



Studies Qualitative Thalassemia Selfcare Management Teenagers

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Article Info

Article history:

Received 21 July 2025

Received in revised form 14 May 2025

Accepted 19 September 2025

Keywords:

Thalassemia

Self-care

Adolescents

Management

Social Support

Abstract

Study This to study self-care management in adolescents sufferer thalassemia major in the Province West Java, with objective For understand How teenager the manage condition his health is good in a way physique and also psychological. Method research used is approach qualitative with design phenomenology, which relies on interview deep against 29 participants aged between 10 and 18 years old. The results of the study show that condition physical, complaints physical, results laboratory, and conditions genetics become factor key in the early diagnosis of thalassemia. Support social from family and friends peers also play a role important in increase quality life teenager sufferer thalassemia. Findings This support importance approach holistic in management disease, which includes maintenance medical, education, and support psychosocial For increase ability teenager in manage condition they in a way independent. Programs such as Self-care Management of Adolescent Thalassemia expected can give contribution significant to strengthening self-care among teenager sufferer thalassemia in West Java.

Introduction

Thalassemia is abnormality genetics serious impact directly to production hemoglobin, so that patient must undergo maintenance term long in the form of transfusion blood and therapy sailor substance iron For control burden iron in body (Azize et al., 2015; Sadiq et al., 2024; Sumendap et al., 2025). Globally, thalassemia has known influence millions of people and in Indonesia, especially in West Java, the prevalence reach number significant although specific data accounting for 43% of total cases national No can confirmed with existing references (Kharyal et al., 2020). Condition This No only cause complications physical, but also has an impact big to quality life and aspects psychosocial sufferers, especially among adolescents (Azize et al., 2015; Brandt et al., 2022; Witt et al., 2023).

Teenager with thalassemia facing challenge double, namely must manage condition chronic medical while pass various phase development crucial psychosocial research. has show that limitations knowledge about disease and necessary therapy can lower self-efficacy as well increase pressure psychological, such as anxiety, image body negative, and price low self-esteem (Kharyal et al., 2020; Shamsi et al., 2017; Li et al., 2024). Social stigma and lack of support social the more to aggravate condition said, so that push the need holistic and interdisciplinary interventions For overcome problem psychosocial problems faced by adolescents with thalassemia (Shamsi et al., 2017; Wangi et al., 2025; Jabeen et al., 2024).

Effective self-care management own role strategic in increase quality life teenager thalassemia sufferers (Mardhiyah et al., 2023; Roshan et al., 2024; Badawy et al., 2023). The presence of systematic knowledge and education related management disease has proven can increase compliance to maintenance as well as facilitate increasing self-efficacy in thalassemia patients (Kharyal et al., 2020; Janatri et al., 2024; M Atia et al., 2021). Empowerment models, such as application approach family-centered through mobile technology, has show results positive in increase quality life children and adolescents with thalassemia (Hemmatipour et al., 2023; Seyed et al., 2021; Mulyana et al., 2023). With Thus, strengthening aspect educative intelligent and participatory Can become key in more self-care strategies effective and sustainable.

In line with findings said, the Teenage Thalassemia Self-care Management Program was designed specifically in West Java integrating approach education structured, support psychosocial, and empowerment teenager in One framework intervention holistic. Through this program, it is hoped that teenager can to obtain information comprehensive regarding thalassemia and strategy management the right disease, which in turn will increase ability they in manage condition in a way independent and optimize quality life (Kharyal et al., 2020; Hemmatipour et al., 2023). Giving counseling and intervention psychosocial expected capable help reduce impact negative anxiety and problems image self that often happened, and bridge gap support existing social (Shamsi et al., 2017; Schleider et al., 2023; Rodrigues et al., 2022). With approach This is the Teenage Thalassemia Self-care Management Program No only focus on care medical, but also on the aspect psychosocial and empowerment are important For reach adaptation a better self Good for teenager with thalassemia.

Review Theory

Thalassemia in Adolescents

Thalassemia is abnormality genetically characterized by the production of abnormal hemoglobin, so cause anemia chronic and dependent to transfusion blood throughout life patients (Srivastava & Behera, 2022). In adolescents, thalassemia does not only impact on conditions physique like fatigue, growth obstructed, and organ complications, but also affect aspect psychological and social, including anxiety, isolation social, as well as low trust self consequence dependence treatment term long (Pouraboli et al., 2017). Therefore that, the role of self-care is very important it is important for teenagers capable understand condition disease, manage therapy routine, and adapt in a way psychosocial in face challenge life as sufferer disease chronic.

The Concept of Self-Care in Management Disease Chronic

Self-care is draft important in management disease chronic, where the individual responsible answer in a way active in supervision health, treatment independent, and taking decision daily For maintain quality life (Orem, 2001). In in the context of thalassemia, self-care includes management timetable transfusion blood, therapy sailor substance iron, pattern eating, activity appropriate physical, and effort guard stability emotional. Research previously show that improvement knowledge and awareness self in self-care related significant with decline complications medical and improvement quality life thalassemia patients, including among adolescents (Rafii et al., 2016).

Management as Intervention Strengthening Self-Care for Thalassemia Adolescents

Self-care Management of Adolescent Thalassemia is A approach educational and supportive designed For empowering teenager thalassemia sufferers in manage his illness in a way independent, structured, and sustainable. This program integrate education health, strengthening psychological coping skills, up to development Network support social, which is proven effective increase self-management skills in thalassemia patients in various countries (Panigoro et al., 2019). In addition that, approach This in accordance implemented in West

Java because height prevalence thalassemia cases in the area and the needs will be the intervention model adaptive local to condition socio-cultural public local (Mariani & Rochimat, 2019).

In thalassemia context in adolescents, disorders genetics This No only result in anemia chronic and requires transfusion blood lifelong live, but also give rise to impact significant psychological and social problems. Teenagers with thalassemia often experience fatigue, disturbance growth, as well as affecting organ complications quality life them. Beside that, pressure psychological like anxiety, isolation social, and decline trust self become problem main thing that needs attention special from the workforce health and educators (Atia et al., 2021; Khoury et al., 2012; Mardhiyah et al., 2022). Research has show that impact psychological This lower effectiveness adaptation teenager to life everyday, so that Handling intervention psychosocial need integrated with management medical.

The concept of self-care is element essential in management disease chronic such as thalassemia. Self-care refers to efforts active individual in monitoring health, settings therapy, as well as taking decision in daily life to maintain quality optimal life (Mardhiyah et al., 2023). Orem's model, for example, emphasizes not quite enough answer individual For do maintenance self through education and training provided by the team medical consisting of from doctors and nurses (Mardhiyah et al., 2023; Urtekin & Eroglu, 2024; Yip, 202). Implementation draft this is not the case with thalassemia only covers management timetable transfusion and therapy class, but also includes control condition emotions and improvement knowledge about disease which in turn contribute to increasing self-efficacy. A number of study explain that self-care programs are supported by innovation technology like mobile application can more make it easier monitoring health and improvement compliance to therapy (Pérez et al., 2019; Siebenhüner et al., 202).

Self-care Management of Adolescent Thalassemia is approach designed interventions with integrate education health, strengthening skills coping, and development Network support social For empowering teenager in manage his illness in a way independent and structured. Approach This in line with effort increase knowledge about disease so that create belief adequate self -efficacy in face impact physical and psychosocial problems faced teenager thalassemia sufferers (Sadek et al., 2020; Taheri et al., 2020) Intervention This also takes advantage of principles technique education interactive and therapeutic psychological like therapy cognitive behavior (CBT) that has proven capable reduce stress and increase patient coping abilities Taheri et al., 2020; Babaei et al., 2019). Besides that, intervention expected more adaptive to condition socio-cultural local, especially in the area like West Java which has high prevalence of thalassemia, with notice values family as well as support community that has proven give influence positive in management disease chronic (Mardhiyah et al., 2023; Halim et al., 2022; Susanah et al., 2022).

Implementation that prioritizes multidimensional approach between aspect physical, psychological and social, are step strategic in optimizing self-care among teenager with thalassemia. Efforts increased self -efficacy and knowledge provided through educational programs This can reduce frequency complications medical and improve quality life in a way overall (Hassani et al., 2024; Bendowska & Baum, 2023). Beside that, support from family and community play a role as source social emotional participate support success intervention this, so that teenager can do adjustment optimally towards various challenges that arise consequence disease chronic this (Kharyal et al., 2020). With Thus, a comprehensive intervention model can be created, integrating aspect education, psychology and social synergy For increase self-management skills in adolescents thalassemia sufferers in general sustainable (Sadek et al., 2020; Taheri et al., 2020; Babaei et al., 2019).

Methods

Study This use approach qualitative with design studies phenomenology, which aims For explore experience, meaning, and perception teenager thalassemia major sufferers related self-care management in life everyday in West Java Province. **Approach** This chosen Because study want to understand in a way in-depth internalization process values, habits, and barriers to self-care experienced by adolescents with condition chronic thalassemia, which is not can measured in a way quantitative but traced through personal narrative and experience subjective.

Study done at home Sick type A which has been accredited namely Hasan Sadikin General Hospital conducted in September - October 2022 with method descriptive qualitative. The goal is For identify problem research and obtain the necessary baseline data For development of care models self in adolescence thalassemia. Research data stage 1 obtained from participants totaling 29 participants at Hasan Sadikin General Hospital Province West Java. Design at the stage Explorative teenager thalassemia with through interview deep about maintenance self For to obtain problem research and obtain the necessary basic data in frame development effectiveness of care models self to management self teenager thalassemia. Recruitment participants in accordance criteria inclusion, as for the purpose identify the basic data required For development of care models self thalassemia. Description results study Stage I consists of from two part main, namely characteristics participants and themes identified through interview sufferer thalassemia. At this stage This will outlined characteristics participants research, results study in the form of themes, sub themes and categories.

Participant in study stage One obtained from participants totaling 29 participants at Hasan Sadikin General Hospital consisting of of 13 men and 16 women, with beat 10 years old up to 18 years. Data collection was carried out with interview in depth. Data is analyzed use method Colaizzi, which involves seven stages start from read overall transcript, extract statement significant, formulate meaning, grouping theme, compose description narrative, until validation results to participant (member checking). Validity and credibility of data are maintained through triangulation sources, audit trail techniques, and confirmation results by participants and colleagues peer. Research This has get agreement ethics from Committee Ethics Health Research Polytechnic of Health Ministry of Health Bandung with number letter permit: XXX/KEPK/2025. All participants given explanation complete about goals, benefits, risks and rights in research, then sign sheet agreement participation (informed consent) before interview conducted. Participant data guarded its confidentiality and only used For needs study.

Result and Discussion

Participant in study stage One obtained from participants totaling 29 participants at Hasan General Hospital Sadikin which consists of of 13 men and 16 women, with beat 10 years old up to 18 years.

Table 1. Characteristics Participant

Participant	Age	Education	Type Sex	HB	Ferritin	Blood Type	BPJS
Participant 1	15 Years	Junior High School	P	6.7	3500	B+	PBI
Participant 2	11 years old	No School	P	7	6000	AB	PBI
Participant 3	15 Years	Senior High School	P	6.2	2790	O	PBI
Participant 4	13 Years	Junior High School	P	7.8	4074	O	3

Participant 5	18 years old	Senior High School	P	7	6000	A	PBI
Participant 6	15 Years	No School	P	8.9	5700	O	PBI
Participant 7	11 years old.	Junior High School	P	6.7	4595	A	3
Participant 8	16 years old	Senior High School	L	9.1	16000	AB	PBI
Participant 9	16 years old	Senior High School	L	8.5	18000	B	2
Participant 10	13 Years	Junior High School	L	8.6	17000	AB	2
Participant 11	14 years old	Junior High School	L	8.3	13000	B+	1
Participant 12	14 years old	Junior High School	L	8.2	8000	A	3
Participant 13	13 Years	Junior High School	P	5.6	2400	A	3
Participant 14	11 years old	Junior High School	P	7	3605	O	3
Participant 15	15 Years	No School	P	8.5	2565	O	PBI
Participant 16	15 Years	Senior High School	P	8.2	3500	O	3
Participant 17	17 years old	Senior High School	L	9	5000	O	2
Participant 18	10 Years	Sd	L	8.6	2550	O	2
Participant 19	17 years old	Senior High School	L	6	3841	AB	2
Participant 20	10 Years	Sd	P	7.7	1021	O	2
Participant 21	10 Years	Sd	L	6	4000	O	2
Participant 22	13 Years	Junior High School	L	6.8	1945	B	3
Participant 23	13 Years	Junior High School	L	8.5	3500	B	3
Participant 24	11 years old	Junior High School	P	6	3500	B	3
Participant 25	15 Years	Senior High School	P	7.7	3500	B	3
Participant 26	13 Years	Junior High School	P	6	5000	AB	3
Participant 27	15 Years	No Sklh	P	6.7	3500	B+	PBI
Participant 28	15 Years	Vocational School	L	7	3000	B+	1
Participant 29	15 Years	Senior High School	L	6	5000	AB	3

Characteristics participants in the study This 29 participants were obtained with the youngest age ten years and oldest eight twelve years. The majority type sex Woman as many as 16 (56%) Education Level partly the largest high school is 9 (41%), some of them elementary school children as many as 3 (10.34%). The average hemoglobin value below 8 as many as 18 (62.02%). Generally over 13 years old as many as 22 (72.41%). For mark ferritin highest eight

twelve thousands and lowest with mark two thousand. Type group blood generally with group O blood was 10 (34.48%). Based on the most BPJS class 12 (41.37%) entered class 3.

Condition Diagnosed Thalassemia

Participant dominated by women, although type sex Not yet proven influence behavior maintenance self in adolescence thalassemia. Along with increase age, ability teenager in do maintenance self the more increase Because understanding they to condition health also develops. Children age schools, especially the older ones old, more independent in manage his health and more active in maintain his health status compared to more children young. Research results qualitative against 29 participants who were interview in - *depth interview* was obtained description maintenance self teenager thalassemia in 5 (five) themes which include: (1) conditions diagnosed thalassemia; (2) impact Sick thalassemia; (3) support family and friends; (4) efforts made child For therapy thalassemia; (5) activity maintenance self.

Sub themes condition physique as condition condition physique diagnosed thalassemia

Condition physique child thalassemia that is complained of temperature body increased and anemia can seen in the quote interview following:

... *time That fever Keep going no down-down..(P2, P9, P14, P16, P19)*
.. *time 5 years old.. I hot..(P11)*
.. *I fever high.. then brought to doctor 2x..then checked hbnya...(P12)*
.. *" time 9 months old I Sick hot high, diarrhea ... (P21)*
.. *time First the test 9 months old, because rather yellow.. pale..(P1)*
.. *at the age of 5 months treated.. hot, weak, pale.. crying continue..(P3)*
.. *"at the age of 5 months I am being treated Because hot ... pale..(P5)*
.. *"yeah Because I lack cell blood red So thalassemia.. time That age 6 months:..(P6)*
.. *" at the age of 9 months I has been transfused because fever.. pale.. " (P7)*
.. *yes.. face pale.. weak..(P2,P8,P9,P12, P13,P14,P15,P16,P17,P18,P19,P20)*
.. *" I looks pale.. weak.. there is fever ... " .. (P 21, P 22, P28, P29)*

Sub themes complaint child as condition condition physique diagnosed thalassemia

Problem complaint children of the disabled thalassemia about nausea, vomiting and weakness can seen from quote interview following: (supported statement)

... *time That I fever.. vomiting" ..(P2)*
.. *yes when carried to House Sick I nauseous vomit he said" ... (P3)*
.. *complaint hot..continue nauseous.. uo.. uo.. like that" ... (P4)..*
.. *I feel nauseous..continue vomiting..(P23,P25)*
.. *yes feel weak.. weak.. (P 3,P 5,P6,P7),*
.. *" when I brought to House Sick tired... tired...(P14,P15,P16)*
.. *" he said I fainted"(P18)*

Sub themes results laboratory as condition condition physique diagnosed thalassemia.

Condition physique in inspection results laboratory with results hemoglobin low can seen from quote interview following:

.. *" I was taken to doctor Then checked hbnya 5 ago treated in the ER" .. (P2)*

..”, when 4 months old.. pale, recommended check laboratory blood the result low”..(P3)

..”just in time That is me typhus.. then check Hbnya low”..(P4)

...” weak.. pale.. then check lab..and hbnya low”...(P5,P6,P7,P9)

..” 5 years old, body hot.. pale then checked blood, the result low... hb is 1.7”...(p11)

..” yes.. hbnya low”..(p15,P16,P17,P19,P21,P24,P26,P29)

Sub themes condition genetics as condition condition physique diagnosed thalassemia

Condition physique diagnosed thalassemia can seen from results genetic conditions, including genetic conditions presented child seen from quote interview following This:

..” I caught thalassemia Because Older brother I also have thalassemia ”..(P4,P15,P28)

..” yes.. little brother I also have thalassemia ”..(P8,P21,P29)

..” time That Mother I was also checked he said carrier”...(P9,P18)

..” my father the result carrier nature”...(P20,P21)

Based on results findings research, can concluded that condition child moment diagnosed with thalassemia shows pattern experience uniform physical and medical, which is summarized in four sub themes main, namely condition physical, complaints physical, results laboratory, and conditions genetics. In the sub theme condition physical, majority participants report symptom fever prolonged, face pale, and body weakness, which often occurs sign beginning before done inspection continued. Sub theme complaint physique show that part big participants feel symptom nausea, vomiting, and weakness significant physical, up to a number of experience faint, condition This often become parents ' reasons bring child to service health. Laboratory results become proof medical main in the diagnosis process, where all participants found own level very high hemoglobin low, so that strengthen suspected thalassemia and become base giving therapy transfusion blood. Besides that, sub theme condition genetics also play a role important in support the diagnosis, where participants disclose existence history family that becomes carrier thalassemia trait or you the sibling also suffers disease this, which strengthens that thalassemia is disease inherited genetics autosomal recessive. The four sub themes the each other complete in explain description complete initial process child diagnosed with thalassemia, either from side physical, complaints subjective, results medical objective, as well as background behind genetics family.

Sub themes condition physique show existence symptom striking clinical features in most big participants, where the conditions temperature body increased and symptoms anemia become sign the beginning that sparked inspection more continued. Symptoms physique This in accordance with characteristics of thalassemia major, which are generally marked by a decline production hemoglobin, causing body lack oxygen that triggers reaction compensation body like fever light and tired chronic (Srivastava & Behera, 2022). Anemia weight that lasts a long time without treatment become trigger main inspection medical further investigations leading to the diagnosis of thalassemia.

On the sub theme complaint physical, participant describe fairly non - specific symptoms bother quality life, such as nausea, vomiting, and weakness. body. Complaints the in a way physiological related with imbalance metabolic and effects from hypoxia network consequence low level hemoglobin in blood (Pujol et al., 2019). Conditions This No seldom ignored as complaint light at first, but along time the intensity increase and impact on activities daily participants.

Next, sub themes results laboratory become component most objective diagnostics in the process of identifying thalassemia, where all participants report hemoglobin low as findings consistent laboratory. Hemoglobin values that are far below normal limits are indicator main

from thalassemia major, which often requires intervention in the form of transfusion blood routine (Rujito et al., 2020). Findings This in line with WHO recommendations regarding importance screening laboratory as step beginning in management anemia that is not visit improving, especially in countries with high prevalence of thalassemia like Indonesia.

Lastly, sub themes condition genetics disclose that history family own influence big on the process of diagnosing thalassemia in participants. In study this, the majority participants mention existence younger brother and sister who also suffer from thalassemia, as well as a father and mother who have status as carrier thalassemia trait (carrier). The autosomal recessive inheritance pattern in thalassemia confirms importance education about screening genetics and counseling premarital in to cut off eye chain disease this (Suyanto et al., 2022). Identification history genetics in family play a role important No only in the diagnosis process, but also in prevention and planning management term long, especially in the area endemic like West Java.

Impact Disease thalassemia

Thalassemia major has an impact big on physical and psychological teenagers, such as limitations activity, distrust self consequence change physical, as well as decline performance academic. Besides that, teenagers are also vulnerable experience disturbance emotional, anxiety, and problems influential social to quality life they. Support psychosocial very required For help teenager in overcome feeling different and constructive trust self.

Interview results deep with teenager sufferer thalassemia show that disease This give complex impact No only in a way physical, but also affects aspect education, economy family, and conditions psychological child. Theme the second one raised from study This namely *impact Sick thalassemia*, broken down in four sub themes that show description real about the burden experienced by children sufferer thalassemia in life daily.

Sub themes change physique with category weakness physical, disorders balance, no lust eating, difference form physique

Change physique with category weakness physical, disorders balance, no lust and difference form physique can seen from quote results interview following This:

.. " I often feel dizzy" ..(P2, P6, P7, P9, P10, P11, P13, P16, P17, P19)

.. " yes if I Like Dizzy That the sign his blood low" ..(P4)

.. I often get tired easily" ..(P5)

.. " time school Like easily tired.. exhausted" ..(P6,P15)

.. " If Lots activity I often easy tired.. listless" ..(P8)

.. " yes I often weak" ...(P11)

.. " if go home school Easily tired.. quickly tired" ..(P3,P14)

.. " sometimes if often play for a long time like nosebleed" ..(P9,P16)

.. " Like weak Keep going often dizzy" .. (P 11,P 2,P14,P17)

.. " if Already will it's time transfusion Like No lust eat ' ..(P3,P5)

.. " There is it's time So No Want to eat.. less appetite like that" ..(P7)

.. " I more short from friends class" ..(P2,P4,P5,P8)

.. " yes I like to feel inferior too because skin more black.. more short" ..(P9)

.. " skin I become black" ..(P12,P15,P16,P19)

Sub themes activity school disturbance with category always permission school, no follow sports, no follow Study group.

- .. " Study school usual, the teacher has know So often permission No school" ... (P1)
- .. " Like permission No enter school",, (P2P9P10)
- ... " seldom follow lesson sports, often permission school" .. (P3)
- ...: since enter grade 5 of elementary school and above often skip school, so go out school" ..(P4)
- .. " to school often absent because often to House sick" ..(P5)
- .. if Already weak seldom school, especially if to the hospital permission No school..(P6)
- .. " No school since enter junior high school" ... (P7)
- ... " normal school.. but often permission No enter school Because must transfusion schedule" ..(P8P9P10)
- .. " School I until junior high school, no continue Because often permission No school" ..(P11)
- .. " Study follow ... but often permission No enter school (P12P13)
- .. " a month often permission, sometimes 2 days..4 days No enter school.. because transfusion schedule..(P14)
- .. Study follow The same only often permission No sign in, routine in a month can be 4 days..5 days permission No school..(P15)
- .. " school disturbed.. often not follow Study group" ... (P16,P17,P18)
- ... " Like left behind Work group.. no follow Study together" ..(P19P20P21)
- .. " sometimes follow sports.. sometimes No follow" sports" ..(P12)
- .. " if the schedule eye lesson sport I often No join in" ..(P13P14)

Sub themes need cost increase with category request buy toys, buy food addition

Sub themes need cost increase with category request buy toys, buy food addition supported with statement following:

- .. " likes buying food What just" ..(P5,6)
- .. " sometimes I often request buy toys" ..(P9)
- .. " if to House sick, definitely I ask for buy in toys" ..(P8)
- .. " I Like ask for buy additional food" .. (P10)
- .. " happy if to House Sick like to buy the food that i want to" ..(P12)
- .. " at home Sick Certain I ask for lego" ..(P20)

Sub themes change psychological child with category motivation down, no excited and disturbed feeling.

Change psychology in children with category motivation down, no excited and disturbed feeling can seen from conversation under This ...

- .. " sometimes No There is spirit" ..(P10,P11,P12)
- .. " often lazy to do whatever want to be at home or at school" ..(P13)
- .. " No enthusiastic learning" ... (P14P15)
- .. " his luggage lazy (lazy to move)" ..(P16)

..” often feel bored”...(P18P19P20)
 ..” sometimes No want to transfuse again”...(P1718)
 ..” bored undergo routine to House sick”...(P21P22P23)
 ..” often No Want to drink medicine”...(P2P3P4P5P7)
 ..” sometimes Like emotion.. want angry-angry”...(P9)
 ...” often feel worried if Want to school ... (P5P8)
 ...” I Like Afraid interact with friends”...(P12P13)
 ..” There is situation I feel chest pain ... trembling”...(P20)
 ..” I sometimes Like feel depression”...(P15P27P28)
 ..” Like worried if Want to heart test pounding fast”...(P28P29)

On the sub theme *change physical*, found that part big participants experience related complaints with weakness physical, such as easy tired, dizzy, and exhausted after activity. Condition This aggravated with disturbance balance body that often experienced by children, especially moment level hemoglobin decrease approaching timetable transfusion. In addition that, the decline lust Eat become complaint general public who participated worsen nutritional status and conditions physique children, especially moment approach time transfusion blood next. Impact term long from condition this also appears in difference form physical, such as greater height short from Friend peers and change color skin become more dark, which is psychosocial trigger feeling inferior and low self in children.

Next, sub themes *activity school disturbed* show that the diagnosis of thalassemia very influence continuity education child. Sufficient absence from school high, good Because timetable transfusion blood and also condition weak physique, causing child must often permission from activity teaching and learning. No only that, participants also tend to No can follow activity physique like sports, as well as activity Study the group that became part important in the process of interaction social and development skills academic they. This is show that thalassemia own significant impact to development social and education child.

Other impacts revealed is *need cost increase*, which is not only related with cost treatment and transportation to House pain, but also demand child will entertainment like toys and food addition as form fulfillment comfort psychological during the treatment process. This is describe burden economy double that must be borne by the family, okay from aspect need medical and also need child For relieve discomfort emotional due to repeated treatment processes.

Sub themes lastly, *changes psychological child*, showing that thalassemia influence condition emotional and mental child in a way significant. Most of participants confess experience decline motivation, lack Spirit in learning and doing activities, as well as often feel boredom and saturation face routine maintenance like transfusion blood and drink medicine. Besides Therefore, a tendency also emerged disturbance feeling like anxiety, an emotion that is not stable, until feeling depression experienced by some child. Situation This show existence impact psychological that requires attention special in maintenance thalassemia, not only in form therapy medical, but also support adequate psychosocial.

Behavior maintenance self in adolescence thalassemia major is very influenced by knowledge about disease, support social, ability management self, and conditions psychosocial they. The more Good the understanding and support received, the more big possibility teenager For discipline in operate care, such as transfusion blood routine, therapy sailor iron, and management stress that arises consequence disease.

Support family and friends

Support family and friends become factor key in help teenager thalassemia undergo maintenance self optimally. Family provide support emotional, practical, informational, and financial, while friends provide a sense of togetherness and enthusiasm. Presence system strong support proven play a role in increase compliance treatment and quality life teenager sufferer thalassemia.

Study This aiming For dig in a way deep experience life teenagers who suffer thalassemia, in particular in context support social that they accept from family and friends peers. Findings study show that support social play role important in the process of adaptation emotional and everyday children sufferer thalassemia. From the results interview, appear two sub- themes main related support social, namely support family and support Friend same age.

Sub themes support family supported by 4 categories, namely father's support, support mother, support Grandmother and support aunt can seen snippet interview under This:

.. *"father, mother, grandmother alternate always buy food" ..(P5P6)*

.. *" I like once in a while accompanied by father, often mother" ..(P1,P2)*

.. *" yes besides my mother Like delivered Auntie... accompanied too" ..(P4)*

.. *" Mother always schedule to poppies before (P15P16P17P18)*

.. *" sometimes I Like delivered aunt if to House sick" ..(P20P21)*

.. *"Father often deliver to House sick" ..(P8P10P19P20P21)*

1. Sub themes support Friend supported with 3 categories, namely give support positive, to be good and loving friend help activities at school, can seen from results information respondents below This:

.. *" if I No school friend Like give know tasks that must be done" ..(P4,P5)*

.. *" friend Like to House do with his/her task" ..(P7)*

.. *" There is friend I like it telling you Task:..(P8)*

Support family is one of very important factor dominant in life teenager with thalassemia. Research data show that family, in matter This is father, mother, grandmother, and aunt, in particular active give attention and support, both in form physique and also emotional. Findings This in line with Family Support theory according to House (1981) which emphasizes that support social from family covers four aspect: support emotional, instrumental, informative, and rewarding. In context sufferer thalassemia, family No only give support practical, such as deliver to House sick and buy food, but also provides a sense of security and comfort that influences resilience psychological child.

Besides support family, support from Friend peers also become aspect important in life social children thalassemia. Interview results show that friends No only play a role as colleague in learning, but also as source moral support and motivation. Statement Respondent like " if" I No school, friends Like give know tasks to be done done" (P4, P5) and" friends Like to House do with his/her task" (P7) shows that Friend own role adaptive in guard connection social and sustainability of the educational process although child must often roll call Because treatment.

Support Friend This in line with the concept of peer support which according to Sarason et al. (1990) played a role in help individual feel accepted in environment. Presence a friend who understands condition health and in general active help in tasks school, make sufferer thalassemia feel still connected with environment socially, reducing feelings of alienation, and strengthen price self and motivation they.

Activity maintenance self

Activity maintenance self covers routine like transfusion blood regular, consumption drug sailor iron, guard pattern Eat healthy, exercise light, and get enough rest. Teenagers involved active in maintenance self tend more Ready face challenge physical and psychological problems caused by thalassemia, so that can undergo a better life productive and quality.

Management maintenance self involving compliance to treatment, pattern life healthy, and management aspect psychosocial support mental and physical balance teenager with thalassemia. Teenagers need understand timetable treatment, choosing nutrition right, recognize symptom dangerous, and involved in community supporters so that they Can independent, confident self, and active in undergo life.

Based on results research, efforts made by children with thalassemia in guard health reflected through five strategies main, namely guard pattern eat, routine drink medicine, do transfusion blood in a way regular, maintain activity physical, as well as guard pattern rest and sleep. In the aspect guard pattern eat, some big Respondent mention that they consume food in accordance parental advice and also team medical, such as multiply consumption recommended vegetables like broccoli (P19, P20, P22) and avoid food tall substance iron like Spinach (P4). Discipline in choose intake food This show awareness they in guard stability level substance iron in body, which is very important For prevent complications serious for sufferers thalassemia. In addition that, compliance in drink medicine also becomes structured habits, including consumption drug sailor iron like deferasirox (P1-P4, P6) and ferriprox (P5), acid folate (P8-P10), to additional vitamins For support Power stand body (P20-P22). Discipline This No only reflect awareness child in guard health, but also shows involvement family in support compliance treatment.

1. Sub theme guard pattern Eat supported by category eat recommended foods and to avoid prohibited foods, can seen from snippet interview following:

..” yes I eat.. drink appropriately recommendation mother”..(P3)

..” I No may eat foods that contain substance iron.. for example spinach”..(P4)

..” Eat drink enough”.. (P3P7P11P20)

..” guard food that is allowed eaten”..(P8)

..” eat foods that are allowed and not allowed may (P9P10)

..” food What just No There is taboos”..(P12P20)

..: I often Eat broccoli Because required”..(P19P20P22)

2. Sub themes routine drink drug supported by category drink drug sailor iron, drinking drug sour folate and taking vitamins can seen from snippet results interview following:

.. yes Eat drug regularly, deferasirox”..(P1P2P3P4P6)

..” always drink ferriprox”..(P5)

.. Yes routine drink medicine (P10P11)

.. Drinking drug routine (P11P12P14P16P17)

..” Drinking medicine 1x a day deferasirox (P20)

..” sometimes I drink sour folate”..(P5P6P7)

.. Every day I drink sour folate”..(P8P9P10)

..” I Like drinking overload”..(P19)

.. if at home Like drink vitamins"...(P20P21)

.. If it is already drink ferriprox sometimes I take vitamins too"...(P22)

3. Sub theme Transfusion actions support by category do routine transfusion can seen from snippet results interview following:

.. Routine transfusion"..(P1P2P4P5P6)

.. yes if Already pale I transfused"..(P3)

.." routine transfusion if hb low"..(P9)

...: yes I perform routine transfusions every 2 weeks once"..(P10P11)

.. transfusi sometimes 3 weeks or 4 weeks once"..(P13)

.." if I yeah routine transfusion"..(P12P14P16P1718)

..." if Already weak pale I direct transfusion"..(P19P21P22)

..." every 2-3 weeks I like to be scheduled for transfusion"..(P20)

.. even though sometimes I bored, but I do routine transfusion"..(P23)

4. Sub themes guard mobilization supported by category limit activities and activities in accordance condition physical, can seen results interview following:

.. yes I guard condition activities, so that no Lots move physical"..(P1)

.." Guard activity physical condition that doesn't tire you out"..(P4)

.." activity limited Because get tired easily"..(P12)

...: Rest Enough guard low energy".. (P13)

.. activities in accordance condition physical.. if tired yeah ... rest..."...(P10P19)

.. Sometimes I No follow heavy sports at school"..(P20)

5. Sub themes guard rest and sleep supported with category get enough rest and do n't stay up late, seen from results interview following:

.."Mom often to advocate Don't stay up late..and i straight away sleep"..(P8)

.." Yes, it is me get enough rest.. do n't stay up late"..(P10P21)

.. sometimes I sleep at 8-9 then get up dawn"..(P22)

Besides that, action transfusion blood that is done in a way routine become step medical main in management thalassemia, in which some big Respondent confess has undergo transfusion every two until four week, depending on conditions physical and level hemoglobin they (P1-P23). Besides transfusion, children this also keeps stability physique with limit activity excessive. They tend adapt mobilization with condition body, avoid activity physique weight, and choose rest when feel fatigue (P1, P4, P10, P19, P20). In addition that, keep quality getting enough rest and sleep is also important part important in strategy maintenance independent, such as No stay up late and sleep more beginning on parental advice (P8, P10, P21, P22). In overall, habits life healthy built by children with thalassemia This reflect adaptation positive and an important form of self-management For support quality life they are in the middle limitations condition health.

Barlow et al., 2005 defines self management as ability individual For manage symptoms and everything consequence life with condition chronic, including in it treatment, physical, social and changes style life. Different things conveyed by Lorig and Holman, that self management No only special For condition chronicle but may also be applied For manage all condition

health Because self management is task throughout life for individual (McCorke et al., 2011). According to Lorig and Holman (2003), the purpose from self management is For guard condition Healthy in psychological status. For reach a level ability individual they need learning about method For manage and control disease. According to Corbin and Strauss in Lorig and Holman (2003) self-management condition chronic must own three ability, namely: managing aspect medical from disease; manage role life including change role as consequence condition his illness and manage it consequence psychological from condition disease chronic. Self management support is very important for nurses and practitioners nursing Because they become line front in management patient condition chronic especially in organization and collaboration (Wagner et al., 2001; Watts et al., 2009 in Kawi 2012).

Conclusion

Study This show that teenager with thalassemia major in the Province West Java faces challenge heavy Good in a way physique and also psychological. Symptoms physique like anemia, fever, and weakness body often become sign the first that leads to the diagnosis of thalassemia. In addition that, complaint like nausea, vomiting, and fatigue physique participate to worsen quality life They. Laboratory results showed level hemoglobin low become proof main in the diagnosis process, which requires action medical in the form of transfusion blood. Impact psychological, including anxiety, disturbance feelings, and decline motivation, also become part important that influences life daily teenager with thalassemia.

Support family and friends same age proven own influence big in success management condition This. Family give support practical and emotional, whereas Friend same age help teenager For still connected with environment social although they often roll call from school. A program that integrates aspect medical, psychosocial, and social very required For increase ability teenager in manage disease they in a way independent.

In general overall, research This emphasize importance a comprehensive and holistic approach in management thalassemia teenagers, who do not only focus on management medical but also on strengthening aspect psychological and social, which can contribute to improvement quality life they

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