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Just a click away... E-mental health for eating disorders

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Chapter 11

Summary and general discussion

In the introductory chapter (Chapter 1) we highlighted that ED are severe psychiatric disorders that represent a significant public mental health concern. Unfortunately, many ED go undetected and the majority of individuals experiencing ED symptoms does not seek and receive health care. Amongst those who do, the current health care services appear only moderately effective. We concluded that there is a need to improve the quality, availability and accessibility of the current health care services. E-health has potential in addressing these challenges and in increasing the efficiency of health care services, thereby potentially lowering the costs of these services as well. Therefore, the focus of this dissertation was on the question of whether and how E-health can help to improve health care for individuals with eating disorder (ED) symptoms. This question was explored by 1) systematically investigating the literature regarding E-health for ED, 2) investigating the potential empowering effects of the e-community 'Proud2Bme', and 3) investigating the fully automated Internet-based intervention 'Featback' with different intensities of therapist support from a clinical, an economical and a qualitative perspective. In this final chapter, the main findings of the studies included in this dissertation are summarized and discussed. The recommendations and clinical implications that follow from the findings in this dissertation are presented. We furthermore consider the strengths and limitations of the research, and finally, we discuss the opportunities and directions for future research.

Summary and discussion

In **Chapter 2**, the literature with respect to Internet-based treatment of ED was systematically reviewed. Most of the included studies investigated an Internet-based cognitive behavioral therapy (CBT), whereas several others investigated CBT delivered by e-mail, the use of e-mail as an adjunct to face-to-face therapy, self-help programs with Internet-based therapist support, or Internet-based unguided self-help. The Internet appeared a promising and acceptable vehicle for delivering ED treatment. Internet-based treatments were found to be superior to waiting lists in reducing ED psychopathology, frequency of binge eating and purging, and improving quality of life. However, the methodological quality of the studies varied and the results of randomized controlled trials were often not reported in accordance with the CONSORT criteria (Schulz et al., 2010; Eysenbach et al., 2011). Several important research gaps and directions for future research were identified. There appeared a lack of economic evaluations and a lack of investigations of predictors, moderators, and mediators of outcome: what works for whom and what is the psychological mechanism that is responsible for participants' change? Also, a lack of knowledge on the role of therapist support within Internet-based

interventions was identified: are Internet-based treatment without therapist support as effective as those without? Does a higher frequency of therapist contact enhance patient outcome?

Chapter 3 reports on a study related to the website and e-community 'Proud2Bme'. Proud2Bme provides a pro-recovery focused, healthy, and positive alternative to potentially harmful pro-ED websites that encourage eating disordered behaviors. Proud2Bme offers a wide variation of information and blogs on diverse topics, as well as a forum and a chat to interact with peers or health care professionals. The e-community aims to increase empowerment by raising awareness and to enhance self-management and promote and facilitate help seeking behaviors. This Chapter includes a cross-sectional investigation of 311 visitors of Proud2Bme who self-reported to have ED problems. We investigated whether, and to what extent, empowerment processes and outcomes were experienced by visitors of Proud2Bme, as well as to explore potential correlates of these processes and outcomes. Results demonstrated that individuals visit Proud2Bme for a variety of reasons, the most popular one wanting to read about personal stories and the experiences of others, but also to enjoy oneself, find information on ED, and finding help. The most frequently experienced empowerment processes were exchanging information, finding recognition, and sharing experiences. Regarding empowerment outcomes, participants reported to feel better informed as a results of visiting Proud2Bme. Furthermore, to a smaller degree, visitors indicated that visiting Proud2Bme increased help-seeking behavior and optimism and control over the future, as well as increased confidence in treatment and the relationship with their therapist. Individuals with generally low levels of empowerment, younger age, and more interactive usage patterns experienced more empowerment as a results of Proud2Bme. In sum, these preliminary results suggest Proud2Bme to be an empowering e-community, helping individuals to take control over their lives and the management of their ED problems, as well as assisting them in their process of recovery.

In **Chapter 4**, the design of a randomized controlled trial (RCT) investigating the second E-health intervention of this dissertation, called 'Featback', was presented. Featback consisted of psychoeducation and a fully automated monitoring and feedback system. This latter comprised a weekly online monitoring questionnaire tapping the four most important areas of ED psychopathology: body dissatisfaction, excessive concern with body weight and shape, unbalanced nutrition and dieting, and binge eating and compensatory behaviors. After completion, supportive feedback messages were automatically generated according to a pre-defined algorithm and sent by e-mail to the participants. The tailored

messages contained social support and advice on how to counteract reported ED symptoms. Eligible participants were aged 16 years of older with self-reported ED symptoms. The trial included four conditions: 1) Featback, 2) Featback supplemented with the possibility of low-intensity (weekly) therapist support by means of e-mail, chat, or Skype, 3) Featback supplemented with the possibility of high-intensity (three times a week) therapist support, and 4) a waiting list control condition. Online self-report assessments were scheduled at baseline, post-intervention (after eight weeks), and 3-and 6-month follow-up. The latter except for the waiting list control condition, who were offered Featback with low-intensity therapist support after the 3-month follow-up. In Chapter 5 to 9, the results of different research questions regarding this randomized controlled trial are reported on.

The effectiveness of Featback and the added value of therapist support was evaluated in **Chapter 5**. Three hundred and forty-five participants with self-reported ED symptoms were recruited via the e-community Proud2Bme and the website of Featback for the RCT as described above. From baseline to post-intervention, the three Featback conditions were found to be superior to the waiting list in reducing bulimic psychopathology, symptoms of depression and anxiety, and levels of perseverative thinking. From post-intervention to 3-month follow-up, more improvements in the Featback conditions as compared to the waiting list were found regarding symptoms of anxiety and depression, as well as ED-related quality of life. No improvements over time were found for symptoms of anorexia nervosa. Contrary to the expectations, supplemental therapist support enhanced satisfaction with the intervention, but did not increase its effectiveness.

In **Chapter 6** we have investigated moderators of intervention response, in order to help identify which individuals may benefit most from Featback and additional therapist support, and which individuals may benefit least. We analyzed a subgroup (*n* = 273) of RCT participants who completed baseline and post-intervention assessments. Both baseline levels of symptoms of anorexia nervosa and bulimia nervosa were found to moderate intervention response. For individuals with relatively severe anorectic psychopathology, Featback without therapist support was found to be inferior to the waiting list and Featback with low- and high-intensity therapist support. For the subgroup with mild to moderate anorectic psychopathology, Featback with and without therapist support was not found to be more effective than the waiting list. For participants with relatively severe symptoms of bulimia nervosa, similar reductions in bulimic psychopathology were found across all four study conditions, whereas participants with relatively less severe bulimic symptoms demonstrated better outcomes in the Featback conditions as compared to the

waiting list in terms of improvements in symptoms of bulimia nervosa. To summarize, the findings in this chapter suggest Featback to be particularly useful for individuals with mild to moderate bulimic psychopathology.

In **Chapter 7** we aimed to investigate mediators of intervention response. In other words: what is the psychological mechanism that is (partly) responsible for participants' change? Identifying critical mechanisms of change could highly inform clinical practice, as the effectiveness of the mental health interventions could be enhanced and maximized accordingly. We analyzed a subgroup of 75 RCT participants who completed the baseline (week 0), mid-intervention (week 4), and post-intervention (week 8) assessment. The results of the conducted cross-lagged panel analyses demonstrated that early changes (week 0-4) in symptoms of anxiety and depression were found to predict later changes (week 4-8) in both anorectic and bulimic psychopathology. However, levels of perseverative thinking were not found to mediate subsequent changes in ED psychopathology. These findings suggest that the reduction of anxiety and depression symptoms is an important mechanism through which Featback exerts its effects. Hence, it might be important to focus on targeting negative affect during interventions or treatments for individuals with ED symptoms. For example, by focusing on learning new ways to cope with negative affect.

The cost-utility of Featback with and without therapist support in comparison to the waiting list was examined in **Chapter 8**. Data from baseline, post-intervention, and 3-month follow-up were included in the analyses (*N* = 354). A societal perspective was adopted including both healthcare and non-healthcare costs. The outcome was measured in term of health-related quality of life: quality-adjusted life years. The results demonstrated no significant differences in costs and outcome between the four study conditions, although the mean societal costs per participant were highest in the waiting list control condition (€2582), followed by Featback without therapist support (€2102), high-intensity therapist support (€2032), and low-intensity therapist support (€1951). Overall, the results of the cost-utility acceptability curves demonstrated that all three Featback strategies (i.e. Featback with no, low-intensity, or high-intensity therapist support) were cost-effective as compared to the waiting list, with no clear preference for one of the three Featback strategies.

Little is known about the type of support that is offered by the therapists (i.e. what do therapists actually do?) and whether certain therapist behaviors are related to specific participant outcomes. These issues were therefore explored in **Chapter 9**. Although all

therapists underwent training in the delivery and methodology of online support and followed a 5- or 3-phase model for delivering chat or e-mail support respectively, there can be variation in the kind of behaviors therapists' show. All therapist communication from e-mails to, and chats with, the participants in the Featback conditions with supplemental therapist support (*n* = 177) were qualitatively explored. Thirty-one therapist behaviors were identified, all defined and explained in a codebook. Subsequently, therapist behaviors were counted in all e-mail and chat communication to the participants. Most frequently, therapists asked questions in order to asses the situation or problem (12.3%), showed empathy or compassion with a participant (12.1%), or provided the participant with advice or tips (11.3%). Next, all 31 therapist behaviors were grouped under higher order categories: 1) support and empathy (*n* = 19,282: 48.0%), 2) assessment and interventions (*n* = 16,149: 40.2%), and 3) formalities and procedure (*n* = 4785: 11.9%). The type or frequency of therapist behaviors was not associated with participant outcomes in terms of effectiveness (i.e. level of ED psychopathology). However, more therapists behaviors related to assessment and counseling relative to behaviors concerning support and empathy, were associated with higher participant satisfaction with their therapist. Also, more therapist behaviors in general were shown to predict higher satisfaction of participants.

Chapter 10 can be regarded as an extension to, and follow-up of, our previous review (Chapter 2). This chapter can furthermore be considered as the foundation for the general discussion (Chapter 11), as it covers the emerging findings, issues, and opportunities regarding E-health interventions for ED in the past few years (2013-2015). Internet-based cognitive behavioral therapy and guided self-help were found to be effective in reducing ED symptoms and comorbid problems. The literature was scarce regarding the use of E-health in the aftercare or maintenance treatment of ED. Regarding the explosive growth in the availability of smartphone applications ('apps') in the treatment of ED, it was alarming to find that the majority of these apps appear to make only limited use of evidence-based treatment principles. Also, many apps appeared to contain variable or misleading information. We furthermore reviewed the literature regarding the question of whether E-health can reach an underserved population and improve access to care. Indeed, emerging evidence suggested that through E-health an underserved population is reached and that there is improved access to care. Nevertheless, important challenges remain. The most important one being the implementation and integration of E-health within the existing health care models. For example, self-help interventions could be incorporated within stepped-care models to provide an early intervention or aftercare. Also, the use of blended care, in which face-to-face and online components are combined, holds promise

in increasing the efficiency of health care services and reducing corresponding costs. The review concluded that E-health is here to stay, but that much more high-quality research is needed to determine the place for E-health in our service delivery systems and to reach the full potential of E-health.

Recommendations and clinical implications

E-health services should never be provided as a goal in itself, but always as a means to improve one or more aspects of the current health care system. In the current dissertation, we have focused on E-health interventions as a means to improve the accessibility, quality, and efficiency of health care services for individuals with an ED. In this section, we aim to translate the current dissertation findings to everyday clinical practice, discussing the clinical implications and recommendations.

Overall, we recommend investing in the development, improvement, implementation, and embedding of E-health services for individuals with ED symptoms in the Dutch health care system for numerous reasons. To begin with, in line with previous literature, findings from the current dissertation show that E-health interventions can reach underserved populations. That is, 28.5% and 54.0% of the Proud2Bme and Featback study sample respectively, reported to have never received treatment. This implicates that E-health interventions could help to decrease the alarmingly high unmet need for health care for individuals with ED symptoms (Hart et al., 2011), and to improve early detection and intervention of symptoms.

E-health interventions could furthermore serve as a means to fast-track individuals to appropriate care. Although not explicitly reported on in any of the individual study reports of this dissertation, approximately 42% of the Proud2Bme study sample reported to have sought professional help as a result of visiting Proud2Bme. Within the subgroup of Featback participants that reported planning on seeking professional help directly after the intervention period, approximately 23% reported that Featback had stimulated them to seek help, and 28% reported that they would presumably not have had this intention without participating in Featback. This suggests that the e-community Proud2Bme and the Internet-based intervention Featback can serve as a means to fast-track individuals to more intensive, tailored care. In turn, early detection of ED symptoms and quicker access to tailored care could enhance ED outcomes, as shorter symptom duration has been found to predict better outcomes (Keel et al., 2010; Le Grange et al., 2014; Steinhausen, 2002).

We found preliminary evidence that Featback is effective in reducing ED symptoms, particularly symptoms of bulimia nervosa, as well as comorbid psychopathology in comparison to a waiting list. In addition, Featback with no-, low-intensity-, or high-intensity therapist support all demonstrated to be cost-effective in comparison to a waiting list, with no clear preference for Featback with and without therapist support. Together with our finding that therapist support clearly enhanced participants' satisfaction and perceived quality and effectiveness of the intervention, our recommendation for implementation would be to provide Featback with at least some sort of therapist guidance. Therapist support is especially recommended for individuals who report relatively high levels of anorexia nervosa, as Featback without therapist support did not appear to be effective in reducing symptoms of anorexia nervosa. As part of the Featback intervention, the therapist can fulfill several important roles. For example, enhancing the adherence to the monitoring- and feedback system by motivating the participant to keep monitoring their ED symptoms. Intervention compliance was only moderate in our randomized controlled setting, in which we aimed to maximize compliance by sending motivational reminders repeatedly and by including a lottery for participants who completed all monitoring- and study assessments. Compliance might be reduced in a real-world setting without any motivational reminders to keep filling in the monitoring questionnaires. Furthermore, therapists could enhance participants' satisfaction with the intervention and thereby improving the perceived quality of care, as demonstrated in the current dissertation. Finally, therapists have to take appropriate action when the monitoring data of participants show severe deteriorations of ED symptoms. An important role of therapists is to direct participants to more intensive tailored care, or to provide one or more low-intensity counseling (online) sessions. In these support sessions, it might be useful not only to focus on dealing with ED symptoms but also on the management of comorbid symptoms of anxiety, as our results suggested that these may represent an important mechanism by which ED psychopathology can be reduced.

Strengths and limitations

The results of the research in this dissertation should be considered in light of several strengths and limitations.

Use of different perspectives

One of the major strengths is the evaluation of Featback from different points of view:

from a patient perspective (i.e. what are the experiences with Featback?), from a clinical perspective (i.e. is Featback effective in reducing psychopathology? What is the added value of therapist support? Is Featback and the supplemental therapist support more effective for particular subgroups of individuals? What are possible underlying mechanisms of change?), from an economic perspective (i.e. is Featback cost-effective in comparison to a waiting list control condition?), and finally, a qualitative perspective in which the type of therapist support was extensively explored and examined in relation to outcome.

Anonymity and lack of clinical diagnosis

Individuals who participated in the research trials investigating Proud2Bme and Featback could participate anonymously, hence no face-to-face meetings were included. One advantage of this approach is that it lowers the threshold of seeking care because barriers such as shame and fear of stigmatization are less of an issue. It is therefore expected that anonymous E-health interventions can improve our reach to underserved populations. Besides the reach, the accessibility of health care services can be increased, as geographical barriers such as living in a remote area are no longer a problem.

A limitation that comes with the anonymity and lack of face-to-face meetings however, is that this might have negatively influenced study adherence (Aardoom et al., 2013). Furthermore, no (face-to-face) diagnostic interviews were conducted and consequently DSM-based ED diagnosis (American Psychiatric Association, 2013) were not available. This is unfortunate, as the DSM is known to establish consistent and reliable diagnoses, and furthermore provides a common language for patients and clinicians to describe and communicate about psychiatric disorders. That being said, in anonymous E-health studies, the Eating Disorder Examination Questionnaire (EDE-Q) (Fairburn et al., 2008) can be used to evaluate symptom severity, by comparing the scores to the norms of a clinical and general population. Also, the EDE-Q can be used to help provide a diagnostic impression of the study population by evaluating participants' body mass index, as well as presence and frequency of binge eating and compensatory behaviors. It is furthermore important to note that Featback cannot be considered a treatment, but rather an (early) intervention program that aims to help reduce ED psychopathology, hence a DSM classification was considered to be of less relevance.

Broad eligibility criteria and heterogeneity

In the included studies investigating Proud2Bme and Featback, we have used rather broad eligibility criteria. The only exclusion criteria for participants were not reporting at least mild ED problems (Featback and Proud2Bme trial), or being younger than 16 years old

(Featback trial). One of the strengths of the use of these broad inclusion criteria is that the study participants are likely to resemble the individuals who make use of this E-health intervention in everyday practice, presumably serving a broad population of individuals experiencing mild to severe ED symptoms. Another strength of such broad inclusion criteria is that it enhances the external validity of the findings. The recruited study sample may well bear close resemblance to every practice, including individuals with various subtypes of ED and comorbidities, thereby enhancing the generalizability of the findings. Furthermore, the heterogeneity of the samples allowed for subgroup analyses in which we were able to investigate for whom what worked, and under what conditions.

A limitation of the broad eligibility criteria is that participants could show large variations in variables such as the presence of comorbid symptoms and the use of co-interventions or medication. In the Featback trial, we have taken these potential sources of bias into consideration by controlling for such variables in the analyses of the study data. The fact that we identified superiority of Featback in reducing psychopathology over and above usual care (i.e. medication and other intervention and treatment programs participants were free to undergo), is noteworthy.

Study dropout

Considerable study dropout rates were present in both the Proud2Bme and Featback trial. More specifically, in the cross-sectional study investigating Proud2Bme, 72.7% (*n* = 226) participants out of the 311 who started the questionnaire completed this questionnaire. With respect to the Featback trial, a total of 354 participants (100%) were assessed at baseline, 273 (77%) at post-intervention, 202 (57%) at 3-month follow-up, and 118 participants (45%) of the available three study conditions at 6-month follow-up. In order to deal with these missing data in the Featback trial, we have first of all used an intent-to-treat approach including all participants who were recruited for the studies. Secondly, multiple imputation approaches were used (Rubin, 1987; Schafer et al., 2002) to handle missing data appropriately. Several important papers (Blankers et al., 2010; Graham, 2009; Schafer et al., 2002; Sterne et al., 2009) and books (Rubin, 1987) have been published regarding how to deal with missing data, recommending multiple imputation approaches. Indeed, simulation studies (Blankers et al., 2010; Eekhout et al., 2014) showed that the use of multiple imputation methods improves the validity of the results when analyzing datasets with considerable amounts of missing data as compared to more traditional approaches such as complete case analysis, mean imputation, and last observation carried forward. Nevertheless, considerable dropout rates remain undesirable and are a limitation of the included studies.

Lack of long-term data

A final limitation of the included studies regarding the Featback trial, pertains the lack of a 6-month follow-up assessment for the waiting list control condition. This was due to ethical reasons, as we considered a waiting period of more than 5 months (i.e. intervention period of 8 weeks and 3-months of follow-up) to be too long. Given that the effects of Featback could only be compared to the waiting list at post-intervention and 3-month follow-up, we do not know whether the found effects would be retained over the longer term.

Directions for future research

There are numerous opportunities and challenges for future research in the field of E-health for ED. The most important ones are highlighted and discussed below.

More research is needed to evaluate the effectiveness and cost-effectiveness of E-health interventions for ED in comparison to usual care or the best available alternative intervention. Furthermore, ideally, our study findings should be replicated in future studies. Many (mental) health organizations strive to implement E-health interventions and insurance companies in the Netherlands are now stimulating the uptake of E-health interventions by rewarding mental health organizations with financial bonuses. Although as demonstrated in this dissertation and in the existing research literature, E-mental health holds great promise in providing (cost-) effective health care services, the evidence-base for E-health interventions for ED in the Netherlands is currently scarce. Hence, establishing an evidence-base is an important direction for future research.

Furthermore, we recommend more studies investigating the role of therapist support within E-health interventions. Direct comparisons are needed. For example, is a particular Internet-based intervention with therapist support (cost)-effective in comparison to the same intervention without therapist support? In addition, the most optimal amount of therapist support in terms of duration and frequency is yet unknown. Ideally, future studies should experimentally test the effectiveness of different intensities of therapist support. What frequency and duration of therapist contacts is needed in order to realize an additional improvement in outcome? Also, more (experimental) research is needed on the most optimal type of therapist support and the level of expertise that is needed. Do certain types of therapist behaviors lead to incremental effects in outcome? Is it necessary that support is provided by a health professional, or may it be effectively provided by trained non-professionals or peers as well? And if so, under which circumstances (i.e.,

what types of E-health interventions) and for whom (i.e., which subgroups of patients) is this true? Finally, although beyond the scope of this dissertation, experimental studies investigating the impact of the medium through which therapist support can be provided, such as telephone, Skype, e-mail, and chat, is interesting.

Another direction for future research is the field of personalized healthcare and the investigation of differential responses to E-health interventions. Personalized healthcare encompasses the tailoring of specific health care interventions on the basis of individual patient characteristics, thereby predicting who is likely to respond to which type of intervention. Research investigating what works for whom, can help to improve the quality of health care services and to allocate the scarce healthcare resources more efficiently.

It would furthermore be interesting to conduct further research into the question of how satisfaction with the fully automated support system of Featback might be enhanced. A qualitative study including interviews with individuals who have participated in the fully automated self-monitoring and feedback system could provide important insights into how the system could possibly be improved. Would it help to change the look and feel of the system? Could the functionality and convenience be improved by offering the possibility of receiving the weekly reminders for the monitoring questionnaires by notifications on one's Smartphone as part of an app, instead of by e-mail? With respect to the content of the feedback messages, we already know that most of the participants' negative comments were about the automated feedback being too general and/or impersonal. It might be interesting to investigate whether the use of human pictures or avatars could enhance the experience and satisfaction of participants by creating a feeling of social presence, hence the feeling that someone is looking after them (Gorini, Gaggioli, Vigna, & Riva, 2008). It may furthermore be valuable to investigate the perceived quality of the individual feedback messages, in order to establish what kind of feedback messages including which content, are valued highest. A better understanding of what works best, could help to improve the quality of the feedback messages. Finally, we believe that the tailoring of the feedback messages could be improved by splitting the category 'binge eating and compensatory behaviors' into two separate categories. Currently, these are combined in one category and the feedback messages always include concerns or advice about binge eating and/or compensatory behaviors, which can be confusing for participants when they only report binge eating behaviors and not compensatory behaviors, or vice versa.

A final direction for future research and clinical practice would be to investigate the potential of Featback as an aftercare intervention for individuals after discharge from ED treatment. Relapse is a common problem among individuals with an ED, even after successful treatment (Field et al., 1997; Keel et al., 2005; McFarlane et al., 2008). The Dutch Multidisciplinary Guideline for Eating Disorders (Landelijke stuurgroep multidisciplinaire richtlijnontwikkeling GGZ, 2006) highlights the importance of developing and investigating relapse prevention programs after treatment, possibly by means of self-help interventions. In addition, qualitative studies support the need and importance of aftercare in maintaining treatment gains, helping with the transition from (intensive) treatment to everyday life and coping with difficulties encountered (Federici et al., 2008). Featback might be a useful means for detecting changes in ED symptoms after discharge of treatment, as it allows for the continuous monitoring of ED symptoms in daily life. Specifically, it could be interesting to investigate the implementation of Featback as a relapse prevention program within specialized treatment centers or even at the level of the general practitioner. Regarding the latter, supporting self-management, psycho-education, improving the functioning of patients with psychiatric problems, and relapse prevention, are already standard tasks of the mental health nurse practitioners (in Dutch 'POH-GGZ') (Dutch Healthcare Authority (NZa), 2016). Transfer of patients following discharge from specialized treatment to the general practitioner level could thus likely be improved by the addition of an Internet-based self-help aftercare program, which can be administered with minimum effort from patients and mental health nurse practitioners. It would be interesting to investigate whether the introduction of Featback on the POH-GGZ level could result in earlier detection of relapse, a reduction of patient delay, and easier and quicker access to tailored care if needed.

Conclusions

E-health for ED, which has been the focus of this dissertation, is promising even though it is still in its infancy. E-health can provide easily accessible, efficient, and effective care, and reaches underserved populations. A careful design of both E-health interventions and research studies is required to study effectiveness and to conduct health economic evaluations. Also, studies need to focus on what works for whom. In the long term, combining prevention, early detection and personalized interventions is paramount in establishing future effective and affordable care for this vulnerable population.