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Abstract

Stressful life events and daily hassles affect people living with HIV (PLWH). However, capturing stress-related events and cognitive impairment is often plagued with recall biases. Incorporating reliable information technology, such as mobile phones, can be a resourceful method for measuring health behaviors (MHB). We report findings from an MHB pilot study with 32 African American, Latino/Hispanic, and White PLWH from Los Angeles. Participants reported perceived stressors in their daily routines using a smartphone Ecological Momentary Assessment (EMA) application. Participants self-initiated in-the-moment stressful events reports for up to 6 weeks. Stressful event EMAs queried perceived stress levels (1–10 scale) and open-ended text

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descriptions. Qualitative analysis of participant text responses was completed using grounded thematic coding. Participants reported multiple stressors in their daily routines, impacting activities of daily living or daily functioning. Eliciting input from PLWH via EMA in real-time is a novel approach for assessing and identifying sources of stress.

Keywords

activities of daily living/instrumental activities of daily living; daily functioning; HIV; life events; mobile phone; stress

Mobile Phone Ecological Momentary Assessment of Daily Stressors among People Living With HIV: Elucidating Factors Underlying Health-Related Challenges in Daily Routines Antiretroviral therapy (ART) continues to reduce the morality rate for people living with HIV (PLWH). Yet, even with ART, persistent experiences of acute and chronic stressors still remain a factor that, combined with other co-morbid conditions such as mental illness, cognitive impairment, substance abuse, other chronic conditions, and opportunistic infections, hamper the ability of PLWH to cope with daily living problems, impacting their well-being and quality of life (QoL; Bloch et al., 2016; Heaton et al., 2010; Moskowitz, Hult, Bussolari, & Acree, 2009). For example, up to 50% of PLWH have some neurocognitive impairment (Byun, Gay, & Lee, 2016; Heaton et al., 2010). Stress and stressful life events also account for some variation in HIV disease progression (Leserman, 2008), with adverse health outcomes. The ability or inability to function on a daily basis is a vital patient-reported outcome measure in advanced stages of HIV infection and neurocognitive decline (Antinori et al., 2007; Bloch et al., 2016; Heaton et al., 2004; Thames et al., 2011). Routine clinical management of PLWH requires a dependable and user-friendly screening assessment of neurocognitive function and impacts on daily routines, via potential deficits in attention/working memory, manual dexterity, learning and memory, learning efficiency, awareness, attention processing, executive function, and information processing (Heaton et al., 2004).

HIV-associated neurocognitive disorders (HAND) are significant neurological complications associated with HIV (Bloch et al., 2016; Cysique, Bain, Lane, & Brew, 2012). There are three criteria for HAND: (a) asymptomatic neurocognitive impairment (ANI), (b) symptomatic mild neurocognitive disorder (MND), and (c) HIV-associated dementia (HAD; Antinori et al., 2007). Non-demented forms of HAND predominate in the combination antiretroviral therapy (cART) era (Bloch et al., 2016; Cysique et al., 2012). The impairments of such conditions (i.e., motor skills or psychomotor functioning, speed of information processing, learning, recall, attention/working memory, verbal fluency, and executive functions) related to neurocognitive function (Heaton et al., 2004) can pose difficulties in the Instrumental Activities of Daily Living (IADLs). The inability to accomplish IADLs, which pertain to medication adherence, attending and making appointments, driving, child care, using the telephone, working, cooking, cleaning, shopping, buying groceries, and finances (Heaton et al., 2004; Marcotte et al., 1999), signals neurocognitive decline associated with difficulty in functioning, inefficiency in work or homemaking (i.e., MND), apathy, clumsiness or unsteadiness, loss of motivation, fatigue, and social withdrawal (i.e., HAD).

For PLWH, experiencing undue stress can impact cognitive function and exacerbate the effects of HIV (Leiphart, 1998; Valdez, Rubin, & Neigh, 2016). The preponderance of cognitive problems (Byun et al., 2016), coupled with biologic inflammatory mechanisms associated with an aging HIV population (Byun et al., 2016; Valdez et al., 2016) and stress (Valdez et al., 2016) highlight the need for additional resources to address and assess these issues. The capacity to provide a method to assess stressors and any underlying cognitive impairments could be a vital tool to help providers monitor the well-being of PLWH and help PLWH manage stress and its accompanying disorders. A reliable and adequate, easy-to-use screening tool could also help PLWH with self-management and facilitate improved delivery of care and support services.

Mobile phone technology is an ubiquitous resource, readily used in health research and intervention, for example, to measure depression, anxiety, and stress (Proudfoot et al., 2013), and symptoms of schizophrenia (Palmier-Claus et al., 2013) and bipolar disorder (Grünerbl et al., 2015). However, there is a gap in research on the use of mobile phones to assess levels of perceived stress and its impact on handling day-to-day activities for PLWH. Everyday functioning or performance of Activities of Daily Living (ADLs) and IADLs are important indicators for monitoring neurocognitive function in PLWH. HIV research has neglected the study of stressors and their effect on everyday function and QoL in PLWH. Eliciting input from PLWH about their perceived experiences of stress can facilitate the management and treatment of stress to improve care and treatment and the management of co-morbidities associated with neurocognitive decline.

Chronic stress, which is difficult to assess, is a huge health concern. Gauging a person's competency in everyday functioning is an important aspect of advancing stages of chronic illness and psychological health issues (i.e., stress, mental health, cognitive decline). Yet it is still a challenge to assess and identify stressors and their immediate sources, which can delay a person's treatment or social support services. The inability to cope with chronic illness can disrupt a person's life, influence the ability to function at work or in the home, cause financial problems (Cleveland Clinic, 2016), and reduce QoL.

In PLWH, psychosocial factors such as stress and stressful events may have a harmful impact on health and QoL (Mugavero et al., 2009). In a study of women living with HIV infection, women with the greatest neurocognitive impairment and emotional distress reported the poorest health-related QoL (Osowiecki et al., 2000). Research has shown high levels of perceived stress associated with poorer medication adherence by PLWH (Leserman, Ironson, O'Cleirigh, Fordiani, & Balbin, 2008; Mugavero et al., 2009). Furthermore, psychological stress can suppress immune function and thereby accelerate disease progression in PLWH (Leiphart, 1998). Studies on chronic cognitive complaints of IADLs in PLWH have also been determined to be on the rise (Cysique et al., 2012) as PLWH age. Simioni and colleagues (2010) revealed that 27% of PLWH in a cognitive screening questionnaire had cognitive complaints. While it is understood that stress is an accompanying feature of HIV, measuring the behavior and stressors involved in everyday life could be imperative to understanding the stress-related problems and cognitive complaints PLWH experience.

Self-reported assessments are commonplace in health-related research and practice, especially when monitoring IADLs (Thames et al., 2011), stress, and stress-related activities. Currently, researchers rely on retrospective self-reports to assess stress and the ability to accomplish daily living tasks or IADLs. Mobile phone self-monitoring is a method that can enhance self-reports, enabling real-time or in-the-moment data collection such as Ecological Momentary Assessment (EMA; Shiffman, Stone, & Hufford, 2008; Stone & Shiffman, 1994) or the Experience Sampling Method (ESM; Csikszentmihalyi & Larson, 1987; Shiffman & Stone, 1998). This approach has provided less biased and more ecologically valid data compared to retrospective and global self-reports and has been made more practicable and scalable through the widespread use of mobile phones in daily life.

The primary aims of the main study, from which our study was derived, were to develop and test the (a) feasibility of using global positioning system (GPS) smartphones to provide a more reliable and valid method for self-monitoring; and (b) potential of GPS smartphones as a tool for self-management of physical and mental health symptoms, adherence, substance use, sexual behaviors, and self-reporting in real time stress and stressful events multiple times per day for up to 6 weeks. The theory and evidence underlying the self-monitoring for selfmanagement hypothesis was based on psychological research findings that self-monitoring and reactivity to self-monitoring supported self-regulation and behavior change (Bandura, 1991; Carver, 1979; Kanfer, 1970; Kazdin, 1974). Social Cognitive Theory, Theory of Reasoned Action, Theory of Planned Behavior, and the Health Belief Model are the foundation of many extensively used interventions with mobile phone applications and text-messaging technology (Reback, Fletcher, Shoptaw, & Mansergh, 2015; Swendeman, Comulada, Ramanathan, Lazar, & Estrin, 2015; Swendeman, Ramanathan, et al., 2015).

We report here on Phase II of the measuring health behaviors (MHB) main study on (a) stress and stressful events to primarily examine the stress-related, open-ended, and brief text-based responses; (b) trends in assessed behaviors and the sources of stress; and (c) use of EMA. EMA methods could facilitate self-monitoring of health-related behaviors and sharing data, for research and clinical purposes as well as to support behavior change in PLWH. Because retrospective methods of self-reporting are subject to recall error and bias, and paper-based methods are easily delayed or ignored, especially regarding stress-related events, our qualitative sub-study gathered data on stressors experienced by PLWH using EMA.

The first step to addressing the challenge of managing stress or cognitive complaints is to use a tool that can accurately assess and identify the sources of stress in a meaningful manner in real time and easy for patients to use. We report on informative text responses in an effort to elucidate the stressors, frequency of stressors and stressful life events, and behaviors experienced by PLWH. We also provide insights into the potentialities of using smartphone EMA with open-ended response options to assess and identify sources of stress and daily functioning for PLWH.

Methods

Recruitment and Eligibility

Our mixed method study was approved by the Institutional Review Board of the University of California, Los Angeles. All participants provided written informed consent prior to participation.

PLWH were recruited by posting flyers at AIDS Project Los Angeles and Los Angeles Gay and Lesbian Center to pilot test a mobile phone application for reporting daily experiences related to living with HIV for up to 6 weeks. A target sample of 50 eligible participants were recruited, of which 34 were randomly assigned to receive smartphones with the self-monitoring application (to compare bi-weekly to Web surveys alone) and 32 self-initiated text-based reports of stressful events during the study period. Inclusion criteria were: ages 18 or older, diagnosed with HIV infection, a client of AIDS Project Los Angeles or Los Angeles Gay and Lesbian Center, currently (in the previous week) sexually active, currently using alcohol or drugs, taking ART daily, and reporting stable housing and sources of income. In addition, participants had to have regular Internet access, own a cell phone (to suggest familiarity with using a cell phone, confirmed during informed consent), and be able to read English (determined during informed consent). These criteria were determined in collaboration with the partner site agencies to reflect the type of clients deemed to be likely candidates for needing and using smartphone selfmonitoring tools for self-management and to minimize risks and incentives for more marginalized clients to sell study cell phones (about $50 USD street value).

To manage potential high-risk human subjects (i.e., suicidal ideation, active drug use) in the research for all phases of the study, a Certificate of Confidentiality was obtained from the U.S. Department of Health and Human Services to protect sensitive data from subpoena. Data were stored on the mobile phones in an encrypted format, using password protections, until cell-reception or Wi-Fi connection enabled data to be transferred from the phone to a secure server managed by computer science partners at the University of California, Los Angeles. Data were monitored on a Web-based data visualization portal on a daily basis by the research team for indicators of extreme distress, homicidal or suicidal ideations, or elder or child abuse that might be reported on the text-based stressful event question (only one report of suicidal thought was reported and was assessed by the study team using the study's emergency and suicide assessment procedures).

Procedures

Participants ($n = 32$) were assigned an Android smartphone with the Ohmage smartphone application installed (www.ohmage.org); Ohmage is an open-source participatory sensing technology platform for mobile phone-based data capture. Smartphones were provided to participants to eliminate any concerns about the use of personal phones (i.e., prevent loss of personal data), and to ensure that the Ohmage application functioned properly. Participants were trained by research assistants to use the smartphone application, which included phone use security lock and customizing time-based alarms for surveys at schedules convenient to the participants' daily routines, during the first in-person appointment (Swendeman,

Comulada, et al., 2015; Swendeman, Ramanathan, et al., 2015). Participants were instructed to carry the smartphone at all times (i.e., during their daily routines), to respond to prompts, and to self-initiate stressful event reports or a text diary entry at any time (Swendeman, Ramanathan, et al., 2015). Participants were prompted by application alarms on the smartphone to complete once daily surveys on medication adherence, sexual activity, and alcohol, tobacco, and other drug (ATOD) use. Prompt alarms were scheduled at the times each participant programmed her/his application alarm to trigger (i.e., time-based reporting) as well as at any time when relevant experiences occurred (event-based reporting; Swendeman, Ramanathan, et al., 2015). Participants were prompted 4 times per day to complete surveys on four emotional (mental health-related QoL) and physical states: sadness/depression, anxiety/nervousness, fatigue, and energy.

In addition to prompted self-reports, participants had the option to self-initiate stressful event reports (i.e., stressors) at any time; these data are the focus of this paper. The stressful event surveys queried perceived stress levels associated with the event (*How stressful was this event?*) on a Likert-type scale with anchors ranging from 1 to10 (1 = *low stress*, 10 = *high stress*) followed by an open-ended text entry to describe the event (*What happened?*).

Participants were incentivized up to $70 USD for completing phone surveys with a target goal of 7 surveys per day on average (up to 294 surveys in 6 weeks). A majority of the participants in all phases of the MHB study chose to complete the phone survey related to stressful events to meet their daily quota of 7 surveys per day (Swendeman, Comulada, et al., 2015; Swendeman, Ramanathan, et al., 2015).

Safeguards were put in place to address the security of the participant-provided data and for the management and storage of data for all phases of the study. Data were temporarily stored on the phone and uploaded every hour when a cellular network connection was available using encrypted protocols via HTTPS connection. Data temporarily stored on the phone were not accessible via the application or in any other way on the phone. Furthermore, the application was password protected and participants were instructed during training about how to set password protection for the entire phone.

Participant survey responses and self-initiated stressful event text logs were automatically timestamped and linked to the participant's assigned study identifier (the login id required to use the Center for Embedded Networked Sensing [CENS]-developed Ohmage mobile phone application). These data were automatically uploaded through an encrypted data channel using HTTPS protocol to a secure password protected CENS server. When participant study phones were returned, they were factored reset and the phone's memory card was reformatted to remove any personal data that users may have had stored on the phone.

The secure password-protected CENS server, where participant survey responses and self-initiated stressful event text logs were stored via a Linux Operating System that had a single-user account in its operating system, could only be assessed by the system administrator, principal investigator, and responsible researchers. Additionally, the My Structured Query Language (MySQL) database where data were stored had its own separate password, which was different from the computer password for additional protection; only the study

researchers had access to this database. The data server was updated weekly for the latest Operating System and MySQL security patches by the system administration and was closely monitored during the study.

Smartphone, Stress, and Stressful Event Reports

Smartphone surveys were arranged into four categories and organized in the smartphone application as follows: ATOD use, sexual behaviors, medication adherence, and physical/ mental health-related QoL. The medication adherence phone survey included 8 items (prompted once daily) using the AIDS Clinical Trial Group adherence questionnaire (Swendeman, Ramanathan, et al., 2015). ATOD phone surveys included 12 items (including skip options; prompted once daily) using measures from prior studies with PLWH (Comulada, Weiss, Cumberland, & Rotheram-Borus, 2007; Swendeman, Ramanathan, et al., 2015). The phone survey of sexual behaviors included 17 items (including skip options; prompted once daily) using a slightly modified version of the National Institutes of Mental Health Multisite Prevention Trial Protocol and is described in detail in prior publications (Swendeman, Ramanathan, et al., 2015). The mental health and physical health phone survey (prompted 4 times a day) used the brief health-related CDC-HRQOL measure (Swendeman, Ramanathan, et al., 2015), which was adapted to cover the past several hours, and rated on a 0–3 scale as follows: *Not at all, A little, Somewhat*, or *Extremely* and also described in detail in prior publications (Swendeman, Ramanathan, et al., 2015).

The phone surveys also included a separate stressful event survey. The stressful event survey (participant initiated) included a question about level of the stress (on a 1–10 scale) with the option to provide a text annotation (Swendeman, Ramanathan, et al., 2015b). The prompt for the text annotation was *Stress Experienced.* Overall, participants in all phases of the MHB study opted to complete stressful event surveys to meet their daily survey quotas in lieu of daily ATOD or sexual behavior surveys (completed every other day on average; Swendeman, Comulada, et al., 2015; Swendeman, Ramanathan, et al., 2015).

User-Experience Qualitative Interviews

Data collected about the usefulness or perceptions of participants regarding the use of EMA were conducted by telephone at weeks 2 and 4, and in-person at 6 weeks after baseline. A brief, semi-structured, open-ended qualitative interview was used to gather user-experience feedback on the Web and mobile phone tools. Further details of these findings are available in an article examining the user experience of EMA (Swendeman, Ramanathan, et al., 2015). In addition, two articles from the main study specifically examined the perceived benefits of selfmonitoring to support self-management via smartphone, and the validity and reliability of daily versus biweekly recall reports. These articles also provide more details on smartphone survey content (Swendeman, Comulada, et al., 2015; Swendeman, Ramanathan, et al., 2015).

Data Analyses

Stressful event reports with text annotations were coded and analyzed using grounded thematic coding methods in Dedoose, a Web-based mixed-method data analysis program. A

trained research associate coded data under the guidance of an anthropologist leading the qualitative data analysis. Upon completion of coding, the principal investigator, lead anthropologist, and research associate reviewed and revised the coding based on consensus agreement. Frequency tables and basic descriptive statistical analyses were generated from data coded in Dedoose.

Results

Participants

Participant ages averaged in the mid-forties (range = 23 – 64) with a median age of 46 years. Participants were African American (47%), White (28%), Latino (19%), Native American (3%), and mixed ethnicity (3%). Most were male (75%), and gay (75%) or bisexual (21%). About half reported graduating from high school (38%) or receiving a college degree (9%); half (53%) were currently unemployed (Table 1).

Stressful Event Reports

During the 6-week period (42 days), participants reported a total of 849 stressful events with an average of 26.5 per participant (range = 1 – 142). Two participants did not provide text responses and four had only one or two text responses. There were 611 reports from 30 participants with text descriptions (average = 20; range = 1 – 140). Thematic analysis revealed four primary themes with 11 subthemes: health (medication adherence, retention in care); comorbidities (general health, mental health, substance use, memory difficulties); social relationships (romantic partners, friends, family); and economic insecurities (financial difficulties, housing). Tables 2 and 3 show quotes supporting the summaries.

Almost 60% of study participants expressed some distress about their health. About 40% reported partner-related stressful events such as arguments, break ups, and physical or mental abuse. Although only 28% of participants reported finance as a stressor, those who did reported financial difficulties as the most stressful events in their lives. In comparison to the other subthemes, finance received the most reports with the highest level of stress ratings from the participants (Table 4).

The length of texts received from participants in the entire study ranged from a minimum of one word (i.e., rent, Xanax, meds) to 105 words with a maximum possible length of 529 characters. Text responses ranged from 9 to 37 words. Stressful events reports were more common in the afternoon, with participants reporting more stressful events between 2 and 5 p.m. The second most reported time frame was in the morning from 8 to 9 a.m.

There was also a wide range of the frequency of texts, as follows: (a) texts every other day within a 2-day time frame, (b) texts every other day within a 3-day time frame, (c) texts every other day in a 1-week period, and (d) texting 5 days in a row. On the extreme, for example, some participants texted 4 times in the same day within an hour on the same stressors or events, texted 6 times on the same day regarding different stressors or events, or texted 8 times in 1 day on the same stressor or event.

Table 4 shows frequencies that stressors were reported and numbers of participants reporting for each of the primary and secondary themes identified in analysis. The most commonly reported themes of stressful events reported by overall frequency and by number of participants were everyday events ($n = 145$, $N = 22$), health ($n = 68$, $N = 19$), partner-related events ($n = 71$, $N = 13$), and finance ($n = 65$, $N = 9$). To illustrate the themes and subcategories, verbatim text responses from the participants' smartphone reports are presented in Tables 2 and 3.

Health, Adherence, and Co-morbidities

Text responses referring to health adherence and co-morbidities as stressors or stressful events are shown in Table 2. Participants expressed a wide range of views about stressors related to health care adherence for both medications and retention in care (i.e., appointment adherence). Many participants reported stressful events related to medication adherence, either as acute and highly stressful situations or as ongoing worries. Participants also noted difficulties in keeping clinic appointments and managing medical information as stressful events with regard to retention in care.

Dealing with co-morbidities was also a problem (Table 2). Participants reported stressful events related to co-morbidities, which included four subthemes: general health, mental health, substance use, and memory difficulties. The most frequent reports of stressful events related to co-morbidities dealt with mental health, particularly depression. Handling memory difficulties was also widely noted. Participants reported a wide range of stressful experiences about daily hassles, which were linked to memory deficits, as well as symptoms or side effects of living with HIV. Participants also reported stressful events related to substance use such as drug and alcohol use, cravings, triggers, withdrawals, and linked risky behaviors.

Social Relationships and Economic Insecurities/Finances

Text responses referring to social relationships and economic insecurities as stressors or stressful events are shown in Table 3. Participants expressed concern in romantic partnerships. Participants reported stressful events with their partners, such as conflicts, breakups, or abuse that intersected with health concerns, housing insecurity, and depression. Some participants reported stressful events related to their friendships and texted that maintaining those relationships involved the intersecting challenges of stigma, physical/ mental abuse, and/or general autonomy. Texts related to family were also initiated by the participants. Many stressful event reports involved family relationships, which tended to be more common for Black/African American, Hispanic/Latino, and Native American participants in our sample. Some reports involved significant life events, such as the death of a family member, while other reports involved relationship difficulties.

Economic insecurities/finances were a huge stressor, which caused a tremendous amount of strain. Twenty-eight percent of participants reported financial stressors generally and specifically related to not receiving disability or other services, or missing payments for much needed services. Housing was also an issue. Participants reported having problems with housing, and that making rent or having a place to stay was a primary concern.

Smartphone Study Participation

In light of our findings, texts related to study participation were identified from a handful of participants as beneficial or facilitated self-management using the cell phone. One participant stated the benefits of the study as, "Went […] got blessed and allowed to participate in this wonderful program – Stress Level 1." Another participant highlighted the importance of selfmanagement,

> I haven't done these surveys for 2 days now. Is Christmas & seems like the last couple days went by so fast that it just slipped thru the cracks. I didn't forget… I place a much higher priority & need for consistency on taking my meds than on doing this survey – Stress Level 7.

For at least some of the participants using a smartphone created self-awareness of health behaviors, daily routines, and environmental triggers for risk or resilience. While two participants expressed concern over missing a survey or not being able to input their meds on the cell phone, the smartphone application still functioned as a reminder. The use of a mobile phone provided an avenue for participants to effectively self-monitor and served as a reliable self-reporting mechanism about their functioning ability in daily routines. Further details that examined the user experience of EMA can be found in another article (Swendeman, Ramanathan, et al., 2015).

Discussion

In this study, we addressed stress, frequency of stressors, stressful life events, and behaviors experienced by PLWH. In addition, we generated an awareness of smartphone EMA and text messaging as a capable resource to gauge stressors for PLWH. Our findings confirm that PLWH experience daily stressors, high to moderate levels of stress, and issues with ADLs/IADLs. Furthermore, the real-time data provided insights into the participant's emotional state, habits, and mental health. Understanding stressful life events is vital to the well-being and QoL of PLWH. Using an innovative self-monitoring method such as a smartphone EMA is indispensable.

Stressors and Stress Levels

Health-related stressful events, including co-morbidities, were the most commonly reported events in our study. Mental health difficulties, predominantly depression, were the primary mental illness symptom reported, but worry and anxiety were commonly indicated throughout stressful event reports. Studies have repeatedly shown an increased prevalence of distress for PLWH, with depression and anxiety being two of the most prominent symptoms (Aouizerat, Gay, Lerdal, Portillo, & Lee, 2013; Valdez et al., 2016). Our findings were also consistent with other studies identifying frequent stressors in PLWH, including housing, partner-related, and financial stressors (Leserman et al., 2008; Mugavero et al., 2009), problems with family or friends (Thompson, Nanni, & Levine, 1996), and daily hassles (Lewis, Abramowitz, Koenig, Chandwani, & Orban, 2015). The findings in our study highlight the need to address the diverse array of needs of PLWH in our sample.

Stressors emanating from coping with HIV can also impact QoL. In their meta-analytical review on coping and stress in women with HIV infection, McIntosh and Rosselli (2012), found that overall perceived stress from daily hassles and/or chronic strains predicted lower reports of optimism and QoL. Although our study did not focus directly on coping, it was rather unclear which stressor or stressors experienced by the participants might have directed a selective coping strategy as a situational or adaptive process for dealing with HIV. Future studies could explore specific coping strategies used by PLWH who are in distress and engaging in alcohol and drug use, such as active coping (i.e., social support seeking, spirituality), or passive and avoidant coping strategies (i.e., disengagement or self-distraction; Moskowitz el al., 2009).

Stressors and ADLs/IADLs

Some of the results in our study suggest that participants may have experienced deterioration in neurocognitive abilities to perform ADLs/IADLs. According to Kotozaki and colleagues (2014), long-term exposure to stressful events can deplete an individual's ability to cope with ADLs. Stressful life events and coping with multiple stressors are common for PLWH (Mugavero et al., 2009) and have been associated with poorer cognitive outcomes (e.g., decreased executive function, attention, and processing speed in men with HIV [Pukay-Martin, Cristiani, Saveanu, & Bornstein 2003] and decreased verbal memory in women with HIV [Rubin et al., 2016]). It is plausible that the distinctive stressors experienced by our participants imply an onset of a debilitating disease. Detection of an emerging illness via smartphone selfmonitoring could help clinicians and patients address new problems early.

A confounding factor in the potential etiologies of neurocognitive impairment is related to PLWH living longer due to the success of ART. Worldwide, approximately 4.2 million PLWH were older than 50 years of age in 2013 (Mahy, Autenrieth, Stanecki, & Wynd, 2014). In the United States in 2013, an estimated 42% of Americans living with diagnosed HIV were ages 50 and older, 25% were ages 55 and older, and 6% were ages 65 and older (Centers for Disease Control and Prevention, 2015). As PLWH age, the normal process of aging may contribute to cognitive impairment (Byun et al., 2016; Cysique et al., 2012), along with the numerous stressors related to aging (Moskowitz et al., 2009).

Recent papers on the assessment of cognitive complaints and difficulties completing ADLs/IADLs by PLWH have noted a need for better assessments (Bloch et al., 2016; Cysique et al., 2012), even for HAND screening (Bloch et al., 2016). Acknowledging patient reports will be central to the success of patient health outcomes. Wilson and colleagues (2016) suggested a need for providers to recognize and target inquiries of HIV symptoms, notably clusters of HIV symptom patterns (such as fatigue, poor sleep, muscle aches/joint pain, memory loss, anxiety, etc.), to improve disease management. Cysique and colleagues (2012) recommended that, in clinical practice, both self-report and informant IADL assessments are needed.

Potential of Mobile Phone Technology

Mobile phone technology can serve as a reliable source of health data, providing in-the-moment self-reports of behaviors and experiences directly from PLWH. Studies have cited

the ease and benefits of mobile phone technology and health-related smartphone applications; users do not feel judged when reporting via cellphone use because it is similar, in their minds, to talking to a machine. The technology is easy to use, and patients can report anything without feeling stigmatized (Muessig et al., 2013; Swendeman, Ramanathan, et al., 2015).

To our knowledge, this is one of the few studies to use mobile phone EMA to elucidate in-the-moment stressful events, perceived stressors, and daily hassles for PLWH. A key finding was the different types of events found stressful by PLWH in prior studies with the use of EMA. Similar examples of stressors, activities, and daily hassles were identified through the use of EMA or ESM through paper diaries, electronic diaries, smart phones/mobile phones, and personal digital assistants in studies of bipolar disorders (Barrett & Barrett, 2001; Shiffman, 2000). Participants in these studies used EMA or ESM technology to self-report stress, mood, daily hassles, thoughts, and activities (Ebner-Priemer & Trull, 2009; Myin-Germeys et al., 2003). Studies examining the experiences of mild to moderate depression, anxiety, and/or stress have also demonstrated the use of a mobile phone application, MyCompass, as a mental health intervention (Proudfoot et al., 2013). Mobile phone technology is an emerging resource for the public health system and is worthy of consideration as a tool to measure and monitor stressful events and QoL issues.

Stress is a public health problem, and locating a suitable tool to detect and manage stress or changes in behavior could help researchers, clinicians, and patients by providing enriched patient data. The first step in detecting and understanding how PLWH live with HIV and aging, its accompanying stressors, and other health problems, is to have a user-friendly instrument that can assess and measure those experiences. Open text options can provide insight into individual thought processes, and how s/he feels, views the world, and handles stressful situations. The second step is to identify sources of stressors for PLWH. Mobile phone technology can aid in this quest. Mobile phone text messages can provide insight into the individual's daily life stressors. They can provide clues to a symptom or a reoccurring issue with the individual. Furthermore, text messages can serve as an alert, a sign that an issue is emerging or escalating. Providers can use these data to identify plausible sources of stress and developing symptoms, especially symptoms related to HAND or distress related to ADLs/IADLs. Mobile applications can house data and serve as viable patient records of symptoms and behaviors in an account of information derived from a user-friendly source.

Swendeman, Ramanathan, and colleagues (2015) argued that a key challenge with the use of mobile health (mHealth) will be to make self-monitoring applications that engage patients and to make data useful for providers, in order to maximize the benefits of data provided by patients. The use of mobile phone technology to assess and understand stress-related events in PLWH can certainly raise awareness for clinicians and researchers. Engaging in mobile health services will also allow users to access health services more readily and produce in-the-moment occurrences to support best practices from clinicians.

Study Limitations

There were several limitations in our study. The sample size was small and, although the sample was diverse, results may not be broadly generalizable. Most participants were unemployed, in their mid-40s, and largely of African American descent, which may have resulted in biases in the types of stressful events reported. Inclusion criteria allowing current alcohol and drug use possibly limited generalizability of our results, but our goal was to recruit participants coping with multiple co-morbidities to preliminarily assess utility of the application for self-management. We also did not collect coping data or explicit neurocognitive data, or evaluate ADLs/IADLs, especially for any duration, implying competencies in daily functioning. Longitudinal studies are needed to investigate factors indicating functional complaints that may indicate a failure in accomplishing ADLs by PLWH.

The incentives for meeting survey quotas may have biased response rates, although incentives were relatively modest at up to $70 USD total for the 6-week total (less than $2 USD per day). Also, participants could freely choose which survey types to complete to meet assessment requirements and so their selections likely reflected domains that were most salient or engaging for that participant. In other words, there was no greater or lesser incentive for choosing to complete a stress survey versus the HRQOL, medication adherence, or drug use surveys. In addition, stressful event EMAs were self-initiated and dependent on the motivation of participants to make reports. The method did not capture all stressful events experienced; however, self-initiated reports were likely to be more salient to participants compared to the alternative of responding to time-based or prompted EMA. Finally, EMA burden posed attrition problems during the last 2 weeks of the study protocol with only 40% of participants still providing EMA responses. Two to 4 weeks of intensive EMA was feasible and acceptable in our participants. Future studies should consider reducing the EMA question burden (i.e., the number of questions, domains, or prompts per day) to extend the duration of acceptable participation.

Conclusions

Stress is central to understanding the clinical challenges and health disparities of PLWH. Stress can affect one's health and well-being. Stress can also significantly impact cognitive performance and everyday function in PLWH (Pukay-Martin et al., 2003; Valdez et al., 2016). Our study found varying degrees of stress-related events and experiences impacting activities of daily living or daily function. PLWH constantly deal with stress and face multiple stressors on a regular basis (Mugavero et al., 2009; Thompson et al., 1996). Stressful experiences and life events can illuminate a host of negative health outcomes such as depression, anxiety, and cognitive impairment in this group. There is a need to discern and address the relevance of stress in HIV.

Given the broad proliferation of mobile phones, innovative self-monitoring methods such as EMA and daily diaries can be more easily implemented with real-time data transfer and monitoring compared to paper-pencil and self-recall based methods. Our findings suggest that mobile applications/EMA for PLWH in the context of mental health or neuropsychology

have the potential to be effective in monitoring the experiences of stress, anxiety, depression, substance use, moods, memory, and stressful events or stressors related to daily hassles and daily function. Monitoring daily function via self-report continues to be the gold standard for assessing and linking declines in ADLs/IADLs with neurocognitive impairment (Heaton et al., 2004; Thames et al., 2011). Mobile phone self-reports could be a feasible tool for measuring potential factors or symptoms relative to daily function in PLWH, and in diseases such as dementia, bipolar disorders, and other mental health issues.

The small but rich data set and results from our study indicate a need for more research on daily stressors, co-morbidities, daily function, retention in care, and adherence to ART. This could pinpoint a rise, decline, or breaking point of internal or external factors socially, environmentally, or cognitively, affecting PLWH. Providing insight into the complexities of stress and cognitive impairment, and assessing and detecting sources and symptoms with mobile applications could be a life-saving process for PLWH. Finally, future research should focus on development of valid and reliable mobile EMA measures of ADLs/IADLs function to inform interventions for PLWH and to improve patient care.

Acknowledgments

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Key Considerations

- People living with HIV (PLWH) continue to experience chronic stressors and cognitive impairment.

- Stressful life events can impact the quality of life for PLWH.

- Integrating mobile apps and text-messaging technology to measure health behaviors are critical strategies for health care providers.

- Smartphones are user-friendly, safe, and reliable.

- Mobile phone technology is a useful method for collecting patient data and monitoring the well-being of PLWH.

Table 1

Demographic Characteristics of PLWH Reporting on Stressful Events (n = 32)

Age, years (range 23–64)	Mean = 46
Gender	
Female	5 (15.6%)
Male	24 (75%)
Transgender	3 (9.4%)
Gender/Sexual Orientation	
Male	
Gay/Homosexual	18 (75%)
Bisexual	5 (21%)
Did not identify	1 (4%)
Female	
Heterosexual	5 (15.6%)
Transgender	
Gay/homosexual	1 (3.1%)
Bisexual	1 (3.1%)
Heterosexual	1 (3.1%)
Race/Ethnicity	
Black/African American	15 (47%)
White/European American	9 (28%)
Latino/Hispanic	6 (19%)
Native American Indian	1 (3%)
Mixed Ethnicity	1 (3%)
Education Level	
Did not finish high school	5 (15.6%)
Completed high school	12 (38%)
GED	2 (6.3%)
Some college	6 (19%)
Associate degree	2 (6.3%)
Completed college	3 (9%)
Did not identify	2 (6.3%)

Note. PLWH = people living with HIV; GED = general equivalency degree (high school).

Table 2

Smartphone Text-Message Self-Initiated Reports of Stressors and Stressful Events: Health and Co-morbidities

Primary Themes with Subtheme	Stress Levels Indicated
Health	
Medication Adherence	
Still can't find medicine.	Stress Level 10
Having HIV every day and knowing I have to keep on meds all the time to keep it at bay.	Stress Level 4
Retention in Care	
I finally made it to my doctor appointment, which I had been lost again. My mind is in complete turmoil.	Stress Level 10
I messed up 2 doctor appointments this morning.	Stress Level 6
I could not find doctor's follow-up papers.	Stress Level 5
Co-morbidities	
Memory Difficulties	
Went to church and left pot of water slow boiling on the stove; had to come home early to turn off.	Stress Level 10
I have lost my glasses and I can't see.	Stress Level 10
Getting late in the afternoon got halfway to that bus stop then realized I forgot my wallet. Started out a second time, I suddenly got bad stomach cramps. Went back not quite making it to the bathroom. Stressing about not getting downtown in time; cramps and diarrhea and a mess to clean up.	Stress Level 8
Mental Health	
Three days of not wanting to do anything but curl up in bed, depression.	Stress Level 8
Been having suicidal thoughts but they are getting better.	Stress Level 7
I feel depressed today and was trying to make myself better by cleaning living quarters, but feel I was doing more harm than good and it stressed me out.	Stress Level 5
General Health	
Was having trouble sleeping and checked my diabetes. My sugar is very high, 316, proceeded to take med and drink lots of water to bring sugar down. Feeling light headed and dizzy.	Stress Level 10
Bad toothache.	Stress Level 10
Went to doctor's this morning and was worried I was not healthy, but it just turns out I'm fine. But run the risk of cancer of the colon.	Stress Level 7
Substance Use	
My folks went out of town and out of the blue I decided to get high. I basically destroyed my veins for no specific reason.	Stress Level 10
Ran out of alcohol. Feel like tearing out my hair.	Stress Level 10
Smoke too much dope, led to unprotected sex. Need to get away from skid row.	Stress Level 9
Just stressed out about my past drug use on Friday.	Stress Level 5
I was having thoughts of using crack.	Stress Level 4

Table 3

Smartphone Text-Message Self-Initiated Reports of Stressors and Stressful Events: Social Relationships and Economic Securities/Finances

Primary Themes with Subtheme	Stress Levels Indicated
Social Relationships	
Romantic Partners	
I am being abused and emotionally hurt by … and need to leave. I have no place to go.	Stress Level 10
Broke up with my lover, stressed out, depressed.	Stress Level 10
An argument with my boyfriend about my other health problems. He says I talk too much about it.	Stress Level 8
Friendships	
I am trying and deal with friend. He is a pervert! Very annoying! Snake in the grass.	Stress Level 10
When my friends, who I now live with, control every aspect of my life, like even when can use the restroom.	Stress Level 9
Trying to keep everyone from finding out that I am gay. By lying saying I have two girlfriends.	Stress Level 4
Family	
Daughter, … posted some years old negative stuff about me on Facebook for all family members to read about how bad of a job I [have] done raising her and her upbringing and my poor choices.	Stress Level 10
I talked to my drunk sister. She was making shit up like I said I thought I was ugly because my hair was falling out.	Stress Level 10
My brother just got out of jail.	Stress Level 8
Family drama.	Stress Level 8
Death of a family member.	Stress Level 7
Economic Insecurities/Finances	
Financial Difficulties	
Denied further disability payments. Need to be dead to qualify.	Stress Level 10
They are threatening to turn off utilities.	Stress Level 10
Money is just one of my many problems.	Stress Level 10
Housing	
I don't want a repeat of eviction like we did from our last place.	Stress Level 10
I have to pass inspection for Section 8 on Thursday morning, causing me tension and stress, and anxious feelings.	Stress Level 10
I have a 3-day notice to move.	Stress Level 10
Being homeless this morning.	Stress Level 3

Table 4

Frequency of Stressors Reported

Themes (Stressors)	Frequency	Stress Level Indicated at 10 Frequency	Total # of Participants Reporting
Health	68	19	19
Everyday Events	145	30	22
Economic Security			
Finance	65	35	9
Housing	35	16	8
Social Relationships			
Partner	71	18	13
Family	23	10	9
Friends	30	5	7
Co-morbidities			
General Stress	39	7	14
Substance Abuse	25	7	9