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Research Article

The Unsteady Mainstay of the Family: Now Adult Children's Retrospective View on Social Support in Relation to Their Parent's Heart Transplantation

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I have nothing to declare.

Background

- Patients' condition is life threatening, most of them are very hopeful about the future
- Patients waiting for heart transplantation with young children are concerned about their partners

wWang LY, Chang PC, Shih FJ, Sun CC, Jeng C. Self-care behavior, hope, and social support in Taiwanese patients awaiting heart transplantation. J Psychosom Res. 2006 Oct;61(4):485-91.

Haugh, K.H. & Salyer, J. (2007) Needs of patients and families during the wait for a donor heart. *Heart Lung,* **36**(5), 319-29.

Background

- It has been shown that young carers with mentally unhealthy parents need support
- They need communication and shared experiences, advice and feedback, outside involvement, acute relief, and structured help with their care commitments

Elf M, Skärsäter I, Krevers B. Thr web is not enough, it's a base'-an explorative study of what needs a web-based support system for young carers must meet. Inform Health Soc Care. 2011 Dec;36(4):206-19.

Background

- The Swedish Health Care law was strengthened in 2010 with regard to children with a parent with a serious physical illness
- The healthcare organization must now pay particular attention to children's needs for information, advice and support
- This needs among children with a seriously ill parent, who waiting for heart transplantation, are unknown today

Swedish health care law
(http://www.riksdagen.se/sv/Dokument-
Lagar/Lagar/Svenskförfattningssamling/Hälso-
och:sjukvårdslag-1982_sfs-1982-763/?bet=1982.763)

Aim

- To describe now adult children’s experiences of social support in relation to a parent’s heart transplantation during childhood

Interviews

- All 13 interviews were conducted by telephone
- The opening question was:
    - What was your experience of support during your parent’s heart transplantation?
- The participants were asked to talk more about the situation and their perceptions of support

Method

- Manifest content analysis
- The now adult children had to be younger than 25 years of age during the heart transplantation
- Interviews were conducted with 13 adult children who had a parent diagnosed with cardiomyopathy or congenital heart disease, and had undergone a heart transplantation

Results

- The median age for the children was 18 years at the transplantation and their parents had been ill before for 18 months (median) and on waiting list 161 days (mean)
- Participants, 9 were female and 4 were male ranging from 23 to 37 years of age, with a median age of 26

Results

Three categories:

- Health care professionals' approaches
- Family and friends' approaches
- Society approaches

Health care professionals’ approaches

- None of the children felt that they had received enough information or support
- They had wanted to be more involved in the process and that any adult asking for their needs

“I wish that they would have involved us more in the process. . . A bit more support, not like the counselor, but so that youfelt that the doctorswere more available for questions, thatwould have been a great help (Child 7)”

Family and friends' approaches

- Most information received children from their parents
- The children avoided to search for information on Internet
- The older siblings were forced to quickly grow up

"You could say that our roles changed, that I
became my dad's right hand from having been a child.
I mean from being his child to being his
right hand (Child 1)"

Society approaches

- The family often had problems with the economy due to lost income as a result of a parent's illness
- In general, no one talked about their situation

"It could have been different if I had received support, counseling. It was a whole new world to me, for instance, the social security office, which I had never been in contact with before, and I did not know how to best deal with all the paperwork. I could also have received some help with a crisis, because many years later I experienced a crisis (Child 12)"

Conclusion

- There was a lack of support for children to heart transplantation patients
- Support in the shape of information was in most cases provided by the sick or healthy parent
- It is of great clinical importance to develop psychosocial support programs for children with a seriously ill parent waiting for heart transplantation (before, during and after surgery)

Conclusion

- Information and assistance relating to cardiac transplantation is a complex and multifaceted issue involving patient-centered, family-related, disease-related and treatment-related factors
- A holistic approach is necessary, in addition transplantation expertise necessary skills to meet the needs of patients with chronic disease as well as their families
- Increase awareness and knowledge of heart transplantation patients in the community in general, and particularly among other institutions

Discussion

- What opportunities do we have to give to these children enough of information and support during the transplantation process?
- How can we involve these children with parents in the process?
- What information and support do they need?

Discussion

- Is it possible for them to meet other children/parents in the same situation and share experiences? How?
- What support people may be useful in different issues they have?
- How do we reach them best?
- How should a possible support program look like?

Thank you for your attention