

Evaluating the Real-World Applicability of Healthcare Transition.

A Qualitative Study Across Disciplines

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Keywords

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Abstract

Purpose

Increasing prevalence and improved survival of children with a chronic disease necessitate effective transition programs for adolescents transferring to adult care services. Despite established benefits, real-world implementation of these programs varies across medical disciplines. This study aimed to elucidate the multifactorial nature of transition implementation and the underlying variations across disciplines from the perspectives of healthcare providers.

Methods

We conducted a qualitative Grounded Theory study using the Gioia method to explore real-world applicability factors of transition by in-depth interviews. Pediatricians and adult care physicians (N=18), representing diverse medical disciplines (i.e., cardiology, pneumology, gastro-enterology and hepatology, nephrology and rheumatology, oncology and hematology, neurology, endocrinology, and urology) were recruited using a theoretical sampling strategy.

Results

We identified a wide range of challenges of implementation, with variation across medical disciplines, resulting in four theoretical domains influencing the applicability of transition programs: healthcare service characteristics, personal factors, adjustability, and continuity. A cross-discipline key barrier for a comprehensive transition program was the absence of a coordinating treating physician for patients with complex health needs.

Conclusion

Current generic guidelines and programs for transition are not as applicable as they are presented. Variations in implementation are fundamentally rooted in basic healthcare principles and differ significantly across medical disciplines. The differences in characteristics of the patient population, medical departments, and the complexity of the care patients require are substantial barriers difficult to overcome. Feasibility and effectiveness-implementation hybrid design studies should be performed.

Implications

To improve transition, strategies should primarily focus on enhancing the domains of healthcare continuity.

Introduction

Improvements in screening, diagnosis, and treatment are leading to more children with chronic diseases transferring to adult care services each year, a trend observed across all medical disciplines (1, 2). Patients at transfer age (defined between 16-25 years) face distinct age-specific, clinical, and psychosocial challenges.

To address these evolving needs effectively, structured and personalized transition programs are recommended (3–8). Transition is defined as the gradual and planned process by which patients are prepared to take charge of their medical management when transferring from pediatric to adult services. Transfer is a part of the transition process whereby the patient is being treated by the new adult-oriented team (9). Numerous programs have

been developed and have demonstrated their benefits, particularly in addressing psychosocial needs (4,5,10,11).

Adolescents and young adults with chronic diseases share some similar needs across medical disciplines, leading to common elements in transition programs (9,12–14) and the development of generic guidelines and models (6,9,12,13,15,16). Key components often include assessment of transfer readiness, patient education, and interdisciplinary planning of a transition trajectory (13). However, the real-world applications of such programs and guidelines vary strongly across medical disciplines, even within a single healthcare setting (15,17,18).

This discrepancy reflects a multifactorial interplay that hinder the prioritization of transitional care and requires more empirical data concerning generalizability of these guidelines. Hence, the objective of this study was to elucidate the multifactorial nature of transition implementation and the underlying variations affecting it. By examining the perceptions of healthcare providers across disciplines, we hope to gain insights into how transition programs could be adapted and tailored for better adoption and effectiveness. Unlike studies that compare contrasting pediatric and adult care perspectives, our research integrates perspectives from both departments, offering a discipline-specific view on transition.

Methods

Research design

A qualitative Grounded Theory approach was chosen, given the paradox of the extensive literature on transition and the poor real-life application of guidelines, prompting the question: why do many physicians discuss transition yet only a few actively integrate it into their practices? We contend that the inductive nature of Grounded Theory research is ideally suited to examine this paradox. Grounded Theory is an inductive research approach that develops theories from systematically analyzed qualitative data (19).

We applied the Gioia method, which focuses on developing new concepts in areas lacking a consensus theory by providing a structured coding framework to enhance transparency and rigor in theory development (20). Recognizing that existing recommendations are often grounded in poor-quality data, the Gioia method views organizational phenomena as shaped by individuals with real-life expertise and experience, capable of sharing their thoughts and actions (13, 20).

We conducted semi-structured interviews with physicians, maintaining a close connection to their experiences during data interpretation. Our qualitative process adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (21).

Setting and participants

Physicians were recruited at Ghent University Hospital between December 2022 and October 2023. To be eligible, they had to be involved in patient care within pediatric or adult departments, including gastroenterology and hepatology, cardiology, pneumology, endocrinology, hematology-oncology, rheumatology, nephrology, neurology and metabolic disorders, and urology. Notably, experience or expertise in caring for adolescents or young adults was not a prerequisite, allowing diversity in perspectives on transition.

Recruitment

We employed a theoretical sampling strategy, allowing us to adapt as our theoretical framework evolved and we achieved theoretical saturation. Diversity in experiences, expertise, and opinions on transition among participants was taken into account (22).

This approach allowed us to identify key patterns and core experiences crucial for the development of our theory (22). To identify potential participants, we consulted department heads to discuss candidates. Subsequently, we contacted those to confirm their interest. Upon obtaining written informed consent, interviews were scheduled, which took place at our hospital or via video-call. Additionally, we ensured within each medical discipline participation from both pediatric and adult healthcare physicians.

Data collection

Three researchers, trained in qualitative research, conducted the interviews using an interview guide and follow-up questions. The guide addressed the following topics chronologically: [1] physician's experience with transition and the current practices within their discipline; [2] perceived positive and negative aspects of current practices; [3] the desired situation of practices; [4] the current (discipline-specific) barriers and facilitators; and [5] the application and applicability of existing guidelines (13). The interviewers concluded with a summarized statement, offering an opportunity to correct or add information. The interview guide was developed by experts in qualitative research and transition, and was piloted. Co-authors not involved in the initial data collection or prior analyses reviewed the interview guide to ensure it covered the full scope of relevant themes, was free from bias, and contributed to the validity and reliability of the tool. Throughout the iterative process of data collection and analysis, adjustments could be made to explore specific areas more in depth; small modifications were deemed necessary. All interviews were audio-recorded and transcribed verbatim manually. Translation followed after coding.

Data analysis

Two authors, a policy advisor on transition and a pediatrician in training, both trained in qualitative research, independently analyzed the data through several steps: line-by-line in vivo coding; comparison of codes and grouping into first-order concepts; axial coding and grouping concepts into second-order themes, with code revision, refining, and rephrasing every 4 interviews; and theoretical coding involving multiple discussions to identify underlying categories at a higher abstraction.

All participants had experience with transitional care, so data-analysis did not make a distinction in between groups.

TABLE 1: Participant characteristics

| Number of participants (n) | 18 |
|---|---------------------|
| Mean age (years; range) | 48,5 years (33-58) |
| Sex | Male: 11, Female: 7 |
| Pediatricians / adult care physicians (n) | 9 / 9 |
| Number of participants per discipline (n): | |
| Cardiology | 3 |
| Pneumology | 2 |
| Gastro-enterology and Hepatology | 2 |
| Nephrology and Rheumatology | 2 |
| Oncology and Hematology | 3 |
| Neurology | 2 |
| Endocrinology | 2 |
| Urology | 2 |
| Number of disciplines with a formal, implemented, and standardized transition program | 2 |

TABLE 2a: Code Tree | Aggregate dimension 1: **Healthcare service characteristics**

| Third order themes | Second order themes | First order concepts |
|--|---|---|
| Characteristics of pediatric vs. adult care | Vertical organization of adult care | Difficult transition due to sub-specialization of physicians (1) |
| | Differences in medical care | Differences in medical care need effective communication (2) |
| | | Policy disparities between pediatric and adult services (3) |
| | | Managing significant policy differences requires careful and gradual consideration (4) |
| | | Different treatment options in adult services (5) |
| | Differences between regional and tertiary care settings | Pediatrician's preference for a holistic approach in regional hospitals (6) |
| Guidelines | Absence of local pathways or guidelines | Reduced accessibility of adults services (7) |
| | | Varied organization and patient flow at adult outpatient clinics (8) |
| | | Absence of age thresholds hinders effective transfer (9) |
| | Presence of local pathways or guidelines | Lack of a well-defined transition approach (10) |
| | | Challenges arise due to vague age limits for transition agreements (11) |
| | | Implementation of guidelines or care pathways support the execution of transition plans (12) |
| Organizational challenges due to schedules | Efficiency | Challenges in applying an existing transition vision locally (13) |
| | | Theoretical frameworks from other contexts are not applicable (14) |
| | Compatibility of schedules | Challenges in efficiently scheduling joint consultations (15) |
| | | Inefficiencies observed during multidisciplinary staff meetings (16) |
| | | Challenges in scheduling multidisciplinary meetings (17) |
| | | Late communication about a transfer impacts overall scheduling (18) |
| Organizational challenges due to location | Administrative support | Compatibility of schedules for joint consultations (19) |
| | | Flexibility is needed for successful scheduling of joint consultations (20) |
| | Physical distance between pediatric and adult healthcare services | Challenges related to schedule meetings or consultations in regional hospitals (21) |
| | | Identified lack of administrative support for scheduling consultations and meetings (22) |
| | | Administrative support is a facilitator for scheduling (23) |
| | | Facilitation of transition through the presence of shared physical locations (24) |
| Personnel power and support | Institutional support | Absence of a fixed location for joint consultations acting as a barrier (25) |
| | | Physical separation as a barrier to effective transition (26) |
| | | The necessity for hospital-wide support to assist staff (27) |
| | Specific support in adult services | Coordination requirements between various care pathways, especially in transition scenarios (28) |
| | | Importance of having a central point of contact for planning transition in complex cases (29) |
| | | Importance of a nurse specialist in facilitating transition (30) |
| | Specific support in pediatric services | Need for nursing support to prevent drop-out during and after transition (31) |
| | | Limitations in psychosocial support within adult services (32) |
| | | Earlier start of transition due to the presence of a nurse (33) |
| | Support tailored to the specific needs of both pediatric and adult services | Association between absence of standardized practices and personnel shortage in pediatric services (34) |
| | | Limited preparation of transition due to time constraints (35) |
| | | A too limited number of patients to consistently schedule joint consultations (36) |
| | | Recognition of the importance of existing nursing support in facilitating transition (37) |
| | | Need for a coordinating person during transition (38) |
| Financial remuneration and funding | Limited remuneration for performance | More physicians (personnel power) has a positive impact on the execution of transition (39) |
| | | Absence of paramedical personnel due to the remuneration issues (40) |
| | Other financing options for pediatric vs. adult services | Recognition of a total absence of support or framework (41) |
| | | Absence of paramedical personnel specifically for certain patient populations (42) |
| | | Acknowledgement of the positive impact of structured reimbursement on ensuring a smooth transition process (43) |
| | | Absence of remuneration of multidisciplinary meetings (44) |
| Financial remuneration and funding | Other financing options for pediatric vs. adult services | Absence of remuneration of consultations with nurse specialists (45) |
| | | Variations in funding availability for paramedical services in pediatric and adult healthcare (46) |

2 of the researchers who conducted the interviews did not participate in this analysis, since the data obtained additionally was used for a separate analysis which they conducted independently. Nvivo Pro 11 software was used. Data saturation, defined as the point where no new second-order themes emerged, was achieved after 13 interviews.

Ethical considerations

The study obtained approval from the ethics committee of Ghent University Hospital (registration number: B6702022000427), and all participants provided written informed consent.

Results

Participant characteristics

Eighteen physicians, split evenly between pediatricians and adult care physicians participated in our study (Table 1). The interviews had an average length of 37 minutes, ranging from 22 to 102 minutes. Six out of eight disciplines lacked a formal, standardized transition program or policy applied to a majority of their patient population. Given that transition encompasses more than coordinating transfer, most practices were deemed insufficient to qualify as transition programs.

Causes of variation in implementation

We identified four aggregate dimensions: [1] healthcare service characteristics, [2] personal and relational factors, [3] adjustability, and [4] continuity (Table 2 a,b,c,d).

1. Healthcare service characteristics

Physicians linked the variation in feasibility and features of transition programs to various healthcare service characteristics, encompassing disparities between pediatric and adult healthcare settings, the availability of local protocols, organizational challenges, staffing constraints, and remuneration models. These elements can either facilitate or hinder the implementation of transition programs.

Characteristics of pediatric versus adult care services

Healthcare structures, practices, and resources differ significantly between adult and pediatric settings. Particularly disciplines managing patients with cognitive disabilities or complex medical, social, and psychological needs perceived this difference as a major transition challenge.

A key observation is the silo-type organization in some adult departments, characterized by a greater number of highly specialized sub-disciplines than in pediatric care, hindering transfer. Physicians also pointed to disparities in medical care

TABLE 2b: Aggregate dimension 2: **Personal and relational factors**

| Third order themes | Second order themes | First order concepts |
|---|--|--|
| Collaboration between pediatric and adult physicians | Transition practices arising from structure | Transition improves through mutual agreements (47) |
| | | Recurring staff meetings between pediatric and adult healthcare providers (48) |
| | | Collaboration growing from medical necessity (49) |
| | Transition practices evolve from personal relationships between healthcare providers | Pediatrician's trust and confidence in physicians from adult services (50) |
| | | Improved collaboration among physicians (51) |
| | | Presence of a constructive relationship between physicians (52) |
| Beliefs | Resistance to support joint consultations | Resistance to participate in joint consultations by pediatric healthcare providers (53) |
| | | Resistance to participate in joint consultations by physicians on adult healthcare services (54) |
| | | Resistance due to prolonged joint consultations (55) |
| | Awareness | Delayed initiation of transition due to a lack of awareness (56) |
| | | Pediatrician's belief in self-sufficiency to care for patients, hindering transition (57) |
| | | Departmental awareness among adult physicians (58) |
| | | Recognition of the significance of psychosocial care (59) |
| | | Joint awareness in both services (60) |
| | Enthusiasm to participate and contribute to transition | Initiative of the pediatrician plays a crucial role in scheduling joint consultations (61) |
| | | The need for someone to take initiative for successful transitions (62) |
| | | Imperative to establish a shared vision by pediatric and adult healthcare providers (63) |
| | | Challenge for pediatricians in relinquishing control (64) |
| Knowledge and training | Knowledge specific to paramedics | Successful transition facilitated by the interest of adult physicians (65) |
| | | Insufficient knowledge of paramedical staff for accurate cognitive assessments (66) |
| | Medical knowledge | Lack of disease-specific knowledge among paramedical staff (67) |
| | | Gaps in knowledge about the scale of the patient population (68) |
| | | Lack of knowledge among physicians (69) |
| | | Insufficient knowledge in pathology among healthcare providers (70) |
| | | Positive aspect of the presence of medical knowledge (71) |
| | Lack of holistic vision/knowledge | Adult physicians lacking a holistic perspective (72) |
| | | Insufficient knowledge about age-specific needs (73) |
| | Barrier to knowledge building | Lack of transfer experiences hinders knowledge development in adult physicians (74) |

TABLE 2c: Aggregate dimension 3: **Adjustability**

| Third order themes | Second order themes | First order concepts |
|--|---|--|
| Differentiation between patient populations | Heterogeneity in the pathology of patient populations | Lack of standardization due to the diverse pathology within patient populations (75) |
| | Differentiation based on psychosocial needs | Certain patient groups exhibit lesser requirements for psychosocial support or transition (76) |
| | Differentiation based on the complexity of care | Insufficient time for discussing advanced care planning (77) |
| | Differentiation based on the complexity of care | Need for multidisciplinary discussions associated with complexity of care (78) |
| | | Reduced necessity for briefing other physicians in straightforward pathology cases (79) |
| | | Increased need for joint consultations in case of more complex pathologies (80) |
| | | Enhanced collaboration between pediatric and adult services when dealing with intricate and complicated cases (81) |
| | Differentiation based on the cognitive abilities | Parents serve as co-patients in cases involving cognitive disabilities (82) |
| | | Specific transition challenges for patients with cognitive disabilities (83) |
| Complex care | Challenges in organizing multidisciplinary care | The involvement of multiple disciplines requires a structured plan for effective care coordination (84) |
| | | Multipathology introduces complexities in determining appropriate transfer timings (85) |
| | | Different paces of transition between disciplines hinders coordinated transfer (86) |
| | | Uncertainties regarding the assignment of responsibilities in complex care cases (87) |
| | | A designated main physician to provide continuity and coordination in complex care transitions (88) |
| | Role of parents | Parents play an integral part in the care and transition of patients with complex medical conditions (89) |

TABLE 2d: Aggregate dimension 4: **Continuity**

| Third order themes | Second order themes | First order concepts |
|----------------------------------|---|---|
| Continuity in care | Partner on the adult side | Patient stop in regional hospital (90) |
| | | Complex psychosocial contexts hinder the transfer to regional hospitals (91) |
| | | Challenges when transitioning to other community care institutions due to limited capacity (92) |
| | | Lack of a healthcare providers with the necessary competences (93) |
| | Unanticipated transfer | Unexpected health issues may lead to unplanned transfers (94) |
| | Continuity of healthcare providers | Patients receive ongoing care from the same team (95) |
| | | Simultaneous follow-up by both pediatric and adult care providers (96) |
| | | Persistence of psychosocial support, even after the transfer (97) |
| | Intermediary or facilitator | The necessity for a person to accompany patients throughout the transition process (98) |
| Continuity in information | Standardized and integrated communication | Insufficient flow of information to the adult physicians during transfer (99) |
| | | Briefings on patient transfer can be conducted on the go (100) |
| | | Absence of feedback after transition (101) |
| | | Improved information transfer during joint consultations (102) |
| | Challenging communication | Challenges in finding opportunities for briefings on sensitive psychosocial information (103) |
| | | Absence of briefings to regional physicians hampers continuity of information (104) |
| | | Inadequate communication between referring parties negatively impacts transition (105) |
| | Record/file | Absence of comprehensive psychosocial records (106) |
| | | Incomplete medical record hinders transfer of information (107) |
| | | Complete medical record contribute to successful transitions (108) |

and infrastructure between adult and pediatric settings, ranging from available treatment options to different healthcare policies, as negatively impacting transition. One physician remarked, *"We don't have the infrastructure and time to perform bone marrow aspirations under anesthesia (...) As a result, these procedures need to be conform to our standards."*

Guidelines

Complex and unrealistic guidelines hindered establishing a protocol in practice, *"We've had a protocol on paper for the past few years that is theoretically sound, but its real-world application has been hindered by the complexity to involve and engage a large number of stakeholders."* For disciplines without a formal protocol, the transition process often became an arbitrary event.

Despite recognizing the importance of transition, many physicians expressed concerns about the feasibility of applying currently existing theoretical models in daily practice.

Personnel power and support

According to some, a key to successful transition is placing the right staff at essential positions. The availability of hospital-wide support that extends beyond specific disciplines and ensures the coordination of transition programs is perceived to be crucial for multidisciplinary transitions. Additionally, the perceived need for psychosocial support and adequate staffing was emphasized by physicians, though it varied across different disciplines. *"Having a hospital-wide framework in place, especially for resources like social workers, would streamline the process. Relying on each single discipline for funding could not be feasible due to limited patient numbers in some specialties."*

Various adult care physicians reported challenges in maintaining staff engagement post-transfer due to time constraints. The impact of this challenge was reported to be greatly dependent on the availability of lump sum financing in their discipline, enhancing continuity of multidisciplinary care and transition support. Disciplines with a larger share of patients eligible for this financing, seemed better equipped for transition. A physician reported, *"In our discipline, transition is particularly effective for certain patient groups, specifically those covered under lump sum financing"*. This financing model also addresses the remuneration gap for nursing and multidisciplinary consultations, particularly affecting disciplines with staffing shortages. It was unclear whether this coverage was also used to support transition for patient groups from the same discipline but not covered by the lump sum financing.

2. Personal and relational factors

Collaboration between pediatric and adult physicians

Collaborations between pediatric and adult care physicians were perceived to be crucial for the development and implementation of transition programs. Regular meetings were reported as facilitating, transforming medical necessity into organizational protocols. Moreover, mutual respect and trust was considered to significantly impact transition effectiveness. In the interviews, strong collaborative and interpersonal relationships among physicians were often associated with smoother transitions. *"Engaging in the transition consultations with the pediatrician was a straightforward decision, given our existing collaboration in research, which paved the way for a seamless transition"*.

Beliefs

The interviews made it apparent that developing a transition program requires committed individuals. Notably, none of the participants were opposed to transition. However, there appeared to be substantial differences in perspectives about the scope of transition and who should coordinate it.

Three main subthemes emerged as key factors in shaping perspectives on transition:

- Awareness, comprising the initiation and perceived need for transition in physicians. A pediatrician noted, *"I believe that it (referring to lacking a transition program) is, to some extent, an issue of mindset. We feel like 'we can manage this on our own'."*
- Eagerness to engage and support the transition process, comprising the need for dedicated individuals. *"It's clear that both groups value transition (referring to pediatricians and adult care physicians). Moreover, it was striking that during a workshop on transition, adult care physicians outnumbered pediatricians, indicating adult care physicians are indeed willing to participate."* (pediatrician).
- Resistance to joint consultations, for multiple reasons as noted in Table 2. *"I find it is a waste of time. I wouldn't opt for a joint consultation. It just doesn't fit with the way I need to structure my day."* (Adult care physician).

Knowledge and training

While many pediatricians and adult care physicians did not consider lack of expertise an issue, certain pediatric specialties, particularly those treating metabolic conditions, struggled with transfer due to a lack of knowledgeable healthcare providers, this being enhanced by transfer delays and therefore the impossibility to gain knowledge. Moreover, the absence of data on patient groups, like their size, limited adult care physicians' ability to evaluate the need and feasibility of establishing a transition program.

"If a substantial number of patients or significant potential is identified, organizing transfer consultations could be feasible. (...) However, the actual number of patients over 16 years in pediatric care remains unclear but is likely higher than we assume."

3. Adjustability

Differentiation between patient populations

Physicians noted that while routine conditions might not require extensive transition protocols, rare or complex conditions demand a more in-depth collaboration and a patient-tailored approach, especially for patients with severe intellectual disabilities. A pediatrician stated, *"Compared to other disciplines, we care for a significant number of patients with intellectual disabilities. For these individuals, standard transition protocols do not suffice due to the distinct needs and abilities of these patients."*

Complex care

The prevalence of patients with complex care needs seemed to vary between disciplines, with those treating more complex conditions facing greater transition challenges. An adult care physician noted, *"In complex cases, the question arises: to whom should the patient be transferred? Which condition is considered primary, and which physician should take the lead in coordination?"*.

4. Continuity

Despite the emphasis on transition, participants consistently highlighted the actual transfer as a significant challenge, impacting both the transition process and continuity of care.

Continuity of care

In certain patient populations, pediatric care involved a team-based approach where adult care physicians participated early on, often in staff meetings. When such a collaboration is absent, physicians suggested appointing a liaison to facilitate the transition process. Another significant issue identified by adult care physicians was the abrupt and unplanned transfer of patients.

Continuity of information

Establishing a standardized approach for sharing patient information was considered crucial to ensure continuity of care. While some disciplines use structured forms, others depend on joint

consultations, meetings, or letters. The challenge lies in sharing comprehensive and sensitive information efficiently. Especially the transfer from a pediatrician to a physician in another service posed a substantial risk for information loss. An adult care physician noted, “A structured transfer document is crucial for an effective follow-up post-transfer. Manually shifting through comprehensive health records is both inefficient and time-consuming. In its absence, the burden of a transfer on healthcare providers would become overwhelming.”.

A grounded theory on the feasibility of a transition program

This article aims to enhance the understanding of the concept, causes of variation, and feasibility of implementing a transition program across different disciplines. It presents the following summarized propositions based on the theoretical foundations (Figure 1):

Proposition 1:

The structure and characteristics of healthcare services vary across different departments and patient groups, leading to disparities in how effectively these disciplines can implement and adapt transition programs.

Proposition 2:

Personal and professional relationships generally evolve gradually over time, driven by medical necessity. Lack of established collaboration and differences in scope on transition hinders efficient communication and the seamless execution of transition.

Proposition 3:

Maintaining continuity of care and information is multifaceted, influenced by factors such as service characteristics, system adjustability, and interpersonal dynamics, all of which contribute to varying implementation.

Proposition 4:

The main challenge in deploying transition programs lies in ensuring continuity of care, particularly during the actual transfer phase, to prevent disruptions and support patient-centered transition pathways

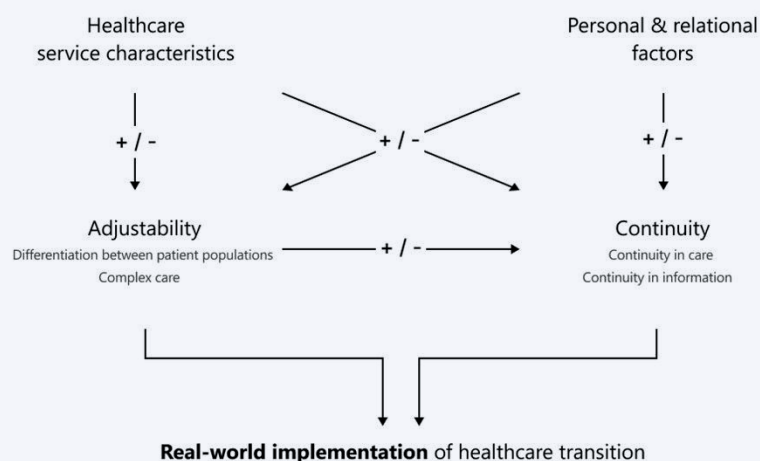
Discussion

This study examined physicians’ perspectives on transition across disciplines to elucidate the multifactorial nature of implementation and underlying variations. To our knowledge, this study is the first to pose a theory on these variations, identifying four theoretical domains: [1] healthcare service characteristics, [2] personal and relational factors, [3] adjustability, and [4] continuity. Despite the study’s focus on transition, predominantly challenges related to the actual transfer were highlighted.

Our findings indicate that the barriers faced during transition are fundamentally rooted in basic healthcare principles, particularly in the concept of healthcare continuity. Healthcare continuity can be defined as the degree to which patients experience a series of healthcare events as coherent, connected over time, and aligned with their needs, typically comprising **relational**, **informational**, and **management** aspects (23). Interestingly, the causes of variation we identified, contributing to the theoretical domain ‘continuity’, correspond directly to these aspects (proposition 3).

Relational continuity, the concept of patients consistently receiving care from the same provider or team, is central to our theory’s second proposition (23). We identified several synergistic

FIGURE 1: A theory on the applicability of transition programs. ‘+/-’ indicates a positive or adverse impact



factors contributing to variations in relational continuity: [1] poor collaborations, making it challenging to find adult care physicians for patient transfer; [2] limited opportunities to build relationships and expertise; [3] loss or lack of coordinated multidisciplinary care due to remuneration issues; and [4] a high turn-over of physicians, whether or not in training, to perform outpatient clinic activities. A cross-discipline, treating and coordinating physician for complex cases could streamline transition paths but also centralize data, thereby providing a single point of contact for the patient (24).

Informational continuity involves the comprehensive transfer of patient information across care episodes, both between patients and providers and among providers themselves (23). Despite all participants having access to the same electronic health record system, noticeable variations in information continuity were observed. Pediatricians pointed out the difficulties in sharing sensitive information that cannot always be documented, while adult care physicians noted the absence of complete and transparent patient health records (25). More effective information exchange could be achieved through population-tailored transfer documents or during meetings and joint consultations (12). Conversely, multidisciplinary transfers or transfers that occur without an established collaboration between pediatric and adult care physicians – such as those to non-academic healthcare providers or to other academic hospitals – often experience significant loss of information (26). Thus, achieving informational continuity necessitates established collaboration among all stakeholders to ensure stakeholder-empowerment and a well-informed transfer.

Management continuity, which ensures a consistent yet adaptive approach to health management and adherence to standard care practices and policies, was a key challenge (23). Participants agreed that adult care should not simply be the appendix of pediatric practices and vice versa, and recognized the lack of resources to adopt pediatric protocols in adult settings (cf. proposition 1) (27). Yet, disparities in policies, for instance in managing procedural fear and pain, lead to patients resisting the transfer (28). Associations with funding models could be observed as a primary cause of variations in healthcare management continuity. Lump sum funding across pediatric and adult departments allows for continuity and adjustability in various domains of healthcare, including psychosocial support and standard care practices, whereas its absence can result in the loss of coordinated care post-transfer (29). For complex conditions, management continuity is achievable through cross-disciplinary and cross-departmental collaboration, coordination, and resource sharing, underscoring the importance

of funding models that promote these kinds of collaborations and introduces quality assurances (23).

All disciplines highlighted the particular challenges of transferring patients living with rare diseases impacting all three continuity domains: [1] relational, due to the lack of experienced and knowledgeable adult care providers; [2] informational, stemming from limited collaborations between healthcare providers or from uncertain prognosis or delayed diagnosis; and [3] management, due to the absence of coordinated practices, protocols, and adequate funding models (30).

Although this is a single-center study, our findings hold relevance for others as we developed a theoretical framework through the abstraction of causes of variation, rather than solely on department-specific challenges. Furthermore, the Belgian healthcare service system is characterized by its universal coverage and equitable access, with the government playing a significant role in regulation and funding. Consequently, introducing additional barriers to a healthcare system, like challenges in access to health insurance, is likely to exacerbate the findings that were observed in the Belgian healthcare system. Our theory can serve as a tool for healthcare providers and hospital services to reflect on their context-specific challenges to implement transition.

Feedback on current literature

This study highlights a significant knowledge gap in the field of transition, particularly in addressing real-world transfer challenges and adapting services to meet the diverse needs of patients within a healthcare setting. While models like "GOT Transition" and "Ready, Steady, Go" propose a generic approach to transition, our findings indicate that the primary challenges to implementing transition are fundamentally but differently rooted in the design of healthcare systems and services (6,9,12,16). Consequently, these one-size-fits-all models currently remain unattainable ideals for various patient populations. As current transition frameworks are mainly developed in experimental contexts, they do not fully account for real-world implementation challenges. Future research should thus develop and evaluate interventions in real-world contexts, targeting healthcare continuity's three key domains to enable the implementation of transition programs. It should also

involve a broader range of stakeholders in designing transition services beyond patients, parents, and physicians, and investigate conditions that affect transition program effectiveness in real-world settings using a multidisciplinary and multiprofessional setup.

Strengths and limitations

This research's strength lies in engaging pediatric and adult care physicians from all relevant disciplines. Our adoption of a theoretical sampling strategy enabled the selection of physicians with varied perspectives on transition. By consulting department heads for participant recommendations instead of relying on our acquaintances, we reduced selection bias.

A key limitation of this study is the focus on physicians, while transitional care is inherently interprofessional. Including perspectives from nurses, social workers, and care coordinators in future research could provide a more comprehensive view on implementation challenges and multidisciplinary collaboration.

Further, the study is conducted in the specific setting of a tertiary hospital with a transition coordinator already in place, so one must be cautious when translating these results to other situations. Also, owing to confidentiality and privacy issues, we were not allowed to link specific challenges to disciplines.

In conclusion, challenges to implementing transition are fundamentally and differently rooted across healthcare services and disciplines. The causes of variation in transition are diverse, primarily related to the actual process of transfer, and more specifically, to the concept of healthcare continuity. Current generic guidelines and programs are not as applicable as they are presented. Our study underscores the need for implementation-effectiveness studies in broader, real-life contexts; including a diverse range of stakeholders to comprehensively evaluate interventions along the transfer journey of patients, assessing their value both to the patient and the healthcare system.

The authors have no conflicts of interest to declare with regard to the topic discussed in this manuscript.

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