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- 1 **Title:** Using Behavioral Theory to Adapt Advance Care Planning for
- 2 Homeless-Experienced Older Adults in Permanent Supportive Housing
- 3 (124/125)
- 4 Short Running Title: Behavioral Determinants of ACP in PSH
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Key Points

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- Older adults experiencing chronic homelessness have low rates of advance care planning (ACP) despite high rates of morbidity and mortality.
- Permanent supportive housing (PSH) is subsidized housing with voluntary supportive services for individuals (PSH residents) experiencing chronic homelessness (i.e., prolonged homelessness and a disabling health condition) and may provide an opportunity to introduce ACP.
- Using the Capability (C), Opportunity (O), Motivation (M), Behavior (COM-B) framework (COM-B) within the Behavior Change Wheel model, we elicited PSH residents and staff reported barriers to ACP including lack of PSH resident and staff ACP knowledge, variable relationships with family/peers and PSH staff, pessimism about ACP outcomes, and lack of staff resources and training.
- Facilitators to ACP in PSH include the belief that ACP is impactful, the
 potential for strong relationships with family/peers and PSH staff,
 stability of housing in PSH, and use of easy-to-use materials, including
 the PREPARE for Your Care ACP program and easy-to-read advance
 directives.
- Suggestions for implementation of ACP in PSH include continued use of easy-to-use PREPARE materials, capitalizing on trusted relationships, PSH staff trainings and conversation guides, and providing ACP in facilitated groups or one-on-one sessions.

Why Does This Paper Matter?

Older adults experiencing chronic homelessness have high rates of morbidity and mortality, a high likelihood of being socially isolated, and of not having their wishes honored at the end of life. Permanent Supportive Housing represents an opportunity to introduce ACP to help honor the medical preferences of this marginalized population.

Impact Statement: We certify that this work is novel and important to
 advance the discussion and implementation of advance care planning
 processes among marginalized and vulnerable populations.

- 66 **Word counts:** Abstract (249/250), Main text (3594/3500)
- 67 Number of tables/figures: 2 tables, 1 figure

ABSTRACT (word count 249/250)

- 69 Background: Older adults experiencing chronic homelessness (i.e.,
- 70 prolonged homelessness and a disabling condition) have low rates of
- 71 advance care planning (ACP) despite high rates of morbidity and mortality.
- 72 Rehousing of homeless-experienced individuals into Permanent Supportive
- 73 Housing (PSH) may present an opportunity to introduce ACP; but this is
- 74 unknown. Therefore, we explored staff and resident perceptions of
- 75 conducting ACP in PSH.

- 76 **Methods:** We conducted semi-structured interviews with PSH staff (n=13)
- and tenants (PSH residents) (n=26) in San Francisco. We used the Capability
- 78 (C), Opportunity (O), Motivation (M), Behavior (COM-B) framework within the
- 79 Behavior Change Wheel model and the Theoretical Domains Framework
- 80 (TDF) to inform interviews, categorize themes, and guide qualitative
- 81 thematic analysis.
- 82 **Results:** The mean age of PSH residents was 67 (SD = 6.1) years and 52%
- 83 were women. Of staff, 69% were women. Important COM-B barriers included
- 84 ACP complexity (C), complicated relationship dynamics (O), resource
- 85 limitations (O), pessimism (M), variable staff confidence (M), and competing
- 86 priorities (M). Facilitators included easy-to-use documents/videos, including
- 87 the PREPARE for Your Care program (C), stability with housing (O), exposure
- 88 to health crises (O), potential for strong relationships (O), and belief that ACP
- 89 is impactful (M). Recommendations included adapting materials to the PSH

- 90 setting, providing staff trainings/scripts, and using optional one-on-one or
- 91 group sessions.
- 92 **Conclusions:** We identified behavioral determinants related to ACP for
- 93 formerly chronically homeless older adults in PSH. Future interventions
- 94 should include using easy-to-use ACP materials and developing resources to
- 95 educate PSH residents, train staff, and model ACP in groups or one-on-one
- 96 sessions.
- 97 **Keywords:** advance care planning, permanent supportive housing, older
- 98 adults, homelessness, implementation science

INTRODUCTION (3594/3500)

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Over half a million people experience homelessness in the United States, 100 with a growing percentage of older adults.^{1,2} Older adults who are currently 101 or recently homeless (homeless-experienced), have worse health status, 102 earlier onset of geriatric conditions at younger ages (i.e., 50 years and older) 103 and increased rates of mortality compared to the general population.^{3,4} 104 105 Geriatric conditions, such as functional impairment, falls, and urinary incontinence, typically first occur in housed adults aged 75 and older.⁵ 106 Despite high rates of morbidity and mortality, homeless-experienced older 107 108 adults have low rates of advance care planning (ACP) - a process designed to prepare people for serious illness communication with family, friends, and 109 110 clinicians, and medical decision making.^{6,7} Although there has been recent discussion about the utility of ACP in relation to healthcare utilization, there 111 112 is consistent evidence that ACP positively effects other meaningful outcomes, such as improved patient/surrogate satisfaction with medical care 113 and communication and decreased surrogate/clinician distress.8-11 Only 20% 114 of older adults experiencing homelessness report discussing their wishes for 115 medical care and fewer than 10% report documenting their wishes.^{6,7} 116 Interventions to increase completion of advance directives in homeless 117 shelters have had some success, but had limited retention of participants. 12 118 People experiencing homelessness have reported that, given competing 119 priorities, they prefer to engage with ACP after they have regained housing.¹³ 120

Permanent supportive housing (PSH) is subsidized housing with voluntary supportive services for individuals experiencing chronic homelessness (i.e., prolonged homelessness and a disabling condition). PSH is the evidence-based means to achieve and maintain housing stability for individuals experiencing chronic homelessness with moderate and high levels of need. Individuals living in PSH (PSH residents) still have high mortality rates; however, with improved stability, they have fewer competing life demands and additional support and resources, which may help facilitate ACP. However, no prior work has examined the factors influencing ACP engagement in PSH. An easy-to-use, person-directed ACP program (i.e., PREPARE for Your Care program with video stories and easy-to-read advance directives) has been shown to be efficacious in safety net settings; however, it is unclear if it is appropriate for use in PSH. In PSH.

METHODS

We conducted a cross sectional study using a convenience sample of PSH residents and staff from 6 PSH buildings in the San Francisco Bay Area. The University of California, San Francisco Institutional Review Board granted IRB approval. The IRB waived written consent, and we obtained verbal consent from all participants. A Community Advisory Board (CAB) comprised of PSH residents and staff guided our recruitment efforts.

Setting and Participants

We used snowball sampling from PSH management, staff, and PSH residents. Staff were eligible if they were English-speaking and employed at a PSH site. PSH residents were eligible if they were age 50 and older, English-speaking, and living in PSH. We excluded PSH residents who scored in the moderate-tosevere cognitive impairment range on the short portable mental status questionnaire, or if they self-reported deafness, severe vision impairment, or a diagnosis of dementia.²⁰ We gave participants a \$25 gift card for participation.

Procedures

We recruited and conducted one-on-one interviews by video, telephone call, or in person, based on participant preference and COVID-19 guidelines, in two waves from April 2020-June 2021. Interviews were audio-recorded and transcribed by an independent transcriptionist. All interviews lasted 60-90 minutes.

We provided the first wave (10 PSH staff and 10 PSH residents) with the easy-to-read advance directive (5th grade reading level) from PREPAREforyourcare.org (PREPARE).²¹ We showed the second wave (3 PSH staff and 13 PSH residents) videos from the PREPARE online video guide and provided a corresponding workbook.^{18,19} Three PSH residents participated in both waves. Video examples showed brief clips with individuals engaging in ACP (choosing a surrogate, communicating future wishes). We asked

participants to explore perceived barriers and facilitators to ACP and use of the PREPARE video and advance directives (ADs) in PSH. We asked about appropriate timing and effectiveness of ACP in facilitated group and one-onone sessions.

We used the Behavior Change Wheel (BCW) and the Theoretical Domains Framework (TDF) to develop a semi-structured interview guide which probed for barriers, facilitators, and behavioral determinants to ACP in PSH. ²²⁻²⁴ The BCW is an implementation framework centered around the understanding of behavior as an outcome related to Capability (C) (i.e., physical or intellectual ability to perform the task), Opportunity (O) (i.e., factors in the physical and social environment that make a behavior possible), and Motivation (M) (i.e., reflective processes or automatic impulses or feelings that drive actions). The TDF is a classification of 14 domains identified through expert synthesis of behavioral theory which maps directly to COM-B and can help identify targets for future interventions (Table 1). ^{22,24,25}

Analysis

We used the BCW and TDF frameworks to describe and categorize themes and guide recommendations for intervention strategies. ^{22-24,26} We took an iterative and inductive approach to analysis. ²⁷ We developed and refined a codebook to standardize thematic content analysis and trained study staff through two virtual live training sessions. Trained study staff independently reviewed and coded interview transcripts. We reviewed and compared coded

transcripts during team meetings of at least three study staff to derive themes. We resolved rare disagreements by consensus between study staff and expert review (author MH) and kept a record of changes. We identified barriers, facilitators, and potential behavioral determinants and mapped each to the COM-B system within the BCW.^{22-24,28} We refined themes by classifying them into TDF domains related to each COM-B category (Table 1, Figure 1).^{22,24,29,30} We then identified BCW strategies for the TDF domains identified.^{23-26,28} The CAB met twice during the study period to discuss prominent themes and provide feedback. We continued interviews until we reached thematic saturation.

RESULTS

We recruited 13 staff and 23 PSH residents from 6 PSH buildings. Staff included 5 managers/directors, 5 resident services leaders and case managers, 1 behavioral health specialist, and 2 registered nurses. Sixty-nine percent of staff were female with median length of PSH employment of 1.9 years (IQR = 0.8-9.8). Fifty-two percent of PSH residents were female, with a median of 67 years of age (SD = 6.1) and a median 4.3 years (IQR = 2.8-6.3) in PSH. Sixty-five percent of PSH residents were non-white (48%) Black/African American, 4% Latinx, 13% Mixed Ethnicity). We described the barriers (Table 2) and facilitators (Table 3) to ACP based on the COM-B system and TDF framework (see Figure 1). We identified themes in 5 of 6 COM-B subcategories and 10 of 14 TDF domains. All themes were mapped

208 onto the COM-B model, TDF domains, and BCW strategies. A few selected TDF domains, themes and quotes from the tables are presented below. 209 210 **Barriers** 211 Capability **Psychological Capability:** Lack of ACP knowledge or experience, length 212 213 and complexity of the ACP process 214 Both staff and PSH residents reported a lack of knowledge about ACP. Staff 215 stated that they did not know how to begin ACP conversations or answer 216 medical questions. Many PSH residents reported poor understanding of the process, said that they didn't know who or which questions to ask, or 217 questioned the legality and permanence of ADs. Two PSH residents 218 219 described hospital visits where they were given a standard AD and were 220 unable to engage because they did not understand the language or 221 implications. Many PSH residents appreciated the self-guided PREPARE videos and easy-222 to-read ADs. However, both staff and PSH residents remarked upon 223 224 difficulties with resident memory, attention, and mental health disorders 225 which might restrict engagement with complex documents independently or 226 in long facilitated sessions. One PSH resident noted that if he was given too 227 much information at once, "remembering the first part, it goes out the 228 window sometimes."

230 Opportunity

231 **Social Opportunity:** Complex resident-staff relationships, interpersonal relationships, and group dynamics 232 233 Participants described variable and dynamic PSH staff/resident relationships. Staff said PSH residents "maybe trust one person in the building one day and 234 235 the next day they might not." PSH residents said they did not "feel 236 comfortable" or "close" to case managers and others cited turnover, lack of 237 PSH staff experience, or lack of trust as potential barriers to ACP discussions. PSH staff and residents described complex and variable inter-resident 238 relationships, which could hinder group introduction or discussion of ACP. 239 240 Some PSH residents described close connections with peers, while others preferred to keep to themselves. PSH residents said that peer relationship 241 242 dynamics were complicated by lack of trust because information "can become a tool they use to manipulate the other person." Participants listed 243 challenges with conflicting personalities, difficulty staying on task, and 244 frequent interruptions, particularly with large group activities. These 245 dynamics could negatively impact motivation for PSH residents to participate 246 247 in large groups or engage in conversations they suspect might put them at 248 risk. 249 Physical Opportunity: Lack of standardized processes for ACP, limited 250

resources
 Staff reported that there were no standardized processes, prompts, or guides
 to facilitate ACP conversations or completion of detailed ADs. Even when

they did discuss ACP with PSH residents, one staff member said, "It's very infrequent that a conversation would result in me saying, 'Hold on a second, I'm going to reach into this filing cabinet and pull an advanced directive." Other staff mentioned that if ACP occurred, it was initiated through individual rather than institutional efforts. Staff noted that while prompts exist to update emergency contacts at specific intervals, similar reminders for ACP do not exist in their workflow. In addition, while some PSH residents were willing to share their ACP wishes and documents, others expressed concerns about privacy, safe storage, and the forwarding of sensitive information in the event of a health crisis. Participants listed concerns that regular staff turnover and limited resources exacerbate the demands on staff and restrict availability for lengthy conversations, saying, "people are feeling really under-resourced" and ACP could be seen as "one more thing". PSH residents described not having "any place to sit down" to write and lack of computers to access the online video guide.

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Motivation

Reflective Motivation: Competing priorities for PSH residents, beliefs
about capabilities and lack of a medical decision maker
Staff and residents voiced concerns that PSH residents' social isolation might
"make it difficult to plan any of this," citing resident estrangement, lack of
strong support networks, and difficulty naming even one emergency contact.
PSH residents said that the medical decision maker (MDM) section was "the

hardest part" of the AD and staff believed that residents did not think it possible to complete the form without naming someone. PSH residents and staff also noted that the MDM conversation might serve as an emotional reminder of social isolation, further limiting motivation. In addition, PSH staff and residents described competing priorities for residents including attending medical appointments, financial concerns, and substance use. Some PSH residents didn't see ACP as a priority because they doubted their wishes would be respected, "[if] I said I don't want no extenuating circumstances... I feel a doctor...[wouldn't] let me die...." Others said they were "just looking to the next couple of hours" and hadn't thought about the future or death.

Reflective Motivation: Competing priorities for PSH staff, beliefs about capabilities and variable confidence PSH staff said that the ACP conversation is "incredibly challenging" and cited their lack of familiarity with medical jargon, lack of confidence navigating conversations about death, and lack of training in ACP. Some PSH staff suspected that others might avoid engaging due to concerns they might "trigger" PSH residents or make them feel "afraid," and others said they preferred trained facilitators take on the responsibility. Additionally, staff said that competing professional responsibilities such as managing acute crises and assisting PSH residents with financial, social, and other needs takes priority and that there likely "wouldn't be much interest" in ACP. As

one staff member said, "even if the client is willing to sit down and go over 300 the form...clients will just tell us, "I don't care, when I die, I die, you figure it 301 302 out, like you make the decisions." 303 304 **Automatic Motivation**: Emotion, fear of death While some PSH residents were able to discuss their own attitudes and 305 306 experiences, many felt their peers might resist talking about death because "a lot of people die here." PSH residents and staff primarily believed that 307 others, such as family and peers, were uncomfortable with end-of-life 308 309 conversation, even if they themselves were not. 310 311 **Facilitators** 312 Capability 313 **Psychological Capability:** Easy-to-read advance directive and video guides are accessible 314 315 PSH staff and residents described the easy-to-read PREPARE AD as "inviting" and "self-explanatory." During interviews, PSH residents were able to read 316 317 and describe the meaning of each page to the interviewer, demonstrating an 318 appropriate level of understanding. In addition, PSH residents liked the 319 PREPARE videos, saying they "brought to mind a lot of questions" and helped 320 them "write down directly what [they] wanted to say." 321

Opportunity

residents exposed to health crises Several PSH residents described a "shift" after "going from a system that does everything within its power to undermine you [shelters] to a place that does everything they can to help you [PSH]." Some cited a new ability to look toward the future, make long-term goals, and move past a mindset of daily survival, with a new desire to "live my life to the fullest." Participants said PSH provides a unique opportunity for ACP discussion "on a good day," when both PSH staff and residents have time, energy, and attention to address the topic, so residents can "go through it at their own pace." CAB members suggested staff give PSH residents six months to one year to establish themselves in PSH before asking to discuss ACP. Additionally, while fear of death might be a barrier to some, to others it can be a facilitator. PSH staff and residents described unique exposure to health crises, chronic illness, and death, due to their prevalence in this setting. They described leaving the building "in an ambulance on a stretcher" or witnessing as a deceased resident was "wrapped in a plastic bag" and taken away. Others listed the prevalence of substance use and the COVID-19 pandemic in the PSH setting as "reminders" about the end of life.

Physical Opportunity: Physical context, PSH provides stability, PSH

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343 **Social Opportunity:** Potential for close relationships in PSH

While relationship dynamics were a barrier for some, for others they were an important facilitator. Some participants listed examples of strong personal

relationships in PSH, calling PSH staff and residents "family." Some said that PSH staff were the best people to engage PSH residents in ACP because they "become your friend" and could bring "feeling in it" that a primary care clinician could not. Although some strongly preferred one-on-one conversations, others were hopeful about groups, saying "we have a good group and people don't go blabbing." Some PSH residents also believed that listening to peers with shared experiences might "break the ice" and encourage deeper engagement.

Motivation

Reflective Motivation: Belief that ACP is important and impactful
PSH residents said it means "a whole lot" to have their wishes respected and
many believed ACP could help them "die with respect and peace and
dignity." Some PSH residents stated that ACP could benefit family members
who would otherwise be left to make difficult decisions without guidance.
Others felt that ACP documentation was most important for isolated
individuals because "if I have no one...the document will state what I want."
Additionally, PSH residents described the importance of naming preferences
for pets and belongings and suggested we add these topics to the AD. Staff
members agreed that ACP was important for resident autonomy and
empowerment.

Automatic Motivation: Emotion: Videos provide relatable examples

PSH residents approved of the PREPARE ACP videos and several confirmed that they could identify with the narratives. One story showing a single man who described himself as a "loner" resonated with many PSH residents. Some said they appreciated that the videos showed options for those without family or close contacts. By delivering emotionally relatable stories, the video guides modelled the importance of ACP and appeared to provide reassurance that residents have the ability to engage and ask the necessary questions. One PSH resident said the PREPARE program "touches base with how they're feeling...sometimes people don't know how to ask questions so this kind of like spells it out for them."

Implementation Recommendations for Behavior Intervention

Techniques

In Figure 1, we mapped themes and listed recommendations for behavioral interventions based on the TDF, COM-B model, and BCW.

To address *capability* barriers of staff knowledge and skills, potential solutions suggested by PSH participants include educating PSH staff and residents about the key components and "impact" of ACP, "training staff members" to initiate and document these conversations, and modeling conversations with "simple" scripts for ACP conversations, such as those in the PREPARE for Your Care program. Such training could also address barriers to staff motivation and confidence. To address PSH resident *capability* barriers related to lack of knowledge and attention/memory for

lengthy conversations or documents, potential solutions suggested by PSH participants include restructuring the context of ACP educational activities by "breaking it down" into smaller segments and leveraging participant preferences for learning. Opportunity barriers related to limited resources and environmental context may be managed with efficient use of short "group sessions", "self-guided" programs like PREPARE, and creation of institutional prompts/procedures to standardize and simplify organizational processes. The use of outside facilitators may be an alternative consideration. Social opportunity barriers could be mitigated by restricting the influence of "difficult" social dynamics and leveraging existing close relationships. Participants suggested that "groups should be optional", selfselected, led by "trained" facilitators, and "limited" in size (4-5 people) or scope (i.e., ACP introduction only). To address additional motivation barriers, facilitated sessions should be "brief", "frequent," and easily accessible to enable participation when "[PSH] residents are ready" to engage. Incentives, such as "snacks" and other rewards could also be provided to encourage PSH resident participation.

DISCUSSION

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In this study, PSH staff and older homeless-experienced PSH residents identified barriers and facilitators to ACP discussions and documentation in PSH. Tools such as the PREPARE easy-to-read AD and online video stories provided education and enhanced participants' *capability* to engage in ACP

414 conversation that might otherwise be unfamiliar or difficult to understand. Established housing and supportive services created greater opportunity for 415 participants to consider ACP; yet lack of standardized procedures and 416 complex relationships between PSH residents and staff complicated this 417 418 potential. While barriers to *motivation* such as pessimistic beliefs, competing priorities, and anxiety about death were common, PSH residents felt more 419 prepared to engage in ACP after obtaining housing. For staff, lack of 420 confidence in their own abilities and negative outcome expectations 421 hindered motivation to engage PSH residents, despite belief in the potential 422 423 benefits. Staff were interested in obtaining more ACP training. We identified several strategies to target these barriers and facilitators using the BCW and 424 425 TDF, including education, training, and ACP modeling using simple scripts for PSH staff. For PSH residents, these included enabling and modeling with 426 427 easy-to-use materials, providing incentives, and optimizing the social 428 environment through optional, self-selected groups. Our work builds upon previously documented findings that PSH creates novel 429 social and environmental opportunities for behavior change. 13 With safety 430 and survival addressed, some PSH residents described greater optimism, a 431 432 "shift" in priorities, and more motivation to plan. When provided with easy-433 to-use resources, PSH residents and staff described ACP as an empowering and dignifying process. PSH staff may be uniquely suited to reduce anxiety 434 by introducing the subject over several months, individualizing the 435 discussion, or simply choosing "a good day" for the PSH resident. Still, 436

interventions to strengthen variable relationships between PSH staff and residents or outside facilitators/trusted peer counselors may be needed in some cases.

The PREPARE easy-to-read AD and video guides appear to improve PSH residents' ability to engage by providing real-time education and step-by-step modeling of ACP. The existing PREPARE tools may be useful to model several ACP topics (i.e., discussions with surrogates and medical providers). Training staff how to use PREPARE tools may also improve staff confidence and motivation to facilitate. Suggestions for change include adding information about pets, belongings, and estranged family to the easy-to-read ADs and showing examples of PSH residents in the video stories.

The well-described familiarity with end of life and chronic illness among PSH residents and staff may create an opportunity to introduce ACP in a group setting. In primary care, groups have been shown to be effective in engaging patients in ACP. 31-34 Despite complex relationship dynamics in PSH, groups may be an important option in this resource-limited setting. Per PSH resident comments, restricting group size, allowing resident self-selection, and providing options for alternative one-on-one sessions may be important considerations to improve engagement. Future studies will explore the most effective role, scope of responsibility, and needed training methods for PSH staff in ACP.

Limitations

Generalizability of our findings is limited due to potential bias related to recruitment from a single region, the small sample size, and exclusion of participants who are non-English speaking or have hearing or vision impairment. Due to the COVID-19 pandemic, we used convenience sampling and recruited participants virtually. This may have led to selection bias in favor of participants with interest in ACP engagement and capability bias in favor of participants with greater technological ability, cognitive faculty, or psychosocial capacity.

CONCLUSIONS AND IMPLICATIONS

The population of older adults experiencing chronic homelessness is increasing with high rates of morbidity and mortality. Innovative and novel strategies for ACP engagement are needed. Future ACP interventions may improve success by addressing behavioral barriers and leveraging facilitators. Future studies should explore utilization of easy-to-use ACP materials, including PREPARE for Your Care, and development of resources to educate PSH residents, train staff, and model the ACP process in groups or one-on-one sessions.

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Author Contributions

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SEP, RS, MK, MAH, PO, BL, and CE contributed to study design, results
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from RS, MK, MAH, LK, BL, and CE.

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614 Figure 1. We applied the Capability Opportunity Motivation Behavior (COM-B) 615 model to understand barriers and facilitators to ACP. Each of the qualitative themes 616 are organized within five of the six COM-B subcategories (psychological capability, 617 social opportunity, physical opportunity, automatic motivation, reflective 618 motivation; not shown: physical capability). Barriers are represented with rounded rectangles and facilitators with dotted ovals. The COM-B model integrates with the 619 Theoretical Domain Framework (TDF) and the Behavior Change Wheel model 25,35-38 620 621 to provide behavior change strategies for implementation. Solid lines connect 622 identified barriers and facilitators to one or more TDF domain, and behavior change 623 strategies to target the TDF domains are listed.