
CONFERENCE ABSTRACT

Map your Burden of Treatment (MyBoT): an arts-based digital communication aid for young people with a chronic condition and their care providers

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Background: Young people with a chronic somatic condition receive treatment to reduce symptoms, but treatment can pose a heavy burden and affect their quality of life. Despite this, they rarely discuss this so-called treatment burden with care providers. Discussing treatment burden can help to identify treatment barriers and personalize care. We developed the digital tool MyBoT to improve communication about treatment burden.

Methods: MyBoT was developed for young people (aged 16-25) who undergo treatment for a chronic condition and their care providers. It was designed and developed by a team of academic researchers, care providers, young people with a chronic condition and a design studio. Additionally, other young people and care providers were invited to advise during the project. The development took place in four stages. The first consisted of a literature study, a design session with young people with a chronic condition and an interview with a care provider. Based on this, the team designed a paper prototype – an initial design of the tool on paper. In the second stage, this prototype was digitalized. This was an iterative process in which team members provided feedback on several versions. During the third stage, a demo version of the tool was applied in six workshops with young people with a chronic condition. Based on their experiences the tool was finalized. In the fourth stage, a dialogue session with young people with a chronic condition and care providers was organized to discuss implementation.

Results: In MyBoT, young people portray their treatment burden by making a 'body map'. This is an image of a body, in which users indicate the impact of treatment on their lives and wellbeing with photos, icons and text. A chatbot asks questions about how they are doing, what they like to do and the impact of treatment on this. Users can print their body map and discuss it with their care provider. Users reported positive experiences with MyBoT. They considered it a useful visual aid to discuss treatment-related topics that are difficult to express in words, such as future planning and non-adherence. Users noted that the tool helps to take control and introduce topics that matter to them during consultations with care providers, because it results in a tangible product (a body map) they can show. They appreciated that the chatbot in the tool treated them as a person rather than a patient, because it covered topics like hobbies, friends and dreams.

Conclusion: Digital body mapping exercises can be a valuable aid in discussing treatment burden. It helps young people with a chronic condition to tell their stories, as they can visualize and show their experiences before they discuss them. This is especially helpful in discussing sensitive topics.

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Next steps: MyBoT is being used in a rehabilitation center and other options for implementation are currently explored. Because of the positive experiences, we are now also developing an arts-based digital communication aid for young people with a mental chronic condition.