



## SELF MANAGEMENT PROGRAMS ON THE QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WITH CHRONIC KIDNEY DISEASE: A SYSTEMATIC REVIEW

Syarifah Aini Tanjung<sup>\*1)</sup>, Nur Agustini<sup>2)</sup>, Dessie Wanda<sup>3)</sup>  
<sup>1,2,3</sup>Universitas Indonesia

\* Corresponding Email: [sharifah.aini11@ui.ac.id](mailto:sharifah.aini11@ui.ac.id)

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### Abstract

**Introduction :** Diagnosis of disease Serious like disease kidney chronic disease (CKD) have implications in many field life children and their families , and can dramatically affect quality their life . One program to improve quality life is by involving self- management monitoring conditions , compliance to treatment and response to sustain quality live . **Method :** review systematically , started with formulate PICO: In patients children and adolescents , whether program management self compared to with intervention standard can influence quality live . Furthermore do search literature from databases ProQuest, ScienceDirect, Scopus, EBSCOhost, PubMed, ClinicalKey , ClinicalKey Nursing, Sage Journal and Google Scholar . **Criteria inclusion** is related research articles self-management child with disease kidney chronic , not review article , in English, research conducted on children and adolescents , and there are version full text . **Results :** Total articles obtained beginning from the entire database is totaled 106,740 articles , once done screening according to criteria inclusion , obtained 9 articles with various type research design . Eight from nine studies show There is the effect of self-management programs on pediatric and adolescent patients with CKD. Self-management program in adolescents with disease kidney Chronic can be education or training , peer support or group base care as well as preparation in terms of transition service health to services mature . **Conclusion:** Self-management program for children and adolescents effectiveness can improve results health , slow down development disease and delaying replacement therapy kidneys ( dialysis ), however self-management is complex and requires support multidisciplinary .

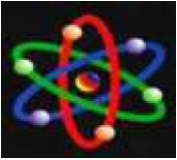
**Keywords:** Children And Adolescents , Quality Life , PGK, Self-Management.

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## INTRODUCTION

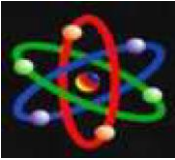
Disease kidney chronic disease (CKD) is damage kidney irreversible anatomical or functional (Kher et al., 2017). According to criteria Kidney Disease Outcomes Quality Initiative (KDOQI), definition disease kidney chronic is damage kidney for 3 months or more, defined as abnormality structural or functional kidney , with or without impairment rate glomerular filtration , which manifests as abnormality pathological marker damage kidney , incl abnormality composition blood or urine , or abnormalities in tests imaging rate less glomerular filtration  $> 60 \text{ mL/ min /1.73 m}^2$  for 3 months or more, with or without damage kidney (Kher et al., 2017). PGK is syndrome clinically characterized by loss function kidney gradually and irreversibly which can further develop become disease end -stage or failing kidney kidney chronic (CKD) (Amanullah et al., 2022). If CKD develops become fail kidney , children need dialysis even to a transplant kidney (Aier et al., 2022). Characteristics characteristic of children with CKD are: etiology or complications cardiovascular , which not only affects patient's health during childhood , but it also impacts the child when become an adult (Becherucci et al., 2016). Children who live dialysis own a number of taboo food . Remember breadth CKD comorbidities in children and challenges treatment lifetime life , unique psychological and social problems can occur (Aier et al., 2022).

Disease diagnosis Serious like PGK has implications in many field life children and their families , and can dramatically affect quality their lives which is called the Quality of Life (QoL). Many terms are

used to describe QoL, however based on statement WHO , QoL can be defined as perception individual about their position in life in context culture and system the values in which they live , and in relation to their (Dotis et al., 2016)goals , expectations , standards and concerns .

Children with CRF face Lots challenge , incl often hospitalized , procedure painful medicals , irregular school absences , and restrictions activity . It can have impact emotional and psychosocial in children , encouraging interest in thinking about quality live , which is increasingly known as results main in settings clinical and population studies children with CRF. Besides that 's youth is a period of transition important going to empowerment, outreach , and development personality . Just don't survive sufficient , and quality endure life has appear as focus fundamental from maintenance comprehensive health (Clavé et al., 2019). Based on result research conducted by Rafly, (2017)at Home Sick Cipto Mangunkusumo , more from half PGK children according parents (54.5%) and children (56.3%) have disturbance quality life especially in function school and function emotion . Old diagnosis  $> 60$  months , type sex women , and levels education medium is related factors with quality life PGK child . Matter this is the same as research conducted by (Sani et al., (2022)at Home Sick General Dr. Center Hasan Sadikin Bandung, obtained that as much as 60% of children with PGK at RSUP Dr. Hasan Sadikin Bandung has quality bad life based on self-report with an average total score of  $56.85 \pm 7.53$ . Based on parent-report , quality life child with PGK included in bad category with an average total score of  $69.43 \pm$





17.07. Lowest total score present in the patient child with existing PGK enter degrees end (PGK 5). PGK is condition period long ( long term condition ) which is not can healed However can managed with treatment and care or therapy , where self-management is component important from maintenance health (Nightingale et al., 2022). Self-management is ability For arrange life with disease chronic , which involves monitoring conditions , compliance to treatment and response For maintain quality life (Barlow et al. 2002 in Havas et al., 2016). This covers a number of aspect like obedience treatment , monitoring symptoms , nutrition , activity physique , and improvement Skills maintenance self . Self-management No only increase obedience patient to plan treatment they but also helps in development Skills coping they For their problem facing (Lozano et al., 2018).

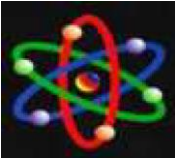
Self-management of disease chronic is dynamic , interactive and iterative processes that require patient For develop strategy multidimensional For overcome their problem experience in life daily (Miller et al., 2015). According to Nguyen et al., (2019) program self-management very useful stage beginning disease kidney chronic , which contributes For slow down development disease , improve results health , and reduce system load maintenance health . Various study about program patient self- management mature with disease kidney chronic has Lots done and proven effective in Indonesia. Wrong only one like research conducted by Astuti et al., (2017) obtained There is influence self management to ability psychosocial adjustments patient with disease kidney chronic . In children and adolescents , study about education self-

management has done by Emiliana et al., (2019) in child and adolescent respondents with Type 1 DM, obtained results that delivery education self-management in animated video form can increase self-management and compliance child in diet setting , action physical education , medication , stress management and blood sugar control . Study about program self-management in children and adolescents with condition chronic has carried out in several countries. Remember importance enhancement self-management patient children and youth with PGK then writer interested For do more review deep with do systematic purposeful review For discuss strategy intervention self-management to enhancement quality live in patients children and youth with PGK.

## RESEARCH METHODS

Identify on stage beginning determine question study with use PICO formula ( Population , Intervention , Comparison , and Outcomes ). Formulation problem with PICO method as following : the specified population is patient children and youth with disease kidney chronic , interventions applied form program management self , comparison or intervention the comparison is intervention standard or maintenance normal , meanwhile expected outcomes is increase quality live , so formula question clinical is —In children and adolescents with disease kidney chronic , is it? program management self compared to with intervention standard can increase quality alive ?. Writing article This done on month October 2022 with search systematic literature use a number of databases . Process determination literature





based on criteria inclusion that is article speak English , subject study is children and youth , and articles rise 2012-2022 years . Criteria defined exclusions is articles that do not available version text complete , and articles in the form review systematic.

After PICO formulation , step furthermore is look for mesh headings from formula question the PICO . Then do search using databases. Databases used is ProQuest, ScienceDirect, Scopus, EBSCOhost, PubMed, Clinical Key, Clinical Key Nursing, Sage Journal and Google Scholar . Keywords search used is self-management programs AND quality of life AND children and adolescents with chronic kidney disease. Besides use online database , researchers also do hand-searched from the reference list Articles are included to add article used . Total articles found is 106740 , next done screening based on criteria inclusion , screening based on title and abstract , then by downloading full text and read it until a total of 11 journal articles were obtained , there were 2 similar articles ( duplicates ) then issued . Total articles used and committed analysis as many as 9 articles . The entire selection process study can be described in the figure the following prisms :

Quality research articles used done using *the Joanna Briggs Institute (JBI) format guide* on each articles that have selected . Whole article evaluation results use *JBI's critical appraisal tools* stated worthy of being included in this study . Ninth articles with *randomized controlled trial* , *mixed method* , *cross-sectional* , *cohort* and study types qualitative fulfil

whole component based assessment JBI assessment criteria.

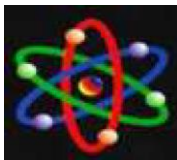
Amount articles used in the study In this systematic study , there are 9 articles with a range of years of publication from 2012 to 2022. The articles reviewed own design Randomized Controlled Trial (Huang et al., 2022; Sezer et al., 2021), mixed method (Sattoe et al., 2013), cross-sectional (Fenton et al., 2015; Zhong et al., 2020), cohort study (Ferris et al., 2015; Johns et al., 2020)and studies qualitative (Nightingale et al., 2014, 2022). The total sample in this study is as many as 364 people consisting consists from divided children and adolescents become group intervention and control groups as well as with the intervention different other . The results of the review can be seen in the table below .

N	Author , year of publication , country of research	Objective	Research design	Sample	Research result
1	(Huang et al., 2022) USA	To test effect a guidebook patient self education to improve knowledge / management self disease kidney chronic , readiness transition maintenance health , advocacy self and skills	RCTs	A total of 49 teenagers aged 11-17 years dengan stadium CKD ≥3.  Kel. intervention 31 youth  Ex . control of 18 adolescents	Intervention education patient significantly independent increase readiness management self participant , advocacy self and awareness from time to time .









7	(Ferris et al., 2015) USA	Gather information about Skills management self and transition maintenance health , through report self , in population wide adolescents and young adults with condition chronic .	cohort	21 adolescents with CKD	STARx develop sensitive , with older patients scoring significant ly higher at nearly every factor compared to younger patients .	English	and health professionals to children with condition chronic	chronic , and 28 professionals health	related to ethnography focused . Rewards included ability to get richer understanding of phenomenon complex each other confession skills that occur during parent / professional interaction maintenance health .
8	(Nightingale et al., 2022) English	explore How teenager with PGK took not quite enough answer For manage condition them and the role of the health professional during process this .	Studies qualitative	16 teenagers ages 13-17 years with CKD, 13 people old , and 20 professionals health	Family will get benefit from support professional health in term integrating time assumption not quite enough answer management yourself by getting independence in their lives and focuses on youth ' doing ' management self .				
9	(Nightingale et al., 2014)	explore interactions between people parents	Studies ethnography	parents of 6 children with the disease kidney	These findings highlight rewards and challenges				

Table 1. Summary results review literature

## RESULTS AND DISCUSSION

Readiness Child and Youth Self-Management. Four article study discuss about readiness children and youth in receive a purposeful self -management program For increase readiness child in undergo maintenance transition from child to mature . Type research obtained that is One article with type study cross sectional , one article with type study cohort study and two articles with type study studies qualitative . Factors that play a role that is factor resilience psychosocial ( efficacy coping , cohesion family , and quality live ) to readiness transition (Fenton et al., 2015). Besides it is also required support person parents and health professionals (Nightingale et al., 2014). Teenager with PGK also took not quite enough answer For manage condition them and the role of the health professional during process This (Nightingale et al., 2022). Studies conducted by Ferris et al., (2015) test





development, reliability, and structure factor tool. For measure readiness transition maintenance health and self-management. Tool This can useful for provider service health. For evaluate readiness transition patient them and skills management self in a multidimensional and appropriate way age which, in turn, should be help provider service health. For adjust and guide possible intervention leads to results more health ok.

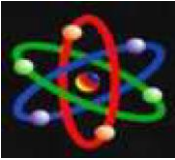
Self-Management Program Through Education. Two articles explain study about self-management programs through educational media. Type research obtained that is One article with type RCT research and one article with type study cross sectional. Research conducted by Huang et al., (2022) form drafting A book guide education patient independent. For increase knowledge / self-management disease kidney chronic, readiness transition maintenance health, advocacy self and skills attention among teenager with disease kidney chronic. Whereas Zhong et al., (2020) researching about education and literacy health. For readiness transition maintenance health and self-management in adolescents and adults young with disease kidney chronic (CKD) or hypertension. Intervention independent education self-management and transition "ALL YOU NEED IS LOVE" in teenagers with PGK is intervention independent form education patient during six planned week. For increase knowledge or self-management disease kidney chronic, readiness transition maintenance health, advocacy self and skills patient. educational programme self-management. This covers education readiness and self-management related transition service arranged health in six module weekly

namely: (1) kidney and its function, (2) management CKD treatment, (3) nutrition, diet, and habits style life with PGK, (4) readiness transition service health, self-management (incl understanding insurance and transfer to adult-focused providers) (5) problem reproduction related to CKD and compliance treatment; and (6) interact in system service health. Every session 15 minutes long. Literacy health defined as ability. For acquiring, processing, and understanding information and services health base. For make decision health. At least One from three teenager own literacy low health and children with literacy low generally own behavior / outcome more health bad. in patients nephrology children and youth at UNC Chapel Hill, literacy health and knowledge nutrition associated with readiness transition service health (health care transition) and/ or management themselves, especially in children teenager. In studies this, skill management self found correlated with knowledge related nutrition with disease. Findings This show that knowledge nutrition can function as a target for intervention. For increase readiness transition service health when patient entered young adulthood and transferred to a people-focused provider mature.

### Training Based Self-Management Group

Three article study discuss about training management self related maintenance based group or peer to peer support. Type research obtained that is One article with type study cohort study, one article with type RCT research, and one article with type study mixed methods. Johns et al.,





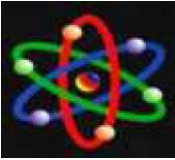
(2020) do studies related intervention maintenance based group ( for 6 months ) versus treatment common in adolescents and adults . Patients were randomly assigned For maintenance based group requested For attended 6 visits clinic monthly . All session started with activity maintenance self , incl measurement pressure blood and other vital signs ( incl heavy body ). on each session , topic certain discussed and their content sourced from material existing education from Program Education Disease Kidney National . Participant motivated For each other share about behavior compliance and compiling strategy with provider services and participants other For apply habit healthy . Studies conducted by Sezer et al., (2021) is develop program training self-management in teenagers based on Individuals and Families Self - Management Theory , which aims For optimizing health and welfare teenager with disease kidney chronic with increase management self . Matter This covers a number of aspect like obedience treatment , monitoring symptoms , nutrition , activity physique , and improvement Skills maintenance self . Training group teenager during visit follow continue in the clinic also works For increase interaction they with their peers , and allows they For share experience and gain access to support psychosocial . Study related to peers is also carried out by Sattoe et al., (2013) Study explore effect from form Specific support peer- to -peer on self-management teenager with disease kidney stadium participating end in activity Camp COOL that is form camp year in the Netherlands national during One special week For adolescents and young adults with disease kidney stadium end.

## DISCUSSION

Self-management on illness chronic is dynamic , interactive and iterative processes required by patient For develop strategy multidimensional For overcome their problem experience in life everyday . Patient self- management chronic is matter important in management disease . Optimal self-management aims For control factor risk and increase management disease . Patient No Again become recipient passive education , however they are also active in determine choice health them . Intervention self-management is a strategy for help patient develop skills and strategies for increase self-management condition chronic. Self -management is very effective on stage beginning disease kidney chronic , which contributes For slow down development disease , improve results health , and decrease burden system maintenance health (Nguyen et al., 2019). Besides That obedience treatment is very important For slow down development and prevention complications (Ferris et al., 2017). For teenager with CKD/CKD, adherence treatment play role central in success transition maintenance health (Health Care Transition) from maintenance child adult - focused nursing (Nicholas et al., 2018). From search literature got 5 themes that is education parent child with PGK, education / training management self For youth , peer to peer support ( support Friend peers in adolescents ), Compliance treatment influence readiness transition , readiness teenager For transition maintenance to adults ( health care transition ). Parent from children with condition chronic responsible answer For do part big parenting clinical at home . because it , member team multidisciplinary obliged







For promote parent learning about gift maintenance and monitoring gift maintenance (Swallow et al., 2012). Stages education can done with method involving parents in practice together, then next with exchange knowledge and negotiation role, and deliver education in accordance need parent (Swallow et al., 2013). Family involved Because own role important in give maintenance to individual with condition chronic (Kokorelias et al., 2019). this known with approach Family Centered Care (FCC) which has developed especially For maintenance child, for value partnership with member family in handle health medical and psychosocial patient (Kokorelias et al., 2019). Because of the kids with condition chronic can experience disturbance quality life (Bai et al., 2017). Self-management can increase ability For arrange life with disease chronic, which involves monitoring conditions, compliance to treatment and response For maintain quality live (Barlow et al. 2002 in Havas et al., 2016). Effective self-management increase results health, slow down development illness and delay therapy replacement kidney (dialysis), however, management self That complex and needy support (Havas et al., 2016). Self-management programs has Lots applied to educational programs disease chronic, which is designed For postpone bad function kidney, avoid depression, and improve quality life (Lee et al., 2016). Self-management program is one of them is through education that is form drafting A book guide education patient independent For increase knowledge / self-management disease kidney chronic, readiness transition maintenance health, advocacy self and skills attention among teenager with disease kidney chronic

(Huang et al., 2022; Zhong et al., 2020). Self-management program this is very useful Because intervention self-management can help slow down development disease become fail kidney (Welch et al., 2015). Different with education standard only focus on self-management tasks medical without notice role or emotional task children and youth with PGK. Adolescence is period transition in which the adolescent gradually develop skills and competencies adaptive and functional, and build identity preparing self they For fulfil roles and expectations public mature (Chulani & Gordon, 2014). Peer support in adolescents can increase trust self, knowledge related disease more many, feel capable For more responsible answer and open to person another, and dare defend self alone. The role of friends is combination proactive become supervisor, adviser, and leader (Sattoe et al., 2013). Each other share related resources and experience with disease or maintenance can function as means important For increase knowledge and improve support emotional (Kokorelias et al., 2019). Intervention peer to peer support form group-based care performed by Johns et al., (2020) obtained that presence teenager in every session not enough optimum, with only 40% of 10 participants attended 3 sessions. Lack of data for intervention in adolescents with PGK underlining necessity study more carry on in group this. Transition maintenance health is process that requires preparation as Suite from services focused on children until mature. Study about management self For preparation transition adolescents to care mature with disease kidney chronic has Lots done (Fenton et al., 2015; Ferris et al., 2015; Zhong et al.,





2020). Program transition done For increase readiness transition and help patient responsible responsible for his health . However in implementation exists challenges faced by teenager with disease chronic and caregiver them , in matter transition not quite enough answer main For activity maintenance health daily from person old to child (Lerch & Thrane, 2019). In management health daily No all person old deliver control to teenager . For teenager with disease chronic disease diagnosed in infancy , people old has develop knowledge special disease and assessment symptom youth as a whole . A number of person old disclose doubt For deliver management disease to teenager Because person old No Certain how to transmit it to child they (Lerch & Thrane, 2019). Studies conducted by Lerch & Thrane, (2019) show involvement person continuous aging be measured Good in quantity and quality time spent caregivers and youth related activities and responsibilities answer management disease . Promotion collaboration in solving problem , knowledge transfer disease , and dialogue open about disease proven reduce conflict , reduce withdrawal person old , and improve obedience teenager through autonomy and self-efficacy .

## CONCLUSION

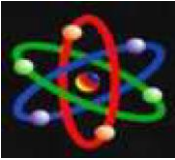
Results from review systematic This show potency importance program self-management in children and adolescents with PGK. Program effective self-management in children and adolescents can increase results health , slow down development illness and delay therapy replacement kidneys ( dialysis ), however

management self That complex and needy support multidisciplinary . In implementation exists challenges faced by children and youth with disease chronic and caregiver them , in matter transition not quite enough answer main For activity maintenance health daily from person old to child . Program self-management in children and adolescents with disease kidney chronic can form education or training , peer support or group base care and also preparation in matter transition service health to services mature . However so , necessary done study more deep regarding strategies for self-management programs in children and adolescents with PGK remembering Not yet Lots study about matter this .

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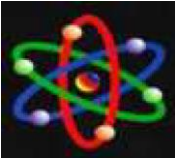
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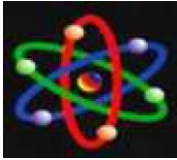
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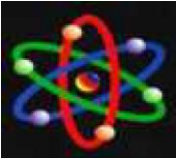




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