**Title**

Symptom Assessment Solutions for In-Home Supportive Services and Diverse Older Adults: A Roadmap for Change

**Permalink**

https://escholarship.org/uc/item/292271k1

**Journal**

Journal of Palliative Medicine, 21(10)

**ISSN**

1096-6218

**Authors**

Odierna, Donna H
Katen, Mary T
Feuz, Mariko A
et al.

**Publication Date**

2018-10-01

**DOI**

10.1089/jpm.2017.0704

Peer reviewed

JOURNAL OF PALLIATIVE MEDICINE
Volume XX, Number XX, 2018
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2017.0704

Brief Report

# Symptom Assessment Solutions for In-Home Supportive Services and Diverse Older Adults: A Roadmap for Change

Donna H. Odierna, DrPH, MS,[1] Mary T. Katen, BA,[1,2] Mariko A. Feuz, BS,[1,2] Ryan D. McMahan, BS,[1]
Christine S. Ritchie, MD, MSPH, FACP, FAAHPM,[1,3] Shireen McSpadden, MNA,[4]
Mark Burns, BA,[5] Aiesha M. Volow, MPH,[1,2] and Rebecca L. Sudore, MD, FAAHPM[1–3]

## Abstract

***Background:*** Millions of older adults require Medicaid-funded home care, referred to as In-Home Supportive Services (IHSS). Many of these individuals experience serious illness, disability, and common symptoms such as pain and shortness of breath.
***Objective:*** To explore whether and how to integrate symptom assessment into an IHSS program to identify and manage symptoms in diverse older adults who receive in-home care.
***Design:*** Qualitative study comprising 10 semistructured focus groups.
***Setting and Subjects:*** Fifty San Francisco IHSS administrators, case managers, providers, and consumers.
***Measurements:*** Two authors double-coded transcripts and conducted thematic analysis.
***Results:*** Four main themes emerged from the data: (1) Large unmet needs: gaps in understanding, training, standard assessment, and untreated symptoms, including identifying loneliness as a symptom; (2) Potential barriers: misunderstanding of palliative care, consumer reluctance, and the added burden on IHSS workforce; (3) Facilitators: consumer and provider buy-in and perceived benefits of such a symptom assessment program, and the ability to build on current IHSS relationships and infrastructure; and (4) Implementation logistics: taking an individualized, optional approach; consider appropriate messaging about quality of life and not end of life; and creating standardized, easy-to-use procedures, tools, training, and workflow to support providers.
***Conclusions:*** An IHSS symptom assessment program is desired, needed, and feasible and can leverage the established IHSS infrastructure and relationships of consumers and IHSS providers to assess symptoms in the home. Acknowledging consumer choice, developing appropriate tools and trainings for IHSS staff, and effective messaging of program goals can contribute to success.

**Keywords:** diverse older adults; geriatrics; In-Home Supportive Services; palliative care end-of-life issues; symptom assessment

## Introduction

Millions of older adults nationwide require in-home care and experience serious illness, disability, and common symptoms such as pain.[1] Managing symptoms can be difficult for older adults who live alone or are dependent on others.[2] Additionally, as health disparities persist into old age, vulnerable older adults have higher rates of functional limitations and are at higher risk of poor quality of life.[3,4]

In-home personal care services (e.g., cleaning, bathing, etc.) are available through Medicaid's personal assistance benefit, known as In-Home Supportive Services (IHSS).

---

[1] Division of Geriatrics, School of Medicine, University of California, San Francisco, San Francisco, California.
[2] Geriatrics, Palliative, and Extended Care, San Francisco Veterans Affairs Medical Center, San Francisco, California.
[3] Tideswell at UCSF and the Innovation and Implementation Center on Aging and Palliative Care at the University of California, San Francisco, San Francisco, California.
[4] San Francisco Department of Aging and Adult Services, City and County of San Francisco, San Francisco, California.
[5] Homebridge Home Care Agency, San Francisco, California.
Accepted March 29, 2018.

IHSS have been shown to reduce healthcare utilization and improve quality of life.[5–8] Yet, little is known about whether or how an IHSS program could support home assessment of common symptoms. To our knowledge, no prior study has explored the use of IHSS programs to assess symptoms for vulnerable older adults. The goal of this study was to explore the feasibility of such a program with IHSS stakeholders.

## Methods

### Setting and participants

In California, IHSS providers may be a client's family or friend or identified through a registry,[9] and the Department of Aging and Adult Services (DAAS) coordinates IHSS.[10] A six-member IHSS advisory board suggested potential stakeholders for recruitment. Eligible IHSS stakeholders included administrators, case managers, IHSS providers, and consumers.

Through snowball sampling, we recruited a convenience sample of participants with an IHSS affiliation of ≥one year and self-reported proficiency in spoken English. Administrators, case managers, and IHSS providers were included if ≥18 years of age and consumers if ≥55. We excluded individuals who self-reported dementia or psychosis, or did not pass a phone screen for cognitive impairment.[11] This study was approved by the Institutional Review Board of the University of California, San Francisco. We obtained informed consent and offered $50 for participation.

### Procedures

We conducted 10 semistructured, 90-minute focus groups, with separate groups for administrators, case managers, IHSS providers, and consumers. We continued recruitment until thematic content saturation was achieved. Discussion guides were informed by the advisory board, palliative care and aging experts, and previous studies.[12–14] We asked about the potential role of an IHSS symptom assessment program, barriers and facilitators, and logistical factors that could impede or support the program's implementation (Table 1).

### Data analysis

All focus groups were audiorecorded, transcribed, and coded using ATLAS.ti 7. We used thematic analysis and synthesized codes into themes.[15,16] To ensure trustworthiness we used deductive and inductive coding, multiple coders, and maintained records of changes.[15,17] All transcripts were double coded, and the inter-rater agreement was 84%, considered good to excellent.[18–22] Disagreements were adjudicated by consensus.

## Results

Fifty people participated in 10 groups; 20 in 4 administrator groups, 9 in 2 case manager groups, 13 in 2 IHSS provider groups, and 8 in 2 consumer groups. Participant demographics are in Table 2. Analysis revealed four overarching themes: (1) unmet symptom needs, (2) perceived barriers, (3) facilitators, and (4) implementation logistics (Table 3).

### Unmet need

Participants described a need to address gaps in IHSS provider training: ''…My provider wouldn't know where to start.'' Participants also discussed high symptom burden among consumers; particularly, pain, depression, shortness of breath, and comorbidity: ''I have problems with my bowels, my hip and…with my feet. Terrible, terrible pain.'' Furthermore, all groups discussed loneliness as an important symptom that requires palliation: ''It wasn't mentioned with all the pain and suffering…you get very, very lonely.'' ''Being ill is a very lonely thing.''

### Barriers

Participants cautioned about potential misunderstanding and cultural perceptions about symptom assessment. An administrator said, ''Now you're telling me that I'm here to help somebody die.'' Participants also warned that consumers might object to overmedicalization of a program historically focused on activities of daily living and may fear sharing medical information with IHSS providers: ''My client was scared that [family] might put her in a home.'' There was also concern that a program may burden overworked IHSS-staff.

### Facilitators

Many consumers welcomed symptom assessment, knowing they would have help getting information back to their medical providers, especially as many are isolated and homebound. Training was also thought to increase IHSS providers' job satisfaction to ''help them feel like they're doing their job,'' and that a program could leverage existing procedures, ''We are already doing [assessment]'' and ''we're in a very unique position…because of established training programs.'' Leveraging existing consumer–provider relationships was also considered a strength: ''Their worker is like family to them,'' and because they are often the only ''eyes and ears'' in the home, they often ''just know'' when consumers' symptoms change.

### Implementation

There were several suggestions for implementation of a program, including: (1) acknowledging choice and ensuring it is optional for consumers and IHSS providers; (2) careful messaging ''to use terms that drive us toward quality of life'' and to address health literacy and cultural differences; (3) leveraging existing training programs; (4) developing efficient workflow and procedures; (5) using scripts, checklists, standard assessment tools–''To have a list of things each time to remind you to check off''; (6) and supporting IHSS staff with expanded skill sets, higher wages, and emotional support, ''because [the job] is not easy.''

## Discussion

To our knowledge, this is one of the first studies to explore the feasibility of an IHSS symptom assessment program. The majority of studies in the home setting have focused on the use of palliative care-trained clinicians to treat common symptoms.[23–25] This study provides a multistakeholder perspective about leveraging the IHSS infrastructure, with

TABLE 1. IN-HOME SUPPORTIVE SERVICES[a] SYMPTOM ASSESSMENT PROGRAM FOCUS GROUP OUTLINES

*All focus groups*

- Overview
    - Introductions, ground rules, consent.
    - Icebreaker: focus group participants describe their IHSS affiliation/role
    - Purpose: to explore possible IHSS Symptom Management Program
    - Define/discuss terms: ‘‘palliative care,’’ ‘‘symptoms,’’ ‘‘symptom management,’’ etc.

*Administrator focus groups*

- Opening discussion
    - Discussion of palliative care in the context of the IHSS Program
    - Common symptoms experienced by IHSS consumers
    - Current role of IHSS personnel in palliative care/symptom management
    - Willingness of staff and older consumers to participate
- Facilitators
    - Agency and workforce strengths
    - Existing mechanisms/infrastructure that could facilitate a program
    - Potential benefits of a program
- Barriers
    - Potential challenges to a program
    - Possible solutions
- Implementation logistics
    - Brainstorm about a program in the context of current IHSS infrastructure
    - How to maximize IHSS providers’ ability and willingness assist with symptom management
    - Workflow, work rules, payment mechanisms
    - Training and other agency’s needs

*Case management focus groups*

- Opening discussion
    - Common symptoms experienced by IHSS consumers
    - Current case management procedures/workflow for assessment and reporting of symptoms
    - Consumer and other attitudes toward palliative care
- Facilitators
    - Need for IHSS Symptom Assessment Program
    - Potential benefit to IHSS consumers/providers/agencies
    - Possibility of leveraging existing training/procedures
- Barriers
    - Potential challenges to a program
    - Possible solutions
- Implementation logistics
    - Brainstorm about an ideal IHSS Symptom Management Program in the context of current IHSS infrastructure
    - Training needs for case management staff and IHSS providers
    - Assessment tools and procedures
    - Time and workflow management

*IHSS provider focus groups*

- Opening discussion
    - Description of current and past clients (IHSS consumers): age, disability, etc.
    - Time spent with consumers, tasks performed, interaction with case management personnel
    - Common symptoms experienced by consumers, current procedures for symptom management
    - Older adults’ attitudes toward IHSS provider assistance with symptom management
    - IHSS provider’s attitudes about possible Symptom Management Program.
- Facilitators
    - Leveraging current training structure/procedures for helping consumers with symptoms
    - Relationship with consumers.
    - Benefits of IHSS Symptom Management Program
    - What IHSS providers would need to enable them to help consumers with symptoms
- Barriers
    - Potential challenges to a program
    - Possible solutions
- Implementation logistics
    - Implementation within current IHSS infrastructure
    - Training and other support for IHSS providers
    - Assessment tools and procedures
    - Time and workflow management

*Consumer focus groups*

- Opening discussion
    - Symptoms experienced by consumer, and how they are currently managed
    - Current role of case manager and IHSS provider in helping with symptoms/reporting to doctor
    - Willingness to accept help from IHSS providers
- Facilitators
    - Best ways for IHSS providers to help consumers with symptoms (i.e., medication reminder, call doctors, make/accompany to appointments, call family/friends, etc.?)
    - Training for IHSS providers/consumers, other needs
- Barriers
    - Potential challenges to a program
    - Possible solutions
- Implementation logistics
    - How to tailor approach for diverse IHSS consumers/providers
    - How to ensure program consistent with consumer-directed focus and consumer autonomy
    - Opinions about possible tools and procedures for IHSS Symptom Management Program

[a] IHSS, in-home supportive services.

nonclinician IHSS providers, to develop and implement a symptom assessment program. We found that such a program is greatly needed and may be an effective way to reduce disenfranchised older adult suffering and improve quality of life. Furthermore, given established relationships, training programs, and mechanisms for reimbursement, IHSS providers may be well positioned to play a role in symptom assessment.

Participants in all groups described substantial symptom burden, including pain, depression, and shortness of breath, often exacerbated by multimorbidity and isolation. What is novel is that all participants also identified loneliness as an important symptom requiring palliation. Loneliness is associated with disability and death in older adults.[26] An IHSS program could include screening for loneliness and incorporate

Table 2. Characteristics of Focus Group Participants ($n=50$)

| *All participants (*n=*50)* | |
|---|---|
| Age (mean, range) | 55, 24–92 |
| Race/ethnicity, *n* (%) | |
| Non-Hispanic White | 25 (50) |
| Non-Hispanic Black | 10 (20) |
| Hispanic | 6 (12) |
| Asian or Pacific Islander | 7 (14) |
| Other, declined to state | 2 (4) |
| Gender, *n* (%) | |
| Female | 34 (68) |
| Male | 14 (28) |
| Other/unknown | 2 (4) |
| Education, high school, *n* (%) | 1 (2) |

psychosocial support into care plans. IHSS providers described their own loneliness and need for support groups to deal with the emotional toll of caregiving.

All groups also talked about the need for additional training for IHSS providers as well as consumers. These educational efforts could leverage existing IHSS provider training and public outreach programs.[27,28] Both IHSS providers and consumers discussed classes as a way to help with isolation and loneliness while learning new skills. An important consideration is that IHSS providers are not trained clinicians and, like consumers, may have limited health literacy.[29] Low health literacy in caregivers is associated with increased hospitalization and decreased quality of life for adults.[30,31] Therefore, it is important to ensure IHSS symptom assessment training and tools are easy to understand and provide step-by-step instructions.

Stakeholders provided several specific recommendations for implementation: to include easy-to-use scripts and checklists;

Table 3. Stakeholder Input for the Development and Implementation of an In-Home Supportive Services[a] Symptom Assessment Program

| *THEME subtheme* | *Stakeholder role* | *Quote* |
|---|---|---|
| *Unmet need* | | |
| Program and training | Consumer | Maybe a provider might have to be trained on these things…Whenever something happens they should know CPR, they should know maybe anything to help…my provider wouldn't know where to start. Where or who to call if I have something happened to me. |
| | Administrator | (Our different agencies) have an ability to really coordinate some sort of system so that we can really provide good palliative care for the clients that we share. It goes beyond what any one of us can do alone |
| High symptom burden | Consumer | I have a bad case of diabetes…and if my sugar drops, it's like my equilibrium is off. I have problems with my bowels, my hip and…with my feet. Terrible, terrible pain. |
| | IHSS provider | My first client—she passed away but she was in a lot of pain, mm-hm; a lot of pain. …It was like I couldn't do nothing for her. |
| | IHSS provider | Walking across the street trying to make this meeting on time. I look back she's an hour behind…She (has) shortness of breath. …She got bronchitis bad. |
| | IHSS provider | My client is scared. I think she is scared of dying and being alone and there is always something, depression or a lot of pain, and she has a pretty hard time all the time. |
| Loneliness | Consumer | I don't have any family, though, here…so I'm without anyone at all. That's the other big thing. It wasn't mentioned with all the pain and suffering and stuff is loneliness. All of my friends are dead, all of them… It's impossible to get to know younger people and so you get very, very lonely because nobody wants to talk to a 92-year-old woman. |
| | IHSS provider | There are only four people in his building that speak English…it's so hard for him …we try to open up avenues for him but it is hard because they fall into depression and they just want to give up…stuck in that building and becoming less mobile. |
| | Case management staff | I feel like probably only 10 percent of [my clients] actually have someone….They're like 80 or 90 and are like ''My kids live out of state.'' |
| *Barriers* | | |
| Culture and misunderstanding | Administrator | It is a barrier that people don't understand what palliative care is… Then they are thinking ''Well, now you're telling me that I'm here to help somebody die'' … So, we run into that philosophical difference…how this could really be helpful to people in terms of their pain management, in terms of making sure that they're taken care of in the most humane way. |
| | Administrator | Another barrier is the cultural competency—there's huge ideas about (a) what palliative care means, and (b) how I'm going to die or not going to die. And especially if we're associating the two…There are certain groups who are not going to have this conversation at all ever. |

(*continued*)

Table 3. (Continued)

| *THEME subtheme* | *Stakeholder role* | *Quote* |
|---|---|---|
|  | Consumer | I think it totally depends on the client…I trust (my current provider) with everything I say, but there's been other providers that even when trying to approach it would make me feel uncomfortable. |
| Overmedicalization | Case management staff | The hired worker, they come in to help them out…"Well, you are here to do your job, what need to be done and then you go home." And that's it. |
|  | Administrator | IHSS consumers… some of them (are) very worried about the medicalization of the program, and is very concerned about providers getting overly trained. |
| Overburdened IHSS staff | Consumer | The thing is, right now the job that they have…It's hard as it is. On top of it, if you want to stick them (with) being knowledgeable in medical issues. |
|  | IHSS provider | There's mental problems now too from the stroke. Sweet guy but a whole handful. I'm getting paid 16 hours per week to look after him and I am so busy with this guy. I'm already working overtime. |
| Staff turn-over | Case management staff | The new people that turn over really fast. …our experienced population is moving into retirement and a new wave is coming in and that has been happening for several years now…The vast majority are very young and very inexperienced; inexperienced in the working world let alone in homecare. |
| Unintended consequences | Case management staff | It looked like she was scared to tell the niece certain things was going on with her because she was scared that they might be getting to put her in a home. … So if she is in pain, she won't say it, or if she needs the bathroom, she won't let you know because she is thinking that her family don't want to deal with it. |
| *Facilitators* |  |  |
| Perceived benefits | Consumer | I, frankly, am happy when my gal says "Have you taken your pills?" because sometimes I'll forget. And she always looks to see if I've taken them or not. And I like that. |
|  | Consumer | I'm all for (my provider following up with my doctor). I mean that way they can say "I was with (X) and she was having shortness of breath, this sort of thing, or she fell yesterday. What do you think I should do? Do you want to see her right away?" I think that's an excellent idea because (it) lets the doctor know what's going on. |
|  | Administrator | And I think the impact on the clients will be really important. I mean, these are clients that are totally marginalized, don't have people who are paying attention to any of this, a lot of them are isolated. They live alone, don't have family, so I think this is—has a lot of potential to truly assist. |
|  | Consumer | I feel like if you're shortness of breath…it's okay for the people that are providing the services to help [the providers] feel like they're doing their job. And that's an important consideration too. *"Are we useful? Are we needed?"* |
| Leverage established procedures | IHSS provider | You are observing anyway. You have to observe and find out how the client is feeling… So we are already doing it. We just haven't formalized what we doing. |
|  | Case management staff | (In-home providers) report to their supervisors if they are noticing that there is something that is concerning–they are our eyes and ears so that we can know how we can better support that situation. |
|  | Administrator | We have training facilities and supervisors, and so I think we're in a very unique position to be able to roll something out like this, and train people and this type of service. |
| Leverage established relationships | Consumer | My provider and I are very close…So it's kind of a very special relationship. …(she) will look at me and say you're not feeling well. And nobody else does that. She just knows. …. And she helps me to talk it through. "Is this serious?" or…maybe I'm going to wait it out a little bit. |
|  | Case management staff | We rely on (in-home providers) to be a set of eyes for those folks who actually need more eyeballing than what they will get from us… Homeworkers that are able to stay with the client for a while…; they are just absolutely invaluable extensions of the clinic. |

(*continued*)

Table 3. (Continued)

| *THEME subtheme* | *Stakeholder role* | *Quote* |
|---|---|---|
|  | Administrator | In-home providers are in most direct contact with the client, is they see changes in their ability to function…I think those that are there all the time see those subtle changes…They're not doing those things that used to bring them joy. |
| *Implementation* |  |  |
| Tailored to consumer choice | Consumer | I wouldn't mind (my provider contacting my family) because I made sure that the person that helps me at home knows my son…As long as I gave permission at the time, that's fine. |
|  | Administrator | Because of the strong consumer focus in this program…They have to be able to feel like they're making some choices and they have the information to do that, that they're not being sort of pushed off to a program. |
| Messaging | Administrator | Rather than describing it in terms that drive us toward medicalization, to use terms that drive us towards quality of life, because the provider and the client can understand that. |
|  | Administrator | I would also be sensitive also to language, because I mean, it's well-known that different cultures respond differently to different words. And so, you want to be sure that not only is it culturally, but also linguistically appropriate. |
|  | Administrator | Sometimes I talk about supportive care. Because it's pretty—it's softer. Very few people don't want support. |
|  | Case management staff | You could frame it in a way that like ''This will lead to you having fewer emergency calls,'' for instance, as this person's provider…. ''This will actually save you a lot of time.'' |
| Training | IHSS provider | It's not just book learning; it's not just watching a video; it is actually doing hands-on so you will go through it. You will talk about it; you will watch a video on it; you'll read about it but then you have to do the practical and then it all sinks in. |
|  | Administrator | I think if your goal is awareness then broad education so that everybody can talk knowledgeably about what palliative care is… I think there would be a lot of value to being able to educate the IHSS workforce in general…and then as consumers make choices about who they trust and want to talk to. |
| Logistics, workflow, checklists | Consumer | Yeah, if the provider sees the client in any kind, in trouble, then oh yeah, he should call the client's friends, parents, relatives….sometimes (they)…might be able to help them better because they know more about them than the provider. |
|  | IHSS provider | To have a list of things each time to remind you to look at, you could check off and like it would be easier for us who personally work with them to write the notes in those little boxes to check off or to add to…. And they have all these things written down step by step of how to do all these things for homecare. |
|  | Administrator | Maybe we could have some sort of like sheet…where it says ''Would you want your care provider to do the following?'' …And then you can sort of tailor it to what they want. |
|  | Administrator | So, you give homecare workers the understanding and the tools…find some way for them to have authority or whatever, to call the health provider…or case manager, ''My consumer is still in a whole lot of pain and I need to do something.'' |
| Provider support | IHSS provider | I think there should be a support group for providers because it is not easy… I think it would be really helpful because we need support. |
|  | Administrator | I would add…care giver support…I wonder what happens when they've been working with somebody for months or years, and that client goes into the hospital, goes into nursing, dies, and how do we help them with their grief? …a lot of the IHSS workers are the most significant people in the client's lives. And they grieve. |
|  | IHSS provider | …you would have more money when you have your certifications they mean that you are sufficient such as myself where I have–dementia current certificate; …If I was to do private pay, I can require and ask for more money |
|  | Administrator | Often informally, we're putting our more reliable higher skilled folks who don't get paid any more. But I wonder with them if they hear this ''Oh, I'm providing premium care now. Do I get paid?'' We're trying to figure out how we do that (provide more pay). |

[a] In-Home Supportive Services.

that tools be quick to administer to avoid provider burden; and that tools include clear instructions about next steps and whom to call. Stakeholders also recommended that programs pay particular attention to messaging and to focus on terms such as ''quality of life'' and ''symptoms,'' and participants suggested discussing the program as a means to help IHSS providers do their jobs and decrease suffering.[32,33] Furthermore, most participants felt it was crucial that the program be promoted as optional for both IHSS providers and consumers.

Because personal care and paramedical activities are included in the IHSS-approved task list,[34] it is possible symptom assessment could be included in the IHSS financial model. Inadequate symptom management at home is a frequent, and often avoidable, cause of emergency room visits.[35–37] Studies also show that palliative care at home can lower healthcare system costs and reduce unnecessary hospitalization.[38] Given the acceptability and perceived feasibility, an IHSS symptom assessment program could spur Medicaid programs to include assessment as a reimbursable skill. Lack of confidence in addressing symptoms and insufficient training are sources of stress for in-home care workers.[6,25,39] Addressing these concerns could benefit IHSS providers as studies show that self-confidence and training improve job satisfaction and retention of home health workers; crucial for this workforce and the elderly population.[40,41] IHSS symptom assessment may also act as a bridge for consumers to primary care and palliative care services.

### *Limitations*

We recruited a convenience sample from one Northern California county with participants who spoke English and could travel to focus groups. This may limit the generalizability of our findings, particularly in other locations that do not allow family or friends to be paid IHSS providers. More research is needed to inform a program tailored for diverse cultural groups and homebound consumers. Paying participants and the influence of focus group members on each other may also have introduced bias.

## Conclusions

An IHSS symptom assessment program is desired, needed, and feasible and can leverage established infrastructure, relationships, and training programs to assess symptoms in the home. Furthermore, loneliness was highlighted as an important symptom requiring palliation. Acknowledging consumer choice, developing appropriate tools and trainings for IHSS staff, and effective messaging of program goals can contribute to success. Further study is needed to design and test interventions that will meet the needs of diverse IHSS programs.

## Author Disclosure Statement

No competing financial interests exist for any authors. This study was supported by National Palliative Care Research Center and Tideswell at UCSF. The funders had no role in the study design or interpretation.

## References

1. Moens K, Higginson IJ, Harding R, Euro I. Are there differences in the prevalence of palliative care-related problems in people living with advanced cancer and eight non-cancer conditions? A systematic review. *J Pain Symptom Manage.* 2014;48(4):660–677.
2. Kutner M, Greenberg E, Baer J. *A first look at the literacy of America's adults in the 21st century. National Center for Education Statistics, U.S. Department of Education.* Washington, D.C. 2005.
3. Breeze E, Fletcher AE, Leon DA, Marmot MG, Clarke RJ, Shipley MJ. Do socioeconomic disadvantages persist into old age? Self-reported morbidity in a 29-year follow-up of the Whitehall Study. *American journal of public health.* 2001;91(2):277–283.
4. Minkler M, Fuller-Thomson E, Guralnik JM. Gradient of disability across the socioeconomic spectrum in the United States. *N Engl J Med.* 2006;355(7):695–703.
5. Benjamin AE, Matthias RE. Work-life differences and outcomes for agency and consumer-directed home-care workers. *Gerontologist.* 2004;44(4):479–488.
6. Delp L, Wallace SP, Geiger-Brown J, Muntaner C. Job stress and job satisfaction: home care workers in a consumer-directed model of care. *Health Serv Res.* 2010;45(4): 922–940.
7. Yamada Y. Profile of home care aides, nursing home aides, and hospital aides: historical changes and data recommendations. *Gerontologist.* 2002;42(2):199–206.
8. Krieger J, Song L, Philby M. Community health worker home visits for adults with uncontrolled asthma: the HomeBASE Trial randomized clinical trial. *JAMA Intern Med.* 2015;175(1):109–117.
9. Services DoS. In Home Supportive Services (IHSS) Program. http://www.cdss.ca.gov/inforesources/IHSS. Accessed October 6, 2017.
10. Department of Aging and Adult Services (DAAS). http://www.sfhsa.org/DAAS.htm. Accessed June 19, 2017.
11. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society.* 1975;23(10): 433–441.
12. Su CT, McMahan RD, Williams BA, Sharma RK, Sudore RL. Family matters: effects of birth order, culture, and family dynamics on surrogate decision-making. *Journal of the American Geriatrics Society.* 2014;62(1):175–182.
13. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage.* 2013; 46(3):355–365.
14. Odierna DH, Bero LA. Retaining Participants in Outpatient and Community-Based Health Studies: Researchers and Participants in Their Own Words. *Sage Open.* 2014;4(4): 1–11.
15. Qualitative research in psychology. In: Braun V, Clarke, V., ed. *Using thematic analysis in psychology.* Vol 3. London, Philadelphia: Arnold, Taylor & Francis.; 2004:77–101.
16. Schreier M. *Qualitative content analysis in practice.* Los Angeles: SAGE; 2012.
17. John W. Creswell DLM. Determining Validity in Qualitative Inquiry, Theory Into Practice. 2010;39(3):124–130.
18. Bernard HR. *Research Methods in Anthropology: Qualitative and Quantitative Approaches.* Thousand Oaks, CA: Sage Publications; 1994.
19. Glaser B SA. *Discovery of Grounded Theory. Strategies for Qualitative Research: Sociology Press, 1967.* New York.
20. Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: what helps and

hampers the experience of making medical decisions for others. *J Gen Intern Med.* 2007;22(9):1274–1279.

21. Rosenfeld KE, Wenger NS, Kagawa-Singer M. End-of-life decision making: a qualitative study of elderly individuals. *J Gen Intern Med.* 2000;15(9):620–625.
22. Vig EK, Pearlman RA. Quality of life while dying: a qualitative study of terminally ill older men. *Journal of the American Geriatrics Society.* 2003;51(11):1595–1601.
23. Bakitas M, Lyons KD, Hegel MT, et al. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: the Project ENABLE II randomized controlled trial. *JAMA.* 2009;302(7):741–749.
24. Jacobsen J, Kvale E, Rabow M, et al. Helping patients with serious illness live well through the promotion of adaptive coping: a report from the improving outpatient palliative care (IPAL-OP) initiative. *J Palliat Med.* 2014;17(4):463–468.
25. Mousing CA, Timm H, Lomborg K, Kirkevold M. Barriers to palliative care in people with chronic obstructive pulmonary disease in home care: A qualitative study of the perspective of professional caregivers. *Journal of clinical nursing.* 2017.
26. Perissinotto CM, Stijacic Cenzer I, Covinsky KE. Loneliness in older persons: a predictor of functional decline and death. *Arch Intern Med.* 2012;172(14):1078–1083.
27. Homebridge. Who We Serve. http://www.homebridgeca.org/who-we-serve/. Accessed October 24, 2017.
28. Authority SP. What is the SF IHSS Public Authority? http://www.sfihsspa.org/sfihss/. Accessed October 24, 2017.
29. Lindquist LA, Jain N, Tam K, Martin GJ, Baker DW. Inadequate health literacy among paid caregivers of seniors. *J Gen Intern Med.* 2011;26(5):474–479.
30. Yuen EY, Knight T, Ricciardelli LA, Burney S. Health literacy of caregivers of adult care recipients: A systematic scoping review. *Health Soc Care Community.* 2016.
31. Levin JB, Peterson PN, Dolansky MA, Boxer RS. Health literacy and heart failure management in patient-caregiver dyads. *J Card Fail.* 2014;20(10):755–761.
32. Brenda M. Morrow CB, Zimkhitha Luhlaza, Kelisha Naidoo, Sarah Pitt. Knowledge, attitudes, beliefs and experience of palliative care amongst South African physiotherapists. *South African Journal of Physiotherapy.* 2017;73(1):8.
33. Kavalieratos D, Mitchell EM, Carey TS, et al. ''Not the 'grim reaper service''': an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. *J Am Heart Assoc.* 2014;3(1):e000544.
34. Program CI-HSSI. IHSS Authorized Tasks. http://www.cdss.ca.gov/agedblinddisabled/res/FactSheets/IHSS_Authorized_Tasks_Color.pdf. Accessed October 31, 2017.
35. Wallace EM, Cooney MC, Walsh J, Conroy M, Twomey F. Why do palliative care patients present to the emergency department? Avoidable or unavoidable? *Am J Hosp Palliat Care.* 2013;30(3):253–256.
36. Delgado-Guay MO, Kim YJ, Shin SH, et al. Avoidable and unavoidable visits to the emergency department among patients with advanced cancer receiving outpatient palliative care. *J Pain Symptom Manage.* 2015;49(3):497–504.
37. Panattoni L, Fedorenko C, Greenwood-Hickman MA, et al. Characterizing Potentially Preventable Cancer- and Chronic Disease-Related Emergency Department Use in the Year After Treatment Initiation: A Regional Study. *J Oncol Pract.* 2018;14(3):e176–e185.
38. Lustbader D, Mudra M, Romano C, et al. The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization. *J Palliat Med.* 2017;20(1):23–28.
39. Herber OR, Johnston BM. The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review. *Health Soc Care Community.* 2013;21(3):225–235.
40. Jang Y, Lee AA, Zadrozny M, Bae SH, Kim MT, Marti NC. Determinants of Job Satisfaction and Turnover Intent in Home Health Workers: The Role of Job Demands and Resources. *Journal of applied gerontology: the official journal of the Southern Gerontological Society.* 2017;36(1):56–70.
41. McCaughey D, McGhan G, Kim J, Brannon D, Leroy H, Jablonski R. Workforce implications of injury among home health workers: evidence from the National Home Health Aide Survey. *Gerontologist.* 2012;52(4):493–505.

Address correspondence to:
*Mary T. Katen, BA*
*Division of Geriatrics*
*San Francisco VA Medical Center*
*School of Medicine*
*University of California San Francisco*
*4150 Clement Street, #151R*
*San Francisco, CA 94121*

*E-mail:* mary.katen@ucsf.edu