Improving the Quality of Life of Patients Living with Neurological Diseases Through Design Thinking

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Abstract

Intractable neurological diseases decrease the quality of life (QoL) of patients due to declines in their physical functioning. This chapter illustrates how design thinking was employed by design students to generate a significant number of creative ideas for improving patients' QoL. The idea creation program was based on a design thinking model in collaboration with the Graduate School of Design at Kyushu University and Kyushu University Hospital in 2022. First, 3 patients explained their symptoms and difficulties in their daily lives to 15 graduate students and 3 hospital staff members. The participants interviewed the patients and noted their findings on sticky notes that were grouped according to the issues that decreased the patients' QoL. Finally, the participants generated ideas for addressing these issues. After the program was completed, the authors coded all the outcomes. The participants created 97 creative solutions comprising a mixture of services and products. The ideas approached the issues in two ways: assisting patients' independent actions in general, and making specific daily scenarios more convenient and pleasant. The codes were classified into four categories: body movement, daily activity, communication, and recreation. In addition to creating more resource-effective outcomes, harnessing creative, solution-oriented approaches in the early stages of product-service development can generate more holistic healthcare settings. While hospitals treat the disease itself, there is room for design-based interventions in services that consider and improve the daily lives of the people living with disease.

Keyword Design thinking, Creative thinking, Quality of life, Intractable neurological diseases, Design education

1 Introduction

Intractable neurological diseases (IND) cause a decline in physical function. In Japan, this category includes Parkinson's disease, spinocerebellar degeneration, multiple system atrophy, and amyotrophic lateral sclerosis. These diseases are characterized by incurable and progressive symptoms. As these diseases progress, patients lose their body movement capabilities, and the burden on their caregivers increases. Thus, the quality of life (QoL) of patients and their caregivers was significantly lower than the national standard (Miyashita et al. 2011).

Medical approaches for these diseases are limited to symptomatic treatments such as rehabilitation, maintenance of muscle strength, and anti-spasmogenic medication, and patients perceive these measures alone as insufficient. Past research on health-related QoL in patients of multiple sclerosis (Faraclas et al. 2022) has reported the lack of comprehensive care as a barrier to fulfilling patients' lifestyle needs. This means that healthcare providers were only focusing on medical and physical symptoms, while understanding essential diet, exercise, and stress management strategies was perceived as necessary for improving health-related QoL.

Innovation in future healthcare services require creativity from thinking outside the box. Divergent thinking and a quantity of ideas are needed to generate innovative ideas not limited to medical approaches but encompassing lifestyle-related approaches to increase patients' QoL. However, patients are not always considered when new services are designed (Searl et al. 2010). Creative thinking and design thinking can be used to explore latent opportunities for innovation. Although there is research applying these two frameworks to the medical field, limited research has dealt with IND.

This study's purpose explores the framework of innovation for patients with IND. The research question was "What are the difficulties that patients experience, and how can we resolve them?" The objective is to identify factors related to the general decline in the QoL of patients with IND through creative thinking and design thinking.

2 Theoretical frameworks

In this chapter, we treat the processes of creative thinking and design thinking as working together. This is a bottom-up approach to the poorly understood subject of patients' lifestyle needs.

Creative thinking

Creative thinking is a complex term with an ambiguous meaning; while some creative endeavors may be considered creative, others may consider them improvisatory (Webster 1990; Ryhammar and Brolin 1999). At the same time, some people consider creativity a spontaneous action, while others consider it a work of genius (Webster 1990). Despite such ambiguity, creative thinking is mostly associated with mental processes and the ability to unique and original solutions (Webster 1990). Therefore, it is strongly associated with problem-solving behavior and creative thinking skills (Newell et al. 1962; Guilford 1967; Webster 1990; Runco 2011), which are considered valuable soft skills that will remain in demand in the future (Dean and East 2019). However, this preference for complex and divergent thinking declines with age (Alpaugh and Birren 1977).

Patrick (1955) defined creative thought as a process of preparation, incubation, illumination, and revision, whereas Amabile and Hennessey (1992) understood creative thinking skills as encompassing three key aspects: creativity, expertise, and motivation. His ideas on convergent and divergent thinking are valuable contributions to creative thinking (Guilford 1967). Webster argues that while both these thinking abilities are associated with creative thinking, divergent thinking is especially closely associated with idea generation, exploration, spontaneous and free-flowing thinking, and non-linear thinking that are generated in an emergent cognitive fashion (Webster 1990; Runco 2011). Divergent thinking is a type of cognition in which memories and perceptions are used to generate a wide variety and quantity of solutions from stimuli or open-ended tasks (Guilford 1967) in fluid and unrestricted processes (Runco 2011). Divergent thinking may lead to the originality of ideas and thus the potential for creative thinking and problem-solving.

Due to the avoidance of risky inventions and innovations that might put patients' lives at risk, the healthcare sector is in need of creative solutions and innovative practices, yet it is mostly more incremental and steady improvements to established practices that are implemented (McMahon and Coughlan 2023). However, creative thinking is a tool for innovation and interdisciplinary education in healthcare (Van de Grift and Kroeze 2016), a sector in which ongoing learning remains a challenge owing to the ever-changing nature of the sector, which experiences ongoing developments to improve healthcare and its products (McMahon and Coughlan 2023). The desire to measure creativity has existed since the early emergence of creativity studies. However, Hocevar (1981) established that inventories of consistent self-reported creative activities are the most defensible technique for establishing, documenting, and analyzing creativity, a practice that should be exploited by the high-volume learning that is essential in healthcare.

Design thinking

The first instance of the application of design thinking is believed to be the title of a book published by Rowe (1991). Dorst (2011, pp. 523–531) argued that professional designers use "quite specific and deliberate ways of reasoning," which can be inductive, deductive, or abductive, and involves engaging in productive thinking that creates value. For designers, thinking can be varied and layered, but most of all, their thinking shapes their "designerly abilities" (Dorst 2011, p. 531). In summary, "design is not one way of thinking: it is a mix of different kinds of thinking, building as it does on induction and problem solving," explains Dorst (2011, p. 525). These different ways of thinking include divergent and convergent thinking, either opening up possibilities or distilling options from those possibilities. Divergent and convergent thinking are both forms of creative thinking (Webster 1990).

According to Brown (2009), design thinking is a human-centered innovation technique that consists of five elements within iterative cycles: 1) Empathizing, 2) Defining the problem, 3) Ideating, 4) Prototyping, and 5) Testing. The design thinking process is widely used to create solutions to problems, commencing from empathizing with the design setting or context, describing, clarifying and defining the problem, and ideating solutions to the problem through divergent and convergent thinking, tool use, and "framing," which is a design skill that is widely used to determine how a designer will work to create value (Dorst 2011, p. 524). The design thinking process then continues to create prototypes from ideas created earlier. The final stages of the prototyping and testing phase involve divergent and convergent thinking as quick and dirty prototypes are created and tested until a suitable design solution is found.

The value of design thinking in healthcare lies in its user-, human-centric, and multidisciplinary approaches (Van de Grift and Kroeze 2016). Studies comparing design thinking interventions to conventional approaches in healthcare have reported user satisfaction, usability, and effectiveness of health product services (Altman et al. 2018). In healthcare, design thinking is most useful early in the innovation process, when problems are not well defined or when the proposed solutions do not deliver the expected results (Roberts et al. 2016). Design thinking works best with process-improvement approaches in healthcare when solutions have reached stages in which they are less abstract and relate more to the day-to-day operations of a healthcare system (Roberts et al. 2016). In the healthcare-focused design thinking framework proposed by Roberts et al. (2016), the focus is placed on the early stages of the design thinking process explained by Brown (2009): empathize, problem definition, and ideation. These authors call for empathic approaches that focus on how healthcare users feel in certain situations to identify disruptive outcomes, prioritize the discovery, understanding, and definition of underlying problems to current problems, promote divergent thinking through opposing ideas and concepts, and uncover and establish the needs of users (Roberts et al. 2016). This chapter presents a similar focus on embedding creative thinking in the early stages of the design thinking process.

3 Methods

The idea creation program refers to a design thinking model that consists of three spaces: inspiration, ideation, and implementation (Brown and Wyatt 2010). This study focuses on the first two spaces of design thinking. It was also part of an educational program conducted as a year-round project-based lecture in cooperation with the medical and design faculties at Kyushu University in Japan. The participants in this study were 15 graduate students from the Graduate School of Design and 3 staff members from Kyushu University Hospital. The program was divided into three steps: (1) medical site visit, (2) problem identification, and (3) idea creation (Fig. 1). We referred to the concepts of divergent and convergent thinking from the theories of creative thinking for idea generation (Guilford 1967). Through the program, we encouraged participants to state whatever come to their minds ("quantity is wanted" and "freewheeling is welcome") to increase the diversity of ideas groups generate (Paulus and Brown 2007).

Fig. 1. The procedure of the idea creation program. Source Authors' own illustration (2023)

First, there was a medical site visit at the Department of Neurology, Kyushu University Hospital, in May 2022. Participants were divided into two teams, and each team had 30 minutes for interview. The interviewees were IND inpatients at Kyushu University Hospital. The first team interviewed one patient and the second team interviewed the other two. Interviewees visited the venue accompanied by physicians, explained their symptoms and difficulties, and demonstrated their physical functioning in daily life. Physicians explained basic information about the patients' diseases and added supplemental information to the patients' comments. Participants asked questions about their diseases and wrote their findings through patients' explanations and demonstrations on paper sticky notes. To generate divergent ideas, they were asked to write at least 10, or as many as possible.

The second step involved a workshop on problem identification using the results of a medical site visit. To ensure the convergence of ideas, this workshop was based on the Kawakita-Jiro (KJ) method, an effective problem-solving technique (Scupin 1997; Nakagawa et al. 2015). In each team, the participants shared their paper sticky notes with findings on a large white paper and grouped these findings according to the problems that decreased the patients' QoL. New paper sticky

notes were generated for each group and labeled with the names of problems. After grouping, all paper sticky notes were converted into digital data and transferred to Miro, a digital whiteboard service. The integration of problems was achieved through the facilitation of the faculty members. Each team explained the details of the groups of problems, and the faculty members sorted these problems using Miro. If a problem was mentioned by both teams, the two mentions were merged.

The third step was idea creation. All the participants had homework of generating ideas as solutions to the identified problems. They were also encouraged to explore creative options that went beyond usual solutions. Each participant had at least one idea. Each idea was described on a one-page slide in Microsoft PowerPoint. The slides consisted of the title, scene of the problem, details of the idea, and illustrations. All slides were converted into image files and pasted near the digital sticky notes of the focused problem on Miro. Finally, the participants gave presentations, explaining their ideas in detail.

After the program, all the digital sticky notes with findings and slides containing ideas were gathered and counted. In addition, the ideas created were coded by the authors according to the scenes of patients' lives.

This research protocol and the data privacy procedures were approved by the Kyushu University Ethics Committee (#23287-00). Written informed consent for participation in this educational program was obtained from each patient, and their information was anonymized.

4 Results

The participants shared 210 sticky notes containing the interview findings. Additionally, they created 97 ideas that were a mixture of services and products for 28 scenes. The idea codes were classified into four categories: body movement, daily activity, communication, and recreation. While only body movement generally assists patients' independent actions, the other three approaches can make specific daily scenarios for patients more convenient and pleasant.

Body movement

For body movement, 13 ideas were coded that approached patients' problems by enhancing their physical functioning. The problems identified regarding this code involved general scenarios: arm motion, neck motion, posture maintenance, standing and sitting, and walking. The approaches of the ideas were directed toward assisting patients' activities without support from caregivers and increasing their choices in their lives. The major ideas were products such as interiors and equipment.

One idea was a chair in which the seat moved vertically. Patients with impaired movement of the lower body are at risk of falling when they stand up and sit down. To address this problem, the seat gently pushes the user's hips. This lift function is considered to provide smooth standing up and stable sitting down, as the seat can rise to fit the standing user's hips and then lowers slowly.

The vertical movement function was also applied to ideas for equipment to support arm movement. Some patients living with IND are incapable of raising their arms above their shoulders. Since there are many situations in which the arms are raised higher than the shoulders, such as hanging clothes and taking something off the upper shelf, this disability reduces patients' range of independent action. To address this problem, a pair of stilts was suggested to change the height of the foothold (Fig. 2). This approach did not recover or support the patient's arm function itself but shifted the entire body higher, including the arm position.

Fig. 2. A created idea coded body movement: a pair of stilts with vertical move function. Source Yuuki Minamii (2023)

Daily activity

The code for daily activity was similar to that for body movement. While body movement treats general physical functioning that can adapt to various scenarios,

daily activity focuses on specific problems, such as toothbrushing, writing, and cooking. The code comprises 58 ideas. Another characteristic of this code is that 55 of the specific daily scenes include working with hands in which IND causes tremors.

The largest number of ideas in this code was 18 solutions for cosmetics. One idea was to create a table with a horizontal mirror and armrests. It is difficult for patients with muscle weakness or tremors to use ordinary dressing tables. Therefore, this idea places a mirror on the table and embeds armrests so that users can hold their hands with lipstick or brush below their shoulders and put on makeup by moving their faces.

Since this study was conducted during the COVID-19 pandemic in Japan, there were also ideas related to infection prevention. The proposed hand-sanitizing machine has multiple rings with nozzles installed at various heights (Fig. 3). This idea was intended for people with wheelchairs who feel inconvenienced by the height of hand-sanitizing machines in public spaces. Moreover, this product covers other diverse physical functions such as short height, including in children.

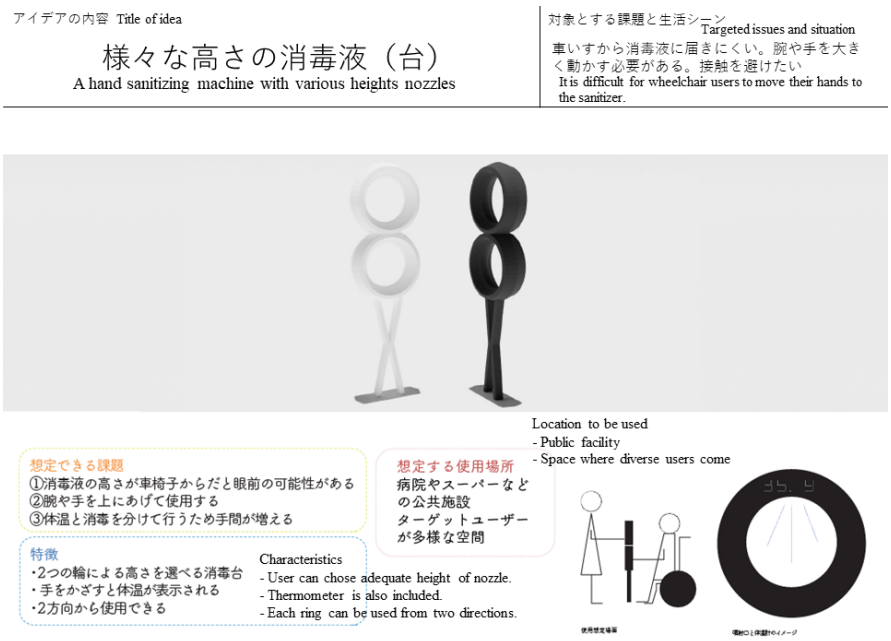

Fig. 3. A created idea coded daily activity: a hand sanitizing machine. Source Akiho Higano (2023)

Communication

While the interviewed patients did not have any speaking disabilities, there were 10 ideas for improving their communication. Although “communication” itself is a general word for a variety of situations, each idea focused on specific scenarios in this study. Related difficulties included sharing ideas with other patients, telling their troubles to others, and being alone. In addition, this code includes ideas for improving patients’ hospital lives by supporting communication.

The idea shown in Fig. 4 is “an umbrella to use when you want to be alone.” Hospitalized patients, who often have caregivers nearby, find it difficult to secure a private space even when they suddenly want to be alone. This umbrella, designed to resemble a lotus leaf, opens and closes at the touch of a button, making it easy to secure and create private spaces. Also, when they want to keep their distance from others, they can tell them, “I’m going to put up my umbrella for a minute” without worrying about offending their caregivers. In addition to being handheld, it can be attached to a wheelchair, the bedside, or a sofa.

Ideas to display signs were generated to support patients who find it difficult to make gestures. These display signs have a keychain and adhesive seal to place on patients’ bodies, and users can write a message in this sign; this device also has a text-to-speech function.

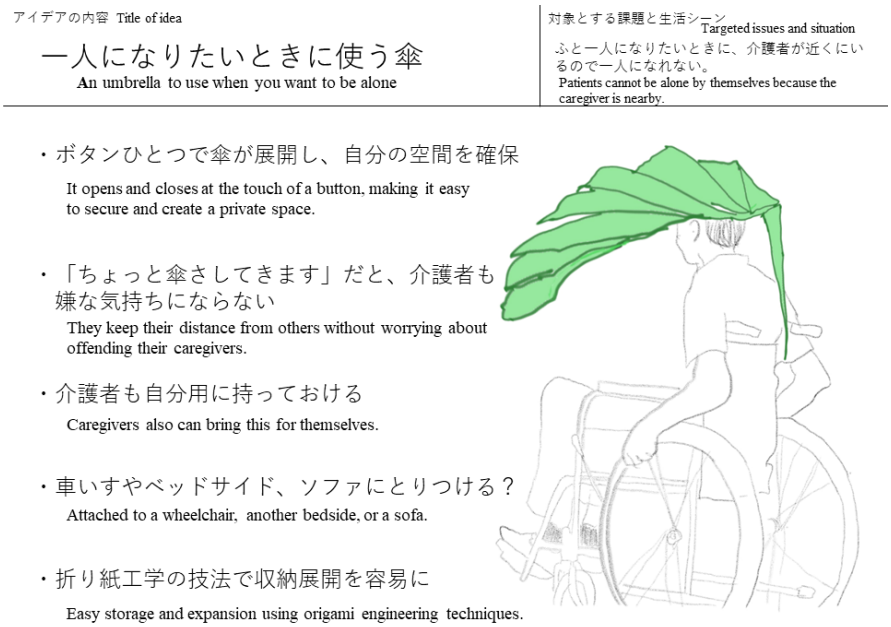

Fig. 4. A created idea coded communication: an umbrella to use when you want to be alone. Source Megumi Hasegawa (2023)

Recreation

The 15 ideas of hobbies and entertainment belonged to the code of recreation. Although this category is less essential than the others, it enhances patients' QoL. The scenes in this category included shopping, fashion, sewing, and outdoor activities. Applications for virtual reality (VR) services are suggested in the code.

An idea that combines a caster walker and head-mounted display (HMD) was suggested (Fig. 5). This is a solution for people who require a caster walker. It is difficult for them to move on rough ground, stairs, or crowded areas. Therefore, the service provides an outdoor VR experience. Users stand with a caster walker and control their view using the HMD; they then experience travel anywhere by a two-wheeled electric vehicle.

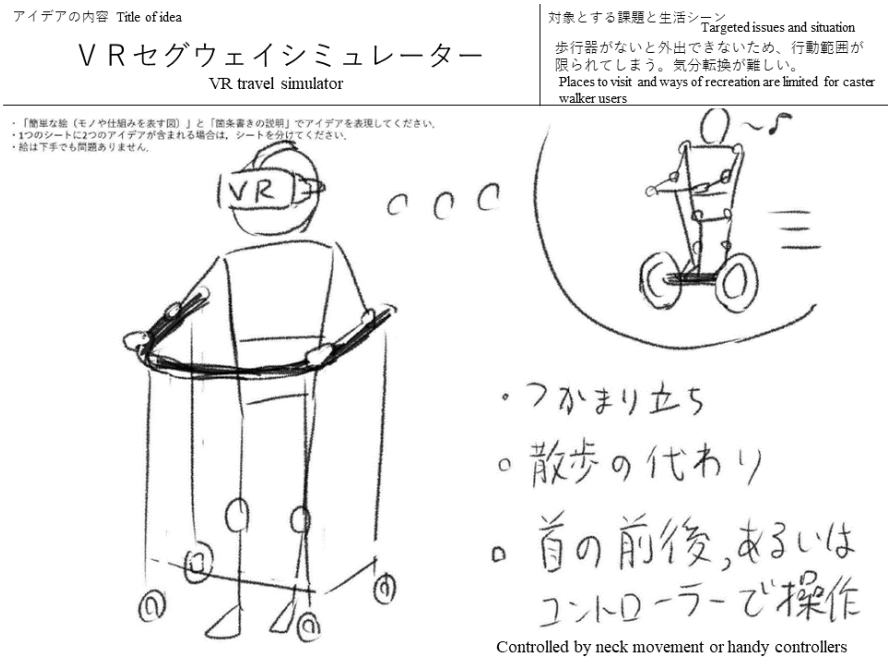

Fig. 5. A created idea coded recreation: a VR travel simulator. Source Katsuaki Oike (2023)

5 Discussion

We launched a project to improve the QoL of patients with IND using creative thinking and design thinking processes. The discussion in this chapter includes

two topics. One is the number of ideas and codes as the direct outcome, and another is the educational program as the framework to generate ideas.

Number of ideas and codes

Nearly 100 ideas were created by the 18 participants. Considering that the goal of ideation is to nonjudgmentally generate a broad range of ideas, this seems to be an adequate and creative result (Deitte and Omary 2019). This outcome was led by facilitation based on design thinking that encourage participants keep two rules ("quantity is wanted" and "freewheeling is welcome") in their minds through the space of ideation (Paulus and Brown 2007; Brown and Wyatt 2010).

The ideas were based on problems identified through interactions between patients and participants. Since medical approaches are limited to symptomatic treatments, ideas that focus on patients with diseases have the potential to provide innovative medical services.

More than 70% (71/96) of the ideas belonged to the codes for body movement and daily activity. Since IND causes patients' physical functioning to decline, these solutions are direct approaches. Regarding physical functioning, a large number of solutions have been studied in the medical and engineering fields. However, this study demonstrated the potential of the design method to generate ideas from a variety of aspects, such as the detailed needs of patients' daily lives. In the medical field, physical functioning is considered more essential than recreation and communication because it is the primary target of treatment. However, patients lose their choice of hobbies and entertainment, and experience barriers to communication, which is a side effect of their physical disorders. These two codes are considered key factors in improving patients' QoL and the area of design expertise.

There is a limitation in that the ideas in this study were based only on a one-time medical site visit due to the schedule of the entire program. The participants met one or two patients, and the interviews were not continuous. Opportunities to interview a variety of patients and caregivers as stakeholders will accelerate participants' identification of problems, which can lead to heightened creative thinking for generating ample ideas. Furthermore, due to the progression of symptoms, patients with IND exhibit varying physical functioning. Long-term projects would have the potential to generate different creative ideas that include various levels of IND progression.

Educational program

This project was an educational program conducted in cooperation with two faculties at Kyushu University. A range of design methods has been applied to various areas of healthcare, and design thinking is a popular method (Lamé et al. 2023). However, one study noted tensions between the design and medical aspects of a project when using creative and design thinking in healthcare(Altman et al. 2018). It took more than a year to launch this program because we had to coordinate a feasible way of completing the study by considering the rules and resources of the two faculties and cultural gaps. However, we conclude that the program benefited both groups.

On the design side, the program provided an opportunity for students to practice in clinical settings. Interventions in medical practice are difficult due to ethical issues. Therefore, one of Kyushu University Hospital's major roles is to open the way for design students to access patients. Although the participants from the design side were graduate students who had acquired a certain level of expertise in design, they did not have any experience tackling actual problems in the medical field. They considered how patients were affected by disease and what was needed to improve their QoL. This process will afford students new perspectives as designers.

From the medical perspective, participants were able to identify patients' problems by adopting a new approach. Medical staff members need to know the various aspects of a patient to improve their healthcare services. However, their approaches are related to treatment, and it is difficult to reach other aspects. This program was an opportunity for them to gain deeper insights into patients' problems that they were not aware of, such as psychological distance from society and the need to enjoy their daily lives. This program also has the potential to include not only staff, but also students from the Faculty of Medicine, since they need to be better prepared to deliver patient-centered solutions to modern healthcare challenges (Trowbridge et al. 2018).

6 Conclusion

This chapter shows how creative thinking and design thinking were employed by design students to generate a significant number of creative ideas for improving patients' QoL. The use of creative thinking enabled substantial numbers of ideas to be generated from a variety of user-focused aspects of patients' QoL during the early stages of a service-product development journey, which is essential for solution-oriented approaches to developing new services and products. However, the results of this study are only a partial step toward following a comprehensive process of design thinking. Future studies require further exploration of the third space of design thinking model: an implementation that develops prototypes and

verification in the clinical field. The continuation of this program will accelerate the understanding of professionalism and lead to innovations in medical services in academia.

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