Betere transitiezorg voor jongeren met chronische aandoeningen

Evaluatieonderzoek van het Actieprogramma Op Eigen Benen Vooruit!

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2013.12
Sociaal-Medische Wetenschappen (SMW)

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Publicatiedatum
September 2013

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Summary

Between 2008 and 2012 a quality improvement programme On Your Own Feet Ahead! was undertaken in three rounds of each 10 teams (Pilot phase, Dissemination phase 2010 and Dissemination phase 2011). The aim of the programme was to improve the transition from child to adult care and improve self-management of adolescents with chronic conditions (12-25 years) in (pediatric) hospitals and (pediatric) rehabilitation centres. The 'breakthrough method' was used as a model for implementing and spreading good practices.

Aim. The aim of this study is to evaluate the effects of the programme. The leading research questions are as follows:

1. Which generic interventions at the program and project level are actually performed in the Pilot phase and which (disease) specific adjustments are necessary? Which generic interventions at the program and project levels are actually performed in the Dissemination phase?
2. What are the effects of the programme on the primary outcomes at the individual (adolescent, parent, care provider), project, and program level in the Pilot and Dissemination phase?
3. What are crucial success and failure factors at the individual (adolescent / parent) project, and program level that influence the effect of the programme in de Dissemination phase?
4. Which best practices can be identified?

Study design. A combination of research methods has been applied. A quasi-experimental design was used in which 30 teams participating in the programme and 9 control teams were involved. In the first two rounds three measurements were carried out (baseline at the start of the programme, end-measurement after 12 months and follow-up after 24 months), in the third round two measurements (at the start and end of the programme) and for 6 of the 9 control teams also two measurements were carried out (with a 12 month period in between).

Care providers from all teams received a written survey. For 24 of the 30 teams we collected survey data among adolescents and their parents. And 13 teams of the Dissemination phase collected data on process indicators.

As part of the qualitative research a number of teams were selected. Teams from hospitals as well as rehabilitation centres were selected, teams that implemented different types

of interventions and represented different patient populations, and teams that were very successful or in contrast had many difficulties in achieving their project goals. We strived for a geographically even distribution as well as an even distribution over the different rounds of the programme. In total 19 teams (of 30) participated in this part of the research.

Results. Best practices from the Pilot phase were used intensively in both rounds of the Dissemination phase which made the implementation of interventions easier. The availability of good practices, tools and structure of the programme supported teams in implementing transitional care.

The approach of the programme seemed applicable for hospitals as well as rehabilitation centres and for different patient populations. Adjustments to interventions were seldom made. All interventions take time, it takes consensus between team members and effort to convince each provider involved to change old habits.

According to professionals, the programme helped to improve coordination between pediatric and adult care, stimulated developing a shared vision and policy for transitional care and improved the transfer process. Adolescents (as well as parents) experienced more attention for non-medical subjects during consultations, were more self-confident and became more independent during consultations. These changes were sustained and further improved in the long run. Even though adolescents do not experience improvements in the organization of transitional care and communication with their care providers immediately after the end of the programme, they do experience these improvements in the long run. Comparison with control teams shows that participating in the programme and implementing transitional care interventions may contribute to improvements not only as perceived by professionals, but also by adolescents and parents.

Improving satisfaction with care through the provision of care tailored to patients' needs and a more supportive role for health care providers improves quality of life. Also more proactive behavior of adolescents may benefit the quality of life of adolescents.

Conclusion. Teams' participation in the programme resulted in improved quality of transitional care. The programme inspired teams to improve transitional care, provided them with several good practices and tools and facilitated the implementation process. However, substantial improvements as reported by adolescents mostly show up in the long run. Almost all teams succeeded in sustaining the implemented new work practices and some of them further developed transitional care after ending the programme.