

THE AYA BOX: A PATIENT CENTERED INSTRUMENT IN COMMUNICATION WITH ADOLESCENTS AND YOUNG ADULTS WITH CANCER AND THEIR CARE GIVING PARENTS

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Introduction

There is a growing recognition that the perception of AYAs diagnosed with cancer is distinctive from that of children or adults. The main objective of this project is understanding how AYAs and their care giving parents experience cancer, diagnosis, hospitalisation, treatment and survivorship to develop a patient centered tool which can be used by the multidisciplinary team.

Methods

A qualitative study was performed based on the principles of grounded theory. 24 semi-structured interviews were held with AYAs between 15 and 25 years of age. Additionally 21 care giving parents (19 mothers and 2 fathers) were interviewed. Sampling was based on situational diversity (e.g. gender, age, social context, education, time since diagnosis). The interviews were transcribed and coded (NVivo7) and constant comparison was used to analyse the data. Data collection and analyses took place in a cyclic process.

Results

From the AYAs' perspective, cancer is something temporarily passing their life-path. Their coping strategies are focused on preserving identity and guarding normal life, not only during treatment, but also in follow-up and survivorship. Findings suggest that AYAs prefer care, tailored to their needs. The AYA box has been developed to meet these specific needs and to enhance the communication with the AYA. The box belongs to the AYA only and contains a booklet with revealing stories of AYAs' experiences, postcards, a unique AYA tag, useful stickers mention feelings or concern, cards with information or instructions, a brief symptom scale and smart aids in communication with their relatives and professional caregivers. The whole multidisciplinary team work with this instrument and can use it to talk about more difficult or emotional topics.

When confronted with the cancer of AYAs, the care giving parents face various fears and insecurities. In relation to each other findings demonstrate poor communication about emotions between the AYAs and the care giving parents. The box can provide a means to promote this communication.

Conclusions

This study revealed that cancer seems to have a different meaning for AYAs than for their care giving parents. The results are translated in a practical box, based on the experiences of the AYAs and can inspire caregivers to provide patient centered care in accordance to the specific preferences and wishes of the AYA.