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# Looking Normal When I Don't See Normal: SEEing What Can Be Done about the Experience of Visual Impairment

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**Abstract.** This paper reports on a phenomenological study that informs experience-design led product development. The study focused on a deep understanding of the lived experience of six visual impaired people (VIP) living in a Danish city. The emerging insights showed that the experience of visual impairment could be understood from four categories: 1) adapting to a new life, 2) belonging to a group and culture, 3) undertaking social obligations, and 4) having one's abilities recognized. Maslow's hierarchy of needs informed the process of relating the categories to a set of emerging design principles, requirements, and implications for social responsibility. This contribution clarifies the type of product solutions that may be needed at the starting stage and the post-starting stage of living with vision impairment (VI).

## 1 Introduction

There are about 285 million people around the world who are suffering VI. Data over the last 20 years shows that there has been significant progress in preventing and curing VI in many countries (WHO Media Centre, 2013). Especially in the Nordic countries, VIP have a much better lived experience than their counterparts in other parts of the world because of the well-developed healthcare system (Gustafsson & Inde, 2009). However, are VIP satisfied with the physical and social treatment offerings? Do the products for VIP have an impact on their expectation for future life experiences? This paper reports on outcomes of a small phenomenological study, set to understand the VIP's life-world, in order to illuminate the possibilities for their experience improvements where design can play a role.

There are four levels of visual function: normal vision, moderate VI, severe VI, and blindness (World Health Organisation, 2010). This work relates to VIP in categories 1, 2, and 3 whose limited vision is insufficient to safely conduct daily activities. The categories and respective values 'presenting distance visual acuity' are defined as:

- Category 1: Moderate VI  
Worse than 6/18, 3/10 (0.3), 20/70. Equal or better than: 6/60, 1/10 (0.1), 20/200
- Category 2: Severe VI  
Worse than 6/60, 1/10 (0.1), 20/200. Equal or better than: 3/60, 1/20 (0.05), 20/400
- Category 3: Blindness  
Worse than 3/60, 1/20 (0.05), 20/400. Equal to or better than: 1/60, 1/50 (0.02), 5/300 (20/1200)

Symptoms can vary according to an individual's situation or the cause of disease. A VI symptom may be displayed as acuity loss (e.g. severely reduced visual acuity, blurred vision,

loss of contrast sensitivity and increased light sensitivity) and as visual field loss (central or peripheral). A VIP may suffer from some or all of them (Bilbert, 2012).

About 80% of sensory input is visual in normally-sighted people (Kasschau, 1980). But, VIP have difficulties with seeing, are unable to see faces, or realise existence of small objects being placed or moving around them, and have difficulty reading and orientating while performing daily activities. VIP use their limited or weak vision quite differently in comparison to normally-sighted or fully-blind people (Pelli, 1987).

**Physical.** Rehabilitation has mainly focused on the development of VIP's self-care and independent abilities for cooking, going outside, reading, cleaning, housekeeping and so on<sup>1</sup>. Many life improvement tools and techniques have been implemented, for example, magnification techniques for reading (Bera, Buser, & Krister, 2008), audible techniques for getting information via hearing. Furthermore, on-going research and development (R&D) projects are focusing on physical solutions for individual use such as talking scanner (Kulyukin & Kutianawala, 2010) and online immediate consultancy system<sup>2</sup>.

**Meta-physical (emotional).** Gustafsson and Inde (2009) said that it would be especially interesting to investigate the quality of life (meta-physical needs) of VIP who are receiving and using physical tools and technologies. Canadian research revealed that VIP are becoming unsatisfied with their current rehabilitation services. Further research on expanding and reforming the VI rehabilitation is urgently needed (Nia & Markowitz, 2007). A survey by the European Blind Union (EBU) showed that VIP and blind people were unsatisfied with their cultural life (Weisen, 2012). Porter (2002) has reported that they may go through many traditional depressive symptoms. While Materna-Lee (2002) has suggested involving family and social support for coping with stress. Hvenegaard<sup>3</sup> added that rehabilitation courses must become more social. In the European Blind Union (2012) member countries, projects have been launched to explore the involvement of family members in the rehabilitation services.

## 2 Designing products from people's experience

Experience design models or frameworks can be (and have been) used to reflect on the research, development, and implementation of (new) product development for people with impairments (also called disabilities) including VIP. Their application may generate ideas and concepts informed by studies on people's lived experience, that it turn, lead to identify situations in need of improvement for enhancing quality of life. Figure 1 illustrates Hassenzhal (2013)'s experience design process for product development. The process starts from the WHY (the needs and emotions in an activity, the meaning, and the experience), which determines or sets the tone of the WHAT (functionality). The HOW (the appropriate way of taking action or the interaction design) is achieved through the functionality, which is able to provide the experience.

Hassenzhal's process may exemplify what Buchanan (see 2001, pp. 14-15) believes "has changed on our understanding of the problem of design knowledge", that "is greater recognition of the extent to which products are situated in the lives of individuals and in society and culture." Such understanding, paraphrasing Buchanan, has given two areas of

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<sup>1</sup> Conversation with Annette Hvenegaard, visual consultant, at *Center for Rehabilitering og Specialrådgivning* (CRS), February 25, 2013

<sup>2</sup> Ibid

<sup>3</sup> Ibid

exploration that are, in a sense, mirror images of the same problem. The first area concerns placing products in their situation of use. The second area concerns the experience that human beings have of products.

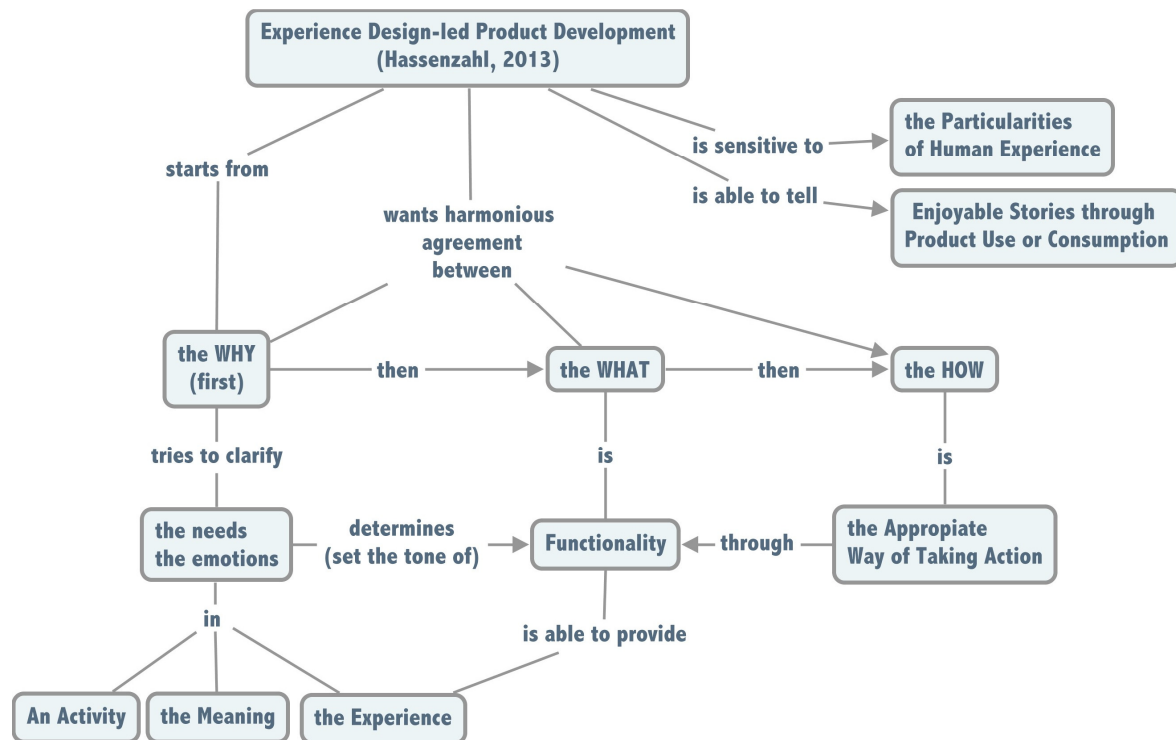


Figure 1: Concept map illustrating Hassenzähl's experience design definition. It highlights the relevant concepts and the relationships among them

**Changing behaviour with a new product through understanding people's deep motivations** can prove difficult when its characteristics or features may greatly alter their life. Brown (2009) suggests building new products based on people's prevailing behaviours. Features with familiar functionality may be an effective way to get people to try something new, such as , products for learning to live and keeping independent as a VIP.

**Maslow's (1943) hierarchy of needs** may help in understanding VIP's experience on the contextual dimension in terms of five levels (when lowest is 1 and highest is 5):

1. *Physiological*: breathing, food, water, sex, sleep, homeostasis, excretion
2. *Safety*: security of body, of employment, of resources, of morality, of the family, of health and of property
3. *Love/Belonging*: friendship, family, sexual intimacy
4. *Esteem*: self-esteem, confidence, achievement, respect of others, respect by others
5. *Self-actualisation*: morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts

When lower level needs are unsatisfied, higher level needs are minimised, even forgotten or denied. But, once lower level needs are well satisfied, higher level needs begin to matter. A person's current hierarchy of needs dominates his/her conscious life and is at the centre of organisational behaviour. This theory is most often used in the study of motivation. As reported in the section 'explaining findings...', this research employed the hierarchy to look at the difference of VIP's contextual and emotional situations in two periods: VIP at the

starting stage of living with vision impairment and VIP at the post-starting stage of living with vision impairment. In a related fashion, Chang and Schaller (2000) applied the theory to explain how emotional support from others affects VIP's rehabilitation. While Kasornsri and colleagues (2009) applied it to discuss how the loss of sight can lead VIP to severe psychological problems.

Hassenzahl's concept of 'WHY', Brown's concept of 'familiar behaviours', and Maslow's hierarchy have been applied or are visible in the R&D of solutions advanced by concepts from the Universal Design movement (Adelson, 2004; Keates & Clarkson, 2003; 2014). Studies and explorations of product solutions have broadened participation and raised awareness about impairment issues that should be looked into (e.g. Web accessibility guidelines). For many examples see the proceedings of the biennial international Include Conferences. The 2010 World Report on Disability (see 2011, p. 100) summarised a UK study on the types of adaptations that may (or not) work in home settings. Figure 2 illustrates the findings and also the gaps identified as "further research is needed in diverse contexts and settings".

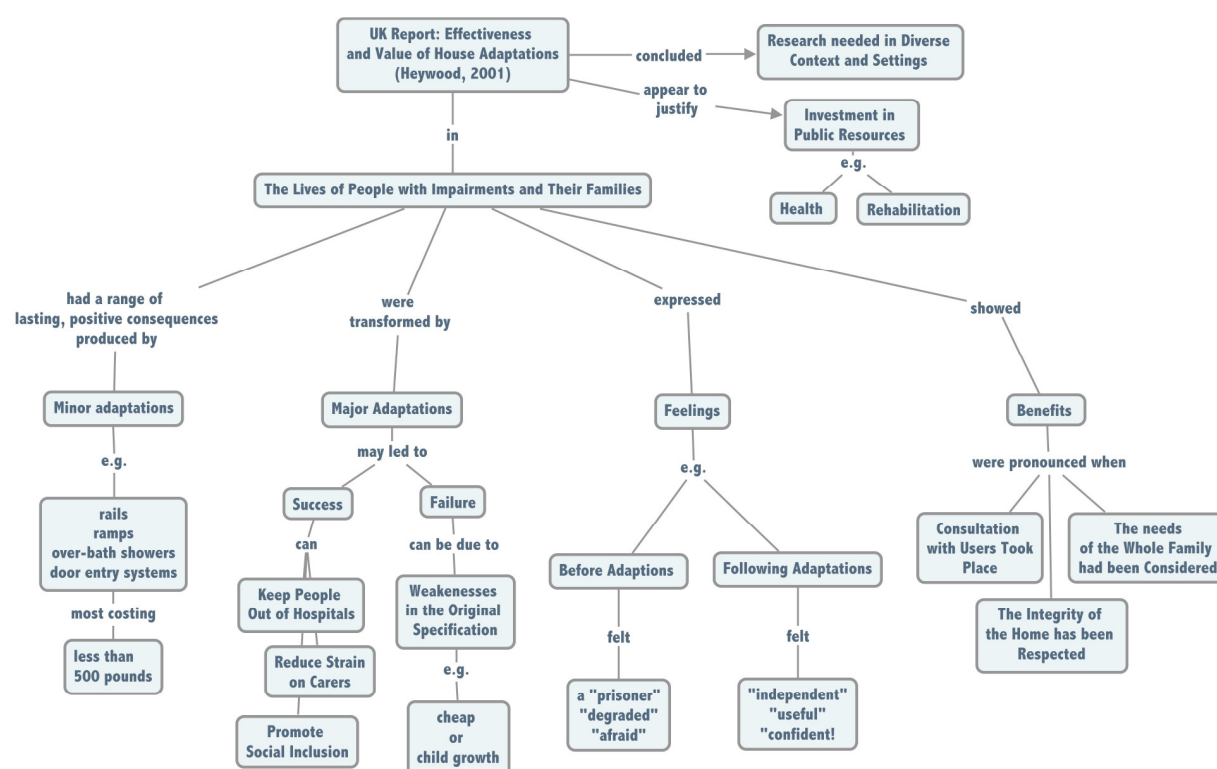


Figure 2: Concept map illustrating findings on the value and effectiveness of adaptations in home settings

From interpreting the map using a human-centred design perspective, it can be inferred that social inclusion is promoted when adaptations (including new designs) lead to solutions that make people feel independent, useful, and confident. These reduce strain in the welfare system, are of a long-lasting duration, and are developed in consultation with users and respect the integrity of the home. Harris (2008) reports on the thoughts and feelings of around 40 people with varied impairments and on their experience using assistive technologies. The useful insights at different levels, for example cost, adoption, exclusion, inclusion, conform with the UK study outcomes reported by WHO. The Disability Studies journals reporting on the perception, physical, emotional, social, and political aspects of people living with

impairments can be quite useful to any process of designing to improve quality of life. In short; the literature is diverse as the venues for dissemination and some of the researchers are people with impairments themselves.

Involving people with impairments in the product design process is not only desirable, but also pivotal for rapid product adoption by a user community. A good number of design studies and explorations have been undertaken and have arrived at similar conclusions on what needs to be addressed when designing for a wider population set, and include people with diverse abilities such as the elderly, disabled, children, and minorities (Chavalkul, Saxon, & Jerrard, 2011; Correia de Barros, Duarte, & Cruz, 2011; De Couvreur, Dejonghe, Detand, & Goossens). For example, Pullin (2009), Keates and Clarkson (2003) point out that designing successful non-stigmatising products requires a conscious decision on the part of the designer and the potential of his/her methods to serve VIP in a way that uplifts the spirit.

When there is a concerted effort between the relevant stakeholders, designers, business and industry, greater numbers of successful products for the whole population will make it into the market (DI&S, 2012). Three examples illustrate; the engineer Robert P. Farran, who has multiple sclerosis, led the team that undertook the R&D of ‘the Delphi Power lift gate’ (n.a, n.d). The R&D of the OXO product’s ‘Good Grips’ was inspired by the CEO’s first hand experience with arthritis disease (n.a, 2014). The eyewear industry successful evolution (Pullin, 2009).

### **3 Methodology: phenomenology**

Experience-design led product development (Hassenzahl, 2013) starts from the WHY – to clarify the needs, the emotions in activities, meaning, the experience (Figure 1). According to van Manen (1990), phenomenology is the best way to extract the essence of lived experience and to reach the reality of matter because the essence of a phenomenon is its contextual description. A phenomenological research on things being experienced can be addressed by the questions of “what something is ‘really’ like (on a contextual perspective)?” Willis (1999) argues that all knowing of an object is on one level subjective and it can vary depending on how people have interacted with the object. Hence he suggests focusing more on experiencing the things than the things being experienced. The research should start with a subjective question of “how did you feel?” and pursue an objective question of “but what was it like?”, so that we get the essential and thorough information about the WHY dimension. Van Manen (1990) also says, it is not possible to grasp lived experience in its immediate manifestation, but it can be reflected as past presence. The research started with conversations with six VIPs in which they were asked these two questions. Their context and emotions were captured via their reflections of lived experience.

#### **3.1 Methods: carrying out and documenting a phenomenological study**

The lived experience of each VIP interviewed was to be described as it appeared to consciousness. Whether it was done through the first author’s embodiments or the interviews, the goal was to grasp individual emotional thinking about a specific experience. However, individual thinking had to be contextually true and real. It was not for us to discover something from the experience, but to understand the truth hiding in the experience.

<i>Participant</i>	<i>Gender</i>	<i>Age</i>	<i>Occupation</i>	<i>Family Status</i>	<i>Vision Situation</i>
P1	F	70	Pensioner	Lives alone. Has a son and a daughter.	Lost peripheral vision (tunnel).
P2	M	26	Graduated master student	Lives alone	Severely reduced visual acuity.
P3	M	32	Government staff	Lives with family	Blurred vision & lost contrast sensitivity
P4	F	40	Teacher	Lives with family	Blurred vision
P5	F	53	Institution staff	Lives alone	Blurred vision & lost contrast sensitivity
P6	M	30	Musician	Lives with family	Severely reduced visual acuity.

Table 1: Personal details of six VIP interviewed

### 3.1.1 Selection of participants

Identified with the help of a consultant from the *Center for Rehabilitating og Specialrådgivning* (CRS), six VIP living in Odense, Denmark were interviewed, three men and three women, ranging in age from 26 to 70 (see Table 1). Participation was limited to VIP who spoke English as a second language, as the first author did not speak Danish. Descriptions of their general situation may be a little different from what they could have expressed in their mother tongue. The CRS could not find any *starting stage* VIP (people learning to live with the impairment) for the interviews. Therefore, information about *starting stage* VIP was obtained by asking the participants to tell stories about how it was like to start living with VI.

### 3.1.2 Embodiment by the designer/first author

Fulton Suri (see 2003, p. 56) suggests trying things ourselves to appreciate other people's experiences, through devising ways to approximate them and learn from our own experience about how situations might be improved. Accordingly, the research commenced with an embodiment, prior to the interviews for promoting emphatic inspiration. 'An experience prototype' was developed that involved wearing a pair of swimming glasses covered with Vaseline that may create the sensation of being visually impaired while conducting four different activities: supermarket shopping, TV watching, cooking and having dinner at home. The contextual knowledge and subjective emotions gained from the embodiments facilitated the interactions during the interviews.

### 3.1.3 In-depth interviews

Informal conversations carried out with each participants in their homes, for one to two hours, focused on individual reflections of what is like to live with VI, and to understand the situations and contexts of a VIP's life on both objective and subjective aspects. According to Coxon (2007), the knowledge acquired from the embodied experience may cause to prematurely judge the information received. Moran (2000) and van Manen (1990) suggest that the researchers must avoid all misconstructions and impositions placed on experience in advance wherever they are drawn from. Pre-understandings must be avoided, assumptions, and suppositions that predispose us to interpret the nature of the phenomenon. It is advised

that when grasping thoughts from the participants, we should try to describe their emotional thinking on their own perspective, and forget about what we think about their experience.

### 3.2 Making sense of data through the SEEing(lite) method

SEEing is a stepwise phenomenological approach, developed by Coxon (2007), for achieving deeper insights to understanding lived experience. Its 3 phases are outlined in Table 2.

<b><i>Phase 1 - Preparation for analysis based on data gathering and pre-processing for real analysis in phase 2</i></b>	
Step one	During the embodiments and the in-depth interviews, data is collected in different formats such as video clips, sound records, and field notes
Step two	Descriptive narratives (data from step one) were transcribed into text for the analysis
<b><i>Phase 2 – The analysis is processed in a Microsoft Excel, given the name ‘SEEing Table’</i></b>	
Step Three	Each interview transcript is broken down into fragments for the analysis. Each fragment is placed in the column titled ‘Step 3’ (Figure 3). 168 fragments were selected based on the information obtained via the interviews and the embodiment.
Step Four	Meanings are developed from each fragment, which may have as few as one or two, or as many as nine meanings. The production of meanings follows the pattern of unveiling the participants’ emotional and contextual perspective, by looking at each fragment not as it is presented but for what other meanings it might have. Column titled ‘Step 4’ (Figure 3) shows meanings listing for participants P1, P6, and Gh (first author). E.g. nine meanings have emerged from P1’s fragment.
Step Five	The 917 meanings produced for ‘Step 4’ were reduced by filtering out the less important meanings – those that were incidental or irrelevant to the lived experience of vision impairment. Only the meanings, ‘essential elements’, that were considered vital to the experience remained for further analysis, and copied into the column titled ‘Step 5’ (Figure 4). 650 meanings were identified as essential elements.
<b><i>Phase 3 - Synthetizing the essential meanings completes the analysis process for understanding the lived experience of six VIP</i></b>	
Step Six	The essential elements are categorised into meta-physical elements (M), representing the spiritual and conscious aspects of the participants’ experience; and physical elements (P), functional and form oriented aspects of the experience. See column titled ‘Step 6’ in Figure 4.
Step Seven	Each element/meaning was weighted using a range of 1 to 7 (from low to high) to consider how intense it relates to VI. The number values are placed in the column ‘Step 7’ in Figure 4.
Step Eight	Extracting the essence hidden in the data required to review ‘Step 5’ and its 650 elements, taking into account the values given to the elements in ‘Steps 6 and 7’. The meanings were grouped according to themes and given a superordinary summary word to form a category. Four categories were generated through this process: adapting, obligation, belonging and recognition. See column titled ‘Step 8’ in Figure 4.
Step Nine	The fragments from ‘Step 3’ were used to inspire and write the stories linked or helping to explain the categories generated in ‘Step 8’ (Figure 4). The categories and stories were shared with the participants so they could provide feedback on the interpretations of meanings. [Note: not enough space to include a sample story]

Table 2: Phases and steps of the SEEing(lite) analysis



SEEing Table		
Part #	Step 3: Fragments	Step 4: Meanings (all)
130	P1 Gh: So, how do you feel about not able to watch TV? P1: Well, I miss it. I feel like, maybe I should turn it on, and just listen to it, because people talk about what has been on the TV, they don't talk about what's been on the radio. Hahaha ... (laugh). If you talk about popular, TV thing, everybody knows what you are talking about. I think I am missing out of it. Hehehe... (laugh). That's culture.	She wants to watch TV
131		People talk about TV
132		People do not talk about radio
133		She wants to talk with other people
134		She wants to know what other people are talking about
135		She wants other people know what she is talking about
136		The information on TV are not on radio
137	P6 His son started to open the fridge door and took a rice-drink box out from the fridge. P6 went to his son, took his box, but his son did not want to let go. P6 took a cup from the cabinet. The father and son all held the box and moved to the sink. The father insisted to help and finally, the son let go and the father started to pour the drink into the cup. The son drank the cup of rice-drink up. The father took the cup from the son and put it into the sink.	Information on TV is popular
138		She wants to be part of the culture
662		His son knows where to find the drink.
663	Gh I felt around with my left hand, until touched a box. Held it on hand, moved close to eyes, but still not able to see; then, shook the box to hear the sound. That time there was a young man walked passing behind me and laughed at my strange behaviours. (Reflection: shopping with low vision made me out of the main stream culture and become strange, I didn't even realise at that moment.)	His son wants to take the drink by himself
664		His son understands his father's difficulty and does not want him to help
665	Gh I try to use other senses to identify the products	On his mind it is his job to help his son
910		I try to use other senses to identify the products
911		The strange behaviours are natural and acceptable for VIPs
912		When I reflect, I feel that I was out of the main group because of the strange behaviour

Figure 3: Data analysis on SEEing Table; Step 3 and Step 4.

SEEing Table				
Part #	Step 5: Essential elements	Step 6: Meta-physical / physical element	Step 7: Weight	Step 8: Categorizing
130	She wants to watch TV	M	5	Belonging
133	She wants to talk with other people	M	6	Belonging
134	She wants to know what other people are talking about	M	6	Belonging
135	She wants other people know what she is talking about	M	6	Belonging
138	She wants to be part of the culture	M	6	Belonging
664	His son understands his father's difficulty and does not want him to help	M	6	Belonging
665	On his mind it is his job to help his son even though he is low vision	P	5	Obligation
910	I try to use other senses to identify the products	P	6	Adapting
911	The strange behaviours are natural and acceptable for VIPs	P	5	Adapting
912	When I reflect, I feel that I was out of the main group because of the strange behaviour	M	6	Belonging

Figure 4: Data analysis on SEEing Table; Steps 5 to 8

## 4 What is the experience of visual impairment like?

The SEEing analysis produced four categories with associated stories, which somewhat helped in the process of understanding the lived experience of six VIP.

### 4.1 Adapting: VIP learning how to adapt to new life while living in a world designed for normally-sighted people

#### 4.1.1 *Recognising disadvantages – activities VIP could not do.*

When the participants started to suffer VI, they quickly realised disadvantages in conducting some daily activities. They would have to spend much more time and put a lot more effort in performing them, but with lesser quality results, in comparison to normally sighted people.

Everything I do, it [*sic*] takes much more time. I have to know where the things are. I have to find the things or make a mistake, and it's just slow, much more slow process, no matter what I do (participant 1).

After recognising their disadvantages, they had to go through an acceptance process of being less able to do lots of things and develop extra tolerance with their own reality.

It's not helping you (by) sitting down and crying 'OH, what can I do' (participant 4).

Of course, you know, I could make pasta, pasta sauce, beef or potatoes, you know, kind of simple stuff. So that's no problem (participant 6).

#### 4.1.2 *Developing abilities to focus on activities VIP could do*

The participants gradually started to think about what they could do. First, they learnt how to live independently and developed new living skills to successfully overcome the VI.

I realised that, wow, I should be serious about this [visual impairment], and get help, you know, do whatever can be done (participant 1)

I got something like this, just to help me [to check temperature of food cooking in the pan], but actually now I use my fingers when I cook a beef or something. It is burning a little bit, but you know [laughed] (participant 6)

At the same time, VIP may have to change hobbies or jobs, learn new skills to carry out their new hobbies or jobs, and discover new suitable activities.

Before, I liked very much volleyball [*sic*]. But you know, since I have been doing so many other stuff [after becoming vision impaired], if I was not blind today, I wouldn't be a musician, for example, that I am very glad, that I became a musician, and I wouldn't have met my wife. We wouldn't have got ... [laughed] (participant 6)

The participants had become used to and satisfied with their new life, but not without suffering with physical difficulties. The quotes show that they 1) have recognised that performing an activity may take a long time and cooking simple meals may be possible; 2) have developed new abilities to sense changes in cooking temperature; and 3) have realised that a new hobby could lead to positive life changing experiences.

## **4.2 Obligation: VIP wanting to contribute to society and their families**

### *4.2.1 Social obligations and responsibilities*

Participants wanted to play an independent societal role by getting a job, or keeping the current one, so that they could live on their own instead of relying on government welfare.

They [the government] want me to work, and I want to work ... most of people like me want to go to work (participant 4)

But sometime it is very difficult to have the politicians to understand the problem. The problem is not the work, is how to get to the workplaces (participant 5)

They also tried to gain respect from others – those with good vision or VI, and did not want to become a burden on others, therefore, preferred to limit their activities outside.

It is a good thing that we don't drive, because it would be terrible if you drove into a child or other persons [*sic*]. ... no, no, no driving (participant 2)

It [is] difficult... walking around, and without banging into people (participant 6)

VIP's interaction with politicians or people from the community had become difficult, and therefore, they have become afraid of losing the ability to continue undertaking their social obligations.

### *4.2.2 Family obligations and responsibilities*

Participants tried to exercise responsibilities associated with their family roles - as father, mother, husband, or wife, as per normal.

Now, we have two kids, so, I need to do a lot of stuff ... But I am blind, partially blind. Because I am a man [laughed], I do something, I [hope to] do it like 'THIS is what I do!' [hitting the dining table] (participant 6).

However, VI had made it difficult. They had to give up lots of home enjoyment so as not to bring trouble to the other family members, due to how their activities are conducted.

I am used to focusing [*sic*] on listening, but I think it's easier for me to watch the TV program together with my wife than sitting to listen to a radio program with her. [Because for her] it could be frustrating to listen to things (participant 3)

[The audio subtitles on TV] is very good, but the family is not so happy about that. They want to read them by themselves, so sometimes it can be a big difficult to see it [TV] with other people [with good vision] (participant 4)

As social beings, VIP also want to make their contributions when interacting socially with their family and others. The inability to drive greatly increases the difficulty of getting to the workplace. Walking around may be disruptive to others and complicates the undertaking of parenting activities.

## **4.3 Belonging – VIP's feeling of being in a group and culture**

### *4.3.1 Social interaction with non-family members*

Participants tried to get into the mainstream culture, be normal, and establish contact with others, for example, talking about current affairs topics.

Well, I miss it [watching TV]. I feel like, maybe I should turn it on, and just listen to it, because people talk about what has been on the TV, they don't talk about what's been on the radio. ... It's culture (participant 1)

When we go to the café and drink a cup of coffee or tea, and then I can hear something they are talking about the movie, but I didn't get ... and then I feel: 'Oh, I have to see the movie one more time' (participant 4)

On the other hand, it was also difficult for normally-sighted people to accept and include them into group activities. Hence often, VIP were unwilling to publicly show the symbols of VI. For example, all participants did not want others to know that they had to use a cane.

Of course I am trying not to look like a freak [in reference to walking with a cane in town]. Nobody wants to do so (participant 6)

The hardest stuff at the beginning was actually the contact with other people. You know, when you are 14, you don't sit around and do small talking during the breaks at the school. You would run around or anyway. But, ... [I can't run] you know.

I didn't want this tool [referring to a cane], didn't want to show everyone that I have this I guess nobody wants to be in this situation (participant 1)

#### *4.3.2 Social interaction with family members*

Participants expressed a high level of satisfaction with family interactions. They joined family activities even if these were difficult to perform, for example, watching TV without scene translation and cooking with family. Their understanding of the situation and high level of support was found delightful and satisfactory.

It [handball] is very fast, and sometimes I can't see if they get a goal. I often see it with my children or with my husband. We sit and talk, and then 'Oh, how is it going?' and then they have to tell me. A lot of fun (participant 4)

I watch [TV] together with my wife, and if she knows very well there is something in visual going on the screen, that you didn't have any chance to catch without [good] vision. So she is very professional to make a sound speech [Laughed] (participant 3)

People, inside or outside the family circle, talk about what has been on TV, not on the radio. Participating in the conversations or understanding what people are talking about in reference to a movie is important for VIP to feel culturally included. They expressed an expectation of becoming part of a group. At the same time, they expected understanding, respect, and support from others.

## **4.4 Recognition: feeling of accomplishment**

### *4.4.1 Abilities being recognised by able family members and able people in general*

VIP's inability to perform certain activities had caused a social misunderstanding of their actual capabilities. People have even doubted their ability to do easy daily work such as keeping the house clean. The fact is that there were still a lot of things the participants could do perfectly well. They expected others could trust them in doing well and recognise their accomplishment and abilities, such as, teaching mathematics in school.

When my wife was away for that week... everything was spick and span, everything was clean. It was good for me to feel that I could take care of business when she was away. Also, of course it was also good for her to know (participant 6)

... then they have chance to learn that, 'Oh, we have a teacher who has low vision, but she teach us mathematics' (participant 4)

#### 4.4.2 *Sense of accomplishment and performance*

VIP would like to show society that they could perform activities as well as normally-sighted people. They were proud of 1) the advantages gained from having to strengthen other senses (e.g. sharper hearing) and cognitive skills (e.g. enhanced memory); and 2) their accomplishments, especially when they compared themselves to normally-sighted people.

It is much easier by remembering things than you going for glasses, and looking at the papers. My colleagues say that I have an elephant's memory [laughed] (participant 4)

I can hear a lot of voices that people with normal sight cannot hear. You know, you can't hear, (because) you don't need to understand what a sound means. Even my wife, we have been living together for many years, is just like: 'you hear that?' [laughed] (participant 6)

## 5 Explaining findings through Maslow's hierarchy

The previous section 'what is the experience of visual impairment like?' summarised the study outcomes. The participants' life has changed at different stages of the rehabilitation. Their needs at *the starting stage* were quite different from those at the *post-starting stage*.

**At the starting stage of living with vision impairment** participants were unable to perform basic daily activities, or handled them with great difficulty, and have lost the majority of skills for dressing, eating, sleeping, and moving around. The new VIP's needs at the physiological level were unsatisfied and dominated their conscious life. Higher level needs such as self-actualization had to be ignored. Satisfying physiological needs required learning new skills for cooking, buying food, reading with magnifying screen, watching TV using a scene translation channel, and listening to the radio more often than not.

VIP started to pursue needs at the safety of body level once basic needs were satisfied, for example, learned how to walk on the sidewalk, to the train station, or safely get onto a bus. A cane became an important tool for orientation, even though in the public's mind it is a symbol associated with being fully blind. Adapting to a satisfactory new life with VI and mastering the tools to fulfil needs at the physiological and safety levels only took several months.

**At the post-starting stage of living with vision impairment** participants expected to have a more social life, had a strong need for loving and belonging, and self-actualization. Close friendships and family harmony became very important to them. They strived to respect others, wanted respect in return, and expected that others recognised their abilities.

The participants had a lot of obstacles and difficulties in exercising or experiencing being loved, feeling like they belonged, and being esteemed by others. For example, VIP normally recognised people through hearing their voices. However, people usually say 'hello' to each other only after seeing and recognising the other party. Hence, this basic rule for social interaction prevented VIP to know who was around them in a café or party. It made it impossible to interact socially with people in those contexts.

Also, there were difficulties and obstacles attributed to alternative ways that VIP had to develop to continue performing certain activities. Watching TV through the scene translation

channel made it difficult for them to sit together and enjoy programmes with family or friends with good vision. The cane led others to underestimate their capabilities, consequently, they did not want people to know they had to use it. This decision demonstrated to others that they had the ability to do things as well as normally-sighted people. Many techniques, tools, and methods that VIP had mastered during the *starting stage* have become a big obstacle and serious problem in their daily life later at the *post-starting stage*.

## 6 Design principles, requirements and implications

### 6.1 Product design opportunities for VIP at the starting stage

Design practices for this stage aim at the R&D of physical solutions, such as canes, audible cooking utensils, audio books, scene translation channel, talking scanner, among others. However, people buy a product not just for the activity that it supports, but also for its meaning and experience (Hassenzahl, 2011).

**First principle;** *never force VIP to use a product even though is usable and useful.* They may not want to look abnormal or risk being stereotyped. These feelings were also reported by participants in Harris (2008)' social study on technologies in the lives of people with impairments. While Keates and Clarkson (2003)'s inclusive design approach includes them as items under the "social acceptability attributes". The questions asked are "does this product stigmatize me in anyway" and "is this product 'cool'?". **Second principle;** *always provide solutions promoting a 'normal' way of interaction.* Two reasons; first, many special solutions VIP had mastered during the starting period became obstacles in their social interaction with others. For example, TV watching using the scene translation channel. Second, most VIP became visually impaired after a physical injury or a disease. Therefore, it has been hard to stop behaving as a normally-sighted person. During a design process, this principle should be considered by building on prevalent behaviours (Brown, 2009). **Third principle;** *a product designed for the starting stage should still be desirable at the post-starting stage of VI.* Its form and function should allow for this transition. The study showed that products specially designed for visual impairment were unattractive. Participants stopped using seemingly complicated tools. For example, even if it hurt a little, they preferred to use fingers for sensing temperature during cooking instead of audible tools. According to Beehr and McGrath (1996), VIP may have matured and become accustomed to things that produce stress - enough to withstand some pain without suffering from adverse consequences.

The first and second principles aim at fulfilment of meta-physical needs, while the third principle aims at integrating the products into VIP's living experience and supporting them during the performance of their activities.

### 6.2 Product design opportunities for VIP at the post-starting stage

After mastering abilities to live independently, participants focused on social interaction and family harmony. The needs of social interaction with normally-sighted people have emerged and become vital. **First requirement;** *focus more on belonging and esteem.* Design practice should aim at supporting social interactions with family, friends and the public, so they can continue to be part of the mainstream culture. Products should take the form of artefacts, processes and/or services. Examples of the latter could be policies, methods, and courses. **Second requirement;** *consider the needs of the normally-sighted people with whom VIP*

*interact*. The shape of products for cooking or scene translation has affected social interactions. Some participants were dissatisfied with their performance, as they generated disharmony in the family. Research undertaken on the effectiveness and value of house adaptations supports these requirements. The benefits of adaptations are “pronounced when the needs of the whole family had been considered” and “the integrity of the home has been respected” (World Health Organization, 2011, p. 100).

### 6.3 Implications for social responsibilities

Some findings show that people expect self-esteem, confidence, achievement and respect. ***First implication; society should give VIP the chance to contribute.*** Participants wanted to go to work as per normal, not only to live, but also find and identify their value to society. They wanted to be trusted in their capabilities to bare obligations corresponding to family roles, and not be treated specially because of their physical condition. Relevant government agencies should play a role in supporting them, for example, with mobility services for getting to work. In parallel, family members should be supportive by offering them a chance to exercise individual obligations as wife, husband, father and/or mother, for example, cleaning the house and cooking simple meals. ***Second implication; society and family members should have more trust in VIP and recognise their abilities.*** When we agree that VIP should be given chances to do more – as more as people with good vision, some may ask: ‘Can they?’ The answer is ‘Yes’. According to Bandura (1997), a person’s sense of self-efficacy can play a major role in the way he or she approaches goals, tasks, and challenges. The possession of high self-efficacy can lead to interpreting physiological issues as normal and unrelated to ability. When VIP believe that they can do things as per normal (e.g. teaching mathematics in a school or being a musician), this belief may lead to success in spite of their impairment.

## 7 Conclusions

The outcomes of an in-depth phenomenological study on the lived experience of six VIP showed that their needs at the starting stage were quickly fulfilled and enabled them to pursue higher level needs at the post-starting stage. For example, they wished to belong and feel appreciated by their family and others through activities such as cooking simple meals or doing housework. They also wished to work and have their abilities recognised. A number of products designed for the starting stage quickly became obsolete because these were stigmatising (e.g. the cane associated with the fully blind) or alternative skills were developed (e.g. sharper hearing and improved memory). Study aspects were summarised in three design principles, two design requirements, and two implications for social responsibility, which together can inform new product development for VIP. The functionality and associated interactions of such products should take into consideration evolving needs and emotions in the activities VIP carry out as individuals, family members, and contributors to society in general.

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