

EXPLORING THE POTENTIAL ROLE OF DESIGN TO REFRAME THE RESOURCES AND THEIR INTEGRATION IN THE PATIENT EMPOWERMENT PROCESS: THE EXAMPLE OF A PATIENT JOURNEY ANALYSIS IN CHRONIC CARE

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ABSTRACT

Chronic illnesses require comprehensive management of various resources to improve patients' overall health during their lifelong journey. As resources are dynamic and evolving concepts (Vargo & Lusch, 2008), the patient empowerment process could help identify and integrate resources that support patients' needs by reframing resources through co-creation and destruction of value. A patient empowerment process framework and one patient journey were created and used to identify the resources and to illustrate the key moments of resources integration during an exemplar patient experience. The resulting patient journey map with an integration of a patient empowerment process framework was used to reflect on the role of service design in identifying fundamental gaps in integrating

resources and facilitating empowerment processes.

INTRODUCTION TO PATIENT EMPOWERMENT AS A PROCESS

Patient empowerment is an essential process that enables patients to gain more control over their health and daily lives (Anderson & Funnell, 2005). Empowered patients can assess their health better and make informed decisions by sharing their experiences and information with healthcare providers (Colombo et al., 2012; van Uden-Kraan et al., 2009). Gibson (1991) suggested that patient empowerment is a process that helps individuals develop their inner capacities to recognize and solve their own problems, mobilize relevant resources, and utilize their knowledge to address their needs and adjust their resources. Since then, various similar concepts such as patient engagement (Thomson et al., 2005), patient activation (Hibbard et al., 2004), patient involvement and participation (Agner & Braun, 2018; Castro et al., 2016), and patient enablement (Hudon et al., 2010) have been associated with patient empowerment. Although these concepts share similarities, they have different



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meanings. These concepts represent an ongoing process, as shown in Figure 01.

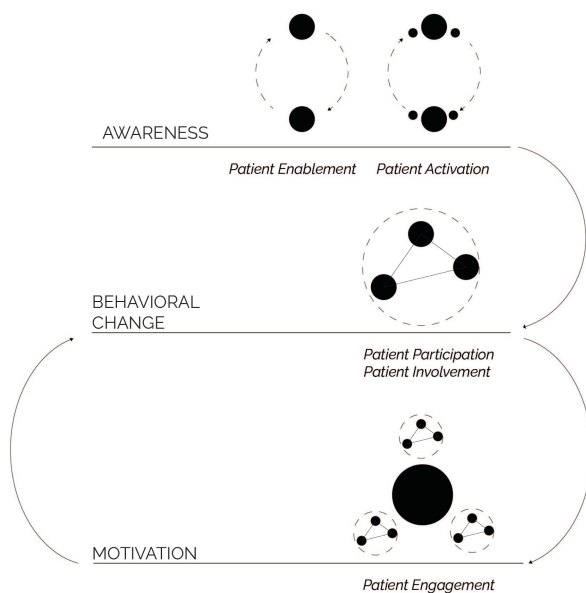


Figure 1: Patient Empowerment Process

The awareness stage is associated with patient enablement and patient activation. Patient enablement involves gaining an increased awareness of one's health status, which is associated with health literacy, and acquiring skills and knowledge to participate in healthcare (Chatzimarkakis, 2010). On the other hand, patient activation is the process of growing awareness of having an essential role in one's healthcare situation and focuses more on specific goals (Hibbard et al., 2004). It is about having goals on more specific domains, and answering questions like "Do you know why you are supposed to take this medication?" (Fumagalli et al., 2015).

The patient empowerment process can then be related with personal change, which includes patient involvement and patient participation (Castro et al., 2016). Both concepts involve an established relationship and collaboration with the healthcare provider (Sahlsten et al., 2018). Patient participation focuses primarily on shared decision-making (Sahlsten et al., 2008), which means interacting with healthcare providers and contributing one's opinion to the decision-making process (Bravo et al., 2015). Patient involvement, on the other hand, includes aspects of self-management and self-care (Hickmann et al., 2022), which refers to the actions individuals take to maintain and improve their own health status (Anderson & Funnell, 2010).

Patient engagement is related to motivation and helps patients discover their own sources of power, evaluate

options, and make choices (Clancy, 2011). Having motivated behaviors can lead to behavioral change, which means these two stages could be an iterative process.

Given the fundamental role played by both the enablement of patients' own resources and the subsequent access to relevant internal resources through patient empowerment processes through these nested concepts, this paper applies the notion of "resources" articulated by the Service Dominant Logic paradigm as a theoretical lens (Vargo & Lusch, 2016).

RESOURCES AND RESOURCES INTEGRATION

Understanding the role of resources and their integration has attracted much attention in service research (Kleinaltenkamp et al., 2012; Ostrom et al., 2015), as resource integration is considered an important key factor for value creation from the perspective of the Service-Dominant Logic (SDL) paradigm (Mele et al., 2010; Peters, 2016), which emphasizes the importance of services, interactions, and relationships between customers and companies in creating value (Vargo & Lusch, 2008).

Service-dominant logic identifies two different types of resources: operant and operand resources (Vargo & Lusch, 2004). Operant resources refer to intangible resources such as technologies, knowledge, and skills (e.g., health literacy and self-care skills), while operand resources refer to tangible resources such as materials (e.g., medicines) and places (e.g., hospitals). Resources are not only represented as tangible or intangible, but they are also defined as the result of a continuous process (Payne et al., 2008) and can be defined as "contextual" and "becoming" (Koskela-Huotari & Vargo, 2016). They are contextual because they are organized by regulative (rules, laws), normative (norms, roles), and cognitive (shared beliefs, understanding) functions (Edvardsson et al., 2014), e.g., the understanding of what is "care" depends on the medical and professional culture. As seen in Figure 2, awareness of contextual resources is the foundation for patients to develop the ability to be part of in their own healthcare. This helps patients to identify and understand the resources that are available to them, such as knowledge, skills, and technologies, as well as the regulative, normative, and cognitive functions that organize those resources.

Resources are also defined as "becoming" because they can be changed and activated through interaction with other actors (Koskela-Huotari et al., 2016), e.g., patients can develop health literacy by accessing effective and relevant information materials. Resources are not fixed things and can be configured differently since actors are also considered a possible and important resource and can be part of the resource integration process (Peters,

2016). As seen in Figure 2, “behavioral change” and “motivation” could be seen as a way of “becoming” a new resource, as individuals acquire new knowledge, skills, and attitudes that enable them to more effectively engage with their environment and achieve their goals. e.g., patients' own motivation to learn can facilitate the integration and application of self-care tools.

Resources do not have inherent value; they only create value when combined with other resources (Chandler & Vargo, 2011; Koskela-Huotari & Vargo, 2016). This means that resources “become” valuable when they are activated and integrated with other resources in a combinatorial process. This paper specifically focuses on the “becoming” of resources and aims to understand how resources can be transformed through a patient empowerment process. Resources have the potential to be reconfigured and integrated into new forms. In this study, we analyze existing resources and explore how they could “become” through design practices.

The purpose of developing this framework is to define the nested concepts in the patient empowerment process to aid in reframing these concepts throughout the process. To better understand the framework, a pilot study was conducted using a semi-structured interview method with a single chronic care patient, based on this conceptual model.

METHODOLOGY

A patient journey map was created based on a semi-structured interview with a chronic care patient. The interview guide was developed from the initial conceptual model of the patient empowerment process, as shown in Fig.02, and focused on the following key research questions:

- 1- What are the essential resources for empowering chronic patients on their healthcare journey? How do patients identify and access these resources?
- 2- What are the critical moments in the resource integration process? How can these moments contribute to value co-creation or destruction?
- 3- How can we identify the fundamental barriers and drivers in the resource integration process?

The interview transcript was used to develop a patient journey map that was divided into three distinct phases: “before diagnosis,” “during diagnosis,” and “after diagnosis.” Additionally, a thematic analysis (Braun & Clarke, 2012) was carried out to identify recurring themes that emerged from the patient's perspective during her journey.

The insights from this analysis were then used to reflect on the potential role of service design.

THE PATIENT JOURNEY MAP

The interviewee, a 33-year-old woman, was diagnosed with rheumatoid arthritis at the age of 24, which caused chronic inflammation of the joints and other parts of the body. Her condition affected her ability to move her fingers, hands, and arms, and later caused digestive problems and irrational bowel syndrome (IBS) due to food allergies. Despite facing numerous obstacles throughout her journey of managing the disease, she gradually managed to access and integrate a diverse range of formal and informal resources to finally effectively manage her condition.

Initially, the patient used emergency services and gained expert help to assess her condition, which could be considered as part of the patient enablement phase. i.e. getting diagnosed based on her symptoms [swollen hands, joint pain] and then understanding why she needs certain medications or can't use hot water in her condition. This increased awareness and knowledge helped her to become an active participant in her own healthcare by seeking knowledge about her condition and starting to question predetermined treatment decisions. This activation led to the behavioral change phase, which is associated with the patient participation and involvement, that in her case meant searching information from the social media. As the patient gained a greater understanding of self-management, she became empowered to more effectively participate in shared decision making with healthcare providers. Her motivation to gain more knowledge was driven by her desire for power and control over her condition, leading her to seek diverse resources to support her journey. i.e., healthcare providers were not the only resources; care providers, influencers, experts in various fields (health, exercise, wellness) began to become more visible through websites, social media, apps, and even some brochures as resources.

THEMATIC ANALYSIS

Thematic analysis was used to understand how the resources integration concept could be used to better understand patient empowerment in her case. Firstly, initial codes were identified, such as “patient education,” “patient involvement,” “being part of the decision-making process,” “information sharing,” “patients' own resources,” “value co-creation,” and “value destruction” to understand the concepts that are nested within the patient empowerment framework with an integration of resources. These initial codes then formed into themes such as “access to resources,” “patient education and information exchange,” “patient involvement in decision making,” and “the impact of patient involvement and resource integration on value outcomes.” These themes were then grouped in the main themes that emerged from this analysis.

Here are the themes that emerged from the single pilot study.

Table 1: Themes that emerged from the thematic analysis

<p>Theme01. The Importance of Trustworthy and Meaningful Information on Patient Empowerment</p>
<p>Accurate, meaningful and trustworthy information in the chronic care journey played a fundamental role in each moment of the process of diagnosis, management and decision-making of the studied patient journey. It was essential for effective chronic care management and decision-making, enabling continuity of care and enhancing patient empowerment through access to diverse resources.</p> <p><i>“...Not knowing the diseases was challenging. On top of it, doctors needed to explain everything adequately to me. I learned everything later. I didnt know what they are doing... I was not given any advice or information on how to live with this disease”</i></p>
<p>Theme 02. The Complementarity of Resource Integration for Balancing Formal and Informal Support System</p>
<p>The interplay of formal and informal support systems was crucial in supporting the holistic health needs of the patient. The integration and development of both personal (e.g. knowledgeable parents) and institutional resources (e.g. hospital) assisted the patient to reach diverse resources in her healthcare journey. The complementarity of resources from different fields played a crucial role in the patient’s ability to effectively manage her condition.</p> <p><i>“...I quickly reached the product [atel for wrist] because my family worked as health professionals and had contacts. Otherwise, my joint would have been damaged. .”</i></p>
<p>Theme 03. Incremental Process of Patient Empowerment through Resources Integration and Access</p>
<p>The process of empowering the patient involved both value co-destruction and co-creation by gradually identifying and bridging the gaps in accessing and integrating the right resources. The process of resources integration for the patient empowerment was clearly a gradual and incremental process, where each step was fundamental to reach the following one, e.g. the diagnosis is a fundamental step to access healthcare resources, which then opens up further search strategies for trustworthy and meaningful resources to the patient's specific needs.</p> <p><i>“I also have IBS syndrome, and my condition is connected with that. I should be cautious about what I need to eat... While searching for IBS, I found an app that was made by a university based on food for people with IBS(irrational bowel syndrome). It helped me to choose the proper nutrition based on my diet.”</i></p>

THE POTENTIAL ROLE OF THE DESIGN PRACTICES TO REFRAME RESOURCES AND THEIR INTERACTION

Service design could support the development of the patient empowerment process that addresses the unique challenges of chronic care by assisting in reframing resources through the lens of patient needs and preferences (Sanders & Stappers, 2014). Mapping available resources through service design practices can identify the resources accessible to patients during the "awareness" stage of their journey, where they are noticing (i.e. noticing that something is wrong and being aware of the symptoms), discovering (i.e. discovering the possible centers to get help), revealing (i.e. reaching and understanding the knowledge about diseases) and identifying (i.e. identifying the patterns of diseases). By identifying barriers and drivers, mapping can facilitate the integration and activation of resources for the next step.

During the chronic care journey, patients may destroy the value of existing resources to create new ones through disruption and making, such as by getting the wrong health information from social media instead of healthcare professionals. Resource integration could lead to both value creation and value destruction, depending on the nature of the resource, the way it is integrated, and the interactions among the individuals involved (Bruce et al., 2019). Co-design practices could identify ways for resources to "become" as they could highlight new venues or strategies to integrate the valuable resources of patients with the ones of healthcare providers or other informal sources.

For instance, a patient who realizes that provided resources are insufficient may transform resources by using social media to follow other patients and gain knowledge instead of following healthcare experts. However, reaching trustworthy and meaningful information in a complex world is not easy, so the patient may need assistance to map resources around themselves. By allowing the patient to speak up for themselves, co-design practices can assist in mapping resources, enabling the patient to be part of the reframing and mobilizing resources. In this way Service design practices could enhance patient empowerment by considering the voice of the patient as a resource itself (Bogaert, 2021), allowing patients to bring their experiences, knowledge, values, beliefs and skills to the service design and improvement process, helping to reshape healthcare resources integration processes (Vargo & Lusch, 2004).

which could be supported by service design practices.

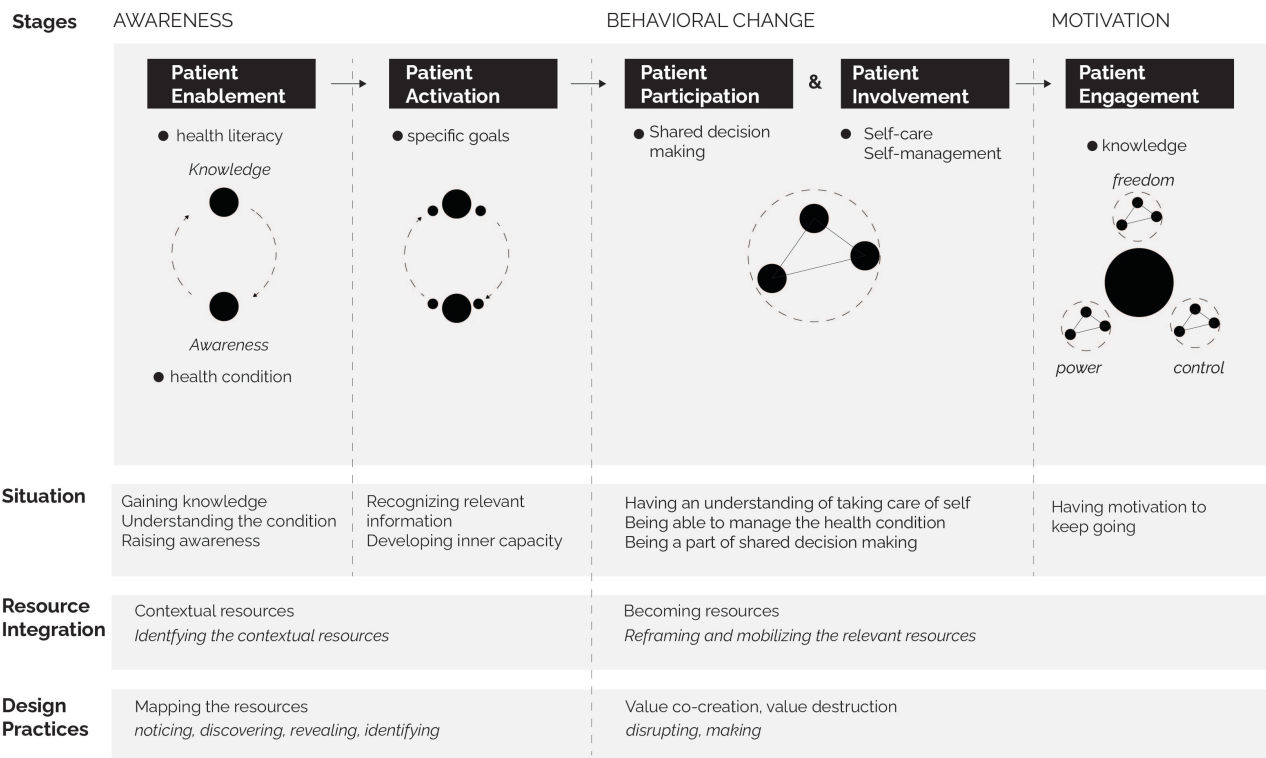


Figure 2: Resource integration with design practices

CONCLUSION

A chronic condition is a long-lasting health condition that typically cannot be cured but can be managed with ongoing treatment and care (WHO, 2023). In recent years, there has been a growing focus on patient empowerment in chronic care which has been linked with similar concepts – i.e. patient enablement, patient activation, patient participation and involvement, patient engagement- however, the definition of it remains still unclear. This exploratory research employed the term "patient empowerment" as an umbrella concept and utilized it as a progressive process that encompasses these similar concepts as stages. Figure 1 shows how these concepts could be interpreted through a progressive patient empowerment process.

Figure 2 instead provides a more detailed overview of the situations that are associated with each stage of the patient empowerment process, as presented in Figure 1. These concepts are interconnected and play a vital role in patient empowerment and the chronic care journey. The purpose of developing this framework was to define the nested concepts in the patient empowerment process adopting the resources integration perspective, in order to document their reframing throughout the process. The patient empowerment process in chronic care requires ongoing and dynamic resources integration and access,

Through mapping resources, service design practices could identify the available resources and the gaps by noticing, discovering, revealing, and identifying contextual resources; and then co-designing new service solutions, helping the reframing by disrupting existing processes and making new opportunities for resources integration.

The purpose of this paper was to reflect on the potential role of service design practices, particularly co-design, in fostering the patient empowerment process by revealing and reframing the resources integration activities (Figure 2). In order to accomplish this, a framework for a patient empowerment process framework was developed and a patient journey was analyzed as a prototype, which identified key moments for resources integration in an individual experience. This led to the creation of a patient journey map, which was used to consider the crucial role co-design practices could have in identifying resources gaps and facilitating empowerment processes (Figure 3). In this case, the patient went through the awareness stage by noticing, discovering, revealing, and identifying resources; then, "behavioral change" and "motivation" stages by disrupting and making the resources, i.e. keeping in touch with other patients to know what she should eat instead of going to nutritionist or used social media for healthcare knowledge. This complex system could be enhanced by facilitating co-design practices to reveal knowledge, beliefs, values, and skills of patients, resulting in them becoming resources.

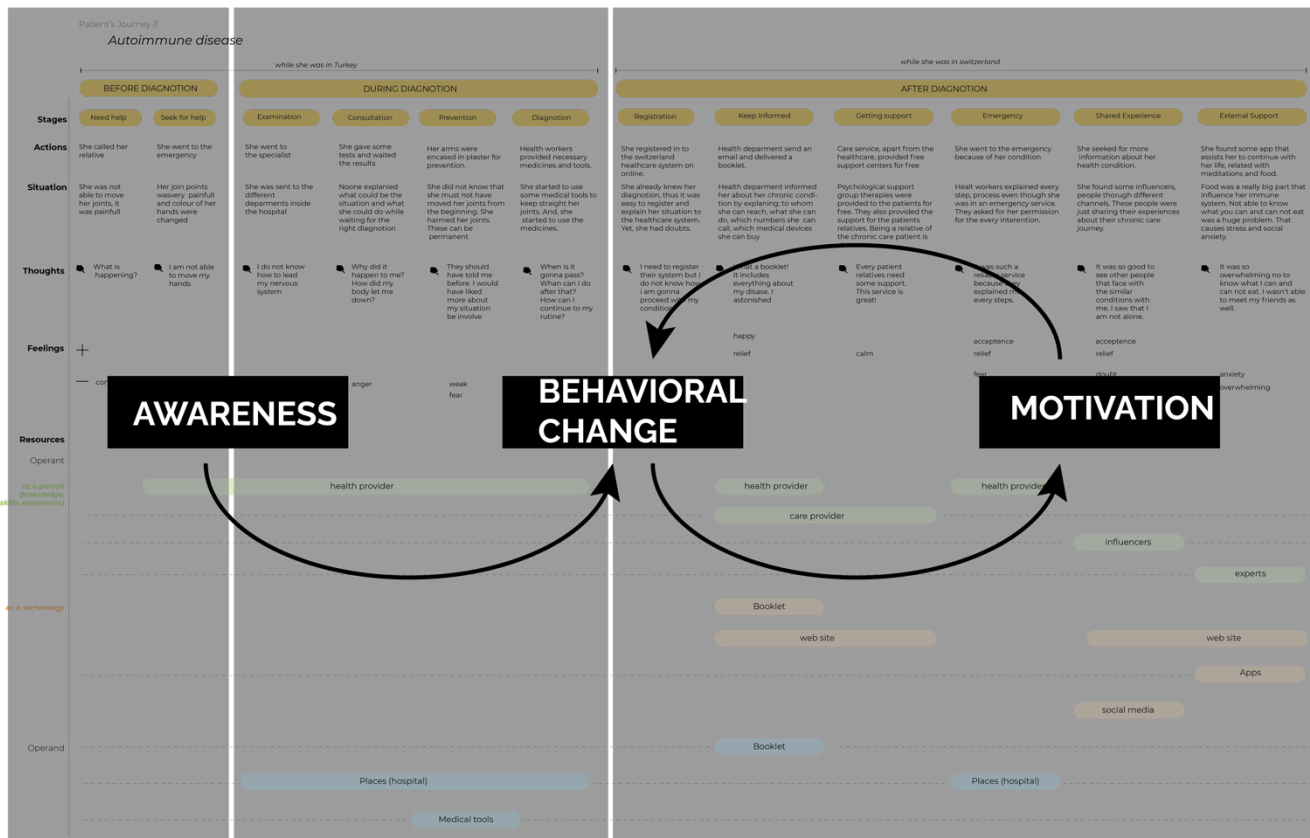


Figure 3: Resulting patient journey map

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