Brief Communication

Addressing challenges and needs in patient education targeting hardly reached patients with chronic diseases

Annemarie Reinhardt Varming, Rikke Torenholt, Birgitte Lund Møller[1], Susanne Vestergaard[2], Gitte Engelund[3]

Health Promotion Research, Steno Diabetes Center, Gentofte, [1]Health Department of Health Collaboration and Quality, Region of Southern Denmark, Vejle, [2]Research & Knowledge, Danish Diabetes Association, Odense, [3]Innocate, Kgs Lyngby, Denmark

ABSTRACT

Some patients do not benefit from participation in patient education due to reasons related to disease burden, literacy, and socioeconomic challenges. In this communication, we address more specifically both the challenges that these hardly reached patients face in relation to patient education programs and the challenges educators face when conducting patient education with hardly reached patients. We define principles for the format and content of dialogue tools to better support this patient group within the population of individuals with diabetes.

Key words: Chronic diseases, dialogue tools, health education, participation

Introduction

For people with chronic diseases, patient education is critical to developing successful health behavior changes.[1] However, some people are "hardly reached" by patient education programs: Those with lower educational and income levels who experience severe co-morbidity or disabilities, few resources, low health literacy, weak social networks, or sociocultural problems.[2,3] They may not be offered participation, fail to attend, or attend without gaining the benefit.[4] Consequently, special attention must be paid to both the recruitment process and program format and content. This report focuses on the challenges, wishes, and needs of hardly reached people with diabetes for patient education program format and content.

Access this article online	
Quick Response Code:	Website: www.ijem.in
	DOI: 10.4103/2230-8210.149324

Methods

The results presented here were obtained through in-depth interviews and workshops with nine patients with diabetes (PWD) who were characterized as hardly reached by educators and five workshops with more than 20 educators engaged in patient education. The results are part of a larger study with the purpose of developing and testing dialogue tools targeting hardly reached patients with chronic diseases and establishing a competence development concept for educators engaged in patient education. The study was performed using design thinking methodology.[5]

During interviews and workshops with PWDs, their challenges, wishes, and needs in terms of patient education pedagogical approaches and formats were explored. Three of five workshops with educators primarily focused on the characteristics and needs of hardly reached patients from the educators' perspectives. One workshop more specifically investigated educators' challenges in relation to hardly reached patients and 1 2-day workshop encompassed exploration of design

Corresponding Author: Dr. Annemarie Reinhardt Varming, Steno Diabetes Center A/S, Patient Education Research, Niels Steensens Vej 8, DK-2820 Gentofte, Denmark. E-mail: are@steno.dk

principles and ideation for development of dialogue tools targeting hardly reached patients.

All interviews and workshops were observed and video-recorded. Data collection was highly user-focused, promoted by the use of "probes" to actively engage participants and explore their preferences for different kinds of dialog tools representing various learning styles.[6] Data collection, analysis, and synthesis were framed by the "The Balancing Person" and "Health Education Juggler" models.[7,8]

Results

To some extent, the challenges of hardly reached patients with respect to patient education fit the categories of The Balancing Person model: Lowered bar related to practical limitations imposed by living with chronic illness, changeable moods related to emotional changes, bodily infirmities related to negative physical changes, and challenging relations related to social changes arising from the limitations of chronic illness. However, this patient group also dealt with challenges that seemed to go beyond diabetes and other chronic diseases and might instead relate more generally to childhood and living conditions. These additional challenges constitute preconditions, which can limit participation in and obtaining a benefit from typical patient education programs [Table 1]. In addition, preconditions were linked to certain behavioral characteristics that educators often find difficult to handle [Table 1].

Table 1: Preconditions and behaviour characteristics related to hardly reached patients with chronic diseases

Limiting preconditions for participation in patient education	Behaviour that can be challenging in relation to patient education
Seeing limitations rather than opportunities	Resistance to change
Wishing not to be present (at the session)	Lacking drive or capacity
Missing recognition	Postponing duties
Lacking or having excessive structuring	Fluctuating engagement
Unsystematic thinking	Unrealistic perception of own situation
Either/or mindset	Unrealistic ideas and goals
Difficulty reading and writing	Reluctant/quiet/shy
Difficulty verbalizing needs/ experiences	Refrains from asking for help
Lower level of abstraction	Is passive, does not contribute to the group
Lower level of reflection	Hyperactive
Learning disabilities	Very talkative
Memory problems	Does not respect limits
Hypersensitivity	Gets easily distracted
Lower self-confidence and self-esteem	Difficulty keeping focus and concentration
Dependence on others	Difficulty understanding messages
High degree of self-centeredness	Limited or no use of personal computer
	Excessive sensitivity to sensory input
	Does not listen
	May appear selfish

These data formed the basis for further work in developing the format and content of dialog tools targeting hardly reached patients with chronic diseases in patient education. A 2-day workshop comprised exploration of design principles and ideation for prototype development. Following the workshop, the data were analyzed and synthesized into design principles and themes for dialog tools to use with hardly reached patients [Table 2].

The challenges for educators in relation to hardly reached patients were explored, analyzed and synthesized using the Health Education Juggler model as a framework [Table 3]. The recommended focus for competence development of educators in terms of the roles in the model also appears in Table 3. Based on the design principles, the challenges of the educators and prototype testing, a toolkit of ten dialogue tools and a guide for educators were developed. Furthermore, the health education concepts

Table 2: Design principles and themes for dialogue tools to use with hardly reached patients

- Design principles
  - Flexibility in using the dialogue tools
    - One-to-one sessions and group-based
    - For use in various situations
    - Linking different themes
    - Varying degree of difficulty
  - Simplicity in structure
    - Be simple to explain and understand
    - Have a clear purpose
    - Be concrete (and not abstract)
    - Be easily read
  - Appreciative approach
    - Be supportive and confirmative
    - Be trustworthy and trust building
    - Be humorous and hope building
    - Have focus on success and be motivating
  - Concrete expression
    - Secure that different learning styles are met
    - Enable visual, tactile, kinesthetic, auditive stimulation
    - Be practical and tangible
  - Focus on patients' different preconditions
    - Younger as well as older patients
    - The common as well as the individual
- Themes
  - Focal points for the dialogue tools
    - To set the scene (safe environment for participation)
    - Support to obtaining physical and mental well-being
    - Clarification of – and support to strengthening relations
    - Generation of knowledge
    - Promotion of motivation, support and ability to act

Table 3: Challenges and recommended competence development for educators

Educator challenges in relation to hardly reached patients	Recommended focus for competence development of educators
The embracer	
Risk of exhaustion	Be conscious of their own role
Difficulties with saying no and defining limits	Learn about group dynamics
Misjudged consideration	Control the desire to be too all-embracing in their care
Tendency to take the "fixer role"	
Different sets of values	
Missing courage	
Daring to cope with psychological problems and difficult subjects	
The facilitator	
Getting everyone onboard	Learn facilitation techniques
Coping with crying	Learn to bring up and handle difficult topics
Appreciating own power	Learn to direct proceedings and keep an overview
Balance between theory and practice	
Too much focus on content rather than pedagogical methods	
Balance between control and no control	
Avoiding conflicts	
Need for control	
Takes challenges personal	
The translater	
Knowing and exploring each patient's need for knowledge	Learn to make medical knowledge meaningful for patients
Talking over the heads of people	Learn to provide medical detail in line with patients' needs
Need to appear omniscient	Train in connecting patients' challenges to medical and practical issues
The initiator	
Ambitions on the patients' behalf	Learn about motivation and change processes
Overly ambitious personally	Acquire tools for setting goals
Daring to let go of the belief that one knows what is best for the patient	Learn to involve group and individuals in finding solutions

of dialogue and participation and former developed tools for patient education inspired development of the new toolkit.[9] The toolkit is presently undergoing a feasibility study involving 76 educators in municipal settings in Denmark. The 76 educators participated in a competence development course lasting a day and a half, which qualified them for participation in the feasibility study. The course included presentation of and training in use of selected dialogue tools and a story-dialogue workshop for interactive learning from experiences among course participants.[10]

Conclusion

Data collection for the feasibility study comprises a web-based questionnaire for educators and seven observations followed by interviews of a sample of participating patients and educators. The results will indicate if the intended function of the dialog tools was achieved and if educators were able to integrate the tools into education programs. The interviews will also reveal more specific experiences of patients and educators with the tools. Based on the results, the toolkit and guide will be updated and offered for general use in Denmark. Future research related to the toolkit should include a larger effect study. In addition, establishing competence development among educators is crucially important to meeting the needs of hardly reached patients with chronic disease.

Acknowledgment

We wish to thank all the participants for their valuable contribution with regards to participation in workshops and interviews. We thank Jennifer Green, Caduceus Strategies, for editorial assistance.

References

1. Jarvis J, Skinner TC, Carey ME, Davies MJ. How can structured self-management patient education improve outcomes in people with type 2 diabetes? Diabetes Obes Metab 2010;12:12-9.
2. Freimuth VS, Mettger W. Is there a hard-to-reach audience? Public Health Rep 1990;105:232-8.
3. Danish Health and Medication Authority. Forløbsprogrammer for kronisk sygdom. Generisk model og Forløbsprogram for diabetes. [Course programs for chronic disease. Generic model and Course Program for Diabetes]. Copenhagen; 2008.
4. Johansen KS, Rasmussen PS, Christiansen AH. Hvem deltager og hvem deltager ikke i patientuddannelse. Evaluering af sygdomsspecifik patientuddannelse i Region Hovedstaden. KORA Det Nationale Institut for Kommuners og Regioners Analyse og Forskning. [Who participate and who do not participate in patient education. Evaluation of disease-specific patient education in the Capital Region of Denmark. Copenhagen: KORA The National Institute of Municipalities and Regions Analysis and Research]; 2012.
5. Brown T, Wyatt J. Design thinking for social innovation. Stanford Soc Innov Rev 2010. Available from: http://www.ssireview.org/articles/entry/design_thinking_for_social_innovation. [Last accessed on 2014 Dec 19
6. Mattelmäki T. Applying probes – From inspirational notes to collaborative insights. CoDesign 2005;1:83-102.
7. Hansen UM, Engelund G, A Rogvi S, Willaing I. The Balancing

Person: An innovative approach to person-centred education in chronic illness. Eur J Person Cent Care 2014;2:290-302.
8. Engelund G, Hansen UM, Willaing I. 'The health education juggler': Development of a model describing educator roles in participatory, group-based patient education. Health Educ 2014;114:398-412.
9. Engelund G. In balance with chronic illness. Tools for Patient Education. 1st ed. Gentofte, Denmark: Steno Health Promotion Center; 2011.
10. Labonte R, Feather J, Hills M. A story/dialogue method for health promotion knowledge development and evaluation. Health Educ Res 1999;14:39-50.

Cite this article as: Varming AR, Torenholt R, Møller BL, Vestergaard S, Engelund G. Addressing challenges and needs in patient education targeting hardly reached patients with chronic diseases. Indian J Endocr Metab 2015;19:292-5.

Source of Support: The study was funded by the Danish Health and Medicines Authority, **Conflict of Interest:** ARV and RT are employed by Steno Diabetes Center A/S, a research hospital working in the Danish National Health Service and owned by Novo Nordisk A/S. Steno Diabetes Center receives part of its core funding from unrestricted grants from the Novo Foundation and Novo Nordisk A/S.SV is employed by the Danish Diabetes Association which is a NGO and independent of commercial interests and views, reflecting any business' interests. The Danish Diabetes Association works with full openness and transparency in the cooperation with external partners. BLM is employed by Region of Southern Denmark and has no conflicts to declare. GE is a self-employed consultant and has no conflicts to declare.

Announcement

iPhone App

A free application to browse and search the journal's content is now available for iPhone/iPad. The application provides "Table of Contents" of the latest issues, which are stored on the device for future offline browsing. Internet connection is required to access the back issues and search facility. The application is Compatible with iPhone, iPod touch, and iPad and Requires iOS 3.1 or later. The application can be downloaded from http://itunes.apple.com/us/app/medknow-journals/id458064375?ls=1&mt=8. For suggestions and comments do write back to us.