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REGULAR ARTICLE

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Complex care pathways for children with multiple referrals demonstrated in a retrospective population-based study

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Abstract

Aim: To identify children with complex medical needs by examining their patterns of hospital care.

Methods: We conducted a retrospective population-based study on 18 577 patients aged 6-12 years from the Haukeland University Hospital register over a 3-year period (from 2013 to 2015). Data were structured to examine the temporal patterns and sequences of referrals, care episodes and diagnoses, including flow across medical specialties.

Results: Over a third of patients had repeated referrals, and 14.9% of all had three or more. Furthermore, 9.3% of patients were referred to both somatic and mental healthcare services. Patients with such combined referrals had a higher number of referrals as well as a higher number of different diagnoses. Overall, there was a high frequency of non-specific diagnoses, and 34.8% of patients still had a non-specific main diagnosis at the end of their hospital contact.

Conclusion: This study demonstrates an increased risk for complex care pathways in children with multiple referrals. Interdisciplinary patterns of referrals were relatively common, particularly for patients in mental health care. These findings highlight the importance of developing interdisciplinary-based approaches for patients with complex complaints.

KEYWORDS

diagnostic overshadowing, interdisciplinary care, mental health, multimorbidity, patient flow

1 | INTRODUCTION

The major challenge facing healthcare services worldwide in the coming decades is the increasing burden of multimorbidity and chronic diseases.[1-6] A large cross-sectional study of primary care patients across all age groups reported a prevalence of multimorbidity, defined as two or more long-term disorders, of 23%.[7] Multimorbidity greatly increases with age. However, similar prevalences have been found in the paediatric population.[8] In a pilot study of children in tertiary care hospitals, Butler et al suggested that "mental disorder in children with a physical condition is very common and has a negative impact on quality of life over time".[9] Patients with multi-system health disorders pose a significant challenge to specialist health services that usually are organised according to the single-disease concept. Thus, patients with multimorbidity are prone to experiencing healthcare fragmentation.

Abbreviations: ICD-10, International Classification of Diseases, tenth revision.

The global prevalence of a chronic physical condition is estimated to affect 25% of children and be increasing.[10] Comorbidities can be classified as either concordant or discordant with chronic illnesses. Furthermore, each medical complaint that is considered an isolated problem may not be deemed significant enough to merit a specific diagnosis, even if the child's functional level is markedly impaired. Functional impairment resulting in poor school attendance can lead to serious long-term social and occupational consequences.[11,12] Clinical experience suggests that a combination of physical and mental health problems may be particularly challenging to manage. Children with anxiety often present with a primary complaint of physical symptoms without reporting any symptoms of anxiety or worry.[13] Generally, groups of concordant conditions with similar treatment approaches pose fewer problems of care coordination than discordant ones such as combined mental and physical conditions.[14]

In a recent report, Grembowski et al[15] defined complexity as misalignment between patient needs and care services provided. Complex care is theoretically characterised by the dimensions of several care components, coupled with a high degree of interrelatedness.[16] The World Health Organization (WHO) defines a complex complaint as a condition in which patients repeatedly present to health services and express a reduced functional level.[17]

Children with complex complaints are often referred to one specific medical specialty or more commonly are subject to multiple consecutive referrals to different specialties. Thus, these children fit poorly into existing healthcare systems that focus on a single-disease approach. The diagnostic process may be delayed or lead to multiple consecutive referrals for the same unresolved medical or functional problem. It is often difficult to specify a complex condition by using a set of single or pairs of specific diagnoses.[18] The traditional way of assessing health conditions and functional level may not be suitable for complex patients. Therefore, an alternative and exploratory approach to identify and assess patients with complex complaints is needed.

In the present study, we focused on the consequences of complexity to the patient flow and patterns of hospital care, concentrating particularly on the phenomenon of repeated contacts as suggested by the WHO definition. We hypothesised that children with complex health-related complaints have a high risk for being placed on cumbersome and complex care pathways. This hospital register-based study of children aged 6-12 years aimed to identify and characterise different patterns of hospital use, as well as the complexity of the care pathways. We also aimed to characterise different groups of children with complex care pathways and identify discriminating factors that could predict such care patterns.

Key notes

- A retrospective study of 18 577 patients aged 6-12 years found over a third of patients with repeated referrals.
- Overall, the frequency of non-specific diagnoses was high, and patients referred to both somatic and mental health care had a higher number of different diagnoses than other patients.
- The study demonstrates a high frequency of repeated referrals, also with an interdisciplinary pattern, particularly for patients in mental health care.

2 | METHODS

2.1 | Setting and study population

We conducted a retrospective population-based study using patient data from the Haukeland University Hospital register. It is a regional hospital providing health care in various clinical specialties, including mental health care. Its local catchment area covers a population about half a million inhabitants, and it also serves the regional population of one million. In Norway, access to publicly funded specialist health services is restricted, with family doctors acting as gate-keepers for primary referrals.

The hospital register contains patient administrative data, including personal information such as age and gender, and the patients' use of various hospital departments by time. The data related to patient flow include the number of referrals and episodes of care. These data were complete, and individual care patterns were specifically constructed in this study using data linkage.

The study included patients aged 6-12 years who had at least one hospital episode from January 1, 2013 to December 31, 2015. We covered a study period of 3 years because the volume of the group of interest was unknown, and such a study length would also allow us to observe the different temporal patterns of referrals and care episodes. The minimum age for study inclusion was 6 years because all children in Norway undergo a medical check-up at their local child health clinic when they start formal schooling. An upper age limit of 12 years was set to avoid the inclusion of children with teenage-related problems.

2.2 | Structuring data material according to analytical perspectives

Two main analytical perspectives were chosen based on the assumption that patients with complex complaints follow complex care patterns: patient flow and patient illness.

In order to study patient flow and patterns of hospital services' use, it was necessary to structure the patient data and hospital episodes into logical sequences. To extract data from the hospital register, we used a file format as specified by the Norwegian Patient Registry.[19] This data format is based on a logic that is well suited for further sequential data structuring. Principles of these data structures and their multi-dimensionality are shown in Figure 1. According to this basic logic, all care episodes within a specific referral are linked, which means that each new primary referral signifies either a new medical condition or a recurrence of a known illness. In

this study, data were further structured so that all primary referrals for a given patient were linked.

All data were sorted according to time sequences and analysed at three different levels: patient, referral and care episode. A care episode represented either an inpatient admission or an outpatient visit. Only referrals and care episodes occurring within our specified 3-year study window were evaluated, making the data censored at both ends. Therefore, information on the children's first care episode ever remained unknown to us if it occurred prior to the start of the study period. The same applied to care histories that continued after this time period.

2.3 | Patient flow perspective and referral patterns

For analyses from the patient flow perspective, we collected data on the number and sequence of primary referrals and their distribution across different medical specialties, including combinations of referrals and care episodes to both somatic and mental health services. According to the hospital registration system, referrals crossing between these two services were considered as separate primary referrals. All referrals with care episodes during the 3-year study period were included.

2.4 | Patient illness perspective

For analyses from the patient illness perspective, we summarised the diagnostic processes and their outcomes by using diagnoses according to the International Classification of Diseases, tenth revision (ICD-10), as well as collected data on the number of different diagnoses set. Special attention was given to non-specific diagnoses, as defined by the ICD-10 as follows: Chapter XVIII: symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified; and Chapter XXI: factors influencing health status and contact with health services.

We also examined the sequential and temporal patterns of establishing diagnoses, for example setting non-specific diagnoses at the beginning and at the end of the series of care episodes. In addition, if a diagnosis classified as specific was presented, we measured the time lag before it occurred. This "diagnostic timeline" was calculated from the point of the first hospital contact following a referral.

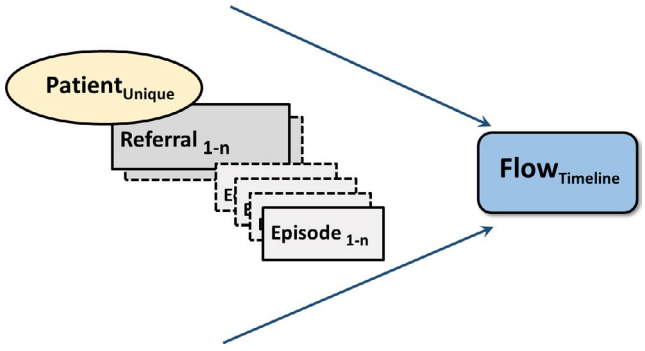

FIGURE 1 Illustration of the logics and multi-dimensionality of the register data

2.5 | Statistics

Data extraction and adjustment were performed by using the SQL-database 2016 (Microsoft), and analyses were conducted by using IBM SPSS Statistics Version 24 (IBM). For descriptive analyses, we used frequency distributions, cross-tabulations and graphical displays. Standard deviation (SD) was used as a measure of variation, and the chi-squared test was used to estimate differences between groups. Binomial multivariate logistic regression was used for our exploratory predictive model, with combined referrals to both somatic and mental healthcare services used as the dichotomised outcome variable. Predictor variables included age, gender, number of referrals, number of different diagnoses, medical specialty at first contact and main diagnostic group at the end of the first referral according to ICD-10 chapter classification. Odds ratios and 95% confidence intervals were calculated. Statistical significance was reached with *P*-values of <.05.

2.6 | Ethics

This study used an adapted version of Haukeland University Hospital's Patient Flow Database, which was set up to monitor and improve treatment and patient flow (approved by the Data Protection Officer, Ref No. 2012/6943). The analysis project has also been approved by the Data Protection Officer at Haukeland University Hospital (Ref No. 2017/12470).

3 | RESULTS

3.1 | Patient flow perspective: characteristics and patterns of hospital use

A total of 18 577 children aged 6-12 years with contacts in the period from 2013 to 2015 were identified from the Haukeland University Hospital register. Of these, a total of 4 800 were new patients, defined as those with no care episodes in the year prior to their first included care episode. Mean age, calculated from all patient ages in 2015, was 9.8 years (SD 2.3), and 55% were boys.

The distribution of referrals to either somatic or mental healthcare services or both is presented in Table 1. Referral to somatic healthcare services, which comprised the various medical specialties, predominated with 91.9% of all patient referrals, compared to 17.4% of referrals made to mental healthcare services. Of note, 9.3% of patients had referrals to both services, that is combined referrals. The results mean that of those referred to mental healthcare services, more than half also had one or more referrals to somatic healthcare services. The most common medical specialty in somatic

TABLE 1 The selected patient groups and their referral patterns

Patient groups sorted by referral pattern	No of patients	% of all patients
Selected patient population	18 577	100.0
Patients referred to somatic services	17 075	91.9
Patients referred to mental services	3237	17.4
Patients referred exclusively to somatic services	15 340	82.6
Patients referred exclusively to mental services	1502	8.1
Patients referred to both sectors	1735	9.3

health care to which referrals were made, was, as expected, paediatrics. For patients with combined referrals, gastroenterology, neurology and infectious diseases were among the most common paediatric sub-specialties with which patients had their first contact.

The mean number of referrals per patient was 1.7 (SD 1.3), with 35.6% of patients having two or more referrals. As shown in Figure 2, patients referred to both mental and somatic healthcare services had a significantly greater number of referrals, compared to those referred to either services only. Thus, 53.1% of those with combined referrals had at least three referrals, whereas only 11.9% and 1.1% of those referred exclusively to either somatic or mental healthcare services, respectively, had three or more.

Moreover, there was variation in gender distribution according to the referral pattern. Thus, the group with referrals to somatic healthcare services only comprised 52% boys, compared to 67% boys in the group with referrals to mental healthcare services only.

3.2 | Patient illness perspective

A large variation was found in terms of the diagnostic groups and their patterns. In our study, we considered non-specific diagnoses as representing unresolved or unclear conditions. Overall, there was a high frequency of non-specific diagnoses. In addition, the group with combined referrals to both somatic and mental healthcare services had a high frequency of psychiatric diagnoses. For the total group with referrals to somatic healthcare services, 27.5% of patients were given a non-specific diagnosis in their first care episode. By the end of the study period, 17.3% of these patients were still without a specific diagnosis. For those who were given a specific diagnosis, the mean time lag was 249 days from the point of first contact to the point of establishing a specific diagnosis.

With all patient groups taken together, the majority (78%) of patients had reached the end of their hospital contact by the end of the study period. Of these, 34.8% of patients had at their last care episode still a non-specific diagnosis.

In addition, we analysed the total number of different diagnoses recorded per patient during the study period. Nearly 60% of all patients had more than one diagnosis, and about one-third had three or more different diagnoses. Furthermore, the number of diagnoses varied significantly depending on the referral pattern, with 80.7% of patients with combined referrals to somatic and mental healthcare services having three or more different diagnoses (Table 2).

3.3 | Combined perspectives and predictive model

Analyses of both the number of referrals and diagnoses showed a significant difference between patients with combined referrals and

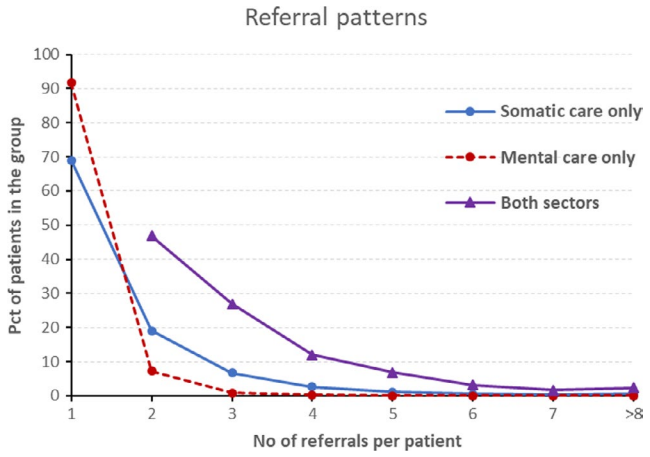

FIGURE 2 Number of referrals by different patterns of service's use

TABLE 2 The number of different diagnoses per patient by referral patterns. Include all contacts with recorded diagnoses during the study period

Categories of referral patterns (N)	No of different diagnoses		
	% with 1	% with 2	% with 3 or more
Patients referred exclusively to somatic care (15 340)	44.3	23.1	32.6
Patients referred exclusively to mental care (1329)	48.5	37.5	14.0
Patients referred to both sectors (1735)	4.8	14.5	80.7

Note: The groups were found significantly different from each other as tested by chi-square analysis: $P < .01$.

TABLE 3 Results from modelling of combined referrals by multivariate logistic regression

Independent variable (reference category)	OR	95% CI	*P*
Sex (male)			
Female	0.70	0.60-0.78	<.01
Age (6-7 y)			<.01
8-9 y	1.22	0.99-1.49	.05
≥10 y	1.38	1.15-1.66	<.01
No of referrals (1-2)			<.01
3-4	5.07	4.32-5.96	<.01
5-6	7.03	5.39-9.17	<.01
≥7	6.11	4.29-8.71	<.01
No of different diagnoses, all contacts (1)			<.01
2-3	10.97	8.14-14.79	<.01
4-5	26.91	19.56-37.02	<.01
≥6	29.73	21.17-41.77	<.01
Medical specialty at first contact (Child and adol. psych.)			<.01
Paed. endocrinology	0.19	0.12-0.30	<.01
Paed. gastroenterology	0.14	0.10-0.20	<.01
Paed. habilitation	0.08	0.05-0.14	<.01
Paed. haematology	0.05	0.03-0.11	<.01
Paed. infectious diseases	0.11	0.08-0.15	<.01
Paed. nephrology	0.14	0.10-0.21	<.01
Paed. emergency care (outpatient)	0.07	0.04-0.11	<.01
Cardiology	0.10	0.06-0.18	<.01
Dermatology	0.07	0.03-0.17	<.01
Surgery	0.13	0.09-0.18	<.01
Otolaryngology	0.10	0.07-0.14	<.01
Internal medicine	0.16	0.08-0.30	<.01
Neurology	0.17	0.12-0.22	<.01
Orthopaedics	0.07	0.05-0.10	<.01
Ophthalmology	0.09	0.05-0.14	<.01
Other	0.07	0.04-0.12	<.01
Main diagnosis at end of first referral (ICD-10 chapter I)			<.01
Chapter IV (Endocrine diseases)	2.30	1.11-4.77	.03
Chapter V (Mental disorders)	2.80	1.45-5.41	<.01
Chapter XXI (Other factors and contacts)	1.99	1.06-3.75	.03
Constant	0.02		<.01

Note: Included cases = 18 237. Excluded cases were generally related to those with no recorded diagnoses.

Only categories with significant odds ratios are listed ($P < .05$).

those referred exclusively to either somatic or mental healthcare services. Accordingly, an exploratory logistic regression analysis was performed using combined referrals as the dependent variable (Table 3). The model found the following variables significant predictors of combined referrals: gender, age, number of referrals, number of diagnoses and medical sub-specialty to which first referrals were made, as well as the main diagnostic group recorded in the last care episode related to the first referral. As to the differentiation between these various diagnostic groups, as measured by their corresponding ICD-chapter, endocrine diseases, mental disorders and the non-specific group were all significantly different from the reference group of infectious diseases. Male gender, being older and having a high number of referrals and different diagnoses, as well as being referred to mental healthcare services first, were found to be highly predictive compared to their respective reference categories. Patients with multiple diagnoses were found to have particularly high odds ratios for combined referrals.

4 | DISCUSSION

In this hospital-based register study, we found that 35.6% of patients had repeated referrals to specialist services, with 14.9% having three or more referrals. In addition, 9.3% of patients had combined referrals to both somatic and mental healthcare services. Furthermore, half of the children in mental healthcare were also referred to somatic healthcare.

Moreover, we found that age, gender and the number of different diagnoses given to patients varied by referral patterns. Patients with combined referrals to both somatic and mental healthcare services were older and had a significantly higher number of different diagnoses. In considering non-specific diagnoses as representing unresolved and unclear conditions, we found that more than a third of patients still had a non-specific diagnosis recorded in their last care episode. For those who were subsequently given a specific diagnosis following their referral to somatic healthcare services, the mean time lag was 249 days from the point of first contact with the care service. The results also confirmed that patients with complex or unclear conditions were not easily identifiable using a specific set of combined or multiple diagnoses.

Even if we could identify complex care patterns defined as repeated or combined referrals to different medical specialties, the interpretation of these findings is not straightforward. Complex care pathways do not necessarily mean inappropriate patient management—some could reflect comorbidities of well-known diseases or the presence of unrelated illnesses. According to the logical structuring of our study data, the attribution to different primary referrals for different illnesses might compensate this uncertainty to some degree. Nonetheless, the high frequency of multiple or combined referrals during the course of patient flow should lead us to question whether at least some of these children could have benefited from a more complementary and simultaneous cross-specialty approach.

The time lag before reaching a diagnostic conclusion could have unwanted consequences for both the children and their parents.[20] Collaboration among patients, parents and family doctors should clearly address joint expectations of all parties involved, especially at the end of the diagnostic process.

Children and their parents, as well as the family doctor, often report poor coordination and communication among health professionals from different medical specialties. Burgers et al found that respondents to their study survey who had high morbidity scores, defined as a combination of the number of conditions and measured health status, reported less favourable experience with coordination of care. Combinations of comorbidity including mental health problems were also associated with lower ratings.[21]

There have been several initiatives and studies on developing alternative care models and concepts for treating patients with comorbidities. A care framework developed by an expert consensus group included components such as comprehensive assessment by trained multidisciplinary teams, as well as care plans and shared decision-making processes that included patients and family members.[22] Comprehensive assessment and interdisciplinary care or collaboration were among those elements most often included in integrated care programmes.[23] Furthermore, Huffmann et al noted in their review that integrated care models targeting *both* mental health and chronic medical illnesses may have superior outcomes, compared to those targeting a single mental disorder.[24] This is of high relevance, as there is evidence showing that children with multimorbidity including both mental and physical domains experience poorer quality of life, compared to children with only a physical or a mental disorder.[25-27]

Development of integrated care models seems to be challenged by the organisation of existing healthcare systems, as well as by the current financial systems.[28] As children have long life expectancy, their reduced function starting from childhood will potentially have significant impact on their long-term quality of life and inclusion in the working society. As a result, early functional impairment could also have important socio-economic consequences affecting society as a whole.

The large number of patients included and the logical principles of data structuring strengthen the results of the present study. However, the relatively short study period did not allow us to investigate long-term patient outcomes. Our focus was primarily to identify sequences of care episodes that were potentially linked or related to a specific medical problem. It is possible that sequences of referrals occurring within a relatively short time span could have a higher probability of being related to the same unresolved problem. However, studying care episodes within a specific time window implied that our data were both left- and right-censored. To test the effect of censoring, we performed a sensitivity analysis to determine whether the patterns of repeated or combined referrals differed according to the length of the study period after the first contact with a care service. We found exactly the same patterns of referrals with a minimum study period of 1 year as with 3 years.

As anticipated, it seems difficult to find a single discriminating factor that would identify a specific group of children who are most in need of an alternative healthcare approach. Results based on our predictive model highlight the need for further research to investigate patient flows that include multiple referrals to both mental and somatic healthcare services. As to volumes, exploring the combination of three or more primary referrals and including both sectors, accounted for five per cent of the total patient population. Our results also suggested that among the most commonly occurring sub-specialties in these combinations besides mental care, were gastroenterology, endocrinology and neurology.

5 | CONCLUSION

This study demonstrates that children with repeated referrals have an increased risk for complex care pathways. Interdisciplinary referrals and care patterns were also found to be relatively common, particularly for patients referred to mental health care. These findings highlight the importance of developing more interdisciplinary-based approaches for patients with complex complaints, particularly to establish an easier way to clarify the diagnosis.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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