

Supports Treatment Compliance by Sharing Happiness and Being Friends: A Case Study in “Sahabat Anak Kanker” Community in Indonesia

Feriana Ira Handian*, Yeni Fitria and Mahmudatul Rodliyatil Falah

Maharani Nursing College, Indonesia

Jalan Simpang Akordeon No.8B, Mojolangu, Kec. Lowokwaru, Kota Malang, Jawa Timur 65143

*Corresponding author: ferianaazar@gmail.com

ABSTRACT

Background: treatment compliance of Acute Lymphoblastic Leukemia (ALL) important to improve morbidity and one of keys to successful treatment in children with ALL. Sahabat Anak Kanker Malang is a non-state community of self-help group cancer engaged to build positive perceptions of patients and families about the fight against cancer in Indonesia. **Objective:** by elaborating Friedmans role theory as a theoretical framework, this research is aimed to explore the role concept self-help group cancer childhood to support compliance care of parent in ALL children. **Method:** this study was conducted by case study in qualitative design with 25 participants from volunteers, health workers and the community. Data conducted in Sahabat Anak Kanker Malang Community, and surroundings area by participatory observation, in-depth interview and focus group discussion. Data were analyzed with data reduction, display, conclusion, verification and assisted by open code software 4.0. **Result:** This research found that this community offered a major program to share happiness with cancer children and being friends for them, motivators as well as facilitators for medication compliance, develop fun hospital atmosphere for children and gain networking to support patients and parents. **Conclusion:** Although they face difficulties when interacting with health worker technically in the treatment room, the activities undertaken by this community get wide positive responses as an alternative program and complete maintenance activities that cannot be fully done by the hospital. **Keywords:** treatment compliance, self-help group, cancer, acute lymphoblastic leukemia, non-state community

INTRODUCTION

The most common cancer in children is leukemia. In Indonesia, the problem of abandonment therapy of leukemia caused by financial reasons (60%). Because of these conditions, 70% of children died in a phase of consolidation, maintenance and early reinduction (Sitaresmi, Mostert, Schook, Sutaryo, & Veerman, 2010). The treatment phase protocol of induction-remission, consolidation and maintenance is at least 2.5 years (Imbach, Kuhne, Aceci, 2004). The support given to parents will have an impact on their satisfaction, both in the decision-making process and in the beliefs of the decisions that have been made (McKenna, Collier, Hewitt, & Blake, 2010). Over the last few years there have been researches related to social support groups for volunteer-based palliative care in some countries of the American region, but research outside of North America is still very limited. Limited evidence that volunteers in direct care roles improve the wellbeing of patients and their families (Candy, France, Low, & Sampson, 2015).

METHOD

This study used case study as part of ethnography in qualitative design through Sahabat Anak Kanker (SAK) in Malang, Indonesia. Participatory observation, in-depth interview and focus group discussion were the tools used to obtain the data from 25 participants from community volunteers, health professional staff and parent of children with Acute Lymphoblastic Leukemia during March-August 2017. Transcript interviews and data were analyzed with Miles and Huberman (1984) methods and assisted by open code software 4.0. To address the issue of validity, combining different ways of looking at it (method triangulation) or different findings (data triangulation) was employed.

RESULTS AND DISCUSSION

Develop Psychological Support

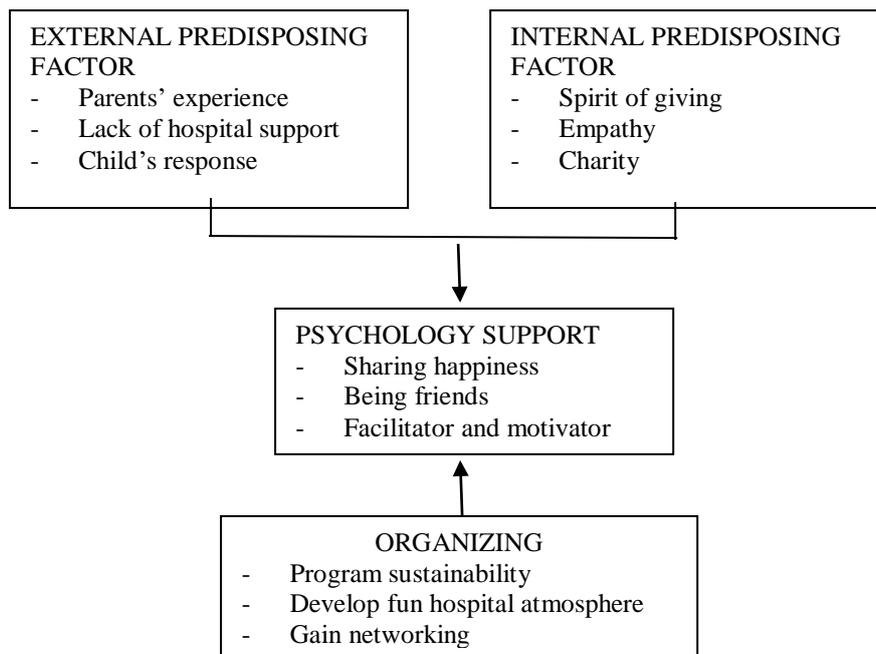


Figure 1 Voluntary Role

Volunteers who joined this community present because of instinctive response. They give spirit and empathy support by sharing happiness, being friends for child and parents, motivators as well as facilitators for parents. This role performance appears because of many situations faced by parents during treatment, not based on external perception of community. This situation different from Friedman conceptual framework that role performance conducted by external expectation on this from people or community (Friedman, Bowden, & Jones, 2003). It concludes that volunteers' role in childhood cancer develop from personal reason after getting external stimulus or parent experience.

Sharing happiness

Voluntary appearing by natural response of humanism. Burden condition during cancer treatment, dying children and high mortality rate of children affected voluntary responses. They develop good situation by sharing happiness for family and children.

“Sharing happiness is our vision” (community leader)

“We hope our affection and attention will entertaining and help their recovery process“ (volunteer 4)

Sharing happiness support held provided with playing, complete play tools, organizing birthday party for children in hospital during treatment, hold monthly event and give spirit by invite child’s favorite character. This action done because of their belief that on happy situation, children will easily have passed the treatment and healing process. This happiness offers opportunities to feel good to children (Stukas, Hoye, Nicholson, Brown, & Aisbett, 2014). Hospice programs with higher use of volunteers were associated with quality of care (Block et al., 2010).

Being Friends

Two parents of children with acute lymphoblastic leukemia explore that during the illness they not only faced chronic burden from the illness but also from community. They feel excommunicated on their own city. People believe that the disease caused by parent sin on past. Volunteers come in parent and children activity during the illness in hospital or at home, develop parent social support group on social media and create many kinds of merchandise which families were shown by it. This strategy makes parents not feel alone for fighting cancer. Overall this benefits in patient-reported primary outcomes, although with a rather small effect size (Siette, Cassidy, & Priebe, 2016)

Be Motivators as well as Facilitators

The chronic illness occurs in family is situational occurrence appearing family crisis. Families faced this condition by adaptation mechanisms by involving sources of support from outside the system (5). Parents receive motivation in spirit form of children began to come to hospital. After the existence of SAK, they more enjoyed the treatment because they were no longer afraid of hospital atmosphere. This motivation also given by volunteers to parents through social media consists of parents with children with cancer. The uniqueness of volunteer’s role may fulfill in care support (Candy et al., 2015). In addition to providing motivation, volunteers also facilitate transportation needs by bridging these interests with local government or sponsors to provide free ambulances.

Consistent with Main Program of Play

Sahabat Anak Kanker have main program on play. This present on regular weekly activity during play therapy. Hospital give room facilities for this. In this room a regular play therapy session class guided by volunteers. One session play therapy done with a maximum duration of 60 minutes with the activity began to color, fairy tales and cubits. When children play activities, volunteers will choose patients who are able mobilized to play in the playroom. Sahabat Anak Kanker with its program, playing, gains a wide of appreciation both national level and local. It is fully designed by the SAK as part of their strategies to promote discourse although technically volunteers face difficulties when interacting with health worker in the treatment room. Volunteers choose the schedule by themselves. They understood there were a few ways to individualize their roles primarily selection (Kramer, Danielson, 2016).

Develop Fun Hospital Atmosphere

Sahabat Anak Kanker Community is currently one of communities remain consistent with the activities undertaken and directly supervised by specialist doctors who are officials in the Hematology Oncology Division of Dr. Saiful Anwar Hospital, Malang. Before they came, the playroom and child-care environment looked the same as the adult ward. But once this community is in the midst of the patient, playroom becomes more vibrant, cheerful and fun for child as it has been equipped with more play equipment, wallpaper wall designed and filled bookcase with storybooks for children. This is as revealed by the following participants “that wallpaper, doctor (Specialist) give to us...we choose by our self” (community leader)

“they have been waiting for...play therapy”(parents)

SAK also organized recreational program by travelling around the city for family and siblings. Volunteers undertook a including emotional support and recreational from this event (Burbeck et al., 2015).

Gain Networking

One of the strategies undertaken SAK to maintain the sustainability of the program is gain networking. This sourced from formal institutions owned by the government either non-government. Government agencies that cooperate with SAK include Health Promotion Division of Dr. Saiful Anwar Malang Hospital, Governmental or Private College and other hospital in Batu Region. Evidence of this cooperation made in the form of a written agreement between the institution and the head of the SAK community. In addition, cooperation is also woven with private institutions and other non-profit institutions. For example, other cancer institutions in Indonesia, such as Pita Kuning foundation, HOPE and Indonesian oncology foundation. With this other, the pattern is mostly done culturally and there is no written agreement yet. For certain activities, the community also collaborates with sponsors and donors of activities. Sponsors who regularly publish are print media newspaper and radio, while for national publications together with MNC in cooperation with HOPE Indonesia Foundation. There was no restriction but more prioritized for the fulfillment of infrastructure activities and consumables needs.

CONCLUSION

The role of volunteers is very important in helping the treatment of children with ALL. Although not yet measurable in this study, however, the volunteer role emerging on its own initiative was able to provide an alternative to improving the quality of care for patients. To further explore the benefits of this support group economically and culturally. Nurses are expected to be able to develop and organize this support group to the stage of basic health services. Technically, hospitals and health workers should increase social responsibility to the community by collaborating on improving health status with non-state community.

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