' either due to low numbers of potential participants or the sensitivity of the topic [10].

We designed two different styles of the study that employed a different set of qualitative study methods. In the study 1, we employed a structured interview and e-mail interview. In the study 2, we adopted an in-depth interview. Two studies were carried out in parallel.

2.1 Study 1: Structured Interviews and Questionnaires

Method and Research Settings. We conducted a structured interview that contained three thematic categories: the conditions of the visual disorder, the conditions of everyday lives, and their felt-need. The topics of the interview were composed of eleven questions including: (a) their profiles and family structures, (b) current conditions of visual disorders and those secular changes, (c) the desires and challenges never to abandon, (d) troublesome circumstances with their everyday lives and the concerns with their social lives especially when interacting with other people, and (e) the concerns or troublesome circumstances related to the appearances of the selves including dressing. The interview session was divided into three sub-sections. First, we emphasized the establishment of a rapport with the participants, the informed consent process, and building a relationship of mutual trust. A structured interview was performed in the second section, by using a set of predefined research questions described above. In the last section, it was followed by an open-ended discussion. The interview session was carried out in December, 2013 in a small meeting room of public facility and lasted for approximately two hours.

Depending on the condition of participants' visual disorders, they were allowed to choose an e-mail interview [12] instead of a face-to-face interview. The questionnaires were composed of the same eleven questions used in the structured interview and were distributed to the candidates of respondents via e-mail. The participants were asked to describe their responses in free format. This study was carried out between October and November, 2013.

Participants. Sixteen participants out of twenty candidates of visually impaired who were identified through snowball sampling participated to the study. Seven respondents (female, aged between 34 and 62, average 46.3) joined a structured interview, and other nine respondents (six females and three males, aged between 18 and 39, average 27) joined an e-mail interview.

2.2 Analysis Results of the Study 1

All interviews were transcribed into texts. The responses in a free format obtained from e-mail interviews were arranged and incorporated into data. The analysis process included: (1) formatting and segmenting textual data; (2) open-coding (with ad hoc codes); (3) writing analytic memos for text segment; (4) performing content analysis by using contextual data such as individual visual performance; (5) re-coding with focus; (6) developing the concepts and core categories.

Observed Felt Needs Reflected the Visual Conditions and Living Environment.

For example, some of participants with visual field contraction and participants of the blindness presented their needs of safely walking outside, timely noticing of an important sign from background, and efficiently handling of household affairs such as cooking and cleaning. The participants of low vision commonly presented examples of the difficulties in their everyday lives included finding out a person in a crowded place, reading a menu and texts in small or colored characters especially on a liquid-crystal display, writing texts with small characters, and playing with a ball game. On the other hand, working participants of low vision described needs of efficiently handling of administrative works such as documentation, making appropriate responses while meeting with others, and safe driving.

Difficulties in a Social Situation. The participants generally insisted that they were happy to enjoy the interactions with the sighted people in various situations as a friend, a colleague, or family. However, they simultaneously stated their difficulties in making smooth reactions and conversations with the sighted people particularly in a meeting or a party with large number of people.

The Appropriateness of the Appearances that Most People of Low Vision Care.

In a general inquiry about their felt-needs for their daily living, only a few participants mentioned they expected a support for their dressing. On the other hand, for a specific inquiry about their appearances, thirteen of sixteen participants responded that they were paying much attentions to the appropriateness of the appearances and make-up.

2.3 Study 2: In-Depth Interviews

Method and Research Settings. Multiple qualitative research methods were employed in the study: semi-structured interviews, life story interviews [2, 28], participant observations, questionnaires, and open-ended discussions. The study was composed of the series of interview sessions that covered the variety of topics for understanding life-world of visually impaired. During the initial session, we emphasized the establishment of a rapport with the participant, and building a relationship of mutual trust. After the informed consent process, we started the series of interviews from descriptive topics such as (a) family structure, (b) a biographical sketch, and (c) current conditions and secular changes of visual disorders. While the interviews were iterated, the topics were gradually deepened into private topics related to *life story*

such as their turning points or memorable experiences (both positive and negative), primary matters of interest including their wishes, and personal experiences of troublesome circumstances in everyday lives. Once the participants began their talk, we carefully avoided interrupting their narratives, particularly during life story interviews. The interview sessions of fourteen times were carried out between October, 2012 and November, 2013 and lasted approximately thirty five hours in total.

Participants. We met with three informants with low vision, “A,” “B,” and “C” (female, aged between 19 and 32 when interviewed) who participated the study 1. They were a graduate or students of a school for the blind in Tokyo metropolitan area.

Table 1. Profiles of the participants (In-Depth Interview)

| # | Characteristics | Description |
|----------|---|--|
| A | (a) age, gender, occupation | early 20s, female, student (school for the blind) |
| | (b) visual acuity (left / right) | 0.06 / 0.08 |
| | (c) visual disorder | achromatopsia (congenital) |
| | (d) visual sensitivity and perception | total color blindness; weak in dazzling light |
| | (e) family (living with) / (living apart) | none / father, mother, younger brother |
| B | (a) age, gender, occupation | late teens, female, university student |
| | (b) visual acuity (left / right) | 0.09 (corrected: left) |
| | (c) visual disorder | developmental glaucoma (exposed 16 years old) |
| | (d) visual sensitivity and perception | unable to see things in dim light; field of vision at 3% |
| | (e) family (living with) / (living apart) | father, elder sister / elder sister |
| C | (a) age, gender, occupation | early 30s, female, acupressure therapist |
| | (b) visual acuity (left / right) | 0.2 / 0.04 (corrected) |
| | (c) visual disorder | cataract (congenital) |
| | (d) visual sensitivity and perception | having difficulty in seeing things in dim light |
| | (e) family (living with) / (living apart) | husband / father, mother, younger sister |

2.4 Analysis Results of the Study 2

All interviews were transcribed into readable narrative texts. The transcripts were indexed with sequential number by the session number, time-code, and a speaker and were subdivided into key experiential units according to a topic mentioned there (segmentation). By combining a basic scheme of the Grounded Theory Approach [5, 37] and analysis procedure of the VPA Method [21], the narrative interviews were interpreted according to the spiral sequence of analysis stages: (1) open-coding with ad hoc codes (by developing categories of information) and writing analytic memos for text segment; (2) retrieving and comparing text segments to which the same codes were attached; (3) inter-connecting the categories; (4) selective coding with focus; (5) developing concepts and the core categories.

Difficulty in Understanding Individual Visual Performance of Low Vision.

People of low vision assumed their families to well understand their visual conditions. On the other hand, most of their family members also believed that they well-understood it. However, it is very hard for the sighted people to understand the detailed conditions of individual visual performance of low vision even if they are family who live together or friends who meet to talk mostly daily.

Ambiguous Identity Swaying between the Sighted and the Blindness. The participants A, B, and C from the in-depth interviews felt that the self-images of people of low vision seemed ambiguous. They revealed people of low vision were much sensitive to being *ordinary* in their actions. They were always carefully paying their attentions on maintaining their actions *natural*, so that the sighted people around them seldom could notice their visual impairments. For example, even close friends often forgot their impairments. People of low vision had an option: to unburden their visual performances, or to behave *naturally* as the sighted people did. The self-images of people of low vision seemed swaying between the sighted and the blindness.

Corrections by the Sighted People Often Caused Them to Fear Making Mistakes.

All the participants reported they had uncountable embarrassing experiences with the sighted people in their daily lives. A and B mentioned similar failures in adjusting the appearances: wearing the front and back of the sweater adversely; seriously mismatching in coordinating color of a cardigan and a skirt; walking with attaching a hanger to the belt of a coat. People of low vision usually suddenly noticed their failures when the sighted people pointed out the failure. They were sometimes depressed all day long once they noticed their failures of wearing inadequate clothes, as they were unable to correct it until went home. They sometimes felt an unexpected indignity caused with a correction by the sighted people, and seemed to feel a kind of mental burdens to participate to a social situation surrounded with the sighted people.

What Does "Royal" Mean? – aha! a Name of Color?! The participants A, B, and C preferred enjoying shopping, basically by themselves. They seldom went shopping either with their friends and family. When shopping, they lacked visual information that they couldn't obtain with their eyes but played an important role for making a decision to buy. For example, they first needed to know a floor plan of a shop and about in which shelf the target clothes would be found. When they reached in front of the shelf, they also needed to know type of clothes, its size, material and color, and about whether it well fitted to them. Unfortunately, a description on a tag of a product usually provided simple, abstract, and too limited information for a customer of visually impaired to decide to buy it. They sometimes asked a staff to escort them while shopping, in most case, it was difficult to communicate smoothly and establish a comfortable relationship with a shop staff who didn't know about individual detailed visual performance of a customer of low vision. The participants seldom used assistive devices for shopping because of its limited capability.

Reluctance in Using Assistive Technologies. Recently, numerous numbers of assistive technologies can be found. Even these tools indicated potential benefits, people of visual impaired often felt a kind of reluctance in using those technologies because those tools sometimes became a two-edged sword. For example, white cane, a spectacle magnifier with thick lens, and EVES are noticeable symbols for people of low vision and the blind. They were afraid that the utilization of an assistive tool demonstrated their impairments and sometimes prompted teasing, or also prompted other people too much to care them.

3 Discussion: Implications for Designing Assistive Prototypes

3.1 Focus on Daily Arrangement of the People's Appearances of Low Vision

The analysis result revealed that 'self-confidence of managing appropriate appearances' was a key for visually impaired to participate to social activities including interaction with the sighted people.

On the basis of the results of our qualitative studies, most participants frequently reported their experiences of failure of dressing and insisted they felt tense during meeting, talking, and dating with other sighted people because they were afraid to give people undesirable and unexpected impressions with their appearances. Although the management of the appearances can be considered as a very small piece of everyday life, it constitutes a foundation of an involvement in a social situation. 'Participation' is one of fundamental elements of QoL. Building 'self-confidence of managing appropriate appearances' is essential to maintain QoL of people with low vision.

3.2 A Call: Comprehensive Support for the Arrangement of the Appearances

The arrangement of the appearances is related to many other facets of daily living: for example, shopping; categorizing and storing clothes into a closet or a chest drawer; coordinating and wearing clothes appropriately for an interaction with other persons; undressing, washing, pairing and organizing clothes, and then preparing clothes for a next occasion. These elements are interconnected with each other and the series of them constitute a comprehensive cycle of the arrangement of the appearances. In order to enjoy 'satisfactory appearances,' it's necessary to success in each step. However, people of low vision often have difficulties or concerns in performing each step of the activities such as organizing clothes.

It's important to provide a total solution that aims to support people of low vision to perform each stage of a comprehensive cycle of the arrangement of the appearances. We focus on the design of smooth connections between the sequential elements of a comprehensive cycle. It aims at achieving the objectives to a reasonable extent with the organized and integrated function of individual components as a whole, rather than individually providing ad-hoc assistance of each stage.

The initial field evaluation on a conceptual design of a total support system was conducted by using a storyboard-based prototype and the analysis is still underway.

At the present, four participants of low vision joined the session. We found that overall responses were positive at least on a basic concept of a system. We also obtained their comments for the enhancements, their emphasis points, and their several unique practices (*bricolage*) of everyday lives, which were devised to cope with the difficulties they have in executing these activities. The results will be incorporated into next improvements in a spiral process of a system development.

4 Concluding Remarks

This paper described an effort of the initial phase of designing an assistive technology that aimed to improve quality of life of people with low vision. In order to investigate the felt-need for the assistive technology for people with low vision as well as their hidden agendas, we conducted a qualitative study by employing multiple qualitative research methods.

The qualitative study revealed several key concepts to interpret people's lived experiences of low vision: for example, the ambiguity of their self-images; both pleasures and burdens in the interaction with the sighted people; a reluctance in using a symbolic assistive device; and an unexpected indignity caused with a correction by the sighted kind people. The analysis results suggested that: frequent failures of managing the appearances inhibited people of low vision from an involvement in a social situation such as an interaction with the sighted people; building 'self-confidence of managing appropriate appearance' facilitated their social activities.

On the basis of the results from qualitative study, we created a conceptual design of a total assistive solution that aims to support people of low vision to perform each stage of a comprehensive cycle of the arrangement of the appearances thorough smooth connections between the sequential elements of the cycle.

Our challenge continues to enhance a methodology for bridging a gap between the outcomes of qualitative research and the design of user experience by investigating an appropriate harmonization among them.

Acknowledgments. This work was supported in part by JSPS Grant-in-Aid for Scientific Research (#23300263). We thank all the participants of our qualitative sessions, and the vice principal of a school for the blind in Tokyo metropolitan area, who devotedly supported our field studies. We also thank Ayako Uchitomi and our laboratory members 2010-2013.

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