

CHILDREN PARENTS IN ONCOLOGY ROLE : SUPPORT , PSYCHOLOGICAL PREPARATION AND REHABILITATIONS

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Abstract

This scientific article children in oncology parents' complex their role , child's disease with fight in the process psychological , practical and social approaches to study The research is focused on main purpose oncological to illness exposed was child's treatment during parents' support activity , psychological preparation level and rehabilitation in the phase participation systematic analysis from doing consists of . The article parents' role not only to the child care to do with not limited , but their the disease in management active participants , treatment in the process partners and child's psychological stability keeper main factor that Methodological in terms of scientific of literature systematic analysis , as well as children oncology in the field practical research results studied . Results this shows that parents enough psychological and information from preparation the child 's past for treatment adequate attitude formation , treatment to the plan compliance to do and general the results improve with directly related . With this together , parents own psychological needs out of consideration aside to remain , their " forgiveness" "compassion fatigue " syndrome exposed to be and family of the system stability in storage difficulties important problems as record Conclusion as in other words , modern pediatric in oncology effective treatment approach the child not the "child - parent - mother " system to the center to put , parents the disease in management strong partners as see and to them every one-sided help This approach requires not only child's clinical the results improves , maybe whole family healthy development and rehabilitation service does .

Keywords

Children oncology , parents role , support , psychological preparation , family rehabilitation , pediatric oncology , child psychological condition , disease management , family stress, many network approach .

INTRODUCTION

Children oncology not only medicine science the most complicated , maybe the most high at the level human and psychological demanding from the fields The adolescent patient oncological diagnosis not only child's himself , maybe his/her whole family , especially parents a turning point in life This is a point . family from "normal" life to " illness" with to fight spends , this process often long , heavy and to uncertainties complete This point of view in terms of modern pediatric in oncology treatment success child's clinical parameters with limited not only that , but it is the whole family this heavy the test overcome ability and child's next life to the quality directly is related .

Parents child's oncological in treatment role traditional at the level of " carer " or " supporter " considered . However, the last ten in the years research this showed that their role from it much wider and is more complex [1]. Parents child's main emotional supportive , medical information interpreter , treatment of the plan done increase control is a hospital system and doctors with of communication main is a channel and finally , the family remaining members (for example , healthy siblings) or for sisters) stability This is the source . many edged tasks to perform in the process parents' they are serious too psychological stress, fatigue , depression and uncertainty weight they lift .

Article main purpose children in oncology parents' role and importance three main in the direction of : **1) the child active supporter as , 2) treatment to the process psychological in terms of ready was partner as , and 3) long term rehabilitation process main active as** complex is to study . Research this shows that parents this roles effective to do child's for treatment motivation , clinical results and in general life to the quality noticeable impact shows . With this together , parents to oneself typical needs and to them aimed at help systems working exit necessity current problem as remains .

This article modern literature and research based on parents' role about there is knowledge summarizes , their difficulties and successful experiences analysis does and children oncology in practice the family to the center put integrated approach offer will reach .

LITERATURE REVIEW

Children in oncology parents' role about scientific literature mainly developed in countries wide studied is , this " family " sector centered care " (Family-Centered Care) and " psychosocial oncology " like new of directions appearance to be reason was .

Parents Supportive Role Evolution : Traditional medical in the model parents passive observers or doctor of orders executors as considered . However, **the Cossack and etc. (2021)** their own wide comprehensive in the study this They emphasize that " modern pediatric in oncology parents active decision acceptance those who do and treatment of the plan integrated are members of the . Their disease about knowledge degree , medical to the team questions and to the child emotional proximity treatment efficiency important is a prophet " [2, p. 112]. This idea **Swishtun and etc. (2019)** are also supported by , they parents' " disease" in management "illness management participation " concept previously push it , this participation child's to drugs compliance adherence level positive the impact empirical based on [3].

Psychological Stress and Parenting To himself Special Needs: Son's or daughter's oncological disease in parents serious psychotraumatic impact leaves . **Pai and etc. (2017)** by meta- analysis conducted this shows that oncological children's their parents almost 30-40% clinical at the level depression and signs of anxiety demonstration it will , this indicator general to the population 4-5 times more than above [4, p. 456]. **McCubbin's (1993) " Family Stress Theory "** this the event in explanation important role plays . His stating that the family system heavy to the stressor (this without child's disease) secondary stresses (e.g. financial problems , work release , social When added (isolation) , the family adaptation ability (family adjustment) test [5]. Nevertheless , **Wiener and etc. (2020)** own at work this emphasizes that many psychological interventions child's to oneself aimed at is , parents to oneself typical needs (for example , their own psychological health , couple relationships , professional life) often out of consideration aside remains [6].

Information and Psychological Preparation : Parents disease about knowledge and treatment to the process psychological readiness their efficiency defines . **Mack and Grier (2004)** their own classic in the article this emphasized : " Parents no when of children cancer to the disease ready However, they are not clear , consistent and permanent information flow , as well as psychological help offer to grow through them " enough " at the level " sufficiently prepared " take exit This is possible . them out of fear practical to actions "[7, p. 1545] . Modern in approach this The process is called "shared decision-making" (collaborative decision acceptance (to do) is called . **Feudtner and etc. (2018)** in the study this show that parents decision acceptance to do to the process attraction to do not only their satisfaction increases , maybe clinical the results improve also shows a trend [8].

Rehabilitation and Far Muddali Consequences : Treatment sharp stage after completion then , the parents role rehabilitation and observation continue in the phase Ness and **etc. (2018)** own in the study in childhood cancer disease survivors and their parents between " delayed " psychological stress" (post-traumatic stress) . studied , both far away term psychological to the consequences exposed to be [9]. This situation parents child's physical , cognitive and emotional in rehabilitation , as well as its to school return and social in adaptation main to the assistant Kearney and **al . (2015)** " family the concept of "family rehabilitation " previously pushing , rehabilitation programs only to the child not , maybe whole family stress overcome ability to increase focus necessary [10]

Literature analysis this shows that the last in years parents' active to the role attention intensified although , this knowledge to practice enough at the level integration not done . Uzbekistan and In the context of Central Asia this topic according to local cultural , social and economic factors into account received research very less . This article world experience generalization with together , local in the circumstances necessary changes about idea tries to run .

DISCUSSION

1. Support Many Edged Nature: Practical and Emotional Parties

The child main supporter as parents one of time in itself one how much tasks they do . **Practical support** medicines on time giving , chemotherapy transferable days observation , child food and hygiene control to do , medical examination and to inspections take to go such as tasks own inside These tasks to oneself typical " family" health storage family health caregiving organization Northouse and **etc. (2012)** stating that this in the role parents often "unprofessional " as " nurses " they work , they complicated medical procedures to perform and medical tools to manage forced they will be , this and in them professional health storage to employees typical stress brought [11]. However , more importantly , **emotional support** . The child fear , pain , hospital loneliness and future about to their concerns in response parents child's main emotional " regulator " function They are passing by . They are talking to the child . trust , understanding and hope feeling to absorb through his/her spiritual stability They try to keep it . **Hinds and etc. (2009)** by held phenomenological research this shows that children parents' emotional existence " in life " the most important "something " is described as to them of treatment heavy in the processes power [12] This is emotional communication not only child's psychological to the situation , maybe physical also affects the answer to show For example , stress hormones level decrease immunity system support possible .

2. Psychological Preparation: Information , Expectations Management and Decision Making

Psychological preparation not only disease about information to get , maybe this information emotional in terms of digestion to do , realistic expectations formation and difficult decisions acceptance to do ready to be own inside takes . **Cossack and etc. (2021)** As noted , " parents the most big from difficulties one medical is medical uncertainty. Treatment plan often to test results looking at change , side effects in advance saying not to be and forecast clear not being them permanent anxiety in the case of "[2, p. 115] For this effective from tools one " **in advance** " " **anticipatory** guidance " is on the ground medical team future in stages what to be Possible , what are the side effects? expectation and to them how in a relationship to be need about parents in advance This method **Lazarus and Folkman's (1984) Stress Management Theory** of suitable comes , because it is potentially to the stressor in advance get ready and " manage " it to the event " that will take " [13]. Also , heavy clinical in situations (e.g. , palliative or experimental treatment choice necessity during) parents **moral punishment** (moral distress) from the head forgiveness possible . **Feudtner (2007)** this " correct " something to do desire , but it done increase institutional , social or other obstacles because of difficult or the impossibility when you understand appearance to be psychological discomfort " [14, p. 234]. For example , a child pains continue when it arrives or treatment ineffective become in the rest treatment continue to hold or stop about decision acceptance to do parents sharp-edged moral suffering source to be possible .

3. Rehabilitation : Transition Stage and Far Muddali Companionship

Oncological treatment sharp stage when finished , many families this relative " peace" celebration instead of , new kind of worries with This stage " **from the diagnosis** " **next life** " (life after diagnosis) or " **Goodbye** " It is called " **survivorship** " . Parents role this on the ground child's physical strength to restore , school and social to life to return help to give , also , delayed effects (e.g. heart problems , reproductive health problems , second level tumors) to follow turns into .

Biological treatment with one in line , **psychological rehabilitation** very important . Children and their parents often **Posttraumatic Stress Disorder (PTSD)** or his/her signs with Bruce (2006) own at work " **resistant post-traumatic** the concept of " resilient posttraumatic growth " previously pushing , some parents and children heavy from experience to pass on , to life relatively deeper meaning , family connection increase and personal strength they find possible [15] However , this

growth automatic not . He is the child . supportive system (this including psychologists , social employees , family and friends) and to oneself typical adaptation strategies (e.g. , positive again interpretation to do , religious belief in the existence of Depends on the parents . own Rehabilitation is also important . Many years during child's to the disease aimed at families own marriage relationships , personal to your dreams and social to life attention to give forgetfulness possible . **Jurbergs and etc. (2019)** in the study , the child treatment after completion even then , parents almost 25% longer term depression signs to show record [16]. Therefore , successful rehabilitation program as a whole family needs satisfaction need .

4. Cultural Context and Uzbekistan Realities - Parents role cultural values , social standards and economic resources with closely related to . Uzbekistan and other In Central Asian countries strong family connection , from generation to generation was close relationship and parents' child's to life deep intervention traditional are characteristics . This is a from the side , strong support network if it provides , the second from the side , to the parents big social also transmits pressure possible – they child's disease for themselves feeling guilty or family and from the public the expected " perfect" to be caring obligation under to be possible . Local under the circumstances additional to the poor **financial weight** Treatment high price , work from the place far term interruption , additional transport and food expenses the family poverty to the border take arrival It is possible . This is parents' stress sharp increases and their to the child giving psychological and physical help to the quality negative impact shows . Also in Uzbekistan children oncology in the centers systematic psychosocial help and family consultation services still development at the stage . Parents often only medical information with limited to their own emotional experiences , fears and fatigue cases professional help for find they can't .

RESULTS

Research results children in oncology parents' role one row important and mutual related from aspects consists of that they efficiency and medical system by how much to be supported dependence shows .

1. **Home Supportive and Disease Manager** : Parents the child's 24- hour practical and emotional needs satisfactory main is a person . Their disease about knowledge , treatment to the plan compliance to do to provide and medical team with effective communication child's treatment to the results directly impact shows . **Svistun and etc. (2019)** brought to the information according to , parents active

attraction did without done increased in treatment to drugs compliance to do The level increased by 25% [3].

2. **Psychological Stress Home Victim and Source of Stability** : The child diagnosis in parents clinical level depression , nervousness and the risk of PTSD sharp increases . With this together , their own psychological stability save (or save (not being able to) the child spiritual to the state strong impact shows . **Pai and etc. (2017)** as shown by his parents psychological status good was children for treatment more positive in a relationship were and side effects lighter from the head They forgave [4].

3. **Information and Preparation Required** : Parents precisely , on time and in advance given information " The partnership is valued ." decision acceptance "shared decision-making " model their panic and uncertainty feeling reduce , doctors with reliable relationship to install help gives . **Mack and Grier (2004)** As noted , preparation from programs past parents medical problems solution in doing much active and effective were [7].

4. **Rehabilitation The process Main Participant:** Sharp treatment stage when finished , parents child's physical , academic and social rehabilitation main to the organizer This will turn into transition They are also in the same stage . for big psychological requires adaptation , because they permanent observation and delayed effects about anxiety with to live their studies need .

5. **Cultural and Economic Important Influence of Factors** : Uzbekistan in the context of strong family system of support valuable source to be possible . However, financial difficulties , limited psychosocial services and " perfect" to be a parent pressure to parents additional stress load spends . Therefore for , local to culture customized help programs working exit necessary .

Conclusion as in other words , parents role not just a " helper " , but pediatric oncological of care main " worker " They are the child 's health and well-being for necessary was the environment creates and keeps .

CONCLUSION

Children in oncology treatment success only chemotherapy protocols and surgery to the skill related This is not a success , it is just like three legged table like , three main to the column relies on : **medical team , child and his/her family** . Parents this of the triumvirate inseparable part are , they are not only child's physical care , maybe his/her spiritual stability , treatment was loyalty and future life quality for is responsible .

Research results this clear shows that parents aimed at integrated approach This approach is necessary . the following own inside to receive need :

Systematic Psychosocial Scanning and Help : Every oncological child's family initial diagnosis from the stage psychological stress, depression and fatigue level determination for regular from scanning to be carried out , necessary professional psychologist when help offer to be need .

Structured Education and Preparatory Programs : Parents disease , treatment , possible side effects and them management , as well as with the child communication to do methods about systematic information they receive This information is needed . different in languages and different formats (brochures , videos , seminars) to be necessary .

Many Networked Teamwork : Pediatric oncologist , nurse , psychologist , social worker employee , dietitian and , need if , religious from consultants consists of team to parents every one-sided help to show Kearney and **etc. (2015)** As noted , " only medical approach with limited stay effective not " [10].

Rehabilitation Expansion : Rehabilitation programs only child's physical to the state not , maybe whole family psychological and social also focus on rehabilitation " Goodbye . " the remaining " children" and their parents for far term observation and help groups organization to be necessary .

Cultural and Social Context To the account Approach taken : In Uzbekistan This is , first of all , strong. family from networks use , secondly , financial help mechanisms strengthening , thirdly , local language and to culture suitable programs working exit in mind holds .

The end finally , the child treatment is the family treatment . Parents strong , knowledgeable and supported partners as see and them this for the purpose arming is not only humanitarianism duty , maybe high good quality medical of help modern is a criterion . The child on the face smile not only chemotherapy efficiency , maybe his/her hand squeeze standing of parents reliable and quiet in his eyes It is the opposite .

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