



Principles of Precision Prevention Science for Improving Recruitment and Retention of Participants

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Published online: 12 March 2018
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Abstract

Precision medicine and precision public health focus on identifying and providing the right intervention to the right population at the right time. Expanding on the concept, precision prevention science could allow the field to examine prevention programs to identify ways to make them more efficient and effective at scale, including addressing issues related to engagement and retention of participants. Research to date on engagement and retention has often focused on demographics and risk factors. The current paper proposes using McCurdy and Daro (*Family Relations*, 50, 113–121, 2001) model that posits a complex mixture of individual, provider, program, and community-level factors synergistically affect enrollment, engagement, and retention. The paper concludes recommending the use of research-practice partnerships and innovative, rapid cycle methods to design and improve prevention programs related to participant engagement and retention at scale.

Keywords Precision prevention science · Participant engagement · Participant retention · Research-practice partnerships · Rapid cycle methods

Precision medicine takes individual variability into account when designing and testing prevention and treatment options. The research conducted within a precision medicine framework identifies the most efficient and effective treatment for a specific person with a specific disease (Collins and Varmus 2015). The idea of precision has been expanded to public health to provide the right intervention to the right population at the right time. The concept is also applicable to prevention science (Khoury et al. 2016). A precision prevention science framework could allow the field to examine existing programs and identify ways to make models more efficient and effective at scale. Specifically, using this frame could help prevention scientists and practitioners tackle problems prevention programs face at scale, such as challenges related to participant recruitment and engagement, which prevent them from having their intended public health impact.

Challenges of Participant Engagement and Retention in Prevention Programs

Underlying prevention programs is the belief that the children, youth, and families in the programs need to receive enough dosage of the content or services in order to achieve the outcomes desired (National Research Council and Institute of Medicine 2009; Holland et al. 2017). Challenges with low enrollment, retention, and engagement are pervasive through different kinds of prevention programs, particularly when brought to scale (e.g., home visiting, teen pregnancy prevention, youth substance abuse, relationship education programs, parenting programs) (Holland et al. 2017; Council 2009). Understanding how and why engagement patterns vary may inform efforts to better recruit and engage families. Does engagement increase over time if families can see how the program is working in their lives (Holtrop et al. 2014)? Does engagement decline if families have a close relationship with the provider and there is provider turnover (Holland et al. 2017)? Understanding the reasons for participant engagement across prevention programs can lead to the development of improved program design and targeted enhancements to programs to address the issue.

Research to understand the problem of enrollment and engagement of participants has often examined participant demographic and risk factors to explain variability. For example,

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both Coatsworth et al. (2017) and Mauricio et al. (2017) in this special issue examined how engagement patterns varied by participant demographics and factors related to family dynamics. The literature examining demographics and risk factors, however, has mixed findings (Damashek et al. 2011; Smith et al. 2017). For example, in some programs, family distress is not only related to higher engagement, but also may be related to lower retention (Damashek et al. 2012; Smith et al. 2017). Some of the variation in findings could be because demographics and broad risk factors are proxies for other factors that explain more of the variation in findings. Spoth et al. (2013) proposed the Translation Science to Population Impact Framework (TSci Impact Framework) that illuminated the critical importance of examining the creation and implementation of evidence-based interventions at all phases, for different populations, and at all levels of the system. Aligned with this framework is the idea discussed in this paper to examine participant engagement with a similar systems lens. Precision medicine and public health research are careful to define subpopulations in more nuanced ways than in the past, segmenting into smaller groups who vary by specific factors such as susceptibility, intersection of risk, or response to specific treatments (Vaithinathan and Asokan 2017). Some prevention science research has begun to examine a broader range of systems level factors for subpopulations that affect engagement, including characteristics of the program delivery or organizational capacity (Holland et al. 2017).

Factors Related to Participant Engagement and Retention

McCurdy and Daro (2001) argue that high-level risk and demographic factors do not fully capture why participants may choose to enroll in and engage with prevention programs. Instead, a complex mixture of individual factors (both mutable and more stable), provider, program, and community-level factors synergistically may affect enrollment, engagement, and retention (McCurdy and Daro 2001). While papers in this special issue acknowledge the importance of all of these factors, none of the papers in this special issue empirically test factors at levels other than the individual, with the exception of Perrino et al.'s (2016) examination of facilitator experience. We posit in this commentary that taking a broader lens on the factors that may predict participant enrollment, engagement, satisfaction, and retention may better identify critical factors in the design and optimization of prevention programs. Precision prevention science would need to consider all of these factors in designing efficient, effective programs. Each factor is discussed in more detail below.

Participant Level Individuals may choose to engage or not engage with prevention programs for a complex set of reasons including a sense of efficacy, motivation, cultural alignment,

community support or stigma, mental health issues, and others (National Research Council and Institute of Medicine 2009). Engaging in prevention efforts can be challenging, as programs are often voluntary and aim to address broader population concerns that may not have been identified by the individual participant, so motivation to participate may not be high. Families may be interested in programs and sign up because they believe it addresses one topic but then disengage when their expectations do not align with the program activities or approach (Michalopoulos et al. 2015).

Participant cognitions and motivations are seen as important for participant engagement (Coatsworth et al. 2017). When participant motivation is cultivated, increases in participation and engagement are evident (Winslow et al. 2017). Families with greater needs may have stronger motivations to participate and remain in the program (Perrino et al. 2016; Smith et al. 2017). A family's readiness to change may also be an important factor. Damashek et al. (2011) found that, when program providers were trained to use motivational interviewing to increase participant readiness, there was increased program engagement.

Another important factor in participant engagement and retention is whether the program has been designed or adapted to fit the participants (Damashek et al. 2012; Gonzales 2017; Parra Cardona et al. 2012). Attention to culture may aid in program utilization and retention (Catalano et al. 1993). Evidence examining culturally adapted programs supports higher recruitment and retention of families (Kumpfer and Alvarado 1995; Kumpfer et al. 2002). Articles in this special issue found evidence that race and ethnicity were related to participant engagement and retention (Mauricio et al. 2017; Perrino et al. 2016). For example, Mauricio found Latina mothers were more likely to drop out early or have declining attendance compared to other participating mothers (though there were no ethnicity differences for participating fathers). Perrino et al. (2016) found associations between greater parental Hispanicism and higher participation in family-based interventions designed for Hispanic youth.

Provider Level Central to enrollment, engagement, and retention are characteristics of providers (OAH 2016). A recent study examining participant retention in home visiting found that provider characteristics explained more variation than family characteristics (Latimore et al. 2017). The quality of the relationships and the nature of the relationships (e.g., supportive) between providers and families is also important for participant engagement (Holtrop et al. 2014). For example, factors include having a strong therapeutic relationship with the implementer is critical to participant engagement (Holtrop et al. 2014; Prado et al. 2005), the skill of the facilitator (Greene et al. 2013), and the quality of initial contact between the provider and participants may a strong predictor of engagement (Prado et al. 2005). In this special issue, Perrino et al. (2016) examined facilitator experience but found no relationship with participant engagement.

Relationship building begins with hiring staff that embody qualities conducive to relationship building—such as being flexible and adaptable, warm, nonjudgmental, engaging, understanding, and able to work within family systems (OAH 2016). From this, relationships can be formed from listening to what participants have to say, connecting in an authentic way, following through, respectfully communicating, and being adaptable when necessary (OAH 2016). In programs that rely on a close relationship between provider and participant, staff turnover has been regularly shown to increase participant drop out (Holland et al. 2017; Latimore et al. 2017). Duggan et al. (2009) find that the alignment between a provider and parents' attachment type can influence the formation of a close relationship. On the other hand, if the provider has difficulty forming an open, positive relationship with the participant, that can be detrimental to engagement. For example, home visitors, who rated families at baseline as likely to have lower levels of service, did in fact have lower retention, a potential self-fulfilling prophecy (Latimore et al. 2017). Paternalistic, patronizing, and confrontational behaviors were reported as barriers to adherence to medication and participation in treatment (Lam et al. 2016; Mallinson et al. 2007).

In addition to the quality of the relationship, the ability of the provider to be flexible and tailor the program to participant needs has been shown to be important to engagement and retention of participants (Damashek et al. 2011). To tailor services to participant needs, as well as to contextual constraints (i.e., less time available for delivery than the program requires), adaptations are often made. Home visitors who were able to tailor and adapt the program to meet the needs of individual clients while still demonstrating fidelity to the program had higher retention of families (Ingoldsby et al. 2013; O'Brien et al. 2012). For example, a factor that the authors believe is related to participant enrollment and engagement was the training of providers in how to appropriately screen and refer families for needs (e.g., mental health services or intimate partner violence) and use that information to tailor services to family needs (Damashek et al. 2011).

As programs become more technology-based, however, the use of a human provider may be optional. Research is beginning to emerge on technology-delivered programs and their impact on engagement. For example, Perrino et al. (2016) found that attendance was higher in self-directed, technology-based programs rather than small group, facilitator-led programs. Technology may also be used to engage individuals in services in between sessions with a human provider (Jabaley et al. 2011; Winslow et al. 2017). It is possible that technology eliminates the physical, financial, and time program-level barriers discussed in the following section that might prevent someone from attending a program.

Program Level Program factors intersect with participant enrollment and engagement around: participant interest and

motivation in the content, ancillary supports to participants (e.g., timing of services, child care, transportation), and functioning of the organization while implementing the program (McCurdy and Daro 2001).

Program content is important in engaging and maintaining participant interest (Holtrop et al. 2014). Parra Cardona et al. (2012) examined the experiences and perceptions of parents who completed the PMTO intervention to understand how the program contributed to change in behaviors. Parents noted that the specific content of the study and delivery methods (i.e., visual aids, role play, home practice assignments, troubleshooting) contributed to the change process (Parra Cardona et al. 2012). Alignment between anticipated content and actual content may also be an important factor in engagement and retention (Michalopoulos et al. 2015).

In addition to content, ancillary supports have been found to be very important in participant engagement. Supports may include transportation, child care, and flexibility of time of services (Spoth and Redmond 2000). In Damschak's study (2011), examining differences in service enrollment and completion of child maltreatment prevention programs, Safe Care+, as compared to usual services, provided families tangible goods related to the stronger participant enrollment and completion. Some programs have found success in implementing ancillary supports to facilitate attendance, such as asking participants to create a plan for participating including how to overcome potential barriers to that plan (Mayer et al. 2015). Other programs use tools, such as technology in between sessions (e.g., texting) or support materials online or in apps, to increase touch-points with families (Pasnik et al. 2015).

Participants' transportation challenges, knowledge of services in further geographic areas, and motivation to seek programs with complex logistical challenges all may hinder engagement and retention in programs (Allard et al. 2003). Participants' proximity to the program, hours of operations, and neighborhood safety can also impact participants' engagement and retention with services (McCurdy and Daro 2001). For example, in a study of fathers' participation in home visiting, fathers cited misalignment between their work hours and when services were available as one of the main reasons for not participating (Sandstrom et al. 2015).

In addition to program content, program operations, organizational functioning, and climate likely play a role in participant engagement and retention. Recent research in home visiting found substantial variation in retention of clients between sites, suggesting that site-level factors are important in participant engagement and retention (Holland et al. 2017). For one program, organizational factors such as the staff's perceived rigidity of supervision and content delivery led to lower participant retention (Latimore et al. 2017). Broome et al. (2007) identified organizational climate and workplace practices to be correlated with client engagement in substance use treatment. Damashek et al. (2011) hypothesized that greater

participation and retention of families in a salary model versus fee for service reimbursement system may have been because the home visitor could be flexible to family schedules, make unscheduled visits, and allow for intermittent calls to families. In addition to the content, more research is needed to understand how the characteristics of implementing institutions may affect their ability to engage and adapt for diverse cultures (Bernal and Domenech Rodríguez 2009). Finally, organizational functioning may contribute to greater or lesser staff burnout and retention, a factor discussed previously as strongly related to participant engagement (Latimore et al. 2017).

Community Level Factors that may affect participant engagement at the community level include social cohesion or capital, difficulty accessing the program (e.g., public transportation), and the support of the community for the program. Crime, social disorganization, and other related factors may present barriers to participation. For example, mothers who lived in communities with poorer overall community health in combination with mother isolation inhibited participation in a home visiting program in Oregon (McGuigan et al. 2003). Other programs describe evidence of higher social cohesion as related to stronger recruitment through word of mouth (Miller Gaubert et al. 2012), strong referral networks among community providers (Miller Gaubert et al. 2012; Zaveri et al. 2015), or building social cohesion to keep participants engaged (Perou et al. 2012). Finally, distance from services along with factors such as lack of public transportation can provide barriers to service utilization (Allard et al. 2003).

Considerations for the Field

We conclude by discussing two specific areas that may be important to achieving precision prevention science given the context of the nested factors at the participant, provider, program, and neighborhood levels that may be related to participant engagement and retention. The recommendations below align with the TSci Impact Framework including the connections between research and practice, the use of innovative designs, the inclusion of potential participants (and providers) in the earliest phases of development, and consumer or market analysis to examine both preferences and barriers for evidence-based interventions in communities to be successful and sustained (Spoth et al. 2013).

Research-Practice Partnerships Research practice partnerships are critical avenues for identifying facilitators and barriers to participant engagement from the perspectives of the participants and providers in community-based prevention programs (Wallerstein and Duran 2010). Ideally, these collaborations should occur at the initial conceptualization of a prevention program but are important at all phases of a program lifecycle.

Using community-based participatory research methods to work together with researchers, providers, and participants can identify the factors related to engagement and retention, incorporate components to address barriers, and empirically test how these factors are related to participant engagement. For example, if the program is perceived as more or less sensitive to different cultures, the program will suffer. Working in partnership with the likely participants of the program, the community leadership and likely providers of the program can inform content, recruitment strategies, and engagement strategies that allow for cultural adaptation and flexibility (Dawson-McClure et al. 2017).

Sometimes the misalignment occurs in the initial stages of community program selection if the chosen program is not aligned with the needs and characteristics of the intended populations. Involvement of community leadership, potential participants, program staff, and other stakeholders in the process may ameliorate this issue. Given the importance of providers to participant engagement, selection of programs needs to align not only with community preferences but also with available infrastructure and supports. For example, discussions can focus on ensuring that there are enough qualified staff that meet the evidence-based program requirements, staff feel supported, community partners have awareness of the issue and program to provide referrals, and there is stability of funding. Since wait-lists and lags between recruitment and programming may influence participant engagement, it is important to ensure that there is a pipeline of qualified staff when staff turnover occurs and to reduce other stressors on participant engagement, such as high caseloads of staff.

Sometimes, adaptations and adjustments to the program may need to occur during implementation. Implementers of evidence-based programs unfailingly report adaptations during the implementation process (Durlak and DuPre 2008). Some researchers emphasize that adaptations are necessary to improve effectiveness (Dusenbury et al. 2003). During implementation, adaptations may be made to the content delivered, the way in which the content was delivered, or in the system of delivery (Stirman et al. 2013)—all program factors that may impact retention. Providers often make adaptations to increase participant retention, meet community needs, and increase program effectiveness. However, implementers and investigators alike have noted that they “struggled with the process of adaptation” (Kelsey and Layzer 2014). This presents another opportunity for partnership between the research and practice communities to ensure that the program is meeting community and participant needs, as well as adhering to program developer and curriculum standards.

Use Innovative Designs to More Rapidly Improve Models and Test New Ideas When barriers and facilitators are clearly articulated through partnerships, using tools, such as mini-trials or fractional factorial designs, can help the team to identify

what matters most to achieving high-quality engagement (Howe et al. 2010). Once a program is in the field continuous quality improvement, techniques can be used to monitor recruitment and retention and test strategies to address any issues (Spoth et al. 2013). For example, testing different techniques for overcoming barriers to participation using mini-RCTs leveraging existing program administrative data can efficiently optimize program administration (Mayer et al. 2015). In the technology field, human-centered design principles are widely accepted as important for designing platforms that gain input from the eventual users to design the most effective solution that is motivating to use to lead to strong adoption and sustainability (Matheson et al. 2015). Some program developers argue that continuing to use top-down data-driven approaches is ineffective for complex behavior change, and if we want effective implementable programs, we must begin to incorporate processes such as human centered design (Matheson et al. 2015; McCurdie et al. 2012). Prevention science can engage more innovative, rapid-cycle methods to address the issues of participant engagement and retention.

Conclusion

Understanding and addressing participant engagement and retention in prevention programs are critical issues for the field. Conceptualizing the multiple factors at different levels that may affect engagement and retention is a critical first step. Designing prevention programs to account for these issues would be the second step. Finally, testing ways to improve factors related to engagement and retention as a path toward achieving precision prevention programs would ensure that prevention science can achieve the ultimate goal of improving population level impact.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval As the manuscript is a commentary and did not involve data collection with human subjects, Institutional Review Board approval was not obtained.

Informed Consent As the manuscript did not involve data collection, no informed consent was required.

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