"Don't Wait Till You Fall Down": Notions of Social Support Among Men Living with HIV in A South African Township

Action-Focused, Plain Language Communication for Overdose Prevention: A Qualitative Analysis of Rhode Island's Overdose Surveillance and Information Dashboard

By

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B.S., University at Albany, 2016

Thesis

Submitted in partial fulfillment of the requirements for the

Degree of Master of Public Health in the Brown University School of Public Health

PROVIDENCE, RHODE ISLAND

MAY 2018

This thesis by Katherine M. Waye is accepted in its present form by the Brown University School of Public Health as satisfying the thesis requirements for the degree of Master of Public Health.

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Katherine Waye is a Master of Public Health candidate with a concentration in Global Health. She is an alumna of The University at Albany, State University of New York and its Honor's College, graduating Summa Cum Laude. Her academic training and research experience focus on substance use harm reduction, overdose prevention as well as other associated harms, like HIV/AIDS. Katherine's interest in public health began during her undergraduate career at The University at Albany where she held a research assistantship at The Global Institute for Health and Human Rights. She currently works as a graduate research assistant with Marshall Research Group at Brown University's Centers for Epidemiology and Environmental Health. During the summer of 2017 she worked under the NIH iALARM project in Cape Town, South Africa to research the effects of peer and familial support on the lives of men living with HIV in the township of Gugulethu. After completing her Master of Public Health degree, Katherine will begin working at Boston Children's Hospital as a project coordinator.

Preface and Acknowledgments

This thesis would not have been possible without the support of my thesis advisors and readers—Dr. Brandon Marhsall, Jesse Yedinak, Dr. Mark Lurie, and Dr. Christopher Colvin. Thank you for your guidance and mentorship. I would like to thank the participants from the Prevent Overdose Rhode Island (PORI) qualitative study and the participants from my research in South Africa for their critical contribution to the studies. In addition, Phumzile Nywagi, thank you for your friendship, translation services, and support in conducting my research in South Africa. Further, my research in South Africa would not have been possible without funding from the Framework in Global Health Scholarship. I would like to also extend my thanks to the Marshall Research Team for creating a terrific work environment, new friendships, and your assistance in all of my research activities. Lastly, to my family and friends, thank you for your love, support, and the words of encouragement during these two years.

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Part I: "Don't Wait Till You Fall Down": Notions of Social Support Among Men Living with HIV in A South African Township

ABSTRACT

This study examined the definition and impact of social support on the HIV treatment cascade among South African men. We conducted a qualitative analysis with 20 men currently receiving antiretroviral treatment in the township of Gugulethu, South Africa. Our study found that fear of private problems being shared throughout the community, especially one's HIV status, as an inhibitor for seeking support with those outside their immediate family. Participants cited societal pressures for men to be strong and a subsequent fear of judgement as barriers to openly discussing their HIV status and leveraging support. While the utilization of social support was indicated by nearly all the participants, it was made evident that men living with HIV still desire greater community-wide support for their HIV. Health strategies that leverage social support should be an effective component in future interventions focused at lowering the growing rate of HIV among men in South Africa.

INTRODUCTION

South Africa is the nation with the highest global burden of HIV/AIDS where approximately 7 million people are living with HIV and approximately 45% are reported to be virally suppressed [1]. Improving the treatment cascade among people living with HIV (PLHIV) is a necessary component in lowering HIV incidence and increasing the number of virally suppressed cases within South Africa [2]. The treatment cascade focuses on promoting HIV testing, subsequent linkage to care and antiretroviral (ARV) treatment, and ARV adherence to ensure viral suppression [3–5]. A key determinant in successful progression along the HIV care continuum is the impact of social support and how it can assist PLHIV in navigating the care process, adhering to treatment, and either delaying or halting their progression to AIDS [6–8]. Social support has been shown to assist PLHIV in better navigating the treatment cascade, where in one study, PLHIV reporting a Medical Outcomes Study Social Support Survey score of 50 (out of 100) or higher were found to have 2.36 greater the odds of predicated ARV adherence [6].

Social support is typically defined as the assistance provided by an individual's social network (i.e. friends and family) usually defined into the following four categories: 1) instrumental factors, like monetary and material goods; 2) emotional support, including expressions of care, empathy, love, etc.; 3) informational, knowledge-based support, and; 4) appraisal linked to self-evaluation or introspection of behaviors [7, 9]. Studies have found that social support can improve psychological adjustment among PLHIV, lower psychological distress, improve quality of life, and enhance self-esteem [7, 10].

Literature has indicated that possible social forces, specifically notions of masculinity, can negatively impact men's experience in the HIV treatment cascade. Studies in South Africa have found that being a man and living with HIV was seen as a failure and inhibited the men's role as a provider [11–13]. Other African studies have found that living with HIV as a man contradicts with taught beliefs of self-reliance and the subsequent need to receive care [13–16]. These social expectations are imperative to note given that men living with HIV in South Africa are less likely to be linked to care after a positive diagnosis and have a higher loss to follow-up rate for treatment compared to that of women [17]. Further, research has found that men living with HIV in South Africa have a higher age-adjusted mortality rate from HIV and a lower median CD4 count compared to that of women [13]. Since masculinity in South Africa is largely driven by concepts of independence and being a provider, leveraging social support may be perceived differently and harder to reach for South African men, especially men living with HIV who are needing to navigate the HIV treatment cascade [18].

Further, little research exists on how gender may affect social support among PLHIV and whether support may be operationalized differently depending on the study site and its cultural expectations [7, 19, 20]. Few qualitative studies exist that examine social support and how it is defined and realized among men living with HIV in South Africa. Given that social support is associated with ARV maintenance, care seeking behavior, and greater linkage to care, it is imperative to understand dimensions of support among men living with HIV in South Africa [7,19].

Therefore, the purpose of this qualitative study was to 1) understand and conceptualize social support among men living with HIV in South Africa and 2) to

identify how HIV has impacted their notions of social support and experience through the HIV treatment cascade. Improving the knowledge surrounding social support networks can allow for health systems to identify areas of opportunity to implement social support-based approaches that improve the treatment cascade among men living with HIV in South Africa.

METHODS

Study Setting and Participant Recruitment

From June 2017 to August 2017, male participants living with HIV were recruited (n=20) from the township of Gugulethu, located approximately 15 kilometers outside of Cape Town, South Africa. Gugulethu has a population of approximately 98,000 with 98.5% reporting Black African race. Participants for this study were recruited from Gugulethu's ARV adherence club and the Hannan Crusaid ARV Center, one of South Africa's specialized health care facilities that provides ARV treatment to Gugulethu residents. Eligibility for the qualitative study included: living in Gugulethu, being over the age of 18, English or Xhosa speaking, and verbal confirmation of HIV status. Eligible participants were recruited with the assistance of health workers at the ARV adherence club and Hannan Crusaid. The health workers would discuss with patients the aims of the study and whether they would be willing to participate while waiting for their medical consultation. Of the 20 male participants, the average age was 44 years (range 24-61 years) and all were black South Africans.

Data Collection

Interested participants were interviewed with a semi-structured interview template to guide an open discussion on what men living with HIV look for in their support networks as well as whether HIV has affected how they ask for and view social support. The research team consisted of one Xhosa-to-English interpreter and one trained interviewer. If participants were comfortable speaking in English, the interviews would occur in English with the support of Xhosa interpretation, if necessary. All interviews took place in a private room located either on the ARV adherence club's or Hannan Crusaid's grounds. Prior to the start of the interview, participants were given a brief background of the study's intent and signed an informed consent form. All interviews were audio-recorded and de-identified. The trained interviewer took notes during the interview and maintained an audit trail to track key ideas and thoughts throughout the interviews. The study was approved by University of Cape Town's Institutional Review Board (#00001938) and by Brown University's Institutional Review Board (#00000556).

Data Analysis

After collection, interviews were subsequently transcribed by the interviewer. The initial coding scheme was derived from the interview template. Four interviews were randomly chosen and reviewed by the first author to test the initial codebook, allow for further refinement, and the addition of new categories that were made apparent following close reading of the interviews. A final coding template was then developed, where all 20 transcribed interviews were coded for analysis. NVivo Version 11 was utilized for coding and data management.

RESULTS

Trusted support networks

Participants listed their immediate family as their primary support networks, including their mothers, wives or partners, children, and siblings. While questions did not focus primarily on how the participants leveraged support specifically for their HIV status, respondents frequently cited their positive HIV status as a primary reason as to why they only utilize their immediate family networks for support.

> "I always speak to my wife before I do anything. For example, if you're sick, you're supposed to speak to the one who's close to you, at least to give you, to say to you to go to the clinic or whatever...The best way, is to try tell someone who is going to be helping me. To, uh, convince me to go to somewhere to be healthy (P14)."

> "For me, like when I find help, I go to my cousin. I can talk about anything when I want to talk with him… He'll tell me anything, anything. No matter what it is. I found I'm this way [HIV positive], I go straight to him he's the one who makes me strong (P10)."

> "The first person I talk to when I'm sick is my sister… She's family, yeah, I know family problems is safe (P11)."

Further, proximity to support networks were cited as an influential factor in who the participants sought for support. Participants said that living in the same household or down the street from their support networks allowed for ease of access in receiving the support that they sought.

> "You know when you live with somebody and you're coming home or come in from work or whatever. You can feel it, you can feel it when you walk up to somebody's arms. Yeah, she's [his wife] very supportive to me and she's there for me even though she's HIV negative (P01)."

> "My brother, my brother he's um, I ask him sometimes, but um sometimes he's not always there because he's a very busy man, you see? So, the people I get close to is my sister and my girlfriend, you see? (P06)"

> "It's very difficult to go to other people that you haven't stayed with. When you need help or something you just ask a member of your family. Is this good or bad or how can we come up with something according to the plan (P12)."

In summary, the majority of the participants relied solely on immediate family as their support networks, largely influenced by the respondent's accessibility and proximity to their support networks.

Distrust of community and friends

When prompted if the participants utilize other support networks, in addition to their immediate family, friends and other community members in the township were viewed as untrustworthy sources for support.

> "It depends on what kind of problem or support you need at that particular time. And the other thing is that it's so difficult to seek help outside, as compared to someone who you are staying with. You know, as compared to someone you just see on the street and ask for help. It's so very much difficult. You'd rather keep quiet (P02)."

> "No. If I go to like the bar, we don't talk there. I'm not talking, I'm not drinking. Just stay and drink orange juice or whatever and just go home. Even from work, straight to my house. I almost always go like that. Even before, I get this problem [HIV status]… I can't trust others. So I keep on, my problem is my problem and my wife's (P14)."

Participants cited judgement-based situations and fear of private, personal problems being shared throughout the community, especially their HIV status, as inhibitors to sharing information and seeking support with people outside their immediate family.

> "Who can I talk to? I can't talk to these people [in the community]. They're going to talk about me. They're going to talk behind my back and all that stuff. I don't need that. Men don't need that. They don't need gossip. (P15)"

> "Actually, I've seen my friend that I used to go to school with, that I grew up with, but he can't even shake my hand. He just makes it like he doesn't hear what I'm trying to say, you see? Those are the things that I've felt like, oh I

> don’t need to ask this guy. I can just see from his eyes that this guy is fully judging me (P06).”

Together, the participants illustrated the influence of community-wide stigma and subsequently, their lack of trust, in sharing their HIV status and seeking support outside their immediate support network.

Forms of Support

While participants cited varying types of social support that they utilized, instrumental and appraisal-based support were spoken of the most frequently. Of the latter form of support, the individuals discussed seeking validation and guidance in consulting health services during all stages of their HIV care continuum, from testing to ARV adherence and common health ailments that may procure.

> “I can go to them [family] and ask for them for something, like if it’s for a stomach or a strange headache. They’ll be like no man, don’t do this. So they are quick, they want to get me something. Because of the disease [HIV] that I’m having, they’re much quicker to judge—go do this, go do that, go do this. Because they are scared that it’ll maybe overcome me. Sometimes if my brother is working, if my cousin is working, they’ll tell me to go do this. They’ll sometimes tell me to go to the private doctor so it can go be quick (P17).”

> “It was quite a long period of time that I became sick and she [partner] was the very first person that noticed that I was not well and she encouraged me to come the clinic. It took me quite a while to come to the clinic, but my partner encouraged me to [go to] the clinic [Hannan Crusaid] because she could tell something was bothering me (P20).”

Participants also stated that their support networks provided instrumental care for them by primarily offering financial support, which was viewed as particularly helpful by participants when they first were diagnosed with HIV and at times too sick to work.

> “My mother. I didn’t tell my mother, all of them, I only told my sister. They saw I was sick. I was lying on the bed. I was throwing up, everything, TB, everything all together. They try to support me, they go, ‘what’s wrong and I go

> no, mom I don't know.' I told her in the beginning. It's TB. I told them just like that. She [sister] keeps on supporting me, giving money monthly to go to the clinic (P11)."

South Africa provides social grants to support low income individuals. However, participants stated that they required additional monetary support either when the grants they were eligible for were not frequent enough or when they acquired too little money for monthly costs.

> "Actually, my siblings and my wife, they help me out a lot. At some points when I don't have money to eat, and I don't have anything to support or to buy, and my wife will pay for me until such time until my grant is approved (P02)."

> "My son normally helps me when I feel like there's financial constraints around and seeing that I'm a pensioner and a grantee (P03)."

However, finding monetary support was also stated by participants as difficult and a situation at times fraught with pain and judgement, even from one's immediate family.

> "If you just call someone and you say, hey please help me, let me borrow some money, and then I'll say I'll give it back. Maybe I say this to my brother and he'll say I can't help you. You sometimes think why won't he give this to me as my brother. You don't feel good...sometimes I just wish I can go to when I was young again. Because if you are young, your mother and father will work for you (P14)."

While participants were not prompted to solely discuss their social support in the context of their HIV status, nearly all of the respondents discussed the leveraging of social support in relation to being HIV-positive and the support's impact on their life with HIV.

The 'Gugulethu Man' and Support Groups

When asked if men go about support differently than women, participants frequently stated that men in Gugulethu were shy and fearful of judgment, whereas

women were viewed as more willing to openly share their life problems and seek assistance.

> "Yeah, the women are much more stronger than us because they seek help often as compared to men because we as men we are so introverted, we don't speak a lot. We'd rather die than seek help... men, they have always felt that they are stronger than women (P02)."

> "I think men need a little bit of other support, because they're afraid to be open. You see, and they don't even care what's happening and if, if they found out they have HIV, they'll just drink and do other things. Stupid things. So they need more support, more than ladies because ladies, they come (to the clinic)... Men and women are different, you see. I think men don't want to be judged and men if you, if you're, HIV you're going to be degraded and you're going to lose, I mean your manship or something like that (P15)."

Due to these pressures as a man to be strong and a subsequent fear of judgement, more than half of the participants believed that there was not enough support for men living with HIV in Gugulethu.

> "They [men] need help. Because some of the men, they're very secretive around here, in Gugulethu and it's very hard to find men that want to be able to speak out about what their personal issues are (P06)."

> "I don't know any other place where people could gather and have support as men around, outside the facility [Hanan Crusaid] in Gugulethu. There's nothing that I know of (P13)."

Participants were then prompted on their views regarding support groups for men living with HIV. Nearly all the respondents stated that support groups would be highly useful for men living with HIV in discussing ARV adherence and to provide encouragement and advice on how to live with HIV.

> "Well, it would be very good to have a support group. It's where we could encourage and support each other from defaulting on medication, to take the medication at proper times and to encourage others, the next generation, not to get infected (P07)."

Nearly half of the participants advocated for a male-only support group due to fears of anonymity as well as perceived beliefs that women would judge them for their positive HIV status.

> "It would be a wise opportunity for men to gather together to have a space where only men are together. Because most of the time when you go to the health clinics, you only find a few guys. Men are really having a problem, support groups need to address it or information needs to be shared across the townships so that men can have a space (P05)."

> "I think men, I mean men they don't want to be mixed with women. You see. And other men, like for example, myself. I am not married I don't need to be talking to ladies about this [HIV] (P15)."

Among the minority who supported mixed gender support groups, the participants stated that HIV was a shared problem and that both sexes must work together to solve HIV in Gugulethu.

> "You've got the same problem and that won't change, you stay like that. Instead of keeping to yourself, share. Don't need female or male stuff. It's one problem. It's not the male stuff or the female stuff. It's one problem. We must fight it together so that our health can be a success (P17)."

> "I think that both genders need it [the support group] because this sickness you get from both genders and both genders can support each other. You don't get HIV because you're alone...I think for me, for both genders it would be very helpful (P09)."

While there was mixed consensus regarding male-only support groups, the participants conveyed the general importance of support groups in advising and encouraging people living with HIV, especially for men living with HIV in Gugulethu.

DISCUSSION

This qualitative study on the notions of social support among men living with HIV in the township of Gugulethu, South Africa provides several key findings on how

black South African men living with HIV view their social support, what sociocultural forces inhibit them from seeking support, and how their life with HIV has impacted the social support they utilize. Notably, our findings indicate that while there are prevailing notions of masculinity for South African men to be strong and independent, men living with HIV desire for and seek social support. The study illustrates the importance of creating environments of support that allow for men living with HIV to further freely discuss their status outside of their family and home.

The study's themes make evident the pivotal role family members play in assisting men during several phases of the HIV care continuum. Family members offered guidance and positive support to participants on HIV test seeking, health clinic appointment reminders, validation for treatment seeking behavior when feeling unwell, monetary support when the men were too sick at the start of their HIV diagnosis, and emotional support when confronted with accepting a positive HIV status. However, studies have found that offering support also places considerable stress, both financially and emotionally, on the caregivers of PLHIV [21–23]. Given that informal family caregiving and support may provide a crucial role in the care continuum for men living with HIV, our study provides important implications for modeling future interventions that consider the role of the family in the treatment and care for men living with HIV in South Africa. Research suggests that either offering assistance or outlets to discuss emotional concerns for family members of PLHIV in resource-poor settings may be useful for this population [22, 23].

Further, our findings indicate that leveraging social support may be associated with the men's disclosure of their HIV status to a support network. Research has found

that social support is related to increased disclosure, however studies have also reported the difficulty of maintaining relationships due to the pressures of HIV [24, 25]. Though the participants reported the existence of social support from family members, HIV-positive men were fearful of other Gugulethu community members discovering their status and thus distanced themselves from seeking support outside the immediate family. Communities can have a direct impact on PLHIV, both as a source of health and well-being as well as stigma [26]. However, there is still a clear need for community-wide interventions that address and de-stigmatize HIV by promoting community support mechanisms. For example, a project in Zimbabwe utilized the technique of 'community conversations', allowing for open and non-stigmatizing discussion on HIV/AIDS to evaluate the community-wide response to HIV and strategize methods for improving the lives of PLHIV [27]. This fosters the development of an 'AIDS-competent community' and may be particularly effective in other resource-poor settings in Africa that face heightened community fragmentation and stigma among PLHIV [28].

While this qualitative analysis illustrates that men living with HIV receive some needed support in the treatment and care of their HIV, it was made evident that the men continue to desire additional support outside of the assistance they receive from their family. Several studies have discovered the efficacy of peer-led support groups in promoting ARV adherence, lowering emotional distress, as well as simply creating safe, social environments for the discussion of HIV/AIDS [28–31]. However, aligning with our findings, men living with HIV in South Africa have been reported to be less willing to openly discuss their HIV status in HIV-related social settings [28]. This indicates the need for support groups that are male only or, alternatively, catered towards fostering a

sense of safety and connectedness for male support group members. Little to no quantitative studies exist on the impact of male-only HIV support groups in communities with strong cultural norms of masculinity [29, 32]. Future efforts should focus on designing validated models for support groups and assessing their effectiveness in fostering support and positive well-being among men living with HIV.

This study has several limitations. First, the study was conducted in the Gugulethu township of South Africa and the findings may not be generalizable to other populations. Additionally, given that our study population consisted of men successfully on ARV treatment, it is likely that we interviewed those who are already succeeding in the HIV treatment cascade. We did not interview people struggling to initiate or adhere to HIV treatment and this subset of the population's forms of social support may vary from those successfully adhering and utilizing treatment services. While some participants were able to speak in English, other interviews were conducted with the assistance of Xhosa-to-English interpretation. There is the chance that certain statements and questions may have been lost or altered in translation. Future research should examine and compare the different forms of social support among men and women living with HIV in South Africa.

CONCLUSION

This qualitative examination makes evident the importance of social support among men living with HIV in South Africa. Additionally, social support, especially from familial networks, provided several forms of support, notably appraisal and instrumental support, in assisting the men living with HIV throughout the HIV care

continuum. While the utilization of social support was indicated by nearly all the participants, it is evident that men living with HIV still desire greater community-wide support for their HIV. Health strategies that leverage various forms of social support may be an effective component in future interventions focused at lowering the growing rate of HIV incidence in men living with HIV in South Africa. The implementation of support groups that are male friendly may be an effective measure in lessening the burden of HIV support for family members, as well as allow men living with HIV to openly discuss their status with individuals outside their immediate social network. To conclude, "What you're talking about is life, you see. Everybody needs support. The only thing we feel for us, the only thing we need in life is support (P12)."

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Part II: Action-Focused, Plain Language Communication for Overdose Prevention: A Qualitative Analysis of Rhode Island's Overdose Surveillance and Information Dashboard

ABSTRACT

Objectives: To determine how people who use drugs (PWUD) perceive and utilize overdose prevention material, and to evaluate action-based, plain language content on Rhode Island's overdose surveillance and information dashboard, www.PreventOverdoseRI.org.

Methods: We conducted 21 semi-structured qualitative interviews with PWUD from February-June 2017 in the state of Rhode Island. Data were audio-recorded, transcribed, coded in NVivo (Version 11), and key themes were developed.

Results: Participants viewed online health promotion and harm reduction materials as a useful approach for overdose prevention. Information displayed as accessible, action-driven statements was seen as most desirable for learning and dissemination. After viewing overdose prevention material, participants reported feeling better prepared for responding to an accidental overdose and motivated to share the infographics and website to other people either at risk for or likely to witness an overdose.

Conclusions: Action-focused, plain language approaches for overdose prevention materials can be effective and of particular use for public health campaigns addressing the United States opioid crisis. Overdose prevention health campaigns should incorporate evidence-based testing to ensure that outreach material is grounded in plain language techniques.

INTRODUCTION

Accidental drug overdose is a growing public health crisis in the United States.[1,2] Between 1999 and 2016, drug overdose mortality more than tripled, with over 63,000 deaths in 2016.[1] A leading factor in the rise of accidental overdoses is the emergence of fentanyl and fentanyl-related analogs in the illicit drug supply.[3] In 2015, the state of Rhode Island reported the fifth highest drug overdose mortality rate in the US.[4] Of all 2016 overdose deaths in Rhode Island, 58% were fentanyl related—a seven fold increase from 2013.[5]

In 2013, Rhode Island Governor Gina Raimondo created the Rhode Island Overdose Prevention and Intervention Task Force to lead the state's response to the overdose crisis.[6] The task force charged an academic team to draft a three year strategic action plan to reduce overdose morbidity and mortality. One of the goals of the strategic action plan was the creation of a statewide, online, publicly accessible drug surveillance and information system.[7] The resulting website, www.PreventOverdoseRI.org (PORI), offers near real-time data on drug use, overdose rates, and prevention, treatment, and rescue interventions in Rhode Island.[7] Alongside the presentation of overdose surveillance data, PORI provides health promotion materials on overdose prevention, recognition, and response, educational material on fentanyl, where to find and how to use naloxone (an overdose recovery drug), and harm reduction information to mitigate overdose risk among people who use drugs (PWUD).

The internet is among the most common health information sources for US adults of all ages; however, research has shown that many online health information resources are of poor quality and/or are difficult to navigate, often due to the overuse of scientific

and technical jargon.[8,9] According to a 2013 national survey, approximately 59% of US adults utilized the internet for health information.[10] Those with less education, lower income, and non-white race are less likely to go online for health information.[10] Although internet use is common, approximately 90% of US individuals have limited health literacy skills,[8] indicating the need to create health communication platforms that focus on providing high quality, yet easily accessible information.

Writing in plain language is a growing technique used to improve the quality of online health materials for those with lower health literacy.[11] This writing style emphasizes communication that succinctly displays health information and engages the target audience in finding, processing, and utilizing the information they need.[11,12] Common traits of plain language writing for health communication are the active voice, minimal to no use of either medical or scientific terminology, brief sentences, and a conversational tone.[11–13] The plain language approach is becoming an important aspect to public health efforts broadly; in 2010, the US Government passed the Plain Writing Act, mandating that federal agencies must use plain writing techniques for the public.[12]

Throughout its development and initial evaluation, PORI was grounded in a plain language approach.[7] PORI's prevention-based web tools and infographics were created with the intent of being easy to use, reader-friendly, and adhere to the Centers for Disease Control's (CDC) "Everyday Words for Public Health Communication".[14] Moreover, all PORI material is tested through the CDC's Clear Communication Index and the Suitability Assessment of Materials (SAM).[15,16] Alongside the testing index, before the launch of PORI in June of 2016, a two-week beta testing phase occurred, with the use of e-mail surveys that requested the input of over 150 community and agency stakeholders.[7]

Despite these initial efforts, PORI has yet to be formally evaluated with one of its key target populations, PWUD.

Therefore, the aims of this qualitative study were to: 1) determine how PWUD perceive, find, and use online health information, especially in relation to overdose prevention; and 2), to evaluate PORI's content and infographics. This qualitative evaluation can assist other programs and online resources on how to test and provide overdose prevention materials for PWUD, using best practices for plain language communication.

METHODS

Participant Recruitment

From February-June 2017, participants were recruited (n=21) in the state of Rhode Island through online classifieds (i.e., craigslist.org), social media postings (Facebook, Twitter, and Reddit), flyers in public spaces, and word of mouth. Before scheduling an onsite, face-to-face interview, we determined eligibility through phone screening. Eligibility for this qualitative study included: (1) living in Rhode Island, (2) being over the age of 18, (3) English speaking, (4) ability to travel to the study site, (5) knowing of the overdose recovery drug naloxone, (6) either experiencing or witnessing an overdose in one's lifetime, and (7) either self-reported non-medical prescription opioid use or heroin use in the past year.

Data Collection

We utilized a semi-structured interview template to guide our discussions with participants on what they look for in overdose prevention materials and their own opinions on PORI's online material. Three trained members of the research team

conducted in-person interviews that lasted up to sixty minutes in the study site's private interview room. Prior to the start of the interview, participants were informed of the project's aims and signed an informed consent document. Participants received a $25USD gift card for their time. Upon completing the interview, each trained facilitator maintained notes to annotate key ideas and events of each interview. The study protocol was approved by the Brown University Institutional Review Board (#1605001495).

The first section of the interview primarily focused on discussing the participant's engagement of online sources for drug use, whether it be for overdose prevention, treatment, or other related needs. We then queried participants on how to promote an overdose prevention website with the following question, "How might we get people to visit a health website when it's related to a topic like overdose or drug use?" Follow up questions focused on identifying strategies to improve the content on overdose prevention websites, with questions such as, "What information do you think people who use drugs look for when it comes to overdose in Rhode Island?" and "How can we get people to visit a website about overdose and prevention in Rhode Island?"

Interviewers then utilized printed infographics from PORI (e.g., Figures 1, 2, and 3) for the participants to analyze and critique. Questions such as, "Do you think these infographics include specific enough directions on how to recognize or respond to an overdose?" or "Is this infographic helpful or unhelpful to you? Why?" assisted in gauging the usefulness of the PORI infographics and how the target population responded to these materials. Finally, participants had the opportunity to view the PORI homepage on laptops and were guided to the "Get Naloxone" webpage, an interactive map that provides the location of naloxone distributors in Rhode Island (Figure 4). Questions such

as, “Does this page include enough information to know where you can get Naloxone?” were asked to test web page usefulness and understanding.

Data Analysis

The interviews were audio-recorded and transcribed by three members of the research team. The coding process began with an initial coding scheme based on the interview template, which then developed as new ideas were made apparent from reading the transcribed interviews. A final coding template was agreed upon by the three members of the research team. Eight interviews were cross-coded by two or more research team members to prevent bias and ensure uniformity in the coding process. NVivo (Version 11) was utilized for data retrieval and management.

RESULTS

Participant Characteristics

Of the 21 participants, 19 (90.4%) reported white race. The average age was approximately 38 years, 13 (62%) reported male gender, and 16 (76%) stated their sexual orientation to be “straight”.

Four themes emerged from the interviews: 1) Sharing or disseminating overdose prevention information; 2) How to talk about overdose or addiction; 3) Key characteristics of overdose prevention materials; and 4) Using action steps to mitigate risk. The most commonly advocated medium for overdose prevention information sharing were the television, shareable products (i.e. flyers and pamphlets), street campaigning, and social media. In general, participants stated that non-judgemental, brief, action-driven messaging were key factors in effectively providing and disseminating overdose prevention information.

Sharing or Disseminating Overdose Prevention Information

Social media was seen as an efficient method for sharing information among friends as well as increasing overdose prevention materials' impact and accessibility. Participants stated that publicizing overdose prevention material through social media sites, rather than simply directing them to a website, could be a useful first step to share information with at-risk populations.

> "Social media is a good way. Um, even on Facebook a lot of people read Facebook… I think Facebook gets a lot of people (white female, age 38, R11)."

> "I would say if you wanted people to be interested especially like young people, I would do it through social media, like connecting in that way...I usually if I see something scrolling down like um, Facebook or Instagram and it catches my eye, I'll read it (mixed race, age 29, R10)."

Participants of all ages stated that shareable products and street campaigning efforts were effective, interactive approaches to reach populations at risk for overdose. Participants suggested offering flyers and handouts in targeted community locations where people at risk of overdose are known to congregate, such as health clinics, treatment sites, support group meetings, and homeless shelters.

> "You know, hand out like flyers, be just like oh here, check this website out, check this website out. Do something proactive, you know (white male, age 29, R06)."

> "Make flyers. I know it sounds silly. That's old school and everything, but it works. Put it in places that you would expect addicts to cluster around (white female, age 27, R16)."

> "Something where they're hearing it instead of them going directly to the internet and looking for it. Because nobody, if, especially if you have an addiction problem and you had somebody, had a loved one that died in an overdose, they're not gonna be [ready] (white male, age 47, R04)."

How to Talk About Overdose or Addiction

Straightforward, non-judgemental communication was the most common approach participants cited when asked, "How do you think people want to be talked to about addiction and the rising number of overdose deaths in our state?" Participants frequently stated that reprimanding or belittling behavior as ineffective in overdose and addiction prevention discussions and materials.

> "Don't come at 'em down grading 'em, 'oh well you have this problem and this issue that needs to be solved' and you feel like a bad person. That's the worst way to go about it (white female, age 32, R14)."

> "Just be real and they will listen more… identify the issues and they'll know how to go about it (hispanic male, age 54, R21)."

> "You want to feel comfortable. You don't want to feel like you're less than something, you know? You want to feel like that person is sincere. You know, empathetic (white male, age 36, R15)."

Relatability of the material was often cited alongside a desire for overdose prevention materials that were factual and increased one's knowledge base. Participants reported looking for information that is not only non-judgmental in nature, but also provides effective steps for behavior change and overdose prevention.

> "Um just straightforward and with information. Good information of what to do. Like um how can you help someone to get the help they need, and like tips on how to look it up, um also what to do if a person's overdosing in front of you. That's a big one. Cuz to this day, I don't really know what to do (hispanic male, age 44, R05)."

> "So to me it's astonishing enough to hear the facts and it makes, it makes me want to like help and do something about it (white female, age 30, R18)."

Key Characteristics of Overdose Prevention Materials

Nearly unanimous factors arising from the testing of the infographics (See Figures 1, 2 and 3) and the "Get Naloxone" page (See Figure 4) were the usefulness of listing instructions through bullets (i.e. action items) and images to guide the reading process.

> "So the information that's on these infographics we talked about I think is, is pretty to the point and concise (white male, age 37, R03)."

> "I think keeping it short and sweet. To the point. Is the best way to do it. Especially in a situation like that [overdose] and people panic. They just, they need simple directions and I think that's the best. That's the best way to do it and I think that's how you guys did it (white female, age 30, R18)."

> "I think that um, if you were to like add a lot of like I don't know like paragraphs and become wordy, I think people will become like, start to like get bored and they won't really read it thoroughly. So like to have the main points, I think is what really matters (mixed race female, age 29, R10)"

> "Each category is bulleted and then explained. So the thing you want to look for, it's right there. You find your bullet point and then you can read it. It's very easy. It's very clearly laid out (white female, age 32, R14)."

Participants stated the lack of medical jargon made the writing style accessible. Participants described how this material would be useful for those who either may not be confident readers or not as well versed in overdose and drug use language.

> "It's not too much. It's just, just enough. Then, for me, I suck at reading. But, that's good in one sentence. That's all you need. I like that (white male, age 37, R09)."

> "It was pretty like straightforward and it's like straight to the point. I mean like, for me, like it's very simple for me, but like maybe somebody that has some trouble reading or understanding things, I think this is pretty good for them (mixed race female, age 29, R10)."

> "I think it's very informative, easy to read, um, not like medical terminology. Some don't have that. Um, so I think it's very. It's written well for the average person I would say (white female, age 38, R11)."

When asked to navigate the "Get Naloxone" webpage (See Figure 3), ease of use was a significant factor for participants ability to find and interpret information. Participants viewed the Rhode Island map displaying locations of where to purchase naloxone as an engaging and useful technique to streamline the process of finding a location that provided naloxone.

> "It is helpful. It would even be helpful to someone like me if I didn't have any naloxone on me. This would be very simple for me to go and just check even if I'm not feeling like committing to some big investigation. I could just click on this page instead of googling everything (white female, age 27, R16)"

> "This is good, giving people information on what, who carries it and how easy it is to get (white male, age 34, R19)"

Using action steps to mitigate overdose risk

After being asked, "By viewing this website and infographics, do you think you could take action during an overdose?", all the participants stated that the two overdose infographics (See Figure 1 and 2) would help them effectively respond to an overdose.

> "Oh, definitely. Absolutely. I'm ready. I'd go right by that [the infographics]... I'm definitely prepared (white male, age 51, R12)."

> "Just the way it was written down and broken down, you know it tells you the signs and then like let's say turning blue, at least you know the reason and then what to do next. It's all in the steps (white female, age 38, R11)."

When asked "After viewing this website and infographics, what would you be willing to share or do afterwards?", participants stated sharing PORI's plain language health resources as an important action step that could assist others in overdose preparedness.

> "I'm gonna go see a friend of mine when I leave. I'm gonna show her. I'm gonna go and show her the website and try to spread the word. You know. That's all I can do (white male, age 51, R12)."

> "I want to show my friends some of this. I definitely do and I want them to really take into consideration what's going on here. You know, 'cuz they need to. (white male, age 36, R15)."

> "I might go home and say to my son, guess what I didn't know, but you know when someone overdoses, you do this and that because he has a couple of friends that use and that um that could happen too and he could be there. So I'll talk to him and he's going to ask me everything and he'll learn something today too (white female, age 42, R02)."

DISCUSSION

This qualitative study evaluating overdose health promotion and risk reduction infographics, resources, and other web-based content provides several key insights on communicating overdose prevention information, especially in the context of an ongoing overdose epidemic. These findings emphasize the importance of overdose prevention information that engages the audience through the use of action-focused items, minimal medical and scientific jargon, and appealing communication by utilizing images and interactive resources (e.g., maps).

PORI and its overdose prevention materials were created with the goal of providing brief, yet informative action-focused steps to enhance one's capacity for overdose response. The action-oriented steps were seen as potentially effective for those in an acute overdose situation, especially given the high-stress and emergency nature of the situation.[17] Further, most participants felt motivated to disseminate the overdose prevention material in their networks, believing information sharing to be an important, yet low-stake role they could take part in to confront Rhode Island's overdose crisis. Research has shown that the way in which information is communicated can influence the effectiveness of public health material's actual impact on behavior change.[18] Providing an intended audience with new skills or resources, like that of action-oriented steps as shown in our study, may have a greater impact on behavior change, rather than other traditional public health communication techniques, such as public service announcements.[19]

The opioid epidemic and the resultant rise of accidental overdoses is continuing to gain national attention.[20] To respond to this crisis, our research suggests that the

dissemination of useful, accessible health information on accidental overdose is imperative. Effective communication is seen as one of the six key components for public health programs to achieve their intended impact.[18] However, The Department of Health and Human Services does not include evidence-based health campaigns, grounded in effective communication concepts, as an important preventative measure in its 5-point Opioid Strategy.[21] Given our findings, and building on the research of other studies, implementing plain language and action-focused health communication material could be an effective strategy for educating and preparing those particularly vulnerable for experiencing or witnessing an accidental overdose.[19,22]

Additional tools that can assist organizations, both at the state and community level, in creating overdose prevention materials that are guided by plain language techniques include the CDC's Clear Communication Index,[15] Suitability Assessment of Materials,[23] and CDC's Everyday Words for Public Health Communication.[14] These resources are free, easy to access on the internet, and provide effective and evidence-based testing options to assess communication materials.[24] Current overdose-related health campaigns predominantly utilize public service announcements as their main tactics; strategies that have been found to be questionably effective in past research.[25–29] These testing tools could assist communities in either creating or modifying overdose prevention health campaigns that are action-based, positive, and relatable to the target population.

Our study makes evident that PWUD value overdose prevention materials disseminated from varying sources—including social networking through street campaigning, social media, and television ads as the most effective outreach sources. Past

studies have found that peer-delivery mechanisms for overdose prevention information as among the most practical and effective for reaching high-risk PWUD who may not be actively seeking services.[28,29] To improve the reach of overdose prevention material, this study suggests that efforts to increase the material's level of exposure should include multiple venues and points of intervention.[30]

This study has several limitations. First, the study is specific to PORI, its materials, and the overdose crisis. Therefore, the study may not be generalizable to other public health issues. The sample is predominantly of white race, consisted of only people who use drugs, and those who ever experienced or witnessed an overdose. This may influence our generalizability and findings regarding the interpretation of overdose prevention materials. Additional research is recommended involving populations at risk for but who have less direct experience with overdose.

PUBLIC HEALTH IMPLICATIONS

In summary, health communication techniques, including plain language writing and action-oriented statements, can become vital aspects of overdose intervention and prevention activities. This study is among the first to qualitatively examine online overdose prevention materials in the United States and provides critical public health implications on how to best communicate overdose prevention strategies to PWUD. The implementation, dissemination, and evaluation of new approaches for overdose prevention campaigns that are practical and information-based could assist in lessening the effects of the United States' opioid overdose crisis at the state and local level.

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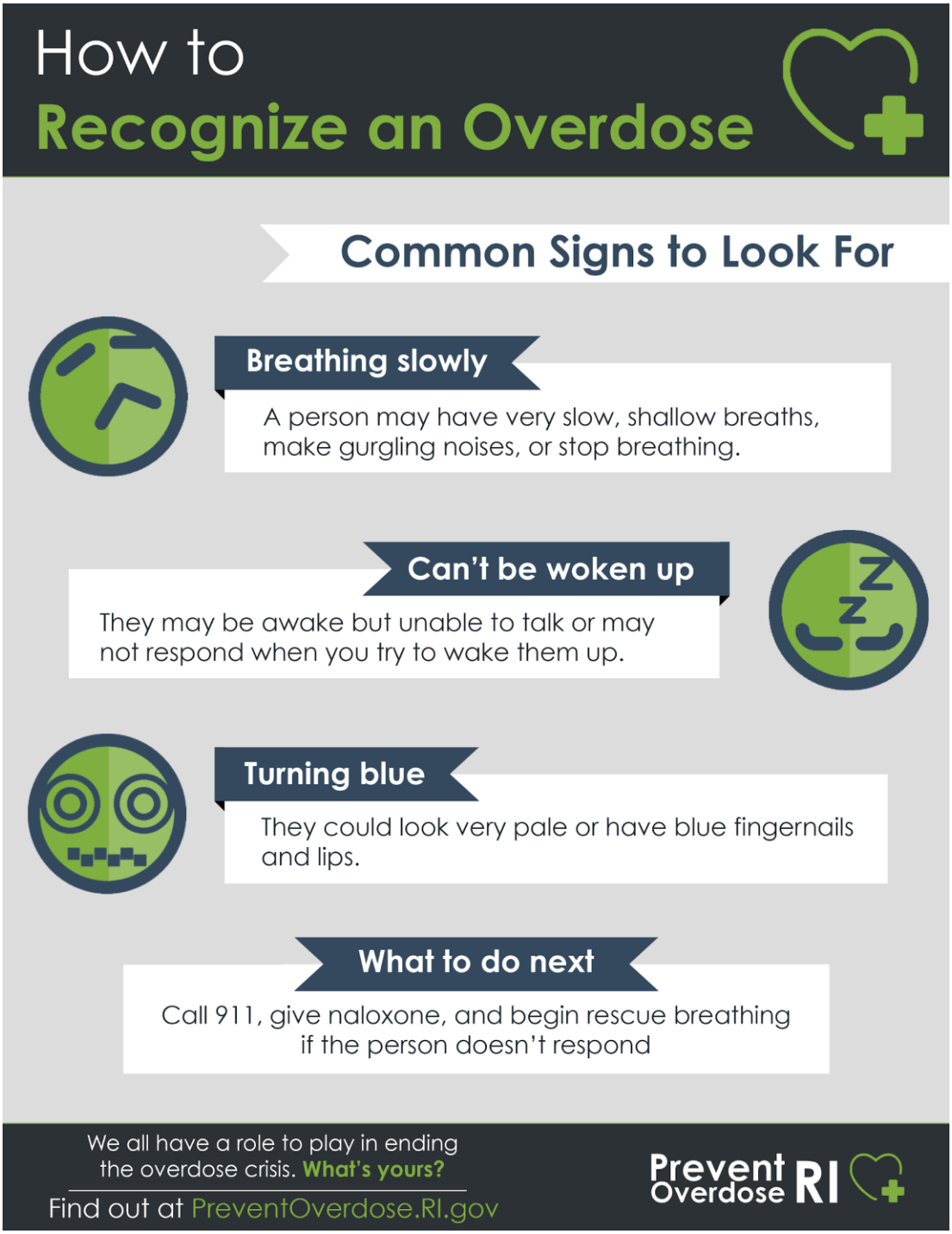
Figure 1: Infographic Summarizing How to Recognize an Overdose[1]



[1] **All infographics can be found at www.PreventOverdoseRI.org**

Figure 2: Infographic Summarizing How to Respond to an Overdose

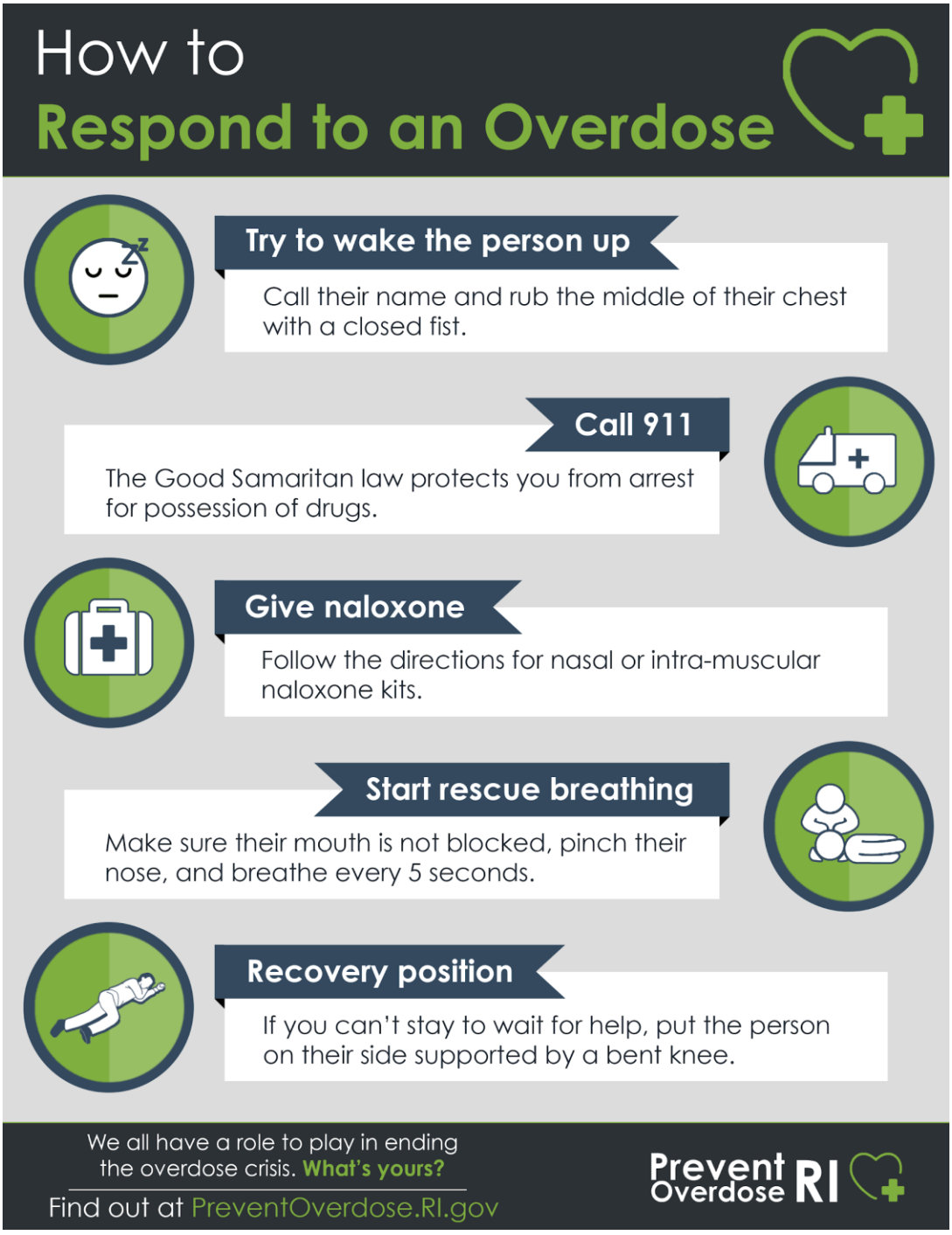


Figure 3: Fentanyl Awareness Infographic

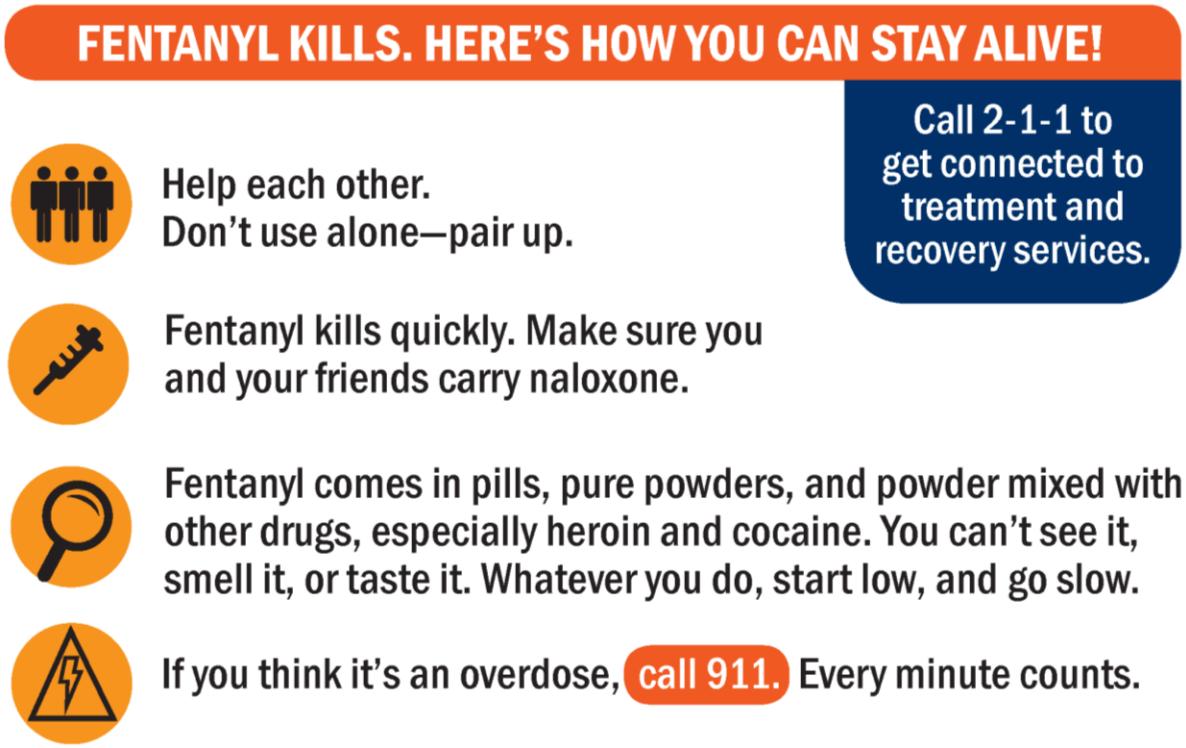


Figure 4: PORI "Get Naloxone" Web Page Excerpt