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Autoimmune rheumatic transitional care model development

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Abstract

Aim To develop a transitional care model for autoimmune rheumatic disease patients based on the needs analysis.

Method Mixed Method, Explanatory sequential design (QUAN-qual) has been conducted. Quantitative data were collected through medical record and structured interviews. Qualitative study has been done through Focused Group Discussion (FGD), based on problems met in previous quantitative study. We have done the coding processed, followed by determining categories and themes to reach the intercoder agreement with peer-debriefing. Analysis of the final results of research was assisted by the external auditor to form a model of care.

Result The quantitative data collection from 27 patients showed that the transition age was 18–19 year-old, age of onset 4–17 year-old, 23 patients (85, 2%) with SLE, 4 patients (14.8%) with JIA. Two patients (7.4%) had different diagnosis from the pediatric clinic, 1 patient (3.7%) had no diagnosis from previous clinic. Drug switching during transition occurred in 14 patients (51.9%) and 3 patients (11.1%) has no known medication history. Data regarding disease activity at initial diagnosis were not available in 26 patients (96.3%). The combined FGD analysis found several key words related to “the need of change” in RSCM autoimmune rheumatic transitional care.

Conclusion A development of transitional care model for autoimmune rheumatic disease consist of documents about service algorithm, transfer documents, systematic work protocols with education check list has been done.

Keywords Transitional care model, Mixed Method, Autoimmune Rheumatic, Systemic Lupus Erythematosus, Juvenile Idiopathic Arthritis

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Introduction

Child onset autoimmune rheumatic disease is a chronic-progressive inflammatory disease that demands long term management; therefore, this requires transition care to ensure continuation of treatment for satisfactory outcome. The 2017 World Bank Data show that majority of Juvenile Idiopathic Arthritis (JIA) and Systemic Lupus Erythematosus (SLE) patients with onset before the age 16 are found in Southeast Asia [1]. There are differences between pediatric and adult health services. Child-oriented health services mostly involve the family, allocate more time to intensive communication with patients and their families, and are able to follow medication adherence while accommodating the patient's immaturity. In adult health services, the higher patient



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volume often prevents health service providers from having intensive communication with all patients [2]. Adult healthcare services face difficulties in understanding the needs of adolescents and obtaining complete medical records about their diseases [3, 4]. Health service providers and institutions often struggle to coordinate transitional health services due to incompetence and lack of time for training, as there are no written transition care protocols [4]. Sabbagh et al. (2018) claim that more than one meeting is needed to build a strong relationship between health care providers and transitional patients [5]. Lack of coordination among specialists and other health care providers and incomplete documentation of medical record could be barriers to effective treatment. Some countries have policies that separate child and adult health insurance, which complicates the transition process [6]. Individuals undergo mental development between ages of 16 and 19 [6]. Adolescents are not fully capable to make decisions like adults, and those with chronic diseases are at a higher risk of developing mental disorders, including depressions and anxiety disorder [3]. A systematic review by Sabbagh et al. (2018) concludes that some patients feel they are not treated as individuals, feel deserted, feel the lack of preparation, and are unable to control their transition process [5].

Transition-aged patients are at risk of poor outcomes. A retrospective single-centre study in Singapore shows that among 31 patients with chronic rheumatic autoimmune diseases (52% SLE patients, 16% MCTD patients, 16% JIA patients, 13% Anti-Phospholipid Antibody Syndrome/APS patients, and 3% vasculitis patients), one-third were hospitalised due to flare before transition, and another one-third experienced an increased disease activity after transition [7]. EULAR emphasises the importance of a transitional care model in adolescence and young adulthood to be initiated as soon as possible, while maintaining communication between pediatricians, internists, patients, and their families, supported by comprehensive medical records [7]. Got Transition attempted to summarise some recommendations in England about transition into 6 steps, which should be carried out jointly between pediatricians and internists [8]. ACR 2021 provided an example of medical resume for transition care of SLE and JIA patients [9, 10]. Nonetheless, the research in the Netherland on autoimmune rheumatic patients (JIA, SLE, Polyangiitis granulomatosis, fasciitis eosinophilic, and Henoch Schonlein Purpura) in transition age found that implementation of transition care is not routinely conducted and is not widespread [11]. Asian countries are experiencing struggles in transition care and cannot immediately adopt guidelines from Western countries due to differences in economic, social, and cultural aspects. Parents' interference were too

dominating in the process, causing barrier to independent medication in adolescents [12].

To date, there is no single indicator to predict a successful transitional health care model. Therefore, a transitional care model in Indonesia is essential for all chronic diseases with onset before 18 years old, including autoimmune rheumatic patients and should be customised to address the problems and requirements of each healthcare service provider. A transitional care model is urgently needed due to the high number of patients requiring transition [13, 14]. Transition care can be implemented in several forms, such as a transition clinic consisting of pediatricians and rheumatologists, rheumatology clinics providing special services for young adults (aged 16–25 years old), and transition clinics with a special transition coordinator to manage patients' schedules for pediatrician and rheumatologist visits [2]. The transitional care model, referring to the Society for Adolescent Medicine, is a planned and intended transition or handover from pediatric care to adult care to treat adolescents and young adults with chronic diseases [15]. The WHO states that transitions of care are more than just clinical transitions, as they include patients' perspectives, experiences, and needs. Several transitional care models for autoimmune rheumatic patients implemented in Europe, America, and Canada, along with their effectiveness evaluations, are explained in Table 1. This research aims to develop a transitional care model for autoimmune rheumatic patients based on needs analysis.

Method

It is better to explain what the data are and what the data sources are before discussing the approach!

This research was conducted using a Mixed Method, Explanatory sequential (QUAN-qual) design. The first phase of the research includes quantitative data collection, which was conducted from April to May 2022 through medical records and structured interviews with autoimmune rheumatic patients. Samples included all patients aged 18–20 years old with disease onset less than 18 years old, and they were treated in the Rheumatology clinic from March 2019 to February 2022 for at least 3 months, had been treated in the pediatric polyclinic for at least 3 months, and were using national health insurance (JKN).

The second phase of the research was conducted through the Focused Group Discussion (FGD) to collect qualitative data. Questions were created by the authors based on hands-on experience in handling transitional patients. The FGDs were held a total three times from June to July 2022, involving patients and their families, the medical team (including doctors, nurses, and psychiatrist), and administrative staffs. In the first FGD, patients

Table 1 Transitional care models for Autoimmune Rheumatic Patients in Western Countries [16, 17]

Programme	Country	Setting	Diseases	Age (year)	Age of Transition (year)	Transition Coordinator	Transition Team Staff	Strategy and Tools	Indicators	Results
Clinical transition pathway for adolescents with juvenile-onset rheumatic and musculoskeletal diseases	Netherlands	Erasmus University Medical Centre Rotterdam	Childhood onset Rheumatic Musculoskeletal Diseases (RMD)	17–18	17.8	Yes	Pediatric & adult Rheumatologist, nurse, other	Not specified	Drop out rate Disease activity: number of tender & swollen joints Erythrocyte Sedimentation Rate Transition Satisfaction Questionnaire Self management skill	3.9% after 3 years Disease activity: number of tender & swollen joints 0 (3–15) mm/hour High patient satisfaction Good self management
DON'T RETARD	Belgium	University Hospital Leuven	JIA	14–16	16	Yes	Pediatric & adult Rheumatologist, nurse, physiotherapist, psychologist	Education, skill development, helpline (transition coordinator), Website: http://www.klueven.be/switch2/rheuma.html Peer support group	Quality of life questionnaire Disease knowledge Improvement in physical, psychosocial, and disease-specific health status Increase in knowledge similar in control group	
Growing up and moving on	United Kingdom	10 healthcare center	JIA	11–17	16–18	Yes	Pediatric & adult Rheumatologist, nurse, physiotherapist, occupational therapist	Education, skill development, communication forum, peer support	Quality of life questionnaire Disease knowledge Patient & parent satisfaction Pre-vocational experience	Improvement in health status Increase in disease knowledge Improvement in patients and parents satisfaction Improvement of vocational readiness marker
Rheumatology transition programme	United States of America	Children's Hospital of Philadelphia/ Hospital of the University of Pennsylvania	Childhood onset Rheumatic Diseases (RD)	17–19	Individualized, after readiness to transfer checked	Nurse specialist	Pediatric & adult Rheumatologist, nurse, social worker	Education, skill development, communication with planner, reference book, website	Not specified	Improvement of adherence to appointments after transfer to adult rheumatology services

Table 1 (continued)

Programme	Country	Setting	Diseases	Age (year)	Age of Transition (year)	Transition Coordinator	Transition Team Staff	Strategy and Tools	Indicators	Results
YARD Clinic (Calgary)	Canada	Alberta children's hospital Calgary foothills Hospital	Childhood onset RD	14–25	Individualized, after readiness to transfer checked	Nurse specialist	Pediatric & adult Rheumatologist, nurse, physiotherapist	Education, skill development, communication forum, peer support	Not specified	Improvement of adherence to appointments Good control of disease during transition Improvement in vocational readiness All patients received allied health care support

YARD Young Adults with Rheumatic Diseases

from each year (2019, 2020, 2021, 2022) and their caregivers were chosen using purposive sampling. The topics revolved around their experiences in transitioning between pediatric and adult rheumatic clinics, difficulties encountered, and suggestions for improvement. The second FGD discussed the ideal patient transition process from pediatric to adult clinics, while the third FGD with administrative staff was about the current transition process and the required documents. Some aspects regarding patients' condition that could not be assessed during quantitative research were evaluated during FGDs, consisting of self-management skills, adherence to medication, and knowledge about the disease, medication, and outcome. Self-management skills were reviewed by asking about the patients' ability to go to the clinic alone without accompaniment.

Univariate quantitative data that were processed using SPSS 26. FGD qualitative data were recorded (audio, photos, and videos) and later transcribed verbatim in the form of notes. Coding was conducted until an inter-coder agreement was achieved through *peer-debriefing*. Final analysis was conducted with an external auditor to develop the transitional care model.

Results

Quantitative results from structured interview and medical records are shown in Table 2.

All the participants in the FGD admitted that they were able to go to the clinic by themselves, but one caregiver insisted on accompanying the patient. Patient knowledge and understanding were assessed during the FGD, and it was discovered that patients had no idea about their disease before being sent to the pediatric clinic in RSCM, but afterward, they had a better understanding of their diseases. Patients' knowledge about medications was evaluated during the FGD, in which all the participants were able to remember the names of the drugs they were taking regularly, when they started taking the medications, and the dosage of their medications. All the participants in the FGD had a good understanding of JKN and how to use it.

The major theme of three FGDs conducted revolves around healthcare service before being referred to the pediatric healthcare service, during treatment at the pediatric clinic at RSCM, during the transition to the rheumatology clinic at RSCM, and during regular treatment at the rheumatology clinic. Combined FGD analysis discovered several keywords surrounding change in transitional health care providing for autoimmune rheumatic patients in RSCM, such as environment differences between the pediatric and adult rheumatology clinic, the dependence behaviour of transition patients, uncertainty of transition algorithm, and technical difficulties of the

registration process. Transition care aimed in this development of transitional health care model is a rheumatology clinic that provides a special service for patients aged ≥ 18 years old with the autoimmune rheumatic disease with onset of less than 18 years old. FGD analysis was then continued to make a needs analysis to improve the transition care model for autoimmune rheumatic patients shown in Table 3.

Based on needs analysis and discussion, a transitional care model (Fig. 1) was made including transition care workflow, transfer document, and transition care guidelines, supplemented with education check list.

Discussion

The transitional care model is basically designed to increase the effectiveness of transferring patients from pediatric settings to adult healthcare settings by enhancing adolescents' and young adults' skills to manage their own health problems according to instructions from healthcare service providers, while also establishing organized, integrated healthcare clinics between pediatricians and internists [4, 5]. Healthcare models provide an illustration of how healthcare is provided to patients. It aims to ensure services are delivered at the right time, right point, and by the right team in the right place [18]. The ideal transition process from pediatric to adult polyclinic includes several key aspects. The first is a complete record of the history of medications given, any changes made and the reasons for them, and future treatment plans. The second is the need for standards/guidelines for patient treatment. The third is preparation of the patient's readiness. Medical staff and administration also agreed on the need for a checklist for transitioning patients from pediatric to adult polyclinic. Implementation of the transition care model for autoimmune rheumatic disease patients has to be attentive into patient's experience, from the admission process to the time when they are dismissed and given medications from the clinic. Similar ideas surrounding success in implementing transitional care were also pointed out in McDonagh et al., and those include the establishment of written policies related to transitional care, individual and flexible transition planning, the presence of a coordinator in the transition process, efforts to improve the knowledge and skills of adolescents, young adults, and families, fostering effective communication and shared care between pediatric and adult healthcare providers, and ensuring the completeness of transfer documents with valid information [19].

Tattersal et al. and Hazes et al. created a transition clinic for adolescences with an autoimmune rheumatic disease managed by both pediatric and adult rheumatologists for patients aged 16–25 years old [2, 11], and

Table 2 Characteristics of Research Subjects

Characteristics of Research Subjects	N=27
Gender, <i>n</i> (%)	
Female	23 (85,2)
Male	4 (14,8)
Treatment funding, <i>n</i> (%)	
National health insurance (JKN)	27 (100)
Private insurance	0 (0)
Self-paid	0 (0)
Language, <i>n</i> (%)	
Indonesian	27 (100)
Foreign language	0 (0)
Last education, <i>n</i> (%)	
Elementary school	0 (0)
Middle school	3 (11,1)
High school	24 (88,9)
Domicile, <i>n</i> (%)	
Jakarta and nearby areas	25 (92,6)
Others	2 (7,4)
Transportation, <i>n</i> (%)	
Personal transportation	12 (44,4)
Public transportation	14 (51,9)
Airplane	1 (3,7)
Boat	0 (0)
Clinical data	
Age at diagnosis, mean (SD), in years	14,52 (\pm 1,7)
Age at transition, median (min–max), in years	18 (18–19)
Age of onset, median (min–max), in years	14 (4–17)
Duration of treatment in pediatric clinic before transition, median (min–max), in years	45 (6–100)
Diagnosis in Pediatric Clinic, <i>n</i> (%)	
SLE	21 (77,8)
JIA	3 (11,1)
Others	2 (7,4)
Not available (N/A)	1 (3,7)
Diagnosis in Rheumatology clinic, <i>n</i> (%)	
SLE	23 (85,2)
JIA	4 (14,8)
Others	0 (0)
Difference in diagnosis between pediatric and rheumatology clinic, <i>n</i> (%)	
Yes	2 (7,4)
No	24 (88,9)
Unknown	1 (3,7)
Medication change after transition, <i>n</i> (%)	
Yes	14 (51,9)
No	10 (37)
Unknown	3 (11,1)
Disease Activity at diagnosis, <i>n</i> (%)	
Remission	0 (0)
Mild	0 (0)
Moderate	1 (3,7)
Severe	0 (0)

Table 2 (continued)

Characteristics of Research Subjects	N=27
Not available (N/A)	26 (96,3)
Disease Activity at transition, <i>n</i> (%)	
Remission	2 (7,4)
Mild	5 (18,5)
Moderate	3 (11,1)
Severe	5 (18,5)
Not available (N/A)	12 (44,4)
Disease Activity 3 months after transition, <i>n</i> (%)	
Remission	6 (22,2)
Mild	9 (33,3)
Moderate	4 (14,8)
Severe	3 (11,1)
Not available (N/A)	5 (18,5)
Quality of Life	
Physical health, mean (SD)	61,41 (± 18,09)
Psychological health, mean (SD)	65,05 (± 17,09)
Social relationship, mean (SD)	60,85 (± 17,38)
Environment, mean (SD)	66,52 (± 16,14)
Medication adherence, <i>n</i> (%)	
Good (pill count ≥ 80%)	25 (92,6)
Poor (pill count < 80%)	0 (0)
Unable to count	2 (7,4)
Adherence to treatment schedule 3 months after transition, <i>n</i> (%)	
Poor (Goes to clinic > 1 month or disobeying doctors)	2 (7,4)
Good (Goes to clinic < 1 month and obeying doctors)	25 (92,6)
Hospitalization frequency 3 months after transition, median (min–max)	0 (0–2)
Social support	
Yes	27 (100)
No	0 (0)

this suggestion has been proposed by the facilitator of the Medical Team and Administration Team's FGD (Fig. 2).

While the idea of a Transition Clinic jointly managed by pediatricians and internists may appear ideal, implementing it in RSCM, particularly regarding JKN funding, could pose several challenges. The administrative team highlighted difficulties in financial claims, particularly in differentiating between pediatric and internal medicine patients. Patients aged 18 years old are not permitted to receive treatment from both pediatricians and internists, and vice versa. There are also challenges in the referral system concerning JKN. The medical team also mentioned limitations in the number of rheumatologists and differences in nursing assessments between pediatric and internal medicine nurses.

The development of a transitional care model for autoimmune rheumatic patients involved interpreting the results of quantitative and qualitative research, guided by theories and similar research. Researchers aimed to

create a transition care model that allows both pediatric and adult rheumatologists to manage transitioned patients without having to work together in the same clinic or room, as suggested by Hazes et al. Transition forums held every three months could serve as a platform for transition care planning and evaluation for pediatric and adult rheumatologists, ensuring treatment continuity while also utilising the JKN funding system. These forums may also involve patients and their caregivers if needed. To address the environmental differences between the pediatric and adult rheumatology clinics, the researcher proposes choosing a particular day and room within the rheumatology clinic for transitioned patients. This room would consist of a doctor and nurse who can guide the patients about the transition care workflow to ensure patient convenience. The attending doctor will assess the patient together with the doctor on duty in the rheumatology clinic for the first 6 months of the transition to establish engagement between patients and attending

Table 3 Requirements of Ideal Transition Care for Autoimmune Rheumatic Patients in RSCM

Transition Care Requirements	Coding	Background	Current situations	Perception regarding Ideal Model of Transition Care
Transfer document	-Documents requirement for transition (pediatric to rheumatology clinic) -Suggestions regarding transfer document	-Pediatrician (A1): "there's no transfer document approved by both pediatrician and rheumatologist, we have filled the transfer document but it's not delivered to rheumatology clinic." -Pediatric Administration (MA): "Transition patients will bring a consultation letter and letter of patient's history." -Patient (P1): "We bring all the laboratory results from pediatric clinic to rheumatology clinic, and we've got interviewed over and over again." -Psychiatrist (PS): "Patients feel traumatized to be asked about their painful experience all over again, and they also afraid that the doctors don't understand about their condition. We have to make a transfer method that approved by both pediatrician and rheumatologist."	-Rheumatology nurse (CR): "There are medical resume and drug records in that resume letter. We will make a report if there are any problems identified"	-Pediatric Administration (MA): "The transfer document should be made by doctors because of their knowledge regarding the medications." -Rheumatologist (R1): "A good transfer document should consist of complete medication history and medication planning, including the reason of stopping or switching any medications in order to assure the medication continuity... it can be adopted from ACR." -Rheumatologist (R2): "Previous attending physician's note can guide our next management planning." -Pediatric nurse (PA): "Paper documents can be lost, its better to be integrated within electronic medical records." -Rheumatology nurse (PR): "Electronic medical record might need longer time to processed, we can use paper documents temporarily." -Pediatrician (A1): "... the education about transition care can be started as early as 16 years old... special case meeting should be held for every 3 months." -Psychiatrist (PS): "...there should be a case manager focused in educating the patients and caregivers..." -Rheumatologist (R1): "The transition patients should be prioritized and meet the attending physician each month for their first 6 months of transition." -Pediatrician (A1): "We need to make special routine forum every 3-6 months prior to transition, to discuss about their condition." -Pediatrician (A2): "The transition care can't be handle by a temporary doctor, there has to be a person in charge of transition process."
Standard Operating Procedure	-Transition age -Transition algorithm -Continuation of patient care -Care guideline -Healthcare worker's coordination -Hospital management's role in autoimmune rheumatic transition care process -Efforts made by Pediatric clinic -Efforts made by Rheumatology clinic	-Pediatrician (A2): "There's a confusion regarding the treatment for patient aged 17.5 years-old but still require our intensive monitoring, but the National health insurance strictly regulate the transfer the patients aged 18 years-old to internal medicine clinic." -Pediatric Administration (MA): "Sometimes we noticed that there's still patients undergone certain protocol in pediatric clinic and haven't get transferred although they have reached 18 years-old until the medication protocol was done." -Rheumatology Administration (MR): "Patients aged 17 years-old in rheumatology clinic can be examined due to certain social indications, and then will be referred to pediatric clinic..."	-Pediatrician (A1): "For special cases, we have tried to invite the internal medicine team from which we would transferred the patient to... we have made Whatsapp group to communicate with patients and caregivers along with pediatric and rheumatologist... for patients having difficulties to understand the information, we will refer them to the psychiatrist. We also have plan to make tutorial video of transfer procedure." -Pediatric Administration (MA): "when patients reached 18 years-old, we will transfer them to internal medicine clinic with a letter of patient's history, and we have told them about the location of internal medicine clinic, the online registration process, and the location of pharmacy." -Rheumatology nurse (PR): "We (the nurse) have been communicating with our patients through Whatsapp."	

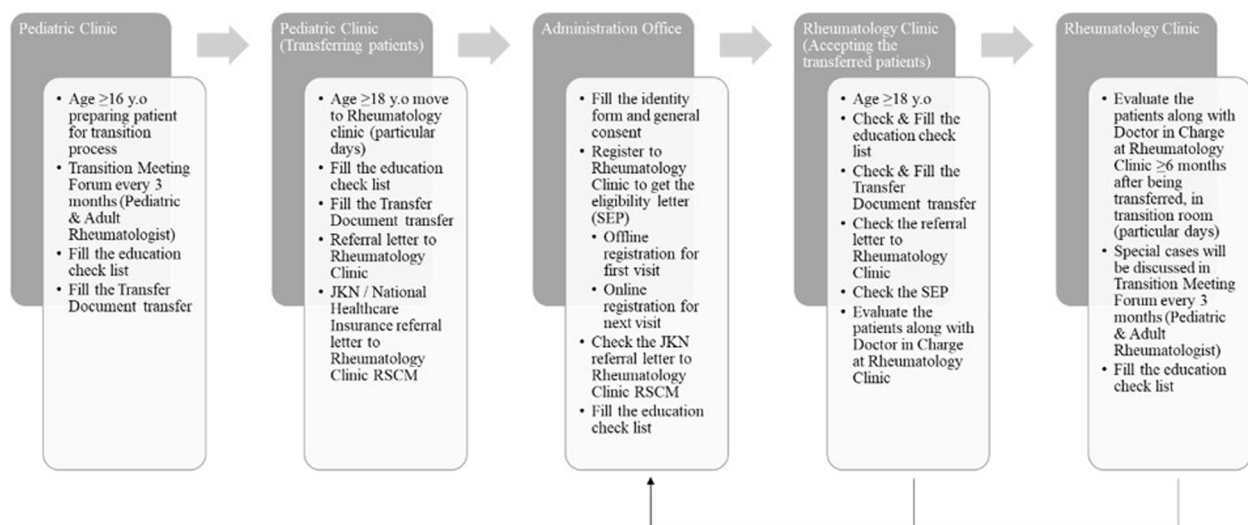


Fig. 1 Autoimmune Rheumatic RSCM patients' Transition Care Workflow

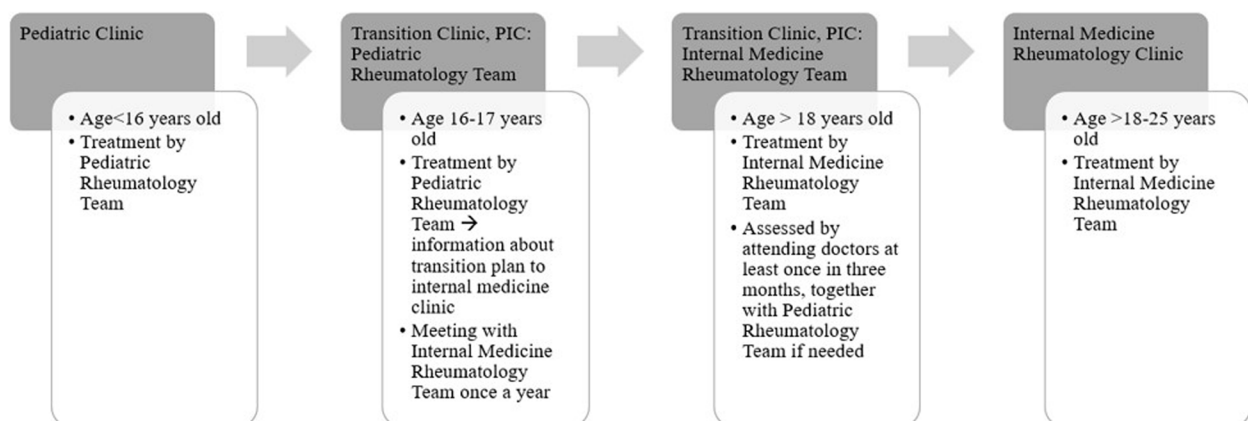


Fig. 2 Suggestions of Transition Clinic Managed Together [11]

doctor. By creating this workflow, transition care can be implemented without additional resources.

This study is the first study in Indonesia regarding a transitional care model for autoimmune rheumatic disease patients. This study also uses a mixed method in order to achieve reliable results. One limitation of this study is that research was only conducted in one health-care centre, not including a multicentre study yet.

Conclusion

A mixed method study with an explanatory sequential design was conducted to develop a transitional care model of autoimmune rheumatic disease patients. According to the analysis from quantitative data and FGD, further development of transition care was needed including workflow, transfer document, and guidelines

supplemented with an education checklist. All together these can be set as the standard operating procedure.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s41927-024-00407-5>.

Supplementray Material 1.

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Authors' contributions

A.A as the main researcher contributed to focused group discussion, data analysis, and manuscript writing C.O helped A.A to conduct the focused group discussion, analyze data, and write the manuscript, and also corresponding to the publication H contributed in directing the focused group discussion and qualitative data analysis. S and N.K as seniors in rheumatology and pediatric

immunology contributed in planning and supervising the research and manuscript R.H and H.S were making sure the research was done according to appropriate methods and ethics as external auditors.

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Availability of data and materials

Collected data for this study are not made publicly available since the data consist of interview transcripts and anonymity of the participants needed to be maintained. Additional data required can be requested through the corresponding author.

Declarations

Ethics approval and consent to participate

All subjects gave their informed consent for inclusion before they participated in the study. The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by Universitas Indonesia Faculty of Medicine Ethics Committee.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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