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Conducting theory-based qualitative interviews with adults with intellectual disabilities  
and their carers: adaptations to facilitate participation

### **Abstract**

Background: Adults with mild-moderate intellectual disabilities have difficulties in accessing traditional evidence-based health promotion initiatives despite experiencing health disparities; yet there are few studies with this group and their carers exploring how their needs can be met. Method: This study adapted a behaviour change theory-based approach to interview this group and their carers and ascertain if this method was feasible and appropriate to explore how healthier behaviour uptake could be improved amongst adults with intellectual disabilities. Results: a community-based, staged recruitment process and iterative approach to data collection and analysis supported successful participation amongst adults with intellectual disabilities in behaviour-change theory-based interview research. Methodological adaptations enabled richer data collection amongst adults with mild-moderate intellectual disabilities and carers. Conclusions: It is feasible and important to include adults with intellectual disabilities in qualitative health research that uses theory-based complex constructs to inform development of person-centred health promotion interventions with this underserved cohort.

*Keywords:* Intellectual Disabilities, Health Promotion, Qualitative Interviews, disparities

## Conducting theory-based qualitative interviews with adults with intellectual disabilities and their carers: adaptations to facilitate participation

### Introduction

Adults with mild-moderate intellectual disabilities face disparities in access to traditional health promotion and illness prevention campaigns relative to adults without intellectual disabilities. Increased life expectancies amongst this population have been accompanied by greater prevalence of overweight, obesity and underweight. Adults with mild-moderate intellectual disabilities appear to be at greater risk of poor dietary intake (Bhaumik et al., 2008; De Winter et al., 2012), low participation in physical activity and highly sedentary behaviours (De Winter et al., 2012; Melville et al., 2017; Stancliffe et al., 2011).

Adults with mild-moderate intellectual disabilities face unique needs and barriers to equitable healthcare access. A significant proportion experience physical impairments and have food sensitivities so implementation of individually tailored support is important (Bergstrom et al., 2014). Their abilities to make healthful choices can be impacted by past experience of responsiveness (or lack thereof) to their preferences by those supporting them, history of institutionalisation (Harris, 2003) and the complexity of choices they are presented with (Smyth & Bell, 2006).

Adults with intellectual disabilities also face wider social and environmental barriers to healthier eating and physical activity. These barriers include difficulties accessing appropriate knowledge and skills training (e.g. cooking or exercise classes) and lack of availability and consistency of social support to implement healthful behaviours due to resource constraints ([redacted] 2020; Cartwright et al., 2015; Cartwright et al., 2017; Matthews et al., 2016; O’Leary et al., 2018; Spanos et al., 2013; Stancliffe & Anderson, 2017). Staff

and carers also may not have high levels of health literacy (Melville et al, 2009), skills and mastery in cooking, promoting participation in physical activity amongst adults with intellectual disabilities and competing support demands to fulfil which may take precedence ([redacted], 2020; O’Leary et al., 2018).

Adults with intellectual disabilities also often experience material poverty (Smyth & Bell, 2006) and low neighbourhood safety impacting exercise participation (Emerson et al., 2016).

It is very important for health services to provide appropriate support to adults with mild-moderate intellectual disabilities for healthier living which meets their needs. However, the voices of this cohort and those supporting them are rarely heard when health initiatives are developed, despite their desire to discuss their health needs (Young & Chesson, 2008) and although they value participation in research (Fraser & Fraser, 2001; Tyrer et al., 2017). Adults with intellectual disabilities face additional barriers to participation in qualitative health research. They may experience ‘*cognitive overload*’ if presented with detailed information resources on the study in a short period, using complex, abstract language. Additionally, they may show ‘*acquiescence bias*’ and agree to participate in research due to a desire to feel compelled to ‘*please*’ the researcher (Coons & Watson, 2013; Sigstad, 2013), particularly if they are accustomed to having their choices ignored in their normative social context (Harris, 2003).

Adults with mild-moderate intellectual disabilities may also often negotiate complex power relations with staff and carers supporting them (Harris, 2003). Carers and staff can also inadvertently act as ‘*gatekeepers*’ to their participation in research. Staff and carers may be wary and protective; feel that study participation may be in the ‘*best interests*’ of the person with intellectual disabilities; or concern that they have undue influence over decision-making by the person(s) they support (Nind, 2008; Goldsmith &

Skirton, 2015). Additionally, external researchers approaching large organisations to recruit participants may need to liaise with several managers before they are able to approach potential participants with intellectual disabilities for study participation (Lennox et al., 2005). For these reasons it is important for researchers to tailor their approaches to include this vulnerable group and supporters in their studies.

A theory based interview study can help health researchers to explore with end user groups how a model can be used to develop an appropriately tailored intervention with them. We chose Social cognitive theory (Bandura, 1986; Bandura, 2001) as we were aware of the individual, social and environmental barriers to increasing healthy eating and physical activity amongst adults with intellectual disabilities and this model encompasses those factors (see fig 1.). However, the perspectives of adults with intellectual disabilities and their carers on how we might use the model appropriately to guide the intervention was missing. We were also aware that these theoretical constructs could be quite complex and difficult for adults with mild-moderate intellectual disabilities to grasp (Willems et al., 2017) and to our knowledge our study remains the first to date to try to interview them using a theory-based approach.

We were also cognisant of the wider barriers adults with mild-moderate intellectual disabilities face in participating in health research and the additional challenges we might face in using this interview paradigm. We aimed to address these barriers by building trust and relationships with community organisations serving this cohort, creating an advisory group involving adults with intellectual disabilities and carers and adapting interview process and analysis.

#### **Our aims:**

- To ascertain if a theory-based approach to interviewing adults with mild-moderate intellectual disabilities and carers was feasible and appropriate to gather data for future behaviour change intervention development.

- To outline and evaluate the processes involved, including recruitment, degree of involvement of adults with intellectual disabilities, staff and family carers in an advisory capacity, interviewing and analysis and inform future qualitative interview research in this field.

## **Method**

We used several strategies to address potential barriers to conducting a theory-based interview study with adults with mild-moderate intellectual disabilities and carers and to involve them in the process (see table 1).

### **Advisory group**

An advisory group was set up for the research project at the social care organization the first author [initials] was '*embedded in*' as trainee psychologist, who had prior experience working with adults with intellectual disabilities and conducting health research with this cohort. The advisory group also included the head of the organisation, fundraising manager, a care service manager and three adults with mild-moderate intellectual disabilities at various points. [initials] made attempts to recruit staff and family carers via organizational contacts but this did not come to fruition due to scheduling conflicts and external pressures facing carers approached at that time.

As the group was small and members had some comfort and familiarity with each other due to prior acquaintance, the research team opted to involve adults with intellectual disabilities and professionals in one group to facilitate process. Each prospective member was approached individually by the lead researcher, to explain the purpose of the advisory group, address any concerns and enable refusal with minimal social pressure to acquiesce to participation. We found that our chosen approach facilitated the agreement of remit of the group, to pace activities and to simplify concepts where appropriate.

Advisory group members helped the research team to check accessibility and appropriateness of research materials, pilot test interview process, identify

potential participants and disseminate findings (see table 2).

Group discussion of overall findings supported [initials] to reflect on key findings and maintain fidelity to study aims. However, the research team designed the interview protocol and collected, transcribed, coded and analysed the data for two reasons. Firstly, we were familiar with behaviour change theories and had chosen a model that past research and evidence suggested would provide an appropriate framework to guide the interview protocol (*masked citation*). Secondly, transcription, coding and analysis followed each other closely in an iterative sequence between data collection waves. It was not possible within the timeframe allowed for us to convene the advisory group with the frequency or time needed to meaningfully analyse the data and use earlier findings to guide use of specific follow up questions for participants in later waves. Co-researchers with mild-moderate intellectual disabilities may have also struggled to cope with these tasks (Frankena et al., 2019). As it was a research aim to establish whether participants from this cohort would be able to engage with the complexity of some of the constructs involved (Willems et al., 2017), their participation in these processes were precluded on this occasion. For those reasons the research team was primarily responsible for interpretation of the data using social cognitive theory as the underlying framework.

### **Ethical approval**

This study was given ethical approval by the [redacted] ethics committee.

### **Recruitment**

We actively recruited participants for the study from community organisations and settings accessed by adults with mild-moderate intellectual disabilities for volunteering, social opportunity and care support (Foster et al., 2011). Recruitment was led by the primary researcher and with the support of the advisory group. [Initials] also reached out to colleagues and professional networks prior to and during data collection phases to further recruit participants for the study, using a snowballing approach.

Inclusion criteria for adults with intellectual disabilities were being aged 18 and above, presence of mild-moderate intellectual disability, ability to provide informed consent, spoken English and possession of sufficient verbal communication skills to participate in interview. Prospective participants were expected to be able to answer open questions with at least short sentences (rather than exclusively 'yes' or 'no' answers, augmented by



use of gesture or Makaton where appropriate). Exclusion criteria included having severe to profound and multiple intellectual disabilities, not being able to provide informed consent to participate in the interview and using non-verbal communication to convey information for open-ended questions.

Carers and staff were eligible for inclusion in the study if they had at least three months experience supporting an adult with mild-moderate intellectual disability and to have provided an episode of support within 3 months prior to the date of the interview. They were also required to have sufficient fluency in English to understand the study and participate in the interview.

### **Informed consent process**

To minimize '*cognitive overload*' amongst adults with mild-moderate intellectual disabilities, a staged process was used to send information about the study to potential participants (see fig 2.).

We recruited participants who demonstrated understanding and interest in the study and were able to communicate this to us independently by attending to relevant verbal and non-verbal cues during the recruitment process. Relevant cues included showing interest in talking about healthy eating and physical activity, nodding, eye contact, smiling, enthusiastic tone of voice, asking relevant questions or when asked, being able to give a short explanation of what the research was about and what it would involve.

During the interview, continuing consent was also sought, to enable participants to withdraw from the study if they wished.

### **Materials**

We developed a diet and activity preferences questionnaire for participants with mild-moderate intellectual disabilities to use just prior to the interview (Appendix A) to monitor for social desirability bias amongst adults with intellectual disabilities. We would expect some variation in food and activity preferences to be present amongst participants. However, a more uniform preference for healthy options across the cohort may indicate

that participants have provided socially desirable responses, considering the relatively low uptake of healthy eating and physical activity in this population. The options given were consistent in category and type to aid internal reliability.

We developed an interview schedule and vignette-based questions using Social Cognitive Theory (Bandura, 1986; Bandura, 2000) to explore specific theoretical constructs in the model (Appendix B, Appendix C). The Interview Schedule was primarily used with staff and family carers and the vignettes were primarily used to facilitate interview participation amongst adults with mild-moderate intellectual disabilities.

### **Analysis**

The qualitative findings were analysed using thematic analysis using a critical realist approach (Braun & Clarke, 2006). Twenty percent of the interview data was secondary coded for methodological rigour in applying theoretical constructs to the findings (*masked citation*).

## **Results**

### **The participants**

Twelve adults with mild-moderate intellectual disabilities and twelve staff and family carers were interviewed for this research study (see table 3). All participants were recruited from a range of settings, including day centres, supported and independent living contexts. Whilst most participants with intellectual disabilities received regular support from paid staff, four were supported by family members (the two were not mutually exclusive: two received support from family and staff) and one did not report receiving any regular support.

### **Questionnaire**

Participants with intellectual disabilities were highly consistent with their preferences of healthy food and activity preferences (Cronbach's alpha = .99). Overall preferences varied significantly between participants, as some

preferred healthy food and drink options, whilst others did not. Most preferred sedentary activities over physically active alternatives.

### **Interview process**

All participants with intellectual disabilities were able to demonstrate some understanding of healthy eating and physical activity, though some were more verbally expressive and detailed than others. The questionnaire also had the unexpected value in aiding rapport built between researcher and participants and that may have facilitated later self-disclosure of behaviours that the latter may have considered to be socially undesirable. For example:

*“I can cook. My mum do it for me... ‘I can do it’, I say okay then.” (laughs, Peter, adult with Intellectual Disability)*

Peter was likely aware that he was expected to cook independently as an autonomous adult but he shared laughter with the interviewer about ‘allowing’ his mother to do it for him, displaying some comfort with self-disclosure and expectations of acceptance from the researcher.

### **The use of vignettes and open questions**

The first subset of interviews with adults with intellectual disabilities involved greater use of vignette-based questions. However, [researcher] noted that participants asked questions to contextualise the scenarios described further. We adapted scenarios to fit the contexts in which participants were living where appropriate to make them more accessible and ‘concrete’ (e.g. stating that the character lived in social care settings and was supported by staff, if that applied to the participant). Care was taken not to change any key features, however, such as those on increasing self-efficacy or what outcome expectancies would matter to the person (e.g. hoped for consequences of eating healthily). Some participants with intellectual disabilities were quite able to answer questions on what outcome expectancies might be important to them for healthy eating and physical activity participation. However many struggled with questions related to self-efficacy and goal setting, for example, responding to questions on these topics with health behaviours people could adopt rather than what would help them to be more ‘confident’ in ability to adopt specific behaviours.

*Interviewer: "I'm gonna ask you to pretend to be the-Jane... She's got a mild learning disability...her doctors asked-told her you need to eat a bit more fruit...And she wants to do that now, because she, you know wants to be more healthy... But she's a bit nervous about it and she's not sure she can do it. What can help her erm be a bit more sure, a bit more confident-Do you think?"*

*Anne: "Erm, see a diet-see a dietician... Erm, go to the gym...And erm do some exercise classes." (Anne, adult with Intellectual Disability)*

It is likely that Anne found this question too abstract and difficult to answer, though care was taken to adapt the scenario given to her circumstances to make the scenario more accessible.

In contrast, the use of earlier data gathered from staff and carers to guide later interviews with adults with intellectual disabilities at each phase was very helpful in practice. The interviews with staff and carers enabled inductive exploration of ways to increase self-efficacy and improve outcome expectancies, goal setting and positive social support amongst adults with intellectual disabilities in practice. The ideas generated could then be explored with adults with intellectual disabilities to gather their perspectives on these issues using an iterative process of transcription, coding and preliminary analysis between interview waves with each sub group (staff and carers and adults with intellectual disabilities respectively).

*Kate: "Some people, you know, have got that ability for a bit of experimentation... Erm I know the first time I ever tried tamarind, er I thought I go into the shop, I bought it I had a little taste"...*

*Interviewer: "What about little, taste tests, do you think that could work with some people?"*

*Kate: "Yeah I mean, going way back in the day, erm a youth centre I worked at we did a kind of multi-cultural day...everybody had to bring in something from their own culture...And erm people were tasting, you know, but they were being experimental." (Kate, Staff)*

In this interview, [initials] and interviewee had a discussion about ‘*taste testing*’, based on a comment made by the interviewee on varying openness by adults with intellectual disabilities to ‘*experimentation*’ by trying new food items. This led to the interviewee sharing their experience of this type of activity in a communal setting where there was no pressure to try the items shared. In turn, that led us to subsequently explore with a participant with intellectual disabilities and autism whether they would prefer to try ‘*taste testing*’ or see a carer role model healthier eating behaviour using a vignette based example:

*Interviewer: “He’s [character with intellectual disability] trying some new fruit that he’s not tried before and he’s a bit nervous because he doesn’t know how it’s gonna taste. Erm so what might help him more, seeing someone like his mum eat it? Or having a little taste test like on a little plate?”*

*Kevin: “Taste test.”* (Kevin, adult with Intellectual Disability)

We used a forced choice paradigm to simplify the question presented to the participant with intellectual disability in this instance by reducing likelihood of ‘*cognitive overload*’ via reducing choice complexity and abstraction. it was effective in doing so to support engagement.

Use of this process particularly helped us to generate closed and specific questions with adults with intellectual disabilities when they struggled with open questions regarding improvement of self-efficacy and how to gather feedback and monitoring processes in acceptable and feasible ways. However, we found that they also generally responded well to open questions that drew upon their own past experiences and beliefs about healthful and unhealthful behaviours, perhaps because this was familiar and ‘*concrete*’ territory.

### **Exploring a sensitive topic: social support**

We explored the quality of social support adults with intellectual disabilities may receive and prefer using varied strategies. Several participants responded better to questions about what they considered to be positive and negative support in general and some were also able to give

examples of what support might be helpful when we used the vignettes as a basis to guide more specific, direct questions on this topic. At times these were the same participants. A few appeared reticent when discussing their own support where they relied on staff to a greater extent, but were more comfortable in making statements about importance of mutually respectful behaviour, including being critical of other adults with intellectual disabilities where they felt respect was lacking. When discussing staff role modelling healthy eating behaviour one participant noted that criticising their own carers could have negative consequences such as censure and pressure to accept support:

*Interviewer: "Do you ever look at staff supporting you and think right, you're healthy, I'm more likely to listen to you and you're not so healthy I'm probably not gonna listen to you or-"*

*Stan: "Well they're saying they are but you-I have to trust them because they might think oh yeah you're being rude about that person...But you can't start giving comments saying... because they want to be saying you have to believe us." (Stan, adult with Intellectual Disability)*

However, in contrast, a few appeared more willing and eager to draw on their lived experiences of positive social support from staff and carers than negative incidents.

*"People support me to make sure I'm getting the right food then-food that's healthy...Make sure I eat the right amount of food, make sure it's something healthy that-that I can eat...That's why people have to go with me when I do my shopping cos I'm not very good at that...I don't know all of these things." (Dean, Adult with Intellectual Disability)*

However, four others were more frank about perceived negative support they experienced and witnessed by staff and family carers, though only four participants were supported by family carers in this study. Those sharing personal negative experiences appeared to be more assertive, confident in sharing their perspectives and less reliant on practical support from the persons they described. We also found that using vignettes could be a helpful 'tool' to facilitate discussion of sensitive issues in an impersonal manner for

some participants, but they were at times too abstract or deemed unnecessary to facilitate discussion for others. Being flexible in approach when asking questions, enabling additional time for participants with intellectual disabilities to process information, seek clarification and formulate a reply and being guided by their responsiveness to them enabled for a better interview process.

## **Conclusion**

This study found that it was feasible for adults with intellectual disabilities to participate in interview-based theory research on how their health needs could be addressed. However, adaptations to interview process and simplification of questions was necessary and there was significant variation in understanding and engagement with the interview process.

## **Discussion**

### **Interview process**

The ongoing consent process prior to and during interview and emphasis on respecting individual choice helped to manage risk of acquiescence bias amongst adults with intellectual disabilities (Coons & Watson, 2013; Sigstad, 2014). The food and activity preference questionnaire also helped to screen for and manage the risk of social desirability bias during interviews. Several participants stated a preference for unhealthier options and their responses were internally consistent, suggesting that social desirability bias may have been less overtly present in this study. However, these biases may have been more present when we discussed sensitive topics. The questionnaire also had unexpected positive value in the interview process as the researcher was able to demonstrate acceptance of participant choices and build trust and rapport, which may have facilitated later disclosure by adults with intellectual disabilities.

Some participants were able to engage with open questions easily whilst others gave much shorter responses (Coons & Watson, 2013; Sigstad, 2014). Vignettes were a helpful tool to enable understanding and discussion of certain concepts, particularly outcome expectancies (Bandura, 1986; Bandura, 2001) and social support. However, they were not helpful for

discussing ways to improve self-efficacy or goal setting, perhaps because they are complex constructs involving self-regulatory cognitive processing (Willems et al., 2017). However, interviews with staff and carers provided rich data on how adults with intellectual disabilities may be supported using these constructs. These interviews generated specific suggestions that could be explored with participants with intellectual disabilities regarding their potential acceptability and usefulness.

### **Power dynamics**

Differential power dynamics impacted data collection during recruitment and interviewing processes. Where adults with intellectual disabilities were more reliant on staff support, there was greater reluctance to explore the topic of negative social support in interview. Asking different types of questions could only mitigate this to an extent. There was also emphasis by several participants on the importance of showing respect to staff and upholding high behavioural standards, including amongst those who were willing to discuss negative social support they felt was important to address amongst carers. The latter arguably reflects greater scrutiny faced by people with intellectual disabilities over their lives and behaviour relative to those without disabilities (Munford et al., 2008).

### **Recruitment**

The study was largely successful in recruiting participants for the study because we had established good working relationships within a community-based social care organisation providing support to people with intellectual disabilities by prior association. These relationships helped us to set up the advisory group involving both staff and adults with intellectual disabilities and to establish contact with allied organisations and potential participants relatively quickly rather than over several months (Lennox et al., 2005). We had gained trust (Munford et al., 2008) and reduced navigation of bureaucracy (Lennox et al., 2005). The researcher also approached professional contacts to recruit participants via their networks in varied community settings, which was particularly helpful for recruitment of family carers and adults with intellectual disabilities living with their families.



These methods enabled the inclusion of participants with intellectual disabilities who may not otherwise participate in advisory group or research activities. This was because most were not involved in self-advocacy groups prior to their participation in this study. We aimed to recruit participants using a range of support services and experiences with health promotion so we could draw on their experience, expertise and interest in the topic, rather than on the basis of easy availability and tokenistic representation (Bigby et al., 2014).

However willingness of staff *'buy in'* still had a significant mediating impact on participation by adults with intellectual disabilities in this study, consistent with past research (Nind, 2008). This may have impacted ~~staffs~~ consideration of whom may be capable and interested in participation when putting potential participants forward for inclusion. We were keen to avoid potential coercion of participants with intellectual disabilities by staff to participate in the research as it may be perceived to be in their *'best interests'* (Coons & Watson, 2013), but steps we took to address this may have inadvertently resulted in greater protective behaviour towards them (Nind, 2008; Goldsmith & Skirton, 2015). Staff and carers were also not available to support participation of adults with intellectual disabilities during interview due to time and resource constraints. It is unclear to what extent this may impact study findings, but it may have precluded participation by those with greater communication difficulties or anxiety about research participation.

### **Advisory group participation in data collection and analysis**

Our study was able to include the advisory group in various other activities, including testing the interview materials for appropriateness and acceptability and dissemination of findings. These processes were very helpful for further development of the materials used, including increasing item precision in exploring the concepts intended and reaching a diverse cohort of participants amongst adults with intellectual disabilities and carers. However, we were unable to recruit family carers to participate in the advisory group due to timing clashes for a partner organisation providing services to this cohort. The organisation was under intense pressure to

provide assistance with educational transitions for young people with intellectual disabilities and their families during this period. A lack of prior working relationships with family carers (Lennox et al., 2005; Munford et al., 2008) and wider time pressures they can face in their role (Cartwright et al., 2015) may also have contributed to this issue. To enable carers to participate in an advisory capacity, it is important to have time to build relationships with them, invite participation and enable flexibility in how they participate, for example by including individual participation and flexibility in attendance at group activities (Littmann, 2021).

We also carefully managed size and power dynamics in our advisory group; we found that having a small cohort, familiarity and inclusivity helpful for effectiveness. However, involving adults with intellectual disabilities and carers as co-researchers in various research phases may require a larger advisory committee and creating a subgroup for adults with intellectual disabilities may be helpful for meaningful involvement in such context (Nind & Vinha, 2012; Tyrer et al., 2017). Managing power differentials that can exist both between academic researchers, carers and adults with intellectual disabilities and between adults with intellectual disabilities and staff and family carers can also be important (Coons & Watson, 2013; Harris, 2003; Nind & Vinha, 2012).

### **Future theory based research**

We recommend that resources and time are made available and allocated for advisory group members to be able to participate in data collection and analysis in future theory-based interview research. We argue that it is morally important to include adults with intellectual disabilities and carers meaningfully in conducting research pertaining to their health needs where possible (Fraser & Fraser, 2001; Tyrer et al., 2017; Young & Chesson, 2008). An advisory group may help academics identify modifiable barriers and facilitators to health behaviour change and map them onto an appropriate theoretical framework to guide data collection and analysis, and collaboratively develop health interventions (Kok et al., 2016).

Staff, family carers and adults with intellectual disabilities may also be willing and able co-interviewers for their peers with appropriate training and support (Frankena et al., 2019; Keonig, 2011). However, adults with intellectual disabilities may struggle with transcription and analysis due to high abstraction and ‘*cognitive overload*’ (Frankena et al., 2019). Therefore, we may share findings from carer interviews with advisory group members with intellectual disabilities in a facilitated discussion, to identify suitable ‘*concrete*’ suggestions to explore with peers in follow up research based on their lived experience (Keonig, 2011, Tuffrey-Wijne et al., 2010).

Following these steps would enable adults with intellectual disabilities and carers to develop skills and networks that foster inclusive participation in doing behavioural science research and help create a ‘*bridge to new worlds*’ (Nind & Vinha, 2012). It can also help adults with intellectual disabilities to discuss their health needs inclusively (Fraser & Fraser, 2001; Keonig, 2011; Nind & Vinha, 2012; Young & Chesson, 2008); enable them to discuss sensitive issues with greater ease and potentially lead to greater engagement in health promotion interventions (Schwartz et al., 2019).

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