Andreja Ljubič, Tamara Štemberger Kolnik, PhD, Andreja Hrovat Bukovšek, PhD

Mapping the Heart Failure Patient Journey to Enhance Navigational Health Literacy: A Qualitative Study in Slovenia

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ABSTRACT – Heart failure is an escalating challenge that requires coordinated care and patient engagement, yet is often impeded by fragmented communication, inconsistent guidelines, and limited support services. The study mapped the care journey of heart failure patients in Slovenia and, through co-creation with diverse stakeholders, developed an integrated care model. A qualitative study was conducted using: (1) a review of official governmental and healthcare websites; (2) in-depth interviews with service users and professionals; (3) interviews with specialized heart failure teams; (4) the patient journey model design; and (5) validation of the proposed pathway. Data was analysed using the reflexive thematic analysis. The participants emphasized the need for standardized pathways, national guidelines, and systematic monitoring. The key priorities included interdisciplinary collaboration, equitable access to rehabilitation, involvement of patient associations, ProBNP testing in primary care, and preventive empowerment programs supporting early diagnosis and self-efficacy. The co-created, stakeholder-validated care pathway can enhance coordination, transparency, and patient-centredness, while reducing informational gaps and strengthening navigational health literacy and patient empowerment.

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KLJUČNE BESEDE: pot, srčno popuščanje, kontinuiteta oskrbe, vključenost deležnikov, model integrirane oskrbe

POVZETEK – Srčno popuščanje je vse večji izziv, ki zahteva usklajeno obravnavo, vključevanje pacientov in sistemsko integracijo, kar pogosto ovirajo razdrobljena komunikacija, nedosledne smernice in pomanjkanje podpornih storitev. Raziskava opisuje pot pacientov s srčnim popuščanjem v Sloveniji ter s sodelovanjem deležnikov oblikuje integrirani model oskrbe. Izvedena je bila kvalitativna raziskava, ki je vključevala: (1) pregled uradnih spletnih virov, (2) poglobljene intervjuje z uporabniki in strokovnjaki, (3) intervjuje s specializiranimi timi, (4) oblikovanje modela poti in (5) validacijo predlagane poti. Analiza je temeljila na refleksivni tematski analizi. Poudarjena je bila potreba po standardiziranih poteh, nacionalnih smernicah in sistematičnem spremljanju. Ključni so interdisciplinarno sodelovanje, enakopraven dostop do rehabilitacije, vključevanje nevladnih organizacij ter ProBNP testiranje na primarni ravni in preventivni program za zgodnjo diagnostiko in samoučinkovitost. Soustvarjena in validirana pot oskrbe lahko izboljša koordinacijo, preglednost in usmerjenost k pacientu ter zmanjša informacijske vrzeli, hkrati pa krepi navigacijsko zdravstveno pismenost in opolnomočenje pacientov.

1 Introduction

Heart failure (HF) is a complex and chronic condition that significantly impacts the patient's quality of life and poses a substantial burden on healthcare systems

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worldwide (Kwok et al., 2022). Despite advancements in medical therapies and care strategies, HF remains a leading cause of hospitalization, readmissions, and mortality, particularly among the aging populations (Di Salvo et al., 2025). The management of HF requires a multidisciplinary approach that spans the entire patient journey, from early diagnosis and acute care to long-term follow-up and rehabilitation. However, gaps in care coordination, accessibility, and patient education often hinder the optimal outcomes (Rao et al., 2022; Liljeroos et al., 2023).

The patient journey for individuals with HF is marked by numerous challenges, including delayed diagnosis, fragmented care pathways, and insufficient integration of services across primary, secondary, and tertiary care levels (Kwok et al., 2022). Giusti et al. (2024) have shown that patients frequently experience lack of continuity in care, limited access to specialized services, and inadequate support for self-management, all of which contribute to poorer health outcomes and reduced quality of life. Addressing these issues requires a systemic approach that not only enhances clinical care, but also considers the social determinants of health and the broader context of patients’ lives (White-Williams et al., 2020).

Recent research highlights the importance of patient-centred and integrated care models in improving the HF care continuum. For example, multidisciplinary teams that include cardiologists, nurses, pharmacists, and social workers have been shown to enhance care coordination, optimize guideline-directed medical therapy, and reduce hospital readmissions (Di Salvo et al., 2025; Rao et al., 2022). Additionally, innovative approaches, such as cardiac rehabilitation, telehealth interventions, and community-based support services, have demonstrated potential in empowering patients and improving long-term outcomes (Epelde, 2024; Richardson et al., 2019).

This article presents the findings from a study that mapped the journey of heart failure patients in the Slovenian healthcare system. With the co-creation with patients, caregivers, healthcare professionals, policymakers, and community services, we propose an integrated model that ensures continuity of care, timely access, and coordinated support across all levels. By addressing the gaps in early diagnosis, care transitions, and patient involvement, the model aims to improve the outcomes, enhance patient experience, and support a more sustainable healthcare system.

2 Methods

In this study, we applied a combined qualitative research approach drawing on multiple data sources to provide an in-depth understanding of the heart failure patient journey within the Slovenian healthcare system. A central element was the co-creation of the pathway through the active involvement of key stakeholders, enabling holistic insights into access to care, clinical pathways, and support mechanisms.

A systematic overview of the sequential research phases is presented below:

- ☐ *Review of online resources* – We examined the official websites of national authorities and healthcare providers at the primary, secondary, and tertiary levels in

Slovenia, focusing on the type and quality of heart failure-related information accessible to patients through official communication channels.

- □ *Qualitative study with patients and healthcare professionals* – Semi-structured, in-depth interviews with patients and healthcare providers involved in heart failure management explored their experiences, challenges, and perceptions of the adequacy of current services.
- □ *Qualitative study with specialized heart failure teams*– Additional semi-structured interviews were conducted with specialist physicians and nurses in hospital-based heart failure teams in all Slovenian hospitals, following early indication of regional differences and gaps in the organization of care and navigation.
- □ *Design of the patient journey model* – Based on the collected evidence, we developed a comprehensive model of the heart failure patient journey in the Slovenian healthcare system, mapping access routes, key touchpoints, diagnostic and therapeutic interventions, and lifelong rehabilitation.
- □ *Model validation through the additional qualitative study* – To ensure accuracy and clarity, a second round of semi-structured interviews with patients and healthcare professionals was conducted to validate and refine the patient journey map.

2.1 Instrument Description

To capture the comprehensive understanding of the heart failure patient journey, we employed qualitative research instruments tailored to each phase of the study: (1) systematic review of online sources, (2) semi-structured in-depth interviews, (3) interviews with hospital and hospital heart failure teams, and (4) validation interviews with professionals and healthcare users.

2.1.1 Systematic Review of Online Sources

We used a structured review protocol to analyse official online sources, including websites of governmental bodies and healthcare institutions at all levels of care. The protocol specified search strategies, inclusion criteria, and a standardized extraction template, with an emphasis on patient-facing information. Guided by the principles of environmental scanning and organizational health literacy (Farmanova et al., 2018), the review assessed the accessibility, relevance, and contextual adequacy of heart failure information, as well as the presence of key terms, patient education materials, and descriptions of relevant programs.

2.1.2 Semi-Structured In-Depth Interviews for Mapping the Patient Journey

Semi-structured in-depth interviews were used to capture subjective perceptions and experiences of patients and professionals (Shaban et al., 2024). Patient interviews addressed (1) diagnosis and initial navigation, (2) treatment and rehabilitation, and (3) living with the disease. Interviews with the professionals focused on (1) patient empowerment across levels of care and (2) strategies used to guide and support patients within the system. Open-ended questions allowed the participants to freely express views, highlighting emotions, lived experience, and the complexity of living with heart failure, thereby informing patient-centred care strategies.

2.1.3 Interviews with Specialized Heart Failure Teams

Building on the initial findings of unequal access, limited patient information, and navigation difficulties, we conducted semi-structured interviews with specialized heart failure teams to examine the patient pathway after the diagnosis and during hospital treatment, with an emphasis on the integration between the secondary and primary care. The instrument comprised twelve guiding questions on diagnostics, communication of diagnosis, multidisciplinary treatment, rehabilitation, and coordination of care, including collaboration with non-governmental organizations. This enabled the analysis of system-level processes and barriers affecting the patients' navigational health literacy.

2.1.4 Validation Interviews for the Patient Journey Map

To evaluate the clarity, relevance, and applicability of the patient journey map, we carried out additional semi-structured interviews with healthcare professionals and selected users. Informed by user-centred design principles (Walden et al., 2020) and reflective qualitative practice, this phase assessed content validity, comprehensibility, and the perceived utility of the graphical model. The core question concerned the usefulness and structure of the model, with interview questions grouped into seven domains: (1) completeness of the journey, (2) quality and safety of care, (3) access to services, (4) coordination across levels of care, (5) responsiveness to patient needs, (6) treatment effectiveness and outcomes, and (7) the role of digital and technological support.

2.2 Sample Description

The sample followed a phased, purposive design, aligned with the objectives of each stage. In the second phase, in-depth interviews were conducted with seven patients diagnosed with heart failure and two healthcare professionals. The primary inclusion criterion was personal experience with heart failure care across multiple levels of the Slovenian healthcare system; additional criteria (age, sex, geographic region) ensured heterogeneity. The experts were included based on their clinical experience in the management of heart failure and their involvement in the national care strategies.

In the third phase, interviews were conducted with specialized heart failure teams in 12 Slovenian hospitals, comprising physicians and nurses involved in inpatient and outpatient care, providing insight into diagnostics, coordination, and interprofessional collaboration.

The fifth phase focused on validating the patient journey map. The final validation sample consisted of four patients, four healthcare professionals (general practitioner, internist, cardiologist, registered nurse), and two representatives of non-governmental organizations (NGO), enabling integration of patient, professional, and civil society perspectives.

2.3 Data Collection and Data Analysis

The participants were purposively sampled to maximise heterogeneity in roles, institutions, and lived experience across the heart failure care continuum. The experts were recruited via the clinical partners, associations, and direct contacts; the patients were approached during routine outpatient visits through physician referrals; and additional representatives of associations and NGOs were invited.

Data collection took place in three sequential phases (February 2023 - January 2024): (1) individual semi-structured interviews with patients and experts, (2) semi -structured interviews with hospital heart failure teams, and (3) validation meetings with a dedicated sub-sample to critically review and refine the draft pathway. All interviews were conducted in person or via secure video conferencing, lasted 30-90 minutes, were audio-recorded, transcribed verbatim, and anonymized. Ethical approval was obtained from the Commission for Medical Ethics of the Republic of Slovenia (No. 0120-62/2022/3).

Data analysis followed an iterative, multi-phase process. The reflexive thematic analysis of Phase 1 and 2 transcripts, combined with the existing clinical guidelines for heart failure management, informed the development of a provisional journey map. This draft was then validated and refined through stakeholder feedback in Phase 3, resulting in a comprehensive, guideline-informed, and co-created representation of the care pathway.

3 Results

3.1 Systematic Review of Online Sources

The review included websites of 68 primary care centres and 27 hospitals (secondary and tertiary levels). A total of 46 relevant hits were identified using the keyword heart failure, with a higher number found on hospital websites. The content most frequently focused on the general descriptions of the disease, its symptoms, incidence, and risk factors. Some entries also addressed treatment options, advice on recognizing heart failure, and guidance on where to seek help. Two posts were more extensive and patient-oriented ("presentation of patients with heart failure"), while additional resources included a video with advice and an informational leaflet. Overall, the content was largely oriented toward patients, with an emphasis on the navigation through the healthcare system, understanding the disease, and self-management. Comparatively, fewer resources were directed at healthcare professionals, where available materials focused mainly on disease understanding and treatment guidance.

3.2 In-Depth Interviews for Identifying Key Stages in the Patient Journey

Table 1 presents the thematic categories derived from the interviews with the patients and healthcare professionals. Three overarching themes were identified. First, Barriers in the Healthcare System highlight a restricted access to professionals, fragmented communication, and patient-related challenges that hinder engagement in care. Second, Key Elements for Disease Management emphasize the importance of professional and family support, consistent information, and patient empowerment through education and self-care. Finally, Proposals for Improvement point to the need for systematic follow-up, integrated services, targeted health literacy initiatives, and specialized rehabilitation programs to strengthen the continuity and quality of care.

Table 1

Thematic Coding from In-Depth Interviews: Identification of Key Stages in the Heart Failure Patient Journey/Tematsko kodiranje iz poglobljenih intervjujev: opredelitev ključnih faz v poteku bolezni pri bolnikih s srčnim popuščanjem

Code (Thematic Category)	*Subcode*	*Subcode Description*	*Illustrative Quote*
Barriers in the Healthcare System	Access to healthcare professionals	Patients report extended waiting times, difficulties reaching physicians, and overburdened staff, although some emphasize positive experiences of daily monitoring.	"I had to wait months just to see a specialist, the whole treatment process felt like it was dragging on forever. "
	Technical Barriers	Fragmented communication, insufficient provision of information, and poor coordination between levels of care hinder effective treatment.	"The nurses did give me some information, but honestly, it often wasn't enough or clear enough. "
	Patient Attitudes	Fear of asking questions, distrust in physicians, and attention-seeking behaviour can limit effective engagement in treatment.	"Some patients were constantly calling for the staff's attention, and it kind of messed up the flow of care for the rest of us. "
Key Elements for Disease Management	Support from Professionals and Family	Healthcare professionals and family members play a central role in providing both emotional and practical support.	"Having my family there and doctors who spoke to me kindly made such a difference, it really helped me feel safe and recover faster. "
	Information Inconsistencies	Patients face inconsistent, incomplete, and sometimes contradictory information, complicating their ability to navigate the healthcare system.	"Going back and forth between different institutions was really confusing, especially since I'd never dealt with that before. "
	Self-Care and Empowerment	Education, empowerment, and health literacy are critical for strengthening self-care, reducing hospital readmissions, and improving quality of life.	"Once I learned how to take care of myself, I felt like I had more control over my condition. "

Proposals for Improvement	System Improvements	Suggestions included systematic follow-up, integration of healthcare services, enhanced health literacy initiatives, and specialized rehabilitation programs.	"I wish there were proper rehab facilities where you could just focus on getting better without all the distractions."

3.3 Interviews with Specialized Heart Failure Teams

Based on the data analysis, the research team concluded that the dataset enables not only the examination of navigational health literacy but also broader dimensions of general health literacy, such as health promotion, chronic disease management, and healthcare utilization, as well as other related domains, including digital and communicative health literacy (HLS-EU Consortium, 2012; Sørensen et al., 2015). Through the identification of codes, we developed thematic areas that were subsequently grouped into the following categories: (1) general health literacy, (2) navigation within the healthcare system, (3) digital literacy, (4) communicative health literacy, and (5) interprofessional collaboration (Table 2).

Table 2

Thematic Coding of Interviews with Specialized Heart Failure Teams/Tematsko kodiranje intervjujev s specializiranimi timi za obravnavo pacientov s srčnim popuščanjem

Category	*Theme*	*Examples of Codes*
General Health Literacy	Health Promotion	Healthy lifestyle; well-being; vaccination recommendations
	Disease Prevention	Self-care (weight management, regular weighing); balanced nutrition; self-monitoring; adapted physical activity
	Healthcare	Education about disease; living with heart failure; home management; medication adherence; patient diary; six-minute walk test; recognition of deterioration
Navigation in the Healthcare System	Regular Monitoring	Heart failure clinic follow-up; cardiology check-up; family medicine monitoring
	Patient Guidance	Navigation in case of problems; referral to reference clinics; healthy lifestyle workshops; non-governmental organizations
Digital Literacy	Patient Monitoring	24-hour blood pressure monitoring; telemedicine
Communication Health Literacy	Communication with patient	Individual and group conversations; written instructions; educational materials
	Checking Understanding	Assessing comprehension during follow-ups; review of patient diaries; telephone consultations; targeted education and re-education
	Involvement of Family	Contact and involvement of relatives; education of family members
Interprofessional Collaboration	Multidisciplinary Team	Physician; nurse; clinical pharmacist; physiotherapist; dietitian; occupational therapist; social worker; psychologist; laboratory specialist; radiology technician; community nurse visits

Based on the collected data, we developed a patient journey map for individuals with heart failure within the healthcare system, which was then validated in the next phase of the research. In preparing the map, we conducted a comprehensive review of the relevant clinical pathways, existing guidelines and official websites of institutions. Particular attention was paid to identifying healthcare touchpoints at all levels of care, as well as available services for patients in the local community, including support, psychosocial and rehabilitation programs. This holistic approach ensured that the patient journey map reflected not only the formal structure of care for patients with heart failure, but also the wider resources and services available to patients in their everyday environment.

3.4 Semi-Structured Interviews for the Validation of the Patient Journey

The final phase of the study centred on the collaborative development, validation, and refinement of the journey map, with a particular emphasis on stakeholder-driven improvements to enhance patient navigation and health literacy. This phase underscored that the main challenges in heart failure care are not primarily financial but structural, relating to coordination, education, and integration across the system. Both patients and professionals emphasized the need for the standardized and unified patient pathways and clinical guidelines at the national level, supported by a systematic monitoring of heart failure patients. Strengthening interdisciplinary collaboration and ensuring stronger connections between the primary, secondary, and tertiary care, as well as with the local stakeholders, were identified as essential. The participants highlighted the importance of expanding rehabilitation services with equitable regional access, and integrating patient associations and preventive workshops as key contributors to health literacy. Finally, introducing proBNP testing at the primary care level and reinforcing patient empowerment preventive programs were recognized as crucial steps to improve early diagnosis, continuity of care, and self-efficacy in disease management. The identified themes are presented below.

Theme 1: Accessibility of Specialist Services, Fragmentation and Systemic Barriers

Both patients and experts identified significant systemic barriers to effective heart failure care, primarily linked to limited accessibility of specialist outpatient services, workforce overload, and fragmented coordination across the levels of care. Long waiting times, difficulties reaching physicians, and insufficient consultation time were reported by the patients: "Doctors are often unreachable by phone … they don't have time for conversation." (P3) The experts, on the other hand, emphasized staff shortages and inadequate infrastructure, particularly in certain regions. The lack of unified national guidelines and reliance on individual initiatives further contribute to inconsistencies in professional knowledge and patient instructions: "… information differs even among professionals, … we are overloaded …" (SPE2). The fragmented communication between the primary, secondary, and tertiary care often results in unclear responsibilities, lost data, and delays, leaving patients uncertain about where to turn for test results or follow-up. Overall, these structural deficiencies reinforce inequality of access, undermine continuity of care, and increase reliance on emergency hospital admissions.

Theme 2: Multidisciplinary Care

Validation confirmed that multidisciplinary care is central to improved outcomes. The involvement of different healthcare professionals was described as crucial. The experts stressed that multidisciplinary monitoring during hospitalization significantly improves patient self-care and quality of life, while reducing rehospitalizations. Also, nurses were repeatedly described as the "first point of contact" (SPE4) and continuous companions along the patient journey. Beyond providing clinical care, they play a central role in education, motivation, and follow-up after hospital discharge. They act as a bridge between the hospital and community care, directing patients to reference clinics, community nursing, lifestyle workshops, and patient associations.

Theme 3: Rehabilitation, Diagnostics, Continuity, and Digital Support

Both patients and professionals emphasized the importance of rehabilitation, with many expressing that programs should take place in the rehabilitation centres or health resorts rather than hospitals. As one participant suggested: "If you dedicate the whole day just to therapies … in a health resort, that would be positive" (P1) The experts further stressed equity of access, highlighting: "Therapeutic programs must be accessible to all patients with heart failure, and health resorts should play an active role in continuing rehabilitation." (SPE2)

The experts further proposed: "ProBNP testing should be introduced at the primary care level and in emergency departments as a standard part of the diagnostic process for suspected heart failure." (SPE1) This would allow for faster and more reliable diagnosis and reduce unnecessary delays in treatment.

After hospital discharge, the continuity of care is ensured in specialized heart failure clinics, where patients receive clinical monitoring, medication titration, additional diagnostics, and lifelong rehabilitation. Digital tools, such as telemonitoring and 24-hour blood pressure monitoring, were highlighted as promising innovations for improving care quality and detecting complications early.

Theme 4: Health Literacy and Patient Empowerment

The interviews highlighted the critical gaps in patient information and health literacy, which limited self-management and confidence in care. The patients frequently described receiving only verbal instructions about the prevention and lifestyle adaptation, which were easily forgotten. As one explained: "If I got it in writing, it would be easier to understand, but otherwise you just forget." (P4) Another suggested: "… better information about prevention and life with the disease, … through oral counselling or leaflets …" (P2) The patients also noted inconsistent advice across providers, creating confusion regarding treatment and daily management. The experts agreed that the issue lies not only in the access to information but also in the comprehension and use.

As one specialist stressed: "At follow-ups, we check understanding and knowledge, provide individual health education, review the diary of vital signs …" (SPE3)

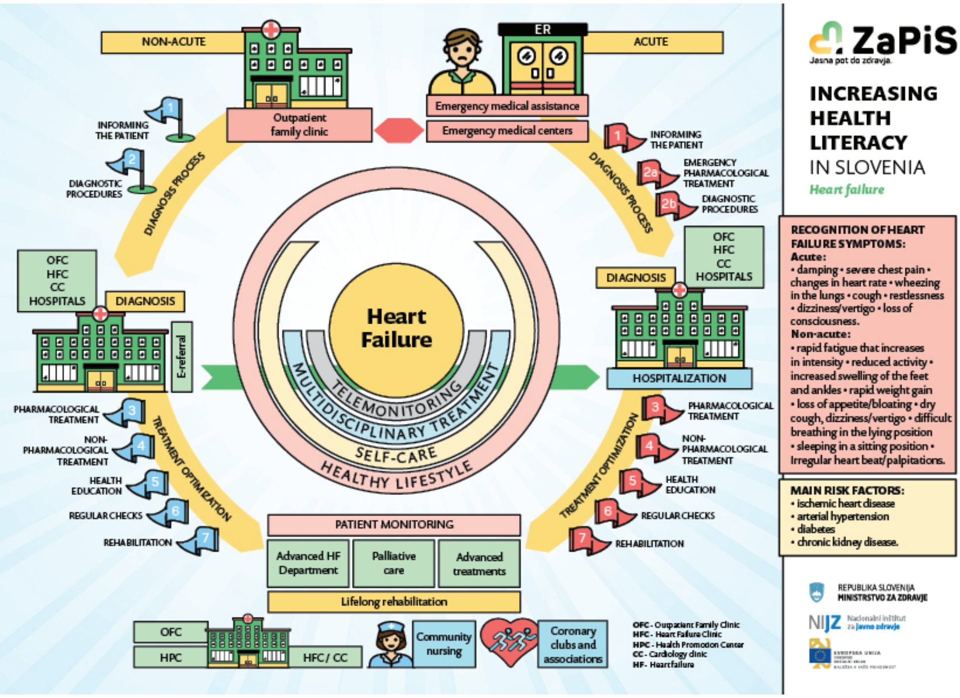
A key element of empowerment was support from family members, who often compensate for the absence of formal psychosocial services. Relatives assist with diet, physical activity, and emotional well-being, as one patient reflected: "My wife helped me understand what I can eat and what I cannot …" (P3) The experts emphasized that families should be systematically included in the education and rehabilitation programs, as this strengthens the patients' self-efficacy. At the same time, the patients' attitudes, such as reluctance to ask questions, distrust of physicians, or attention-seeking, were identified as barriers to constructive collaboration with healthcare professionals.

A comparison of perspectives across the participant groups and research phases revealed notable differences in how the heart failure care pathway is experienced and understood. The patients emphasized the challenges related to access, long waiting times, inconsistent or insufficient information, and uncertainty during the transitions between the levels of care. The healthcare professionals, in contrast, predominantly highlighted the systemic constraints – staff shortages, workload pressures, and the absence of unified national guidelines – which they believed contribute to informational inconsistency and hinder the continuity of care. The specialized heart failure teams further underscored the importance of early diagnostics, strengthened multidisciplinary collaboration, and expanded rehabilitation services. The validation phase confirmed these distinctions: while the patients stressed the need for clear, coherent information and structured navigation support, the professionals emphasized system-level standardization and improved interprofessional communication as critical to addressing the current gaps.

The model's visual and stepwise approach, including decision points, responsibilities, and timelines, was identified as decisive for promoting health literacy and effective system navigation. Figure 1 illustrates the mapped journey of heart failure patients within the Slovenian healthcare system.

Figure 1

Heart Failure Patient Journey in the Slovenian Healthcare System/Pot pacienta s srčnim popuščanjem v slovenskem zdravstvenem sistemu



4 Discussion

The patient journey for individuals with heart failure is complex and multifaceted, requiring a strong emphasis on navigational health literacy, patient empowerment, self-efficacy, multidisciplinary collaboration, and co-creation within the healthcare system. Navigational health literacy plays a central role, enabling patients to understand their condition, engage in self-management, and effectively navigate healthcare services. Evidence suggests that patients with higher levels of health literacy achieve better self-care and experience fewer hospitalizations (Chen et al., 2020). However, fragmented communication and inconsistent information continue to hinder effective navigation (Štemberger Kolnik et al., 2024). These challenges were also reflected in our research, where both patients and professionals emphasized the need for standardized and unified national guidelines, supported by a systematic monitoring of heart failure patients.

Patient empowerment, supported through education and ongoing guidance, is equally critical. Empowered patients are more likely to adhere to treatment and engage actively in care (Hickmann et al., 2022). Closely linked is self-efficacy, the belief in a person's ability to manage health, which has been shown to improve self-care behaviours in chronic conditions, such as heart failure (Nesbitt et al., 2021). Validation findings underscored this need by highlighting the importance of reinforcing patient empowerment programs at the primary care level and within the local community, ensuring accessible preventive support initiatives that help patients strengthen their self-management skills and cope more effectively with their condition.

Multidisciplinary collaboration further strengthens self-efficacy by providing consistent, tailored support across different professional roles, including physicians, nurses, pharmacists, and dietitians (Rao et al., 2022). Validation results confirmed this by pointing to the need to strengthen the interdisciplinary connections and ensure a closer integration between the primary, secondary, and tertiary care, as well as with the local stakeholders. Introducing diagnostic tools, such as proBNP testing, which may facilitate earlier diagnosis and support patients' confidence in managing their disease, was further emphasized as a crucial step to improve accessibility to rapid diagnostics at the entry point into the healthcare system. The importance of digital tools, such as telemonitoring, 24-hour blood pressure monitoring, and digital diaries, was emphasized, which can enhance early detection of deterioration and increase the effectiveness of treatment (Dibek et al., 2025). Expanding rehabilitation services with equitable regional access was also recognized as essential for ensuring the continuity of care and supporting patients' long-term management.

Co-creation in healthcare involves patients actively participating in their care, which can significantly enhance their health literacy and self-management capabilities. The development of patient journey maps, as highlighted in recent studies, facilitates a better understanding of the patient experience and identifies key touchpoints for intervention (Wu et al., 2025). This collaborative approach not only empowers patients, but also fosters a sense of ownership over their health, leading to improved adherence to treatment and better health outcomes (Fomo et al., 2025). In this respect, integrating patient associations and preventive workshops into the patient pathway, as emphasized by the participants in the validation phase, is a meaningful step toward co-creation and health literacy promotion.

Although the patient journey model was developed within the Slovenian healthcare system, its core components – navigational health literacy, early diagnostics, multidisciplinary coordination, patient empowerment, and clearly defined transitions of care – align with the internationally recognized principles of heart failure management. As such, the model holds potential for transferability to other clinical or geographical settings, particularly those facing similar challenges of fragmentation, unequal access, or limited coordination between care levels. While local adaptation would be necessary in systems with different organizational structures or resource constraints, the model's foundational elements – standardized patient pathways, transparent responsibilities, and active involvement of patients and families – remain broadly applicable and relevant.

5 Conclusion

Enhancing navigational health literacy, fostering empowerment and self-efficacy, and promoting multidisciplinary and co-creative approaches are vital to improving the patient journey for individuals with heart failure. Overcoming systemic barriers through standardized, integrated care and targeted support can significantly improve the outcomes and quality of life. Future research should continue to explore innovative strategies, including technological solutions and collaborative practices, to further empower patients in managing their condition.

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Andreja Ljubič, dr. Tamara Štemberger Kolnik, dr. Andreja Hrovat Bukovšek

Model poti pacienta s srčnim popuščanjem za dvig navigacijske zdravstvene pismenosti: kvalitativna študija v Sloveniji

Srčno popuščanje predstavlja globalno naraščajoč izziv za zdravstvene sisteme, saj zahteva kontinuirano, usklajeno in pacientu prilagojeno obravnavo. Kljub napredku v zdravljenju ostaja srčno popuščanje eden vodilnih vzrokov za hospitalizacije, ponovne sprejeme in smrtnost, kar je zlasti povezano z nepopolno integracijo različnih ravni zdravstvene oskrbe, omejenim dostopom do strokovnjakov ter pomanjkanjem kontinuirane podpore pacientom (Kwok idr., 2022; Liljeroos idr., 2023). Kot poudarjajo Rao idr. (2022) ter Di Salvo idr. (2025), učinkovita obravnava pacienta s srčnim popuščanjem temelji na multidisciplinarnosti, zgodnji diagnostiki in strukturirani vseživljenjski rehabilitaciji, medtem ko White-Williams idr. (2020) izpostavljajo tudi vpliv širših socialnih determinant zdravja na izide zdravljenja. Zaradi teh razhajanj postaja navigacijska zdravstvena pismenost ključni element pri razumevanju bolezni, sprejemanju odločitev in samostojnemu upravljanju kroničnega stanja (Chen idr., 2020; Nesbitt idr., 2021). Pričujoča študija je s kombinirano kvalitativno metodologijo celostno preučila pot pacientov s srčnim popuščanjem v slovenskem zdravstvenem sistemu ter z uporabo načel soustvarjanja vključila paciente, svojce, zdravstvene delavce, specializirane time za obravnavo pacientov s srčnim popuščanjem, zdravstvene odločevalce in predstavnike nevladnih organizacij. Raziskovalni pristop je združeval pet komplementarnih faz: sistematični pregled spletnih strani državnih institucij in zdravstvenih ustanov, polstrukturirane intervjuje s pacienti in zdravstvenimi delavci, dodatne intervjuje s specializiranimi timi za obravnavo pacientov s srčnim popuščanjem v vseh slovenskih bolnišnicah, oblikovanje modela poti pacienta ter

končno validacijo z uporabniki in strokovnjaki. Podatki so bili analizirani s pomočjo refleksivne tematske analize, kar je omogočilo identifikacijo ovir, potreb in priložnosti za izboljšanje obravnave. Sistematični pregled spletnih virov je pokazal, da so informacije o srčnem popuščanju na spletnih straneh zdravstvenih domov in bolnišnic večinoma splošne, redkeje podrobno klinično ali uporabniško usmerjene. Med 68 zdravstvenimi domovi in 27 bolnišnicami je bilo identificirano le 46 vsebinsko relevantnih objav, predvsem na bolnišničnih straneh. Vsebine so se v večini osredotočale na opis bolezni, simptome, dejavnike tveganja in osnovne možnosti zdravljenja, redkeje pa na rehabilitacijo, vlogo svojcev ali dolgoročno samooskrbo. Dostopnost in preglednost podatkov se med ustanovami močno razlikujeta, kar kaže na neenotno raven organizacijske zdravstvene pismenosti v zdravstvenem sistemu (Farmanova idr., 2018). Poglobljeni intervjuji s pacienti in strokovnjaki so razkrili tri večje tematske sklope. V prvem sklopu so bile izpostavljene ovire v sistemu: dolge čakalne dobe, omejena dostopnost zdravnikov, preobremenjenost kadra, pomanjkanje časa za pogovor, razdrobljena komunikacija med ravnmi oskrbe in strah pacientov pred spraševanjem. Drugi sklop predstavlja ključne elemente za uspešno obvladovanje bolezni: strokovna in čustvena podpora zdravstvenega osebja in družine, dosledne in med seboj usklajene informacije, postopno opolnomočenje in spodbujanje samooskrbe. Tretji sklop so predlogi za izboljšave, ki vključujejo sistematično spremljanje pacientov, integracijo storitev, razširitev rehabilitacijskih programov ter razvoj ciljno usmerjenih izobraževalnih in preventivnih delavnic. Intervjuji s specializiranimi timi za obravnavo pacientov s srčnim popuščanjem so dodatno poudarili pomen zdravstvene pismenosti kot večdimenzionalnega koncepta. Komunikacijska dimenzija zdravstvene pismenosti se kaže v prilagojenem svetovanju, pisnih navodilih, preverjanju razumevanja in vključevanju svojcev. Strokovnjaki so poudarili potrebe po zgodnji diagnostiki, med katero pomembno vlogo zavzema določanje proteina NT-proBNP v krvi (presejalni test za srčno popuščanje) na primarni ravni, kar bi omogočilo hitrejše prepoznavanje bolezni in zmanjšalo nepotrebne napotitve ter hospitalizacije. Prav tako so poudarili pomen digitalnih orodij, kot so telemonitoring, 24-urno spremljanje krvnega tlaka in digitalni dnevniki, ki lahko izboljšajo zgodnje zaznavanje poslabšanja in povečajo učinkovitost obravnave (Dibek idr., 2025). Za učinkovito obvladovanje srčnega popuščanja je nujna dobro organizirana multidisciplinarna obravnava, ki vključuje zdravnike, medicinske sestre, farmacevte, fizioterapevte, dietetike, psihologe in druge strokovnjake. Medicinske sestre so bile opisane kot ključni akterji v komunikaciji, edukaciji in spremljanju pacientov skozi celotno pot, tudi po odpustu iz bolnišnice. Validacija razvitega modela poti pacienta je potrdila, da glavni izzivi pri obravnavi SP v Sloveniji niso le finančni, temveč predvsem strukturni. Potrjene so bile uporabnost, preglednost in praktična vrednost modela. Uporabniki so ocenili, da vizualna predstavitev pomembno prispeva k razumevanju prehodov med ravnmi oskrbe, omogoča boljšo orientacijo v sistemu ter povečuje občutek nadzora nad lastnim zdravljenjem. Med ključnimi izboljšavami, ki jih je treba sistemsko uvesti, so izpostavili: uvedbo proBNP testiranja v primarnem zdravstvu in urgentnih službah, kar bi pospešilo diagnostiko, razvoj nacionalno usklajenega protokola za obravnavo srčnega popuščanja, krepitev interdisciplinarnega sodelovanja, večjo vključenost lokalnih skupnosti in nevladnih organiza-

cij, regionalno enakomernejšo dostopnost rehabilitacijskih programov ter krepitev preventivnih programov za opolnomočenje pacientov v primarnem zdravstvu. Skladno s sodobnimi raziskavami (Rao idr., 2022; Epelde, 2024) validacija potrjuje, da integrirana in pacientu prilagojena oskrba zmanjšuje fragmentacijo in izboljšuje izide zdravljenja. Raziskava poudarja, da sta navigacijska zdravstvena pismenost in opolnomočenje pacientov ključna dejavnika za uspešno obvladovanje srčnega popuščanja. Pacienti z višjo stopnjo zdravstvene pismenosti izkazujejo boljšo samooskrbo, večjo adherenco ter manj hospitalizacij (Chen idr., 2020; Nesbitt idr., 2021). Soustvarjanje modela poti pacienta dodatno spodbuja občutek vključevanja in razumevanja lastnega zdravljenja, kar potrjujejo tudi druge raziskave o uporabniško usmerjenih pristopih v kliničnem okolju (Walden idr., 2020; Wu idr., 2025). Študija hkrati opozarja na strukturne ovire sistema, med katerimi so najpomembnejše pomanjkanje usklajenih smernic, neenakomerna regionalna dostopnost storitev, zamude pri diagnostiki ter nekontinuirana obravnava med ravnmi oskrbe. Raziskava potrjuje, da celostno zasnovana, soustvarjena pot pacienta s srčnim popuščanjem predstavlja ključen korak k izboljšanju kontinuitete oskrbe, preglednosti sistema ter večji vključitvi pacientov v lastno zdravljenje. Takšen model presega tradicionalne linearne klinične poti, saj upošteva dejanske izkušnje pacientov, njihove potrebe ter sistemske okoliščine, s katerimi se srečujejo na prehodih med ravnmi zdravstvene obravnave. Rezultati jasno kažejo, da bolj usklajeni in standardizirani procesi – od zgodnje diagnostike, kamor sodi tudi uvedba proBNP testiranja na primarni ravni, do razširitve dostopnih rehabilitacijskih programov – pomembno prispevajo k hitrejšemu prepoznavanju bolezni, učinkovitejšemu zdravljenju in manjšemu številu nepotrebnih hospitalizacij. Poleg strukturnih izboljšav raziskava izpostavlja tudi nujnost krepitev preventivnih, edukativnih in psihosocialnih aktivnosti, ki so temelj opolnomočenja pacientov in njihovega dolgoročnega obvladovanja bolezni. Navigacijska zdravstvena pismenost se kaže kot osrednji mehanizem, preko katerega pacienti dobijo znanje in spretnosti za učinkovito uporabo zdravstvenih storitev, razumevanje navodil ter ustrezno samooskrbo. V tem kontekstu model poti ne predstavlja zgolj tehničnega opisa postopkov, temveč uporabno in večplastno orodje, ki pacientom, svojcem in strokovnjakom omogoča jasnejšo orientacijo, lažje razumevanje odgovornosti ter boljšo povezanost med različnimi ravnmi sistema. Soustvarjanje, ki je temeljni princip raziskave, se je izkazalo kot izjemno pomembno, saj vključevanje pacientov, zdravstvenih delavcev, nevladnih organizacij in odločevalcev omogoča bolj realistično, izvedljivo in trajnostno zasnovo integriranih modelov oskrbe. Validacija poti dodatno krepi legitimnost predlaganih rešitev in odpira možnosti za njihovo implementacijo v širši zdravstveni kontekst. Celovito gledano rezultati raziskave nudijo dragocena izhodišča za nadaljnji razvoj zdravstvenih politik in implementacijo integriranih modelov oskrbe, ki temeljijo na enakosti, multidisciplinarnosti in pacientu prilagojenih pristopih. Okrepljena navigacijska zdravstvena pismenost, visoka stopnja pacientovega opolnomočenja ter učinkovito medpoklicno sodelovanje predstavljajo ključne vzvode za bolj kakovostno, pravično in trajnostno obravnavo pacienta s srčnim popuščanjem v Sloveniji. Vse to kaže, da usklajen, soustvarjen in jasno strukturiran model oskrbe ni le priložnost, temveč nujen korak k sodobnemu in pacientu prijaznemu zdravstvenemu sistemu.

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Andreja Ljubič, MSc in Nursing, lecturer at the Faculty of Health Sciences in Celje
E-mail: andreja.ljubic@fzvce.si
ORCID: https://orcid.org/0000-0003-1310-8793

Tamara Štemberger Kolnik, PhD, Associate Professor at the Faculty of Health Sciences in Celje
E-mail: tamara.stemberger-kolnik@fzvce.si
ORCID: https://orcid.org/0000-0002-8241-0550

Andreja Hrovat Bukovšek, PhD, Associate Professor at the Faculty of Health Sciences in Celje and employed at the Celje General Hospital
E-mail: andreja.hrovat-bukovsek@fzvce.si
ORCID: https://orcid.org/0000-0003-1271-2737