REPORT TO THE TWENTY-EIGHTH LEGISLATURE
STATE OF HAWAII
2015

PURSUANT TO HCR 78, SESSION LAWS OF HAWAII 2014, REQUESTING THE DEPARTMENT OF HEALTH TO CONVENE A FAMILY CAREGIVERS WORKING GROUP TO EXAMINE AND ASSESS THE ROLE OF CAREGIVING FOR PATIENTS RELEASED FROM HOSPITALS, THE STATE OF THEIR OVERALL CIRCUMSTANCES, AND THE RESOURCES IN THE COMMUNITY NEEDED AND AVAILABLE TO ASSIST THEM

PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
MARCH 2015

EXECUTIVE SUMMARY

In accordance with House Concurrent Resolution No. 78, H.D. 1, S.D. 1, Session Laws of Hawaii 2014 (SLH 2014), and at the request of the co-chairs of the Working Group, the Department of Health is submitting a report on behalf of the Family Caregivers Working Group that outlines its findings and recommendations relating to the role of caregiving for patients released from hospitals, the state of their overall circumstances, and the resources in the community needed and available to assist them.

The working group was comprised of key stakeholders from across the state, including stakeholders representing hospitals, health care systems, and other health care organizations and agencies, the state and county offices on aging, the Department of Health, a member of the State House of Representatives and a member of the State Senate who served as co-chairs, stakeholders representing community organizations, and stakeholders representing family caregivers. They shared their viewpoints, examined objective data, and heard presentations from clinical professionals and executive administrators during eight meetings held over a six month period of time.

The working group could not reach consensus on whether legislation should be required to address the role of caregiving for patients released to home from hospitals. As a result, this report is submitted representing the majority of working group participants. Nevertheless, all working group participants agree that the role of family caregivers is important to the medical recovery of a patient at home following discharge from an acute care hospital. Further, the majority of participants recognize the integral roles of a complex set of professional caregivers and processes that are required to work together to produce optimal outcomes for the patient and that those processes should be allowed to continue to work and to evolve and improve synergistically rather than by state mandate.

REPORT TO THE LEGISLATURE

Introduction

HCR 78, SLH 2014, requested the Department of Health (department) to convene a family caregivers working group to examine and assess the role of caregiving for patients released from hospitals, the state of their overall circumstances, and the resources in the community needed and available to assist them.

Objectives of HCR 78

As identified in HCR 78, the objectives of the resolution are as follows:

1. The department is requested to convene a family caregivers working group from a list of potential participants.
2. The family caregivers working group is requested to submit a written report of its findings and recommendations to the Legislature no later than twenty days prior to the convening of the Regular Session of 2015.

Objectives of the Working Group

As identified in HCR 78, the objectives of the working group are as follows:

1. To examine and assess issues contained in Senate Bill 2264, Regular Session of 2014, including but not limited to:
    a. The role of caregivers;
    b. The state of current practice of caregiver designation, notification, involvement in discharge planning, and training;
    c. The role hospitals should play in the training of caregivers;
    d. The role others might or should play in the training of caregivers to assure the best outcomes for all patients released from hospitals;
    e. Legislative and regulatory recommendations on how best to involve caregivers in patient discharge and prepare caregivers for after-care tasks, and;
2. Submit a written report no later than twenty days prior to the convening of the Regular Session of 2015.

Establishment and Composition of the Working Group

HCR 78 requested the department to invite the participation of the following:

1. The Director of Health, or the Director's designee;
2. One representative and one family care representative from AARP Hawaii;

3. The Director of the Executive Office on Aging, or the Director's designee;
4. One representative from the Healthcare Association of Hawaii;
5. One representative from each Oahu hospital facility or one representative from each hospital or health care system where multiple private Oahu or neighbor island hospitals are under a single hospital or health care system;
6. One representative from each Hawaii Health Systems Corporation region;
7. One representative and one family care representative from a home health care organization;
8. One representative from a Skilled Nursing Facility;
9. One representative from each of the County Area Agencies on Aging;
10. One representative and one family care representative from the Kokua Council;
11. One representative from Hawaii's health insurance or mutual benefit society health plans;
12. One representative and one family care representative from the American Cancer Society;
13. One representative and one family care representative from Papa Ola Lokahi;
14. One representative and one family care representative from an Alzheimer's Disease treatment organization;
15. One representative and one family care representative from Kokua Mau;
16. One representative and one family care representative from a hospice organization;
17. One representative from the Hawaii Long Term Care Association;
18. A member of the Senate appointed by the Senate President, who shall serve as co-chair; and
19. A member of the House of Representatives appointed by the Speaker of the House, who shall serve as co-chair.

The Director of Health invited participants from the above list of organizations and most invitations were accepted. See Attachment A for a list of the participants.

In addition, the department obtained an opinion from the Office of Information Practices (OIP) that determined that Hawaii's Sunshine law requirements did not apply to this working group. This would allow working group members to discuss the issues without the formalities of public notice requirements of meetings and without formally meeting as a working group.

Working Group Meetings

The working group met eight (8) times beginning on July 28, 2014, with the latest meeting held on January 12, 2015. Notes of each meeting were recorded and distributed to working group participants and to members of the public in attendance at the meetings. The agenda, meeting notes, and presentation materials from each meeting are available from the co-chairs.

Findings and Conclusion

Findings

1. Caregivers play a vital role in providing care for persons who are discharged from acute care hospitals and who require continued care needs for short or longer periods of time.[1]

2. Caregivers are often family members without clinical training or experience, i.e., spouse, parent, child, or other close relative.[2] Caregivers desire appropriate caregiver training or instructions.[3]

3. Professional caregivers and medical resources are widely available in the community through home health agencies, private duty nurse agencies, durable medical equipment suppliers, hospices, and others.[4] Public and private health insurance normally covers the cost of these services but patients may have to pay out-of-pocket for some services such as from private duty nurse agencies depending on their health insurance coverage. Regardless, there is a need to better link caregivers with the appropriate medical resources in the community.[5]

4. Primary care physicians (PCP) play a significant and integral role in providing care to the patient upon discharge. Care may be provided directly or indirectly. Post-discharge physician office visits may be necessary and physicians may authorize follow-up care through licensed care agencies, physician specialists, or other professional clinicians. They also prescribe necessary medications.[6] Nevertheless, the apparent lack of available PCPs in the community is a concern.[7]

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[1] AARP presentation at 9/22/2014 meeting

[2] AARP presentation at 11/12/2014 meeting

[3] AARP statement at 12/11/2014 meeting

[4] Comments of various working group participants at initial and subsequent meetings

[5] Comments of working group participants at 12/11/2014 meeting

[6] Maui ADRC presentation and acknowledged by Maui Memorial and other major hospitals at 12/2/2014 meeting

[7] Comments of working group participants at 12/11/2014 meeting

5. Care coordinators are available throughout the state from private non-profit and public organizations, such as through county Aging and Disability Resource Centers (ADRC) through the counties' offices on aging. The availability of care coordinators may be limited in some locales or islands.[8] Oahu is developing an ADRC, and hospitals have care coordination processes in place for hospital discharge planning purposes. Oahu hospitals are willing to work in conjunction with the future Oahu ADRC.[9]

6. Stable funding is needed for ADRCs on the neighbor islands especially if current Medicare funding were to cease and funding is necessary to establish an Oahu ADRC.[10]

7. Caregiver training is available throughout the state from private non-profit and public organizations such as the Kapiolani Community College Kupuna Education Center, AARP, Queen's Foster Family Community Care Programs, and others.[11] Training fees may be required.

8. Hospitals begin the discharge planning processes at or prior to admission of the patient. The processes are described in their respective policies and procedures (P&P). Copies of actual P&Ps were not provided to the working group since they are proprietary according to the hospitals but some hospitals orally described their processes for the group. According to the hospitals that described their processes, designated caregivers are identified and the patient's discharge plan is based on who the caregiver is. Hospitals offer to involve patients and caregivers in discharge planning, discharge instructions, and follow-up care needs. Hospitals attempt to follow-up with patients on a scheduled basis in an effort to ensure compliance with care instructions and to avoid inappropriate readmissions.[12]

9. All hospitals who participate in Medicare are required to adhere to state licensing requirements and to Medicare's conditions of participation (CoP) and certification requirements on discharge planning.[13] [14]

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[8] Presentations by Maui ADRC at 12/2/2014 meeting, Kauai Care Transition Program at 8/25/2014 meeting

[9] Comments of working group participants at 12/11/2014 meeting

[10] ibid

[11] Presentations by various agencies at 11/12/2014 meeting and resource listing provided by the Executive Office on Aging

[12] Presentations by various major hospitals at 9/22/2014 and 10/27/2014 meetings

[13] Comments of working group participants at 12/11/2014 meeting

[14] Memo dated January 16, 2015, provided to the co-chairs by the Healthcare Association of Hawaii that provides detailed information on Medicare's CoP relating to discharge planning.

10. Hospitals accredited by the Joint Commission (JC) follow JC's discharge planning standards.[15] [16] All major hospitals in Hawaii and several smaller hospitals on the neighbor islands are accredited by the JC.

11. Hospitals are provided financial disincentives and incentives to avoid inappropriate readmissions. Medicare imposes penalties based on readmission rates.[17] [18] HMSA initiated a pay-for-quality reward program for hospitals where 20% of the program is weighted to discharge planning and readmission reduction.[19]

12. Hospitals recognize the need to comply with Medicare's CoP and with the JC standards regarding discharge planning. As a result, hospitals provide instructions and information to caregivers to ensure the care needs of the patient after discharge are understood. This improves post-hospital care and reduces inappropriate readmissions. Hospitals participate in a variety of programs aimed at reducing such readmissions. The Hawaii Care Transition Program involved neighbor island hospitals and county agencies. On Maui, the readmission rate for all causes and all conditions among Medicare fee-for-service patients dropped from 18.3% to 13.2%. Hawaii and Kauai counties also had reduced readmissions.[20]

13. The Pharm2Pharm (P2P) program was implemented by hospitals statewide.[21] For example, Pali Momi participated in the program with the goal to improve health and healthcare while reducing costs. The program focused on medication education prior to or upon discharge for high risk patients who were admitted for medication related problems or for recurrent admissions for uncontrolled chronic conditions. The program included follow-up phone calls after discharge.[22]

14. Hawaii has lower overall readmission rates for the Medicare fee-for-service population compared with national rates. Hawaii's Medicare fee-for-service population comprises about 55% of Hawaii's Medicare population; there is no data for Medicare Advantage health plans. Hawaii is among the leading states with the lowest Medicare 30-day

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[15] Comments of working group participants at 12/11/2014 meeting

[16] Memo dated January 16, 2015, provided to the co-chairs by the Healthcare Association of Hawaii that provides detailed information on the Joint Commission's standards relating to discharge planning and the Joint Commission's response to concerns raised by minority members of the Working Group.

[17] HHIC presentation at 11/12/2014 meeting

[18] Memo dated January 16, 2015, provided to the co-chairs by the Healthcare Association of Hawaii that provides information on Hawaii's hospital readmissions.

[19] HMSA presentation at 10/27/2014 meeting

[20] Hawaii Care Transition Program (HCTA) presentation at 8/25/2014 meeting

[21] Comments of HAH and major hospitals at 12/11/2014 meeting

[22] Pali Momi presentation at 8/25/2014 meeting

readmissions rate per 1,000 beneficiaries. For all Medicare fee-for-service readmissions, Hawaii has approximately 26 readmissions per 1,000 beneficiaries for a 2.6% readmission rate compared with a national median of approximately 45 readmissions per 1,000 beneficiaries for a 4.5% readmission rate.[23]

15. Hawaii continued to perform better than national averages for more complex cases. For acute myocardial infarction (AMI), Hawaii's rate was 17.8% compared to 18.3% nationally. For heart failure, Hawaii's rate was 21.4% compared to 23.0% nationally. And for pneumonia, Hawaii's rate was 17.0% compared to 17.6% nationally.[24]

16. In a comparison of readmission rates among Hawaii's public and private health insurers and other payor sources, Hawaii Health Information Corporation (HHIC) found that "Overall, Hawaii('s) potentially preventable readmission rates ranged from 3.5 percent for the privately insured to 9.5 percent for Medicare beneficiaries." [25] Med-QUEST's readmission rate was 6.2% while Hawaii's overall rate was 6.5%.[26]

17. Working together the Maui ADRC and Maui Memorial Medical Center achieved the highest percentage reduction in readmission rates for the Medicare fee-for-service population in Maui County than was achieved by any other county in the United States who participated in the CMS care transitions intervention program.[27]

18. Information on the cost and potential savings of avoiding readmissions was presented[28] [29] but the working group found that the rate of readmissions, the favorable comparison of Hawaii's rate of readmissions to the national rate, penalties imposed by Medicare, payment rewards given by private insurers and health plans, and actions taken by hospitals and others to train and inform caregivers, improve post-hospital care, and reduce readmissions were the more significant measurements for consideration.

19. There are many reasons for readmissions and many readmissions are unavoidable due to the complexities of the patients' medical conditions. However, while the working

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[23] HHIC presentation at 11/12/2014 meeting

[24] ibid

[25] Letter dated January 22, 2015, provided to the co-chairs by the HHIC that provides a context to better understand the number of readmissions and their associated hospital charges relative to total admissions and total overall charges, and to clarify how public and private insurers gather and use readmission data.

[26] ibid

[27] Maui ADRC presentations at 8/25/2014 and 12/2/2014 meetings

[28] AARP presentation at 9/22/2014 meeting, HHIC presentation at 11/12/2014 meeting, and HMSA presentation at 10/27/2014 meeting

[29] Letter dated January 22, 2015, provided to the co-chairs by the HHIC that provides a context to better understand the number of readmissions and their associated hospital charges relative to total admissions and total overall charges, and to clarify how public and private insurers gather and use readmission data.

group found the need for the community to continue to improve post-hospitalization care, there is also a need to better determine the connection between improving that care and the training of unskilled family caregivers especially considering the increasingly complex needs of patients.[30]

20. Mandating the hospitals to be responsible for training family caregivers would likely open hospitals to lawsuits and significant legal fees. Statutory language to indemnify hospitals from such liability is questionable as to whether that will prevent lawsuits and whether such language will hold up in courts.[31] The working group does not possess the legal expertise to make a definitive determination or finding on this issue.

Conclusion

The family caregiver working group meetings brought together many stakeholders from across the state, from a variety of types of providers, from state and county governmental agencies, from private insurers and health plans, and from private and public hospitals. Discussions were candid and interactive and allowed for an open exchange of objective data and information, and the expression of professional expertise, personal experience, opinions and points of view.

Early on, the working group participants struggled to agree on what the problem was as well as the scope of the problem. There was a clear need to review objective data and to hear about the experiences and activities of key stakeholders, several of whom were members of the working group.

The working group considered all information presented at the meetings. The group concluded that some resources and incentives exist at hospitals and in the community to allow family caregivers to obtain training to provide follow-up care for loved ones discharged from acute care hospitals. Some of these resources are currently funded by Medicare on a limited timeframe and future funding is uncertain such as for ADRC resources on the neighbor islands. Other resources include discharge planning staff at hospitals who work with the ADRC to improve care to discharged patients while reducing inappropriate readmissions. The ADRC resources will need support if or when Medicare funding ends.

The working group concluded the discharge processes can continue to be improved and hospitals are actively working internally and with available community resources to make improvements as evidenced by the various initiatives which were implemented and the resulting reduction in the state's readmission rates.

Nevertheless, consensus could not be reached on the entire list of findings, on the conclusions, and on all of the recommendations especially the need for legislation to mandate certain activities by hospitals. Specifically:

- a minority of working group participants believe:
    - hospitals do not do enough to identify and train family caregivers;

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[30] Comments of working group participants at 12/11/2014 meeting

[31] Presentation by Healthcare Association of Hawaii (HAH) and rebuttal by AARP at 12/2/2014 meeting

  - hospitals must be mandated by the state to do more; and
  - statutory language can be crafted to indemnify hospitals from tort liability.

- a majority of working group participants believe:
  - hospitals play a significant role in discharge planning by working with patients and caregivers prior to or at the time of patient discharge;
  - hospitals have taken positive steps internally and in working with community agencies to improve caregiver training and post-hospital care, and to reduce readmissions;
  - federal penalties and financial rewards from private health insurers incentivize hospitals to reduce inappropriate readmissions;
  - hospitals are viewed as deep pockets and, therefore, are targets for lawsuits; and
  - a state mandate will do more harm than good.

As a result, this report and recommendation is submitted following a majority vote of the working group participants. A minority report is included in this report and follows the below Recommendations of the Working Group.

Recommendations of the Working Group

Based on the findings and conclusions noted above, the working group recommends the following to the 2015 Hawaii Legislature. Recommendation number one (1) is recommended following a majority vote of the working group participants while unanimous consensus was reached on the remaining recommendations by all working group participants.

1. Take no action at this time to mandate hospitals to provide caregiver training.
2. Consider state funding for one or more definitive studies by an objective organization to assess gaps in caregiver training, a market study to determine the availability, utilization, and costs of existing community resources, and an assessment on the apparent lack of PCP availability and post-hospitalization involvement for at-risk populations, while taking into account the complexity of the health care industry and the many highly involved public and private stakeholders.
3. Consider state funding options for county offices on aging and/or for Aging and Disability Resource Centers (ADRC) statewide to improve their abilities to work with hospitals and other professional and family caregivers to improve post-hospitalization care to patients who are discharged to home and to reduce inappropriate readmissions especially if or when federal funding ceases. This includes finding ways to duplicate on Oahu the successes on the neighbor islands.

4. Consider improving state funding for at-risk populations to better cover the cost of physician office visits and hospital services to encourage more physicians to become PCPs for this population.

5. As the term of the working group continues through June 30, 2016, request the working group continue to meet to identify the current industry standards on discharge planning, how hospitals comply with those standards, and what additional activities, if any, can be agreed upon by hospitals, family caregivers, and community care coordinators and stakeholders to jointly implement that will improve family caregiver identification and provide for appropriate trainings. Request the working group to submit a second report prior to the 2016 legislative session on this recommendation.

Minority Report[32]

Introduction

The HCR 78 Working Group was able to reach consensus on several recommendations. The only recommendation on which consensus could not be reached was to "[t]ake no action at this time to mandate hospitals to provide caregiver training." Because no consensus could be reached on that particular recommendation, the working group took a roll call vote. The majority of working group participants present voted in favor of that recommendation.[33]

This minority report is written solely to address the recommendation "to take no action at this time to mandate hospitals provider caregiver training". We do not agree with this no-action recommendation, and propose instead that further discussion on this important topic be continued in the open and deliberative forum that is provided through the legislative process.

Specifically, we recommend a legislative solution that contains the core elements of Senate Bill 2264 in which:

1) Patients are given the opportunity to designate a family caregiver when admitted into a hospital, and to have that caregiver's name recorded in the patient's medical record;

2) The family caregiver is notified if the patient is to be discharged to another facility or back home; and,

3) The hospital offers to provide an explanation and live instruction to the family caregiver of the medical tasks – such as medication management, injections, wound care, and transfers – that the family caregiver will perform at home.

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[32] Of the thirty four (34) members of the HCR 78 Working Group, AARP identified the following seven (7) persons who have agreed to sign on to the Minority Report. Since this was done outside of the Working Group meetings, the Working Group cannot verify these signatories: Cory Chun (American Cancer Society), Kealoha Takahashi (Kauai County Agency of Elderly Affairs), Barbara Service (Kokua Council), Pamela Scott (Alzheimer's Association, Aloha Chapter Headquarters), Norma Circle (Maui County Office on Aging), Audrey Suga-Nakagawa (AARP Hawaii), and Stuart Ho (AARP Hawaii).

[33] Members voting "yes" were: Department of Health, Executive Office of Aging, Office of Aging Hawaii County, Hawaii Health Systems Corporation Maui Region, Castle Medical Center, Hawaii Pacific Health, Kaiser Foundation Hospital, Kuakini Medical Center, The Queen's Health System, Healthcare Association of Hawaii, Hawaii Long Term Care Association, Hawaii Association of Health Plans, Hospice Hawaii (2 votes), Castle Home Care, and Kokua Mau. Members voting "no" were: House of Representatives Co-Chair, Senate Co-Chair, Office of Aging Maui County, AARP Hawaii (2 votes), American Cancer Society, Alzheimer's Association, and Kokua Council.

This new legislation takes into account the recent developments and lessons learned in other states that enacted similar legislation in 2014 while successfully addressing liability and other concerns from hospitals. As noted in further detail below, such a common sense legislative solution is supported by between 86% and 95% of Hawaii registered voters aged 45 and older.

Findings

Family caregivers are the backbone of the long-term services and supports system in Hawaii, but their contributions are frequently unrecognized and largely unsupported. Nearly 250,000 unpaid family caregivers in the state are caring for an aging parent or loved one, helping them to live independently in their own homes. These caregivers provide services valued at approximately $2 billion annually. When someone is released from the hospital, it is most often their family members and friends who are on the front lines, helping to carry out discharge instructions and provide the after-care necessary to keep their loved ones healthy and safe at home. Their help is crucial to preventing hospital readmissions and keeping their loved ones out of costly nursing homes.

The help provided by family caregivers can also be complicated and demanding. In a recent national survey conducted by the AARP Public Policy Institute and the United Hospital Fund, almost half (46 percent) of family caregivers reported performing medical and nursing tasks for care recipients with multiple chronic physical and cognitive conditions.[34] These tasks include managing multiple medications, providing wound care, preparing food for special diets, using monitors, and operating specialized medical equipment. These tasks were in addition to the assistance they were already providing with bathing, dressing, eating, and other household tasks. Most caregivers said that they received little or no training to perform these medical and nursing tasks.

Despite multiple requests, only some hospitals represented on the Working Group provided copies of their written patient discharge protocols and policies to allow the Working Group to assess the "current practice" of family caregiver involvement. Others provided only a verbal summary of discharge processes. Likewise, the Healthcare Association of Hawaii did not provide an overall summary and comparison of the discharge procedures of its member hospitals as requested by the Working Group. Although hospitals may claim that family caregiver involvement is already required of them in the Medicare Conditions of Participation, those rules do not contain explicit requirements that the names and contact information of family caregivers be recorded in a patient's medical record or that family caregivers be given advance notice that a patient is being discharged or transferred, and only call for hospitals to provide education and training to caregivers "as needed." The testimonies of many family caregivers in Hawaii in support of Senate Bill 2264 during the 2014 legislative session and since that time show that when family caregiver involvement is left strictly to the hospitals' discretion, too many

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[34] Reinhard, Susan C., Carol Levine, and Sarah Samis. *Home alone: Family caregivers providing complex chronic care*. Washington, DC: AARP Public Policy Institute, 2012.

of them are left without the information and instruction they need to help keep their loved ones safe at home following a hospital discharge.

Hawaii residents have been clear that more is needed to support family caregivers in this area. When asked in a recent survey (attached), Hawaii residents overwhelmingly support the three basic interventions contained in Senate Bill 2264. A telephone survey of 1,000 Hawaii registered voters age 45 and older conducted between August 28 and September 9, 2014, found that:

- Nearly all (95 percent) support requiring hospitals to explain and demonstrate medical and nursing tasks that family caregivers will need to perform after the patient returns home with 79 percent *strongly* supporting this proposal;

- Nearly all (94 percent) support requiring hospitals to keep a family caregiver informed of major decisions, like transferring or discharging the patient, with 75 percent *strongly* supporting this proposal; and

- Over four in five (86 percent) support requiring hospitals and care facilities to record the name of a patient's family caregiver in the medical record upon admission with 58 percent *strongly* supporting this proposal.

The need to address this issue has only been reinforced by additional information that has come to light since the end of the last legislative session. In particular, the Hawaii Health Information Corporation's Insight #2 (released in September 2014) shows the significant costs of potentially preventable hospital readmissions in the state. According to HHIC, there were approximately 5,500 30-day hospital readmissions in Hawaii in 2013, with associated charges of almost $239 million. Some of the hospitals have argued that this figure needs to be put in the broader context of how many patients are discharged each year in Hawaii. We have no objection to that, but it does not change the fact that the HHIC report itself is the source of the $239 million figure representing the cost of potentially preventable hospital readmissions. These costs are borne by all payers in the healthcare system (Medicare, private insurance, self-pay, etc.), but a large percentage – 22 percent, or over $52 million – are paid by the state's Medicaid/QUEST program. The magnitude of this issue, and the potential savings to the state, add to the urgency with which Hawaii should address hospital discharges and seek to better prepare family caregivers for their role in that process and its aftermath.

Recent studies and trials conducted in Hawaii show the promise of increased family caregiver involvement. As described to the Working Group, local care transition programs involving neighbor island hospitals and county agencies, and related efforts by the Hawaii Medical Service Association, show that increased follow-up and family caregiver involvement by hospitals can reduce readmission rates. We believe that increased family caregiver involvement and training even before a patient leaves the hospital are complimentary efforts that will bring about similar benefits. Still, the focus of this issue should be on the real experiences, difficulties, and stresses of family caregivers as they help their loved ones after a hospital discharge and on what Hawaii can do to better support them. Although certain factors, such as the federal Hospital Readmissions Reductions Program, are incentivizing hospitals to voluntarily adopt programs that include greater family caregiver involvement, Hawaii should not let the hospitals' self-interest be the only driver of change in supporting family caregivers.

Finally, the Working Group discussed at length the concerns expressed by some hospitals about the potential for legal liability resulting from legislation such as Senate Bill 2264. First, to the extent negligence actions can *already* be brought against hospitals relating to discharges, the CARE Act does not change the liability landscape in any meaningful way. Further, while Senate Bill 2264 was amended to include a limitation of liability provision based on other Hawaii statutes, we offer as a recommendation the following language, which was included in a similar bill in New Jersey (A2955/S2127) that passed the legislature unanimously and was signed by Gov. Chris Christie in November 2014:

> *Nothing in this act shall be construed to create a private right of action against a hospital, a hospital employee, or any consultants or contractors with whom a hospital has a contractual relationship.*
>
> [and]
>
> *A hospital, a hospital employee, or any consultants or contractors with whom a hospital has a contractual relationship shall not be held liable, in any way, for the services rendered or not rendered by the caregiver to the patient at the patient's residence.*

We note that the New Jersey Hospital Association was involved in developing this limitation of liability language and took a "neutral" position on the bill overall. Hawaii hospitals should work with legislators and other stakeholders to similarly address their concerns in this manner.

Recommendations

We recommend that the legislature pursue a commonsense legislative solution that contains the core elements of Senate Bill 2264:

1) Patients are given the opportunity to designate a family caregiver when admitted into a hospital, and to have that caregiver's name recorded in the patient's medical record;

2) The family caregiver is notified if the patient is to be discharged to another facility or back home; and,

3) The hospital offers to provide an explanation and live instruction to the family caregiver of the medical tasks – such as medication management, injections, wound care, and transfers – that the family caregiver will perform at home.

Conclusion

We appreciate the opportunity provided by this Working Group to further discuss the issues facing family caregivers as they help their loved ones following a hospital discharge. We applaud the working group's ability to reach consensus on several important issues. We believe it is critical, however, to continue this discussion in the context of legislation, which is what necessitated this minority report. The type of legislative solution described above could ensure that there is a consistent, minimum level of support that is provided to unpaid family caregivers throughout the state. Hawaii cannot sit by and hope that policies and programs to help family caregivers with their role following a hospital discharge will naturally develop, while other states, like New Jersey and Oklahoma, are addressing this challenge head-on with legislative solutions. Hawaii's family caregivers need help, and legislative action in this area can ensure that they receive that help in every hospital in the state.

Attachment A

INVITEE	PARTICIPANT / DESIGNEE
Department of Health	
Linda Rosen, M.D., M.P.H. Director of Health Chair	Keith R. Ridley, Chief Office of Health Care Assurance
House of Representatives Co-Chair	Gregg Takayama, Representative Hawaii State Capitol
Senate Co-Chair	Suzanne Chun Oakland, Senator Hawaii State Capitol
Executive Office of Aging Department of Health	
Wesley L. Lum, Director	Cullen T. Hayashida, Ph.D. Kupuna Education Center Kapiolani Community College
Hawaii State Hospital Department of Health	
Lynn N. Fallin, Deputy Director	Mark A. Fridovich, Ph.D., Chief Adult Mental Health Administration
Office of Aging City & County of Honolulu	
Nalani Aki, Executive on Aging	Joel Nakamura, Grant Specialist Office of Aging City & County of Honolulu
Office of Aging Hawaii County	Alan Parker, Executive on Aging Hawaii County Office of Aging
Office of Aging Kauai County	Kealoha Takahashi, Executive on Aging Kauai Agency on Elderly Affairs

INVITEE	PARTICIPANT / DESIGNEE
Office of Aging Maui County	
Deborah Stone-Walls Executive on Aging	Norma Circle, Program Specialist Aging and Disability
Hawaii Health Systems Corporation Oahu Region	
Derek Akiyoshi Interim CEO Oahu Region	
Hawaii Health Systems Corporation West Hawaii Region	
Jay E. Kreuzer CEO West Hawaii Region	
Hawaii Health Systems Corporation East Hawaii Region	
Howard Ainsely CEO East Hawaii Region	
Hawaii Health Systems Corporation Kauai Region	
Scott E. McFarland Interim CEO Kauai Region	Freddie Woodard, Jr., Regional COO - Kauai Hawaii Health Systems Corporation
Hawaii Health Systems Corporation Maui Region	
Wesley Lo CEO Maui Region	Kristian Stone, Director of Social Services Hawaii Health Systems Corporation
Castle Medical Center	
Kathryn Raethel, FACHE, MHA, MPH, RN President & Chief Executive Officer	Laura Westphal, Vice President for Patient Care Castle Medical Center

INVITEE	PARTICIPANT / DESIGNEE
Hawaii Pacific Health	
Ray Vara President & Chief Executive Officer	Michael Robinson, Director Government Relations Hawaii Pacific Health
Kahi Mohala Behavioral Health	
Leonard Licina Chief Executive Officer	Leonard Licina Chief Executive Officer
Kahuku Medical Center	
Stephany N. Vaioleti, FACHE Chief Executive Officer	Kori Napa'a, LSW Social Services
Kaiser Foundation Hospital	
Leanne M. Hunstock Chief Executive Officer	Phyllis Dendle Director, Government Relations
Kuakini Medical Center	
Gary K. Kajiwara President & CEO	June Drumeller Senior VP & Chief Clinical Officer
The Queen's Health Systems	
Arthur Ushijima President & CEO	Paula Yoshioka Senior VP, The Queen's Health Systems
Rehabilitation Hospital of the Pacific	
Timothy J. Roe, M.D. President & Chief Executive Officer	Audrey Torres Rehabilitation Hospital of the Pacific
Shriners Hospitals for Children	None, Declined Participation 7/31/14

INVITEE	PARTICIPANT / DESIGNEE
Wahiawa General Hospital	
R. Don Olden Chief Executive Officer	
Ann Pearl Nursing Facility	Alisa Racelo, LBSW, NHA Administrator
Healthcare Association of Hawaii	
	George W. Greene President & Chief Executive Officer Healthcare Association of Hawaii
Hawaii Long Term Care Association	Robert T. Ogawa, President Hawaii Long Term Association
Hawaii Association of Health Plans	
Jennifer Diesman, President Hawaii Association of Health Plans	Dave Heywood, Vice President Hawaii Association of Health Plans
AARP Hawaii	
Barbara K. Stanton State Director	Stuart Ho AARP Volunteer Issues Leader
Family Representative	Audrey Suga-Nakagawa AARP Executive Council Member
American Cancer Society	
Erin Moncada, Senior Director Community Engagement Network, Inc.	Cory Chun, Hawaii Government Relations American Cancer Society Cancer Action
Family Representative	Pending

INVITEE	PARTICIPANT / DESIGNEE
Alzheimer’s Association Aloha Chapter Head Quarters	
Christine Payne Executive Director & Chief Executive Officer	Pamela Scott, Program Coordinator Alzheimer’s Association Aloha Chapter Head Quarters
Family Representative	Pending
Hospice Hawaii	Kenneth L. Zeri, R.N., M.S. President & Chief Professional Officer
Family Representative	Terri T. Fujii
Castle Home Care	Emilie L. Smith Executive Director
Family Representative	Beth Hoban
Kokua Council c/o Harris United Methodist Church	
Larry Geller President	Barbara J. Service
Family Representative	Pending
Kokua Mau	Jeannette Koijane, M.P.H. Executive Director
Family Representative	Pending
Papa Ola Lokahi	Sharlene Chun-Lum Executive Director
	Gayle K. Bonham Executive Assistant
Family Representative	Pending

References

The following are references of the full meeting notes/minutes and/or presentation materials corresponding to the footnotes contained in the HCR 78 Report.

1. Steve Tam, “The CARE Act: What It Means for Hawaii”, *AARP*, September 22, 2014

2. Steve Tam, “2014 AARP Caregiving Survey: Opinions and Experiences of Hawaii Registered Voters Age 45 and Older” & “2014 AARP Caregiving Survey of Hawaii Registered Voters Age 45 and Older: Support for Family Caregivers When Loved Ones are Hospitalized”, *AARP*, November 12, 2014

3. HCR 78, “December 11, 2014 Meeting Minutes”

4. HCR 78, “July 28, 2014 Meeting Minutes”, “August 25, 2014 Meeting Minutes”, “September 22, 2014 Meeting Minutes”, “October 27, 2014 Meeting Minutes”, “November 12, 2014 Meeting Minutes”, “December 2, 2014 Meeting Minutes”, and “December 11, 2014 Meeting Minutes”

5. HCR 78, “December 11, 2014 Meeting Minutes”

6. Deborah Stone-Walls, “Benefits of Working with the Aging and Disability Resource Centers to Assist Family Caregivers in Coping Effectively with Hospital Discharge of Seniors Needing Care”, *Maui County Office of Aging*, December 2, 2014

7. HCR 78, “December 11, 2014 Meeting Minutes”

8. Deborah Stone-Walls, “Benefits of Working with the Aging and Disability Resource Centers to Assist Family Caregivers in Coping Effectively with Hospital Discharge of Seniors Needing Care”, *Maui County Office of Aging*, December 2, 2014

   Audrey Suga-Nagawa, “The Kauai Care Transition Program at Kauai Veterans Memorial Hospital, Hospital Discharge Planning Gran Final Evaluation Report”, *County of Kauai, Kauai Agency on Elderly Affairs*, August 29, 2013

9. HCR 78, “December 11, 2014 Meeting Minutes”

10. HCR 78, “December 11, 2014 Meeting Minutes”

11. Peter A. Sybinsky, Ph.D., “Hospital Readmission Rates”, *Hawaii Health Information Corporation*, November 12, 2014

    Wes Lum, “Community Resources Available for Caregiver Training”, *Executive Office on Aging*, November 12, 2014

12. Steve Tam, “The CARE Act: What It Means for Hawaii”, *AARP*, September 22, 2014

    Donna Sheather, “HCR 78 Caregiver Task Force Request for Information”, *The Queen’s Health Systems*, September 19, 2014

    HCR 78, “September 22, 2014 Meeting Minutes”

    Dionicia Lergapa, “Kaiser Permanente (KP) Response to: Caregiver Task Force Request for Information [HCR 78]”, *Kaiser Permanente*, October 27, 2014

13. HCR 78, “December 11, 2014 Meeting Minutes”

14. George Green, Esq., “Clarifying Information Related to Draft Family Caregivers Working Group Report: Finding 10-12”, *Healthcare Association of Hawaii*, January 16, 2015

15. HCR 78, “December 11, 2014 Meeting Minutes”

16. George Green, Esq., “Clarifying Information Related to Draft Family Caregivers Working Group Report: Finding 10-12”, *Healthcare Association of Hawaii*, January 16, 2015

17. Peter A. Sybinsky, Ph.D., “Hospital Readmission Rates”, *Hawaii Health Information Corporation*, November 12, 2014

18. Peter A. Sybinsky, Ph.D., “Letter Addressed to Co-Chair Chun Oakland and Co-Chair Takayama”, *Hawaii Health Information Corporation*, January 22, 2015

19. John T. Berthiaume, M.D., “Care Transition Program”, *Hawaii Medical Service Association*, October 27, 2014

20. “Hawaii Care Transition Program”, August 22, 2014

21. HCR 78, “December 11, 2014 Meeting Minutes”

22. Lois Nash, B.S., Pharm, M.S., “Report on Pharm2Pharm Program”, *Pali Momi Medical Center*, August 25, 2014

23. Peter A. Sybinsky, Ph.D., “Hospital Readmission Rates”, *Hawaii Health Information Corporation*, November 12, 2014

24. Peter A. Sybinsky, Ph.D., “Hospital Readmission Rates”, *Hawaii Health Information Corporation*, November 12, 2014

25. Peter A. Sybinsky, Ph.D., “Letter Addressed to Co-Chair Chun Oakland and Co-Chair Takayama”, *Hawaii Health Information Corporation*, January 22, 2015

26. Peter A. Sybinsky, Ph.D., “Letter Addressed to Co-Chair Chun Oakland and Co-Chair Takayama”, *Hawaii Health Information Corporation*, January 22, 2015

27. Deborah Stone-Walls, “Benefits of Working with the Aging and Disability Resource Centers to Assist Family Caregivers in Coping Effectively with Hospital Discharge of Seniors Needing Care”, *Maui County Office of Aging,* December 2, 2014

28. Steve Tam, “The CARE Act: What It Means for Hawaii”, *AARP*, September 22, 2014

Peter A. Sybinsky, Ph.D., “Hospital Readmission Rates”, *Hawaii Health Information Corporation*, November 12, 2014

John T. Berthiaume, M.D., “Care Transition Program”, *Hawaii Medical Service Association*, October 27, 2014

29. Peter A. Sybinsky, Ph.D., “Letter Addressed to Co-Chair Chun Oakland and Co-Chair Takayama”, *Hawaii Health Information Corporation*, January 22, 2015

30. HCR 78, “December 11, 2014 Meeting Minutes”

31. HCR 78, “December 2, 2014 Meeting Minutes”

34. Susan C. Reinhard, RN, Ph.D., “Home Alone: Family Caregiving Providing Complex Chronic Care”, *AARP*, October 2012

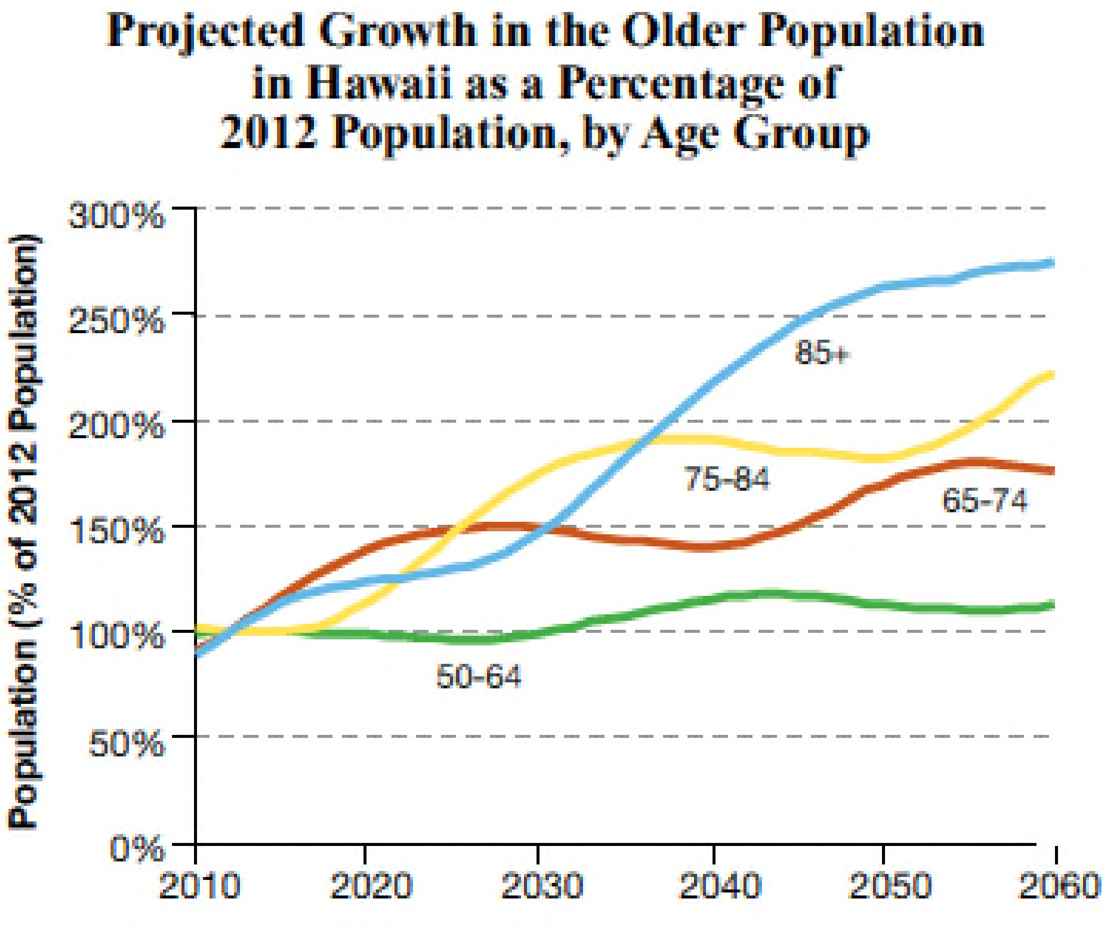
The CARE Act: What It Means for Hawaii

HCR78 Caregiver Working Group

September 22, 2014

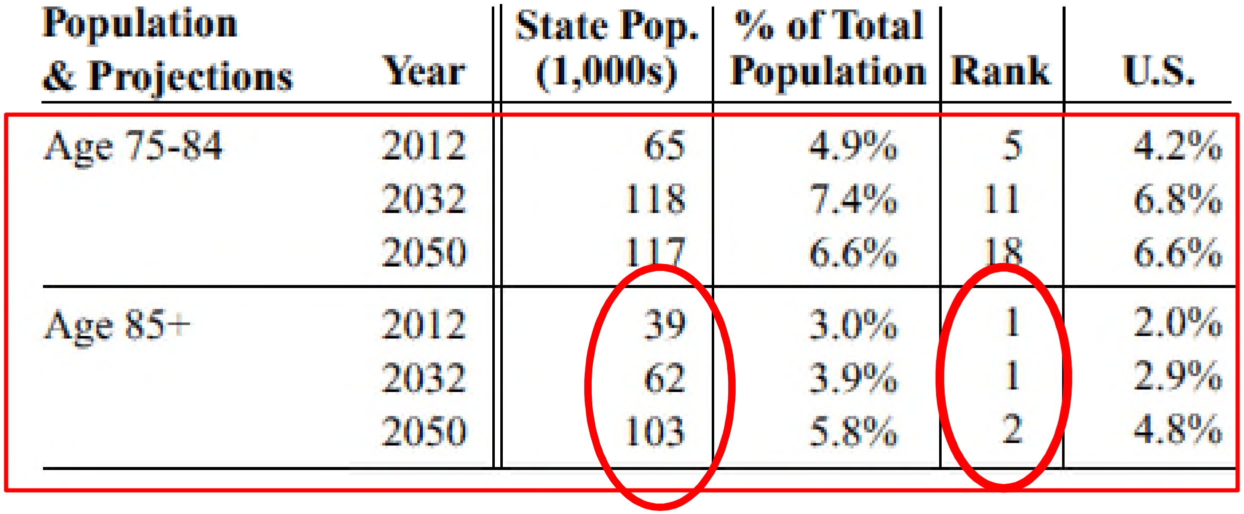
AARP®
Real Possibilities

The Challenge –
Shifting Demographics in Hawaii



Source: AARP Public Policy Institute, *Across the States 2012*

Shifting Demographics in Hawaii (cont.)



Population & Projections	Year	State Pop. (1,000s)	% of Total Population	Rank	U.S.
Age 75-84	2012	65	4.9%	5	4.2%
	2032	118	7.4%	11	6.8%
	2050	117	6.6%	18	6.6%
Age 85+	2012	39	3.0%	1	2.0%
	2032	62	3.9%	1	2.9%
	2050	103	5.8%	2	4.8%

Hawaii's has the oldest population in the nation!

Source: AARP Public Policy Institute, *Across the States 2012*

Caregivers “r” Us

“There are only four kinds of people. Those who have been caregivers, those who are caregivers, those who will be caregivers and those who will need caregivers.”

Family caregivers:

- Help loved ones **live independently at home** and out of costly institutional care, like nursing homes.
- Provide an **average of 20 hours a week** of care
- Others provide full-time 24/7 care.
- Many still **maintain a job** outside the home.
- They administer medicine and care, most often **without any training**.

AARP

Family Caregivers: The Backbone of the LTSS System

Economic Value of Family Caregiving in Hawaii in 2009:
$1.99 billion

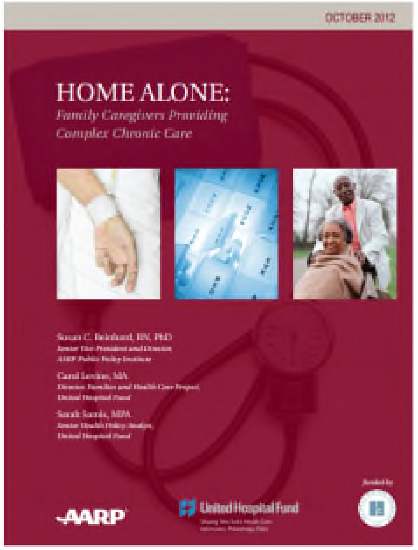
- In Hawaii, **247,000 people** (about 1 of 5 people) serve as a caregiver & provide **$1.99 billion** worth of services.
- Alternative – pay approximately **$4 billion** for a paid caregiver
- High cost – make family caregivers the only choice

Transitional Care – Hospitals to Home

- As population ages, situation will be more critical, as more Hawaii residents, will be admitted & discharged from hospitals *(Need no. of discharges by Hawaii hospitals)*
- In 2012 23% of Hawaii home health clients were hospitalized
- Hospitals are being viewed as the place where good transitional care must begin
- Family caregivers take over when discharged from hospitals

AARP's *Home Alone* Report

- Family caregivers perform complicated medical/nursing tasks and medication management
- Training is limited
- Most care recipients do not receive home visits by health professionals
- Performing medical/nursing tasks may prevent nursing home placement
- Caregiver quality of life affected



OCTOBER 2012

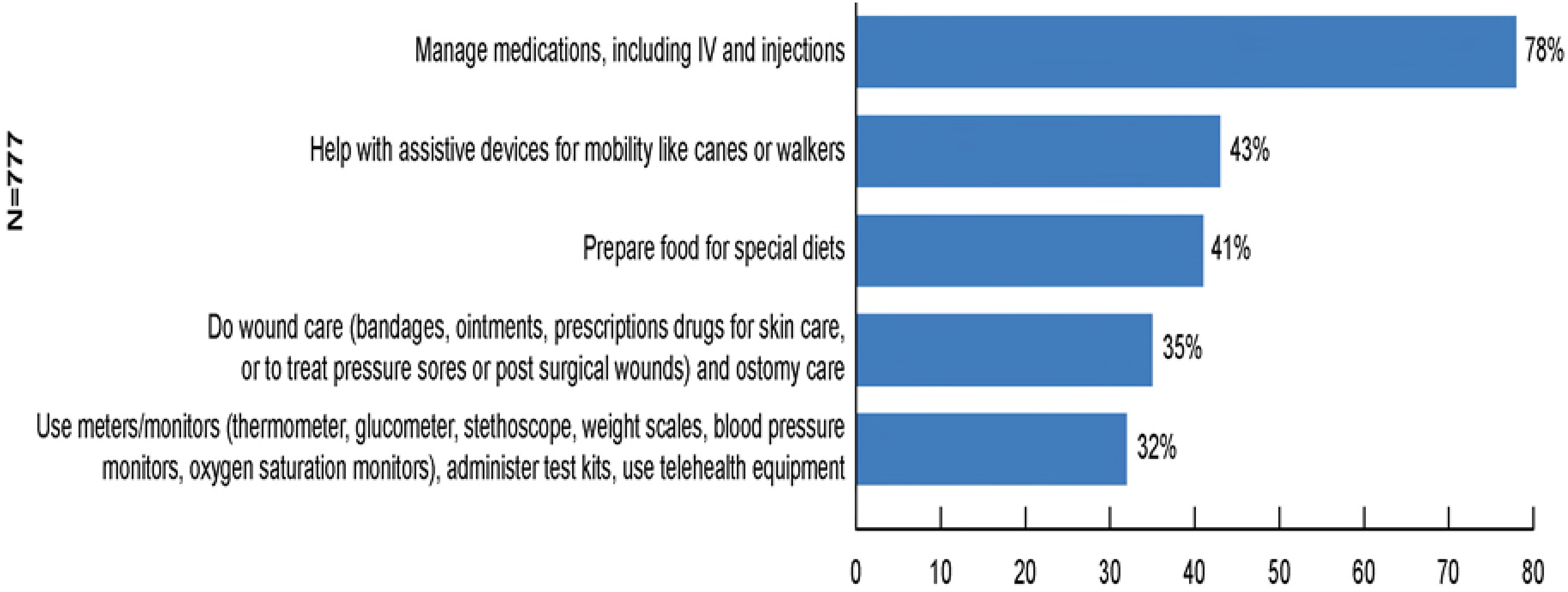
HOME ALONE:
Family Caregivers Providing Complex Chronic Care

Susan C. Reinhard, RN, PhD

Carol Levine, MA

Sarah Samis, MPA

Home Alone – Medical/Nursing Tasks

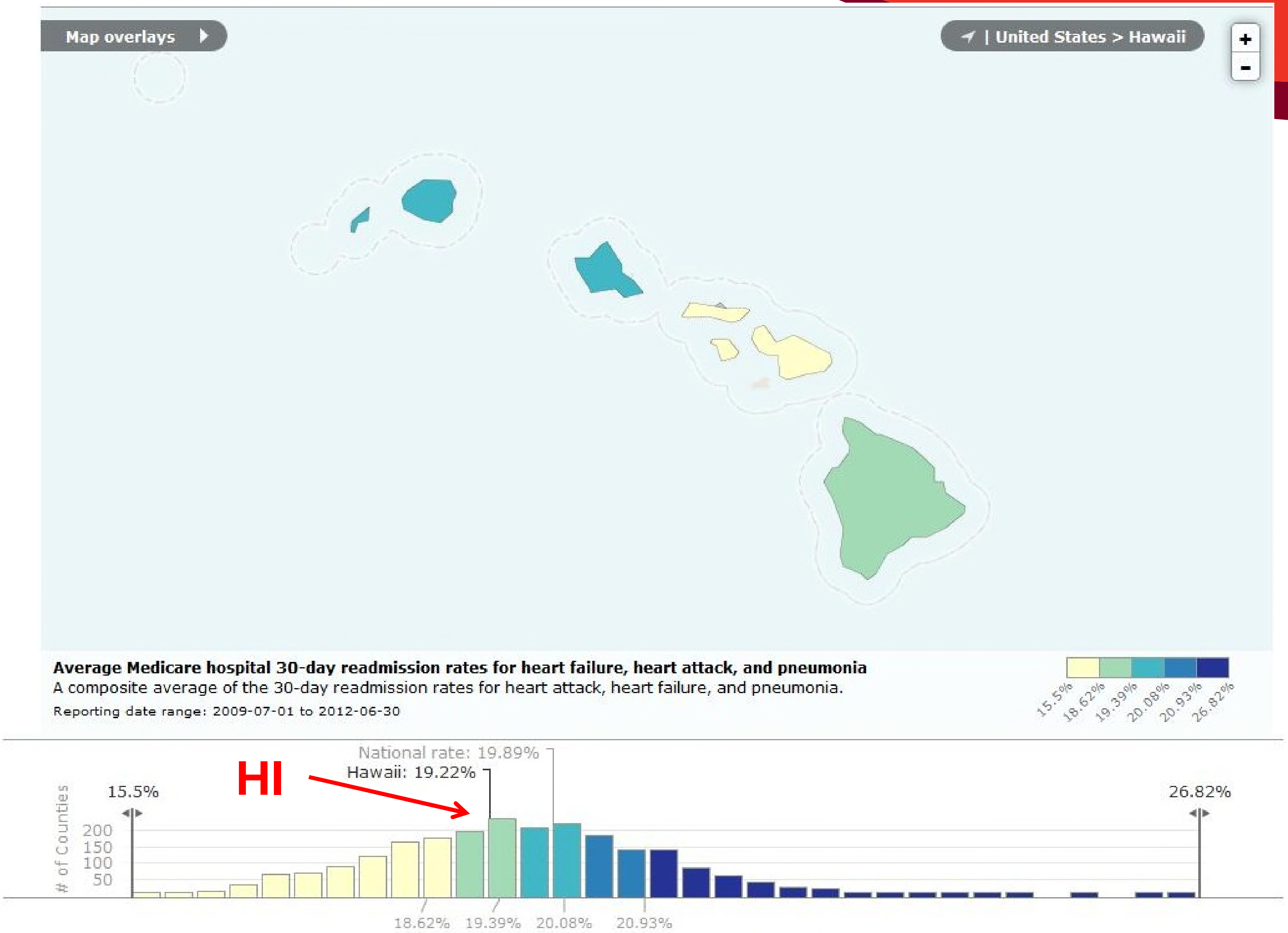


Training Family Caregivers – Cost Effective Solution to Improving Care at Home

Caregivers can Help Prevent Hospital Readmissions

Cost of Hospital Readmissions (National)

- 1 of every 8 Medicare beneficiaries who leave the hospital is readmitted in 30 days. *(Need HI readmission number)*
- Medicare alone reports spending $17.8 billion a year on patients whose return trips to the hospital could have been avoided.
- Under the Affordable Care Act (ACA), hospitals are penalized with a cut to their Medicare payments if these avoidable readmissions continue to occur.



Average Medicare hospital 30-day readmission rates for heart failure, heart attack, and pneumonia
A composite average of the 30-day readmission rates for heart attack, heart failure, and pneumonia.

Reporting date range: 2009-07-01 to 2012-06-30

The CARE Act

Caregiver

Advise

Record

Enable

The CARE Act

The purpose of the CARE Act is to ensure that hospitals include the caregiver in discharge planning and provide necessary training

- **Provision #1: Designation**
  - Record the name of the family caregiver upon admission into the hospital
- **Provision #2: Notification**
  - Contact the family caregiver(s) prior to discharge to another facility or home
  - Sets a time limit prior to discharge or transfer

The CARE Act

- **Provision #3: Consultation**
  - Hospital consults with caregiver on discharge plan, taking into account the caregiver’s capabilities and limitations
  - Discharge plan includes contact information for necessary health and community resources
- **Provision #4: Training**
  - Hospital gives caregiver the opportunity to receive instruction and live demonstration on all after-care tasks included in the discharge plan to be performed by the caregiver
  - Caregiver gets opportunity to ask questions

Caregiver Standards

In Hawaii:

- No requirement for caregiver designation, notification, or training.

Medicare:

- No requirement - caregiver designation or notification
- "As Needed" – caregiver involvement in discharge planning or training

Caregiver Standards

Joint Commission:

- No requirement for caregiver designation & inclusion in medical record. Only legal representative.
- No requirement for caregiver notification upon discharge. Hospital discretion if a family member (caregiver optional) should be provided discharge information.
- No requirement for in-person caregiver training. Hospitals inform family members (caregiver optional) about post-discharge care options (e.g., ongoing care, treatment/services needed). Hospitals to provide written discharge instructions.

AARP:

- **Stronger requirements for caregiver involvement that are not purely at discretion of hospitals**

Support for the CARE Act

Cancer Action Network℠
American Cancer Society®

FCA
FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

nac
NATIONAL ALLIANCE FOR CAREGIVING

CAREGIVER ACTION NETWORK
CAN™

Public Polling

Our polling and focus group work shows major support:

- Oklahoma poll showed **98% public support** -- *"Not a single respondent said they were against this idea."*

SoonerPoll.com

- Nationally, among possible policy helps for caregivers, “keeping caregivers informed” and “caregiver training” consistently rated as the #1 and #2 most supported options **across all polled groups**:

40-54	55-69	70+	Dem.	Ind.	Rep.

Mahalo

AARP
Real Possibilities

2014 AARP Caregiving Survey: Opinions and Experiences of Hawaii Registered Voters Age 45 and Older

Hawaii registered voters age 45+ want to live independently at home for as long as possible with the help of family caregivers. They strongly support having community services that will enable people to remain in their own homes as they age.

- Over three-quarters (75%) of Hawaii registered voters age 45+ say they **want to receive care for themselves or their loved ones at home with caregiver assistance** when the basic tasks of life become more difficult due to aging or illness.
    - The vast majority of Hawaii registered voters age 45+ says it is important to have **services that allow people to stay in their own home** as they age (86%) *and* more **resources and training** for family caregivers (77%).
    - Hawaii registered voters age 45+ believe it is important to have **strong community supports** to help people remain in their own homes as they age including hospice (85%), visiting nurses (81%), and well-trained certified home health care providers (81%).

- More than half (53%) of Hawaii registered voters age 45+ **are currently providing or have provided unpaid care to an adult loved one** who is ill, frail, elderly or has a physical or mental disability.
    - Nearly all (92%) Hawaii caregivers age 45+ believe it is important to be able to provide care so that their **loved ones can keep living independently in their own home**.
    - More than four in five of these caregivers are helping or have helped with shopping (86%), transportation (85%), meals (83%), and household chores (82%).
    - At least seven in ten **are helping or have helped with more complex tasks** like medication management (72%) and other nursing and medical tasks (70%).

- More than three in five (62%) Hawaii registered voters age 45+ say **it is likely that they will provide unpaid care to an adult loved one in the future.**

- Nearly all (91%) Hawaii registered voters age 45+ would support **a proposal to provide short-term help from a home health aide so family caregivers can take a break from caregiving duties.**

- The vast majority of Hawaii registered voters age 45+ **supports proposals to help family caregivers on the job**:
    - Three-quarters or more support ensuring **employers cannot fire employees for taking time off for caregiving** (86%), and requiring employers to provide a limited amount of **unpaid leave** (85%) **and some paid leave** (77%) to employees for caregiving purposes.

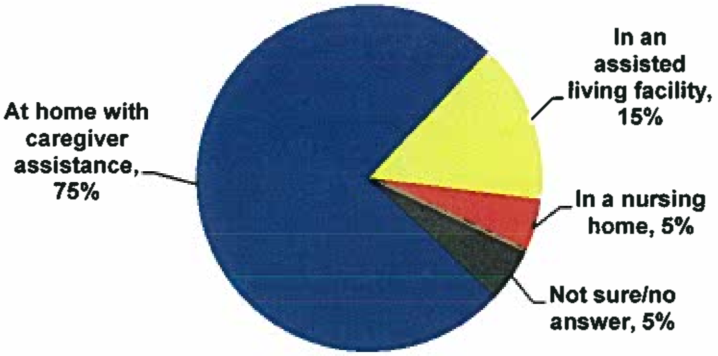
- Nearly all Hawaii registered voters age 45+ **strongly support proposals that would help family caregivers when their loved ones go into hospitals**:
    - More than nine in ten support requiring hospitals to **explain and demonstrate medical tasks** that family caregivers will need to perform after the patient returns home (95%) and **keep family caregivers informed of medical decisions regarding the patient** (94%).
    - Over four in five (86%) support requiring hospitals to **record the family caregiver's information in the patient's medical record**.

- The vast majority (88%) of Hawaii registered voters age 45+ **strongly supports a proposal to provide a state income tax credit to family caregivers who incur expenses for the care of an older family member living with them.**

Living Independently

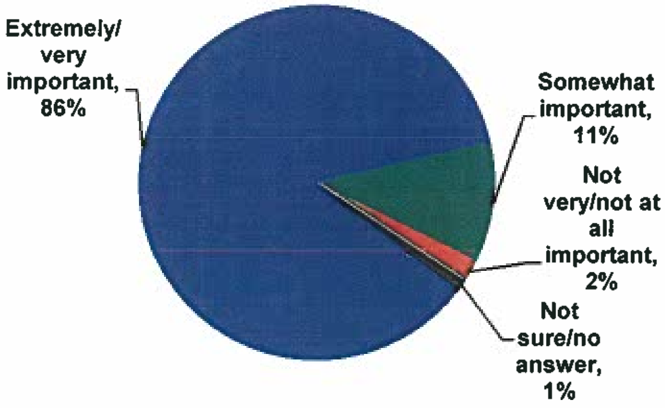
Most (75%) Hawaii registered voters age 45+ want to receive care for themselves or their loved ones at home with caregiver assistance when the basic tasks of life become more difficult due to aging or illness.

Where Do Hawaii Registered Voters Age 45+ Want to Live When Basic Life Tasks Become More Difficult?
(n=1,000)

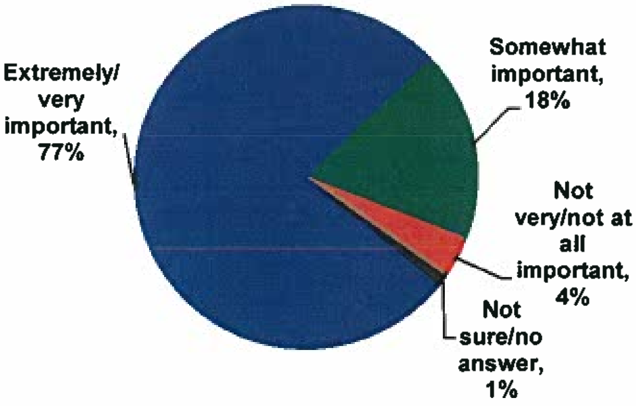


The vast majority of Hawaii registered voters age 45+ believes it is important to have services that allow people to stay in their own home as they age for as long as possible (86%) and more resources and training for family caregivers so they can continue to help their loved ones live independently (77%).

Importance of Having Services that Allow People to Stay in Their Own Homes as They Age
(n=1,000)



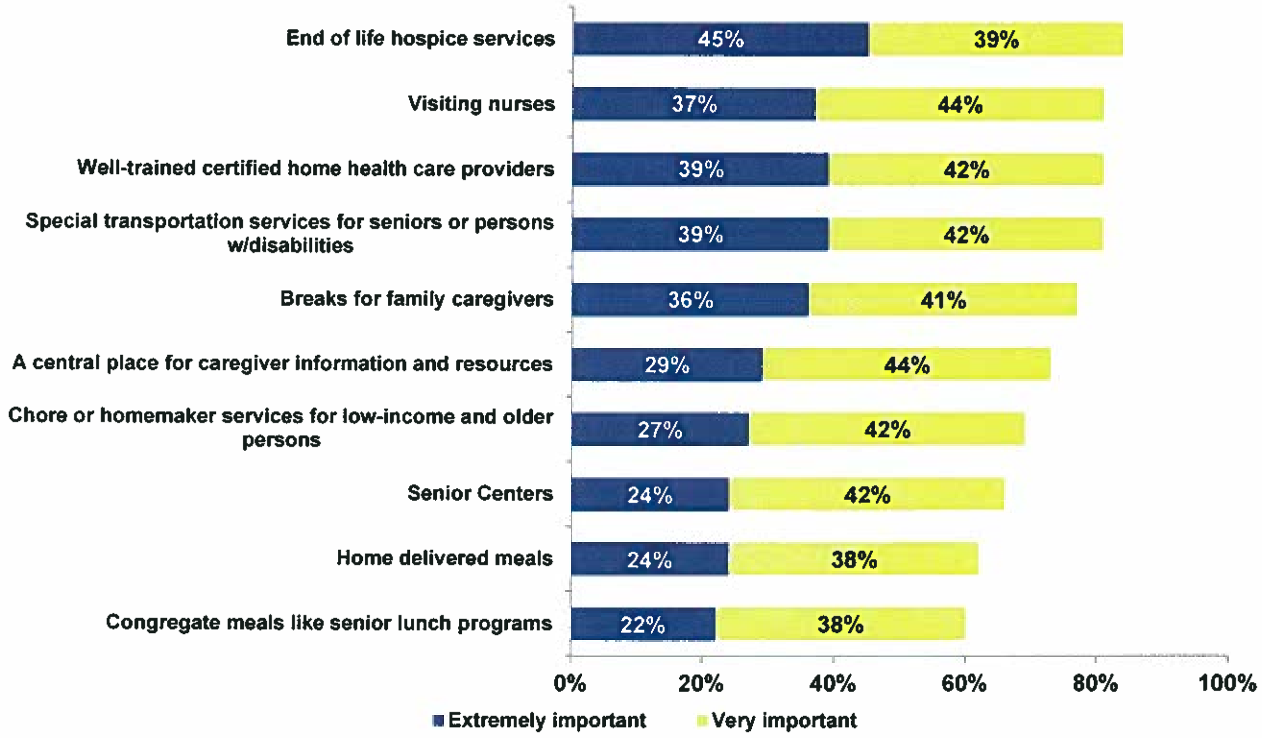
Importance of Having More Resources and Training for Caregivers
(n=1,000)



Hawaii registered voters age 45+ believe it is important to have strong community supports to help people remain in their own homes as they age.

- ✓ At least four in five believe having hospice (85%), visiting nurses (81%), well-trained certified home health care providers (81%), and special transportation services (81%) in their communities to help people live independently is extremely or very important.
- ✓ At least seven in ten say it is extremely or very important to have breaks for family caregivers (77%), centrally located information for caregivers (72%), and homemaker services (69%) in their community.
- ✓ About three in five say having senior centers (66%), home delivered meals (61%), and senior lunch programs (59%) in their community is extremely or very important.

Community Services of Importance to Hawaii Registered Voters Age 45+
(n=1,000)

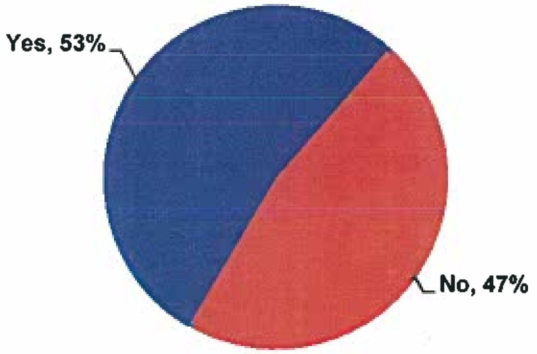


Family Caregivers

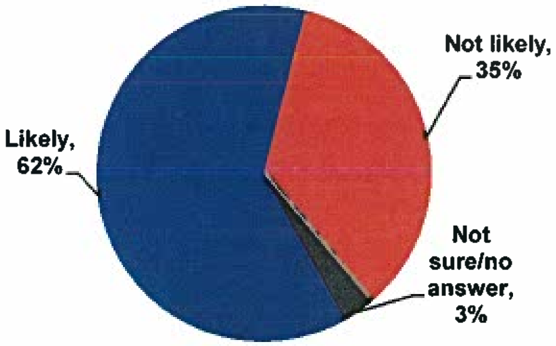
More than half (53%) of Hawaii registered voters age 45+ are providing or have provided unpaid care for their loved ones *and* the majority is also likely to provide unpaid care in the future (62%).

- ✓ Over half of Hawaii registered voters age 45+ say they are currently providing unpaid care (21%) or have provided unpaid care (32%) for an adult loved one who is ill, frail, elderly, or has a physical or mental disability. The average age of the person they are caring or have cared for is 81 years old.
- ✓ Moreover, over three in five (62%) Hawaii registered voters age 45+ report that they are likely to provide unpaid care to an adult loved one in the future.
- ✓ The average age of Hawaii caregivers is 62 years old and the majority is female (59%), married (65%), has a two year college degree or higher (66%), working either full or part-time (53%) and has an annual household income of less than $100,000 (58%).

Are Hawaii Registered Voters Age 45+ Currently Providing or Have They Provided Unpaid Care to an Adult Loved One?
(n=1,000)



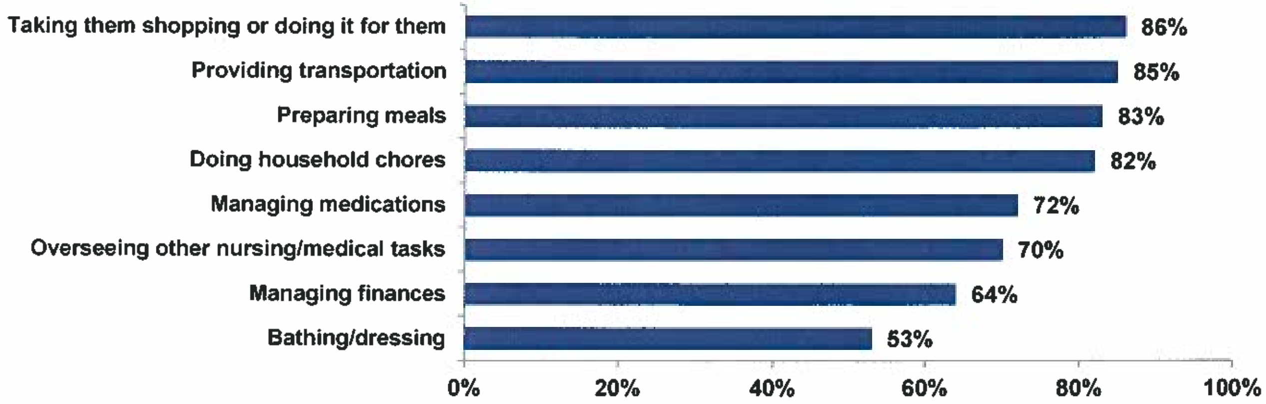
Likelihood of Needing to Provide Care for an Adult Loved One in the Future
(n=1,000)



Hawaii <u>caregivers</u> age 45+ are helping or have helped the loved ones in their care with activities like shopping (86%), transportation (85%), meals (83%), and chores (82%) as well as more complex care like medication management (72%) and nursing and other medical tasks (70%).

- ✓ Many are also helping with or have helped with other tasks like managing finances (64%) and bathing and dressing (53%).

Daily Activities that Hawaii Caregivers Age 45+ Are Providing or Have Provided*
(n=529, Respondents Who Are Current or Past Caregivers)

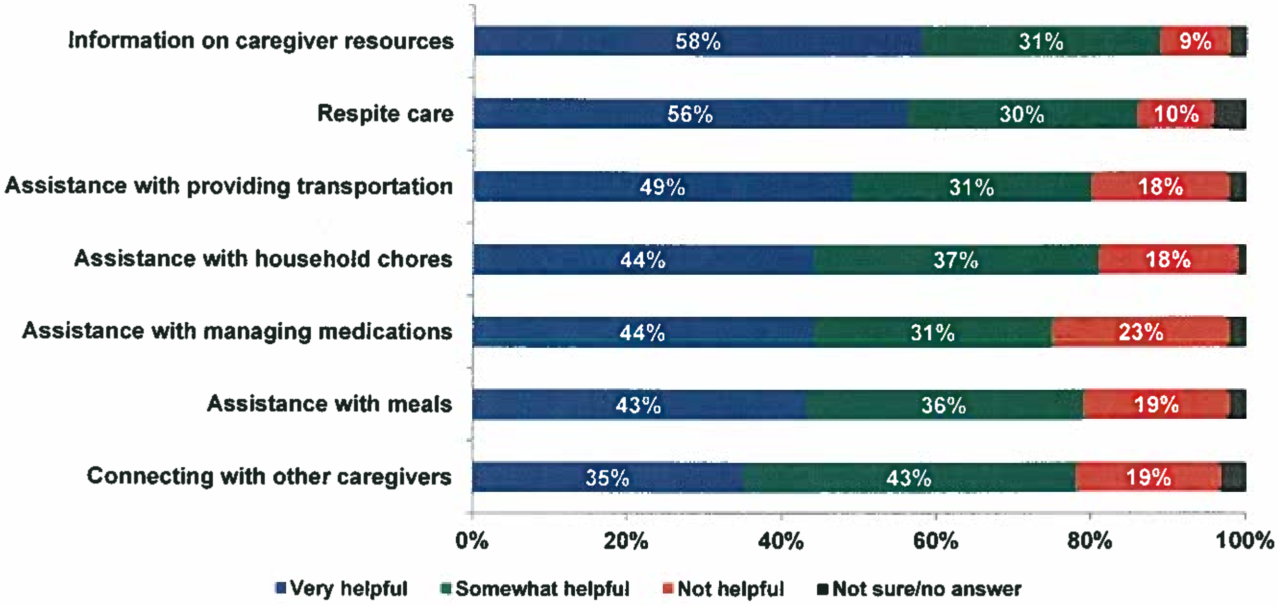


*Graph shows respondents who checked "yes" under each type of daily activity.

Hawaii registered voters age 45+ say they would find information about available caregiver resources (58%) and respite care or breaks from caregiving responsibilities (56%) the most helpful.

- ✓ Just under half say they would find assistance with transportation (49%), household chores (44%), understanding how to manage medications (44%), and help with providing meals (43%) very helpful.
- ✓ Just over a third say it would be very helpful to have opportunities to connect with other caregivers in similar situations (35%).

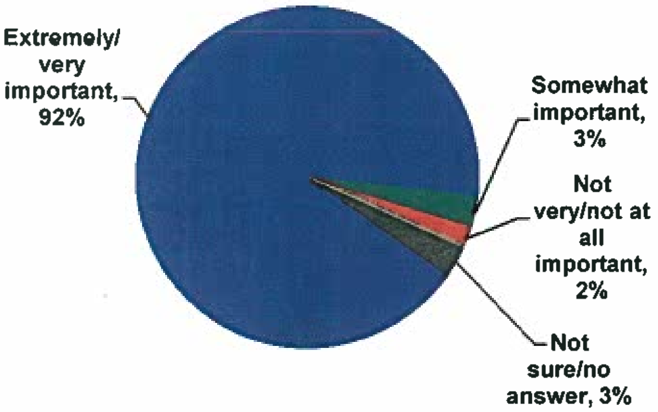
Helpfulness of Types of Caregiver Support Among Hawaii Registered Voters Age 45+*
(n=1,000)



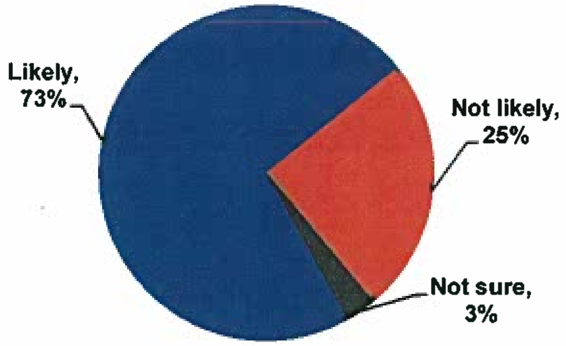
*Percentages less than 5 percent are now shown.

Nearly all (92%) Hawaii caregivers age 45+ believe it is important to be able to provide care so that their loved ones can keep living independently in their own home and many of these caregivers (73%) say it is likely that they will provide caregiving on an unpaid basis in the future.

Importance of Providing Care to Adult Loved Ones Among Hawaii Caregivers Age 45+
(n=529, Respondents Who Are Current or Past Caregivers)



Likelihood of Needing to Provide Care for an Adult Loved One in the Future Among Hawaii Caregivers Age 45+*
(n=529, Respondents Who Are Current or Past Caregivers)



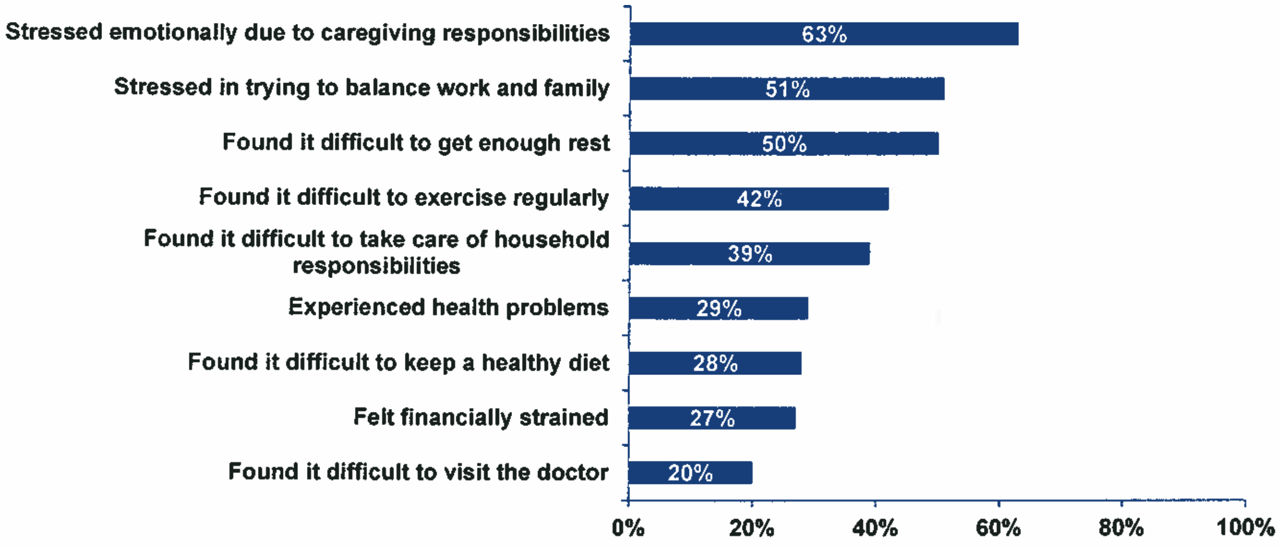
*Percentages may not add up to 100 percent due to rounding.

Support for Family Caregivers at Home

Many Hawaii caregivers age 45+ report having felt emotionally and financially stressed as well as not being able to take care of their needs and the needs of their other family members.

- ✓ At least half of Hawaii caregivers report having felt emotionally stressed in general (63%) and stressed in trying to balance their work and family (51%) as well as having found it difficult to get enough rest (50%).
- ✓ About two in five say they have found it difficult to exercise regularly (42%) and take care of their household (39%).
- ✓ A plurality also report having experienced health problems (29%), difficulty in keeping a healthy diet (28%), felt financially stressed (27%), and difficulty finding time to visit their doctor (20%).

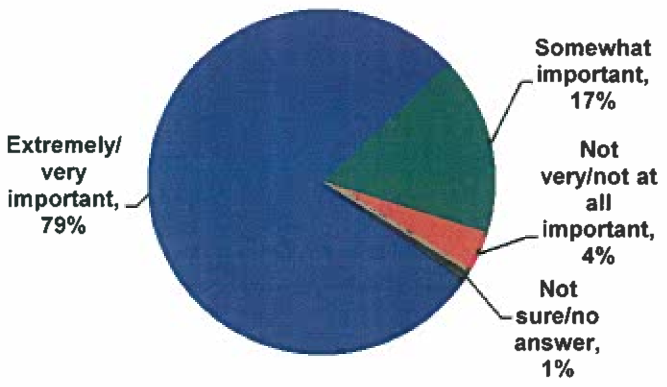
Experiences of Hawaii Caregivers Age 45+*
(n=529, Respondents Who Are Current or Past Caregivers)



*Graph shows respondents who checked "yes" under each type of experience.

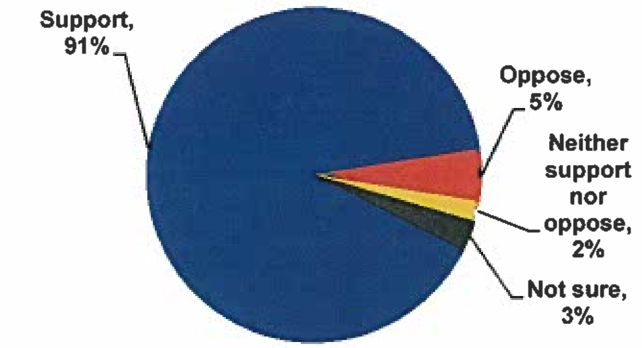
The vast majority (79%) of Hawaii registered voters age 45+ believes it is important to have community services that allow family caregivers to take a break from their caregiving duties and nearly all (91%) would support a proposal to provide short-term help from a home health aide so caregivers can get a break.

Importance of Having Services that Allow Family Caregivers to Take a Break Among Hawaii Registered Voters Age 45+*
(n=1,000)



*Percentages may not add up to 100 percent due to rounding.

Support for A Respite Care Proposal Among Hawaii Registered Voters Age 45+*
(n=1,000)



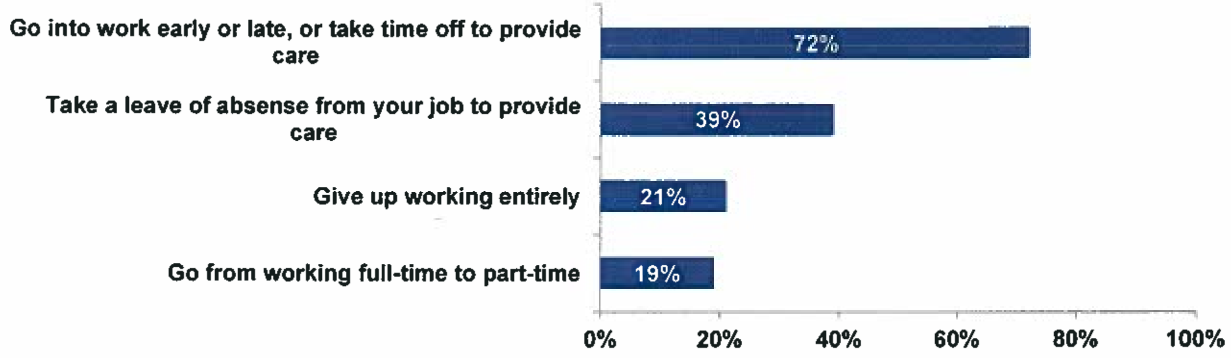
*Percentages may not add up to 100 percent due to rounding.

Support for Family Caregivers in the Workplace

Many Hawaii caregivers age 45+ have had to make adjustments to their work schedules or give up working altogether in order to care for an adult loved one.

- ✓ More than three in five (61%) Hawaii caregivers say they work or have worked full or part-time while providing care to an adult loved one.
- ✓ Nearly three-quarters (72%) of these working caregivers have had to go into work early or late, or take time off to care for a loved one. Further, three-quarters (75%) of these caregivers have had to adjust their work schedules once a month or more to provide care.
- ✓ Many working caregivers have also had to take a leave of absence (39%), work reduced hours (19%), or give up working entirely (21%) to provide care for an adult loved one.
- ✓ Over half (51%) of Hawaii working caregivers report feeling stressed out in trying to balance their job and family.

Workplace Actions Hawaii Caregivers Age 45+ Have Had to Take in Order to Care for an Adult Loved One*
(n=529, Respondents Who Are Current or Past Caregivers)

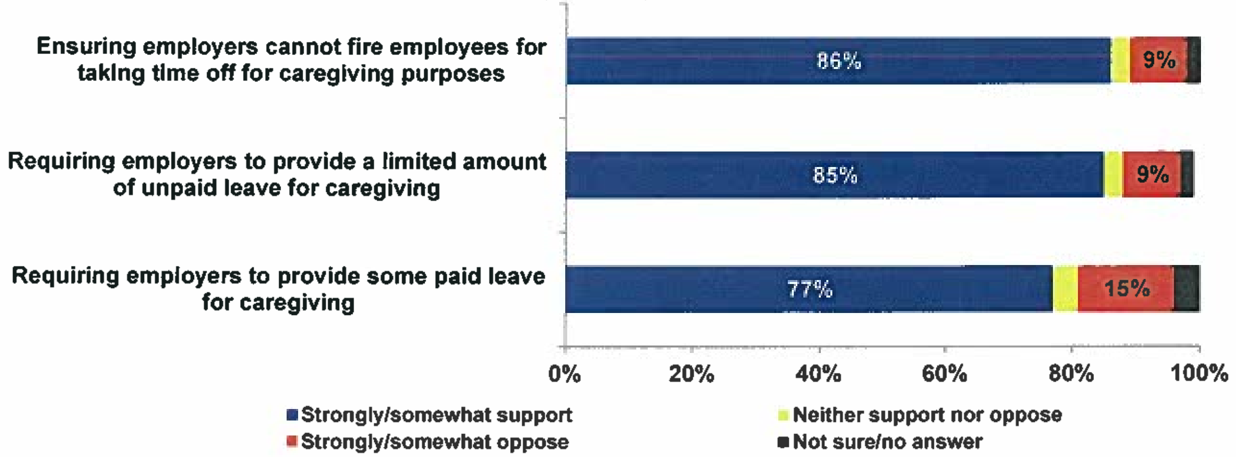


*Graph shows respondents who checked "yes" under each type of action.

The vast majority of Hawaii registered voters age 45+ strongly supports proposals to help family caregivers care for their loved ones and continue to work.

- ✓ More than four in five support ensuring that employers cannot fire employees who take time off to provide care for their adult loved ones (86%).
- ✓ Similar proportions also support requiring employers to provide a limited amount of unpaid leave (85%) and some paid leave (77%) to employees for caregiving purposes.

Support for Proposals to Help Family Caregivers in the Workplace Among Hawaii Registered Voters Age 45+*
(n=1,000)



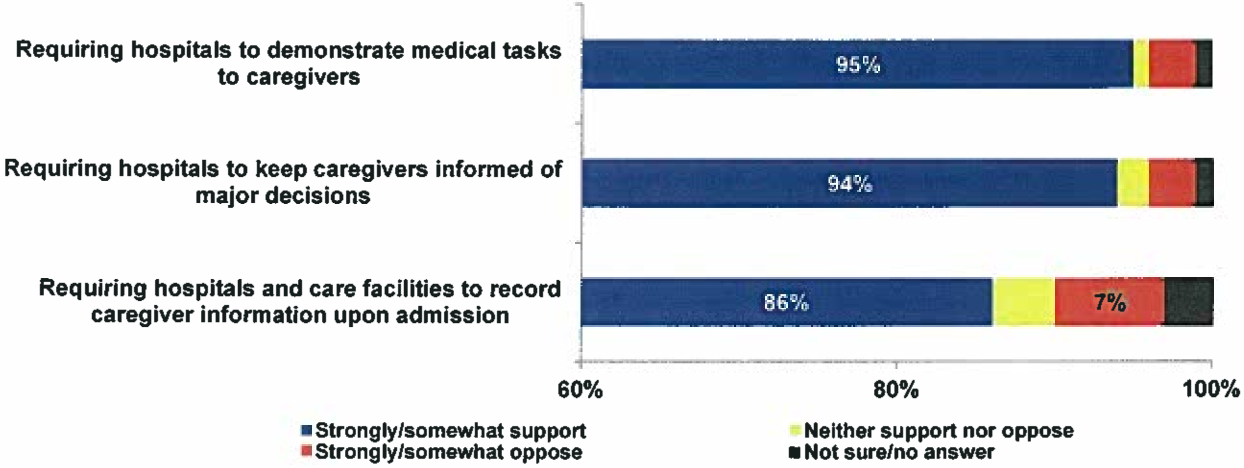
*Percentages less than 5 percent are not shown.

Support for Family Caregivers When Loved Ones are Hospitalized

Nearly all Hawaii registered voters age 45+ strongly support proposals that would help family caregivers when their loved ones go into hospitals, and then transition home.

- ✓ Nearly all Hawaii registered voters age 45+ support requiring hospitals to explain and demonstrate medical and nursing tasks that family caregivers will need to perform after the patient returns home with 79 percent *strongly* supporting this proposal.
- ✓ Nearly all support requiring hospitals to keep a family caregiver informed of major decisions, like transferring or discharging the patient with 75 percent *strongly* supporting this proposal.
- ✓ Over four in five support requiring hospitals and care facilities to record the name of a patient's family caregiver in the medical record upon admission with 58 percent *strongly* supporting the proposal.

Support for Proposals to Help Family Caregivers When Loved Ones Go into Hospitals Among Hawaii Registered Voters Age 45+*
(n=1,000)



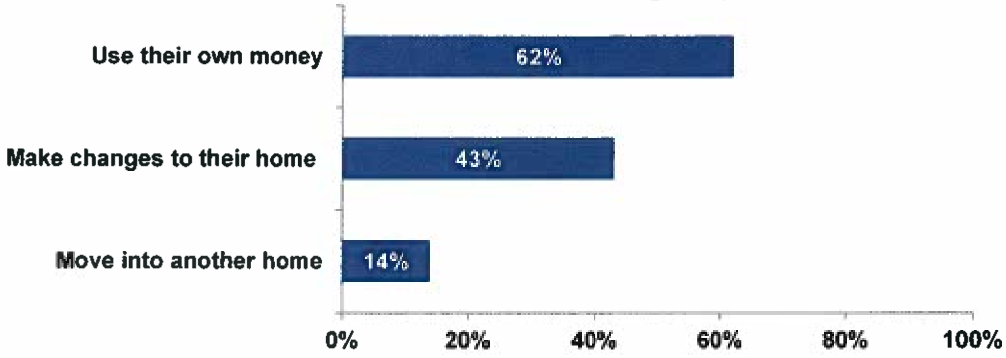
*Percentages less than 5 percent are not shown.

Financial Support for Family Caregivers

The majority (62%) of Hawaii caregivers age 45+ has used their own money to help provide care to their loved ones.

- ✓ Over three in five (62%) Hawaii caregivers say they have used their own money to help provide care for their loved one. In fact, over a quarter (27%) says they have felt financially strained because of their caregiving responsibilities.
- ✓ More than two in five (43%) report having to make changes to their home for the loved one in their care, while another one in seven (14%) have actually had to move into another home to care for their loved one.

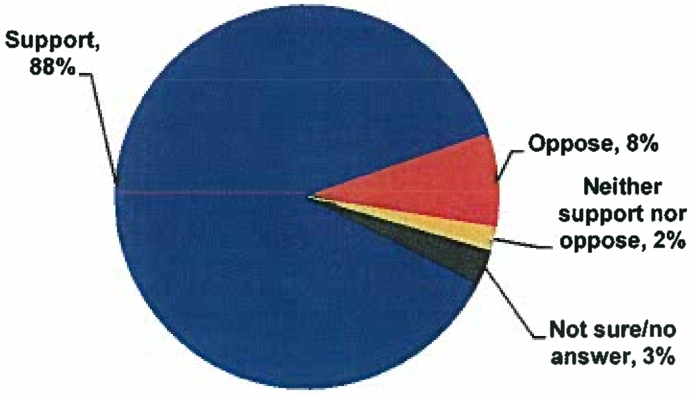
Actions Hawaii Caregivers Age 45+ Have Had to Take in Order to Care for an Adult Loved One*
(n=529, Respondents Who Are Current or Past Caregivers)



*Graph shows respondents who checked "yes" under each type of action.

Hawaii registered voters age 45+ overwhelmingly (88%) support providing a state income tax credit to family caregivers who incur expenses for the care and support of an older family member living with them.

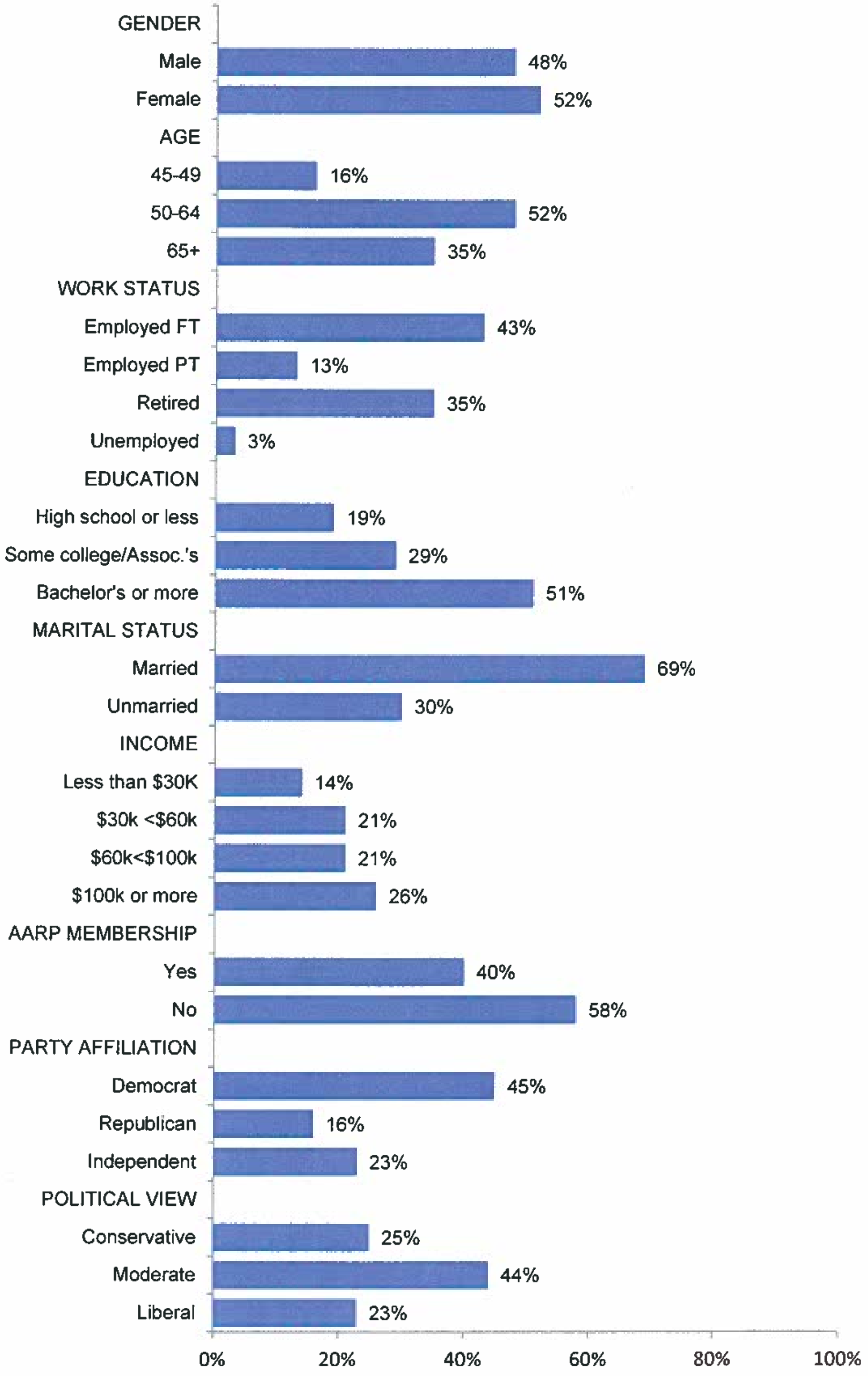
Support for a State Income Tax Credit for Family Caregivers Among Hawaii Registered Voters Age 45+*
(n=1,000)



*Percentages may not add up to 100 percent due to rounding.

DEMOGRAPHIC PROFILE OF HAWAII RESPONDENTS

(n=1,000)



ANNOTATED SURVEY

2014 AARP Survey of Hawaii Registered Voters Age 45 and Older on Caregiving
Weighted by Age, Gender and County of Residence
(Weighted n=1,000, Sampling Error = +/-3.2%)

INTRODUCTION/SCREENER

Hello, this is ______ calling from Precision Research. We are not telemarketers and are not trying to sell you anything. We are interested in your views on caregiving and helping older people in Hawaii live independently as they age. Your views are important and we would greatly appreciate your participation. All your responses will be kept entirely confidential.

INTERVIEWER INSTRUCTIONS: IF NECESSARY, THE FOLLOWING INFORMATION CAN BE PROVIDED TO RESPONDENT.

- We are not permitted to disclose the sponsor at the beginning of the survey because there is a concern it could bias responses. If you would like that information when we are finished with the interview, I will provide it to you.
- We are not selling anything, and we will not ask you to contribute to any organization.
- Your opinions will be kept confidential and used for research purposes only.
- The interview should take about **15** minutes depending on your answers.

SCREENING QUESTIONS

S1. Our study is interested in the opinions of people in certain age groups. Could you please tell me your age as of your last birthday? **[IN YEARS] __________ [RECORD ACTUAL AGE AND USE THE AGE GROUPS BELOW TO KEEP TRACK OF HOW MANY RESPONDENTS WE ARE GETTING IN EACH GROUP.]**

1000	N=
	[DO NOT READ] Under 45 **[ASK TO SPEAK TO SOMEONE 45 OR OLDER AND REPEAT INTRO AND THEN ASK S1. IF NO ONE 45 OR OLDER, TERMINATE.]**
16.3%	45-49
17.0%	50-54
31.3%	55-64
35.4%	65+
-	[DO NOT READ] Refused **[GO TO S2]**

S2. [RECORD RESPONDENT'S GENDER. ASK ONLY IF ABSOLUTELY NECESSARY.] "To ensure it is recorded accurately, could you please state your gender?"

1000	N=
47.8%	Male
52.2%	Female

S3. In which county do you live? **[READ COUNTIES ONLY IF NEEDED]**

1000	N=
14.9%	Hawaii **[ASKQUESTION S5]**
5.4%	Kauai **[SKIP TO QUESTION S6]**
67.9%	Honolulu **[SKIP TO QUESTION S6]**
11.7%	Maui **[SKIP TO QUESTION S6]**
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

S4. Do you live closer to Hilo or Kona?

149	N=
42.9%	Hilo
25.2%	Kona
26.4%	[DO NOT READ] Someplace else
5.0%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

S5. Are you registered to vote in Hawaii?

1000	N=
100.0%	Yes
-	No **[THANK AND TERMINATE]**

MAIN QUESTIONNAIRE

1. A family caregiver is someone who provides UNPAID care for an adult loved one who is ill, frail, elderly, or has a physical, mental, or emotional disability. This unpaid care may include assisting with personal needs like bathing and dressing, household chores, meals, shopping, transportation, or managing finances or medical care.

Are you currently a family caregiver providing UNPAID care to an adult loved one?

[INTERVIEWER NOTE: IF THE RESPONDENT ASKS IF THE PERSON THEY ARE PROVIDING CARE TO HAS TO LIVE WITH THEM THE INTERVIEWER SHOULD SAY "THIS PERSON DOES NOT HAVE TO LIVE WITH YOU."]

1000	N=
20.9%	Yes, I am currently providing care to an adult loved one
79.0%	No **[SKIP TO QUESTION 17]**
0.1%	[DO NOT READ] Not sure **[SKIP TO QUESTION 17]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 17]**

QUESTIONS 2 THROUGH 17 ARE FOR CURRENT CAREGIVERS

2. What is the age of the person you are providing care for? **[INTERVIEWER: IF THEY ARE PROVIDING CARE TO MORE THAN ONE PERSON, ASK THEM TO ANSWER BASED ON THE PERSON THEY ARE PROVIDING THE MOST CARE TO.] [RECORD AGE IF KNOWN AND GIVEN; IF NOT KNOWN OR GIVEN, TRY TO RECORD IT IN THE RANGE BELOW.]**

209	**N=**
-	_______ **[RECORD AGE]**
-	Under 18 **[SKIP TO QUESTION 17]**
4.4%	18-49
1.8%	50-59
1.0%	60-64
92.3%	65+
-	[DO NOT READ] Not sure
0.4%	[DO NOT READ] Refused

3. Still thinking about the person you are providing care to the most, which of the following daily activities are you providing? Are you **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH H.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Assisting with bathing or dressing

209	N=
39.6%	Yes
60.4%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Providing transportation to appointments

209	N=
83.5%	Yes
16.1%	No
0.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Taking them shopping or shopping for them

209	N=
86.7%	Yes
13.3%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

d. Helping them with meals

209	N=
81.1%	Yes
18.9%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

e. Helping them to manage finances

209	N=
64.9%	Yes
34.8%	No
0.3%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

f. Aiding with household chores

209	N=
78.5%	Yes
21.5%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

g. Overseeing their medication management

209	N=
70.2%	Yes
29.3%	No
0.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

h. Being responsible for other medical or nursing tasks

209	N=
66.0%	Yes
30.9%	No
3.2%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

4. Are there any other activities that you are providing?

209	N=
33.3%	Yes **[ASK Q5]**
63.8%	No **[SKIP TO QUESTION 6]**
2.9%	[DO NOT READ] Not sure **[SKIP TO QUESTION 6]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 6]**

5. What are they? **[RECORD RESPONSES]**

____

6. Have you ever been employed either full or part-time while providing care to your adult loved one?

209	N=
62.3%	Yes **[ASK Q7]**
36.6%	No **[SKIP TO QUESTION 11]**
1.0%	[DO NOT READ] Not sure **[SKIP TO QUESTION 11]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 11]**

7. Now thinking again about the adult loved one you are currently providing care to, did you ever have to **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH D. RECORD A RESPONSE FOR EACH ITEM.**]?

a. Go into work early or late, or take time off to provide care for a loved one

130	N=
77.4%	Yes
22.6%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Take a leave of absence from your job to provide care for a loved one

130	N=
46.1%	Yes
53.9%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Go from working full-time to part-time to provide care for a loved one

130	N=
23.8%	Yes
75.3%	No
0.9%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

d. Give up working entirely to provide care for a loved one

130	N=
19.8%	Yes
80.2%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

8. Are there any other things related to your work life that you ever had to do in order to care for your loved one?

130	N=
16.2%	Yes **[ASK Q9]**
83.8%	No **[SKIP TO QUESTION 10]**
-	[DO NOT READ] Not sure **[SKIP TO QUESTION 10]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 10]**

9. What were they? **[RECORD RESPONSES]**

---

10. [IF Q7A=YES ASK]: You mentioned that you had to go into work early or late, or take time off to provide care to an adult loved one. How often would you say you had to take time away from work or adjust your work schedule to provide care for someone? Would you say **[INSERT AND READ EACH ANSWER CATEGORY.]**?

101	N=
14.6%	More than once per week
8.8%	Once per week
31.0%	Several times per month but less often than once per week
12.7%	Once per month
30.7%	Less than once per month
2.3%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

11. Now thinking again about the adult loved one you are currently providing care to, did you ever have to **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH C.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Use your own money to help provide care

209	N=
66.1%	Yes
32.9%	No
0.5%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

b. Make changes to your home for the loved one in your care

209	N=
44.2%	Yes
55.8%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Move into another home to accommodate the loved one in your care

209	N=
11.5%	Yes
88.5%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

12. Are there any other things you ever had to do?

209	N=
22.6%	Yes **[ASK Q13]**
72.8%	No **[SKIP TO QUESTION 14]**
4.5%	[DO NOT READ] Not sure **[SKIP TO QUESTION 14]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 14]**

13. What were they? **[RECORD RESPONSES]**

14. As a caregiver have you ever **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH I.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Felt stressed out emotionally due to your caregiving responsibilities

209	N=
64.0%	Yes
33.9%	No
2.2%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Felt stressed out in trying to balance your job and family

209	N=
50.6%	Yes
48.3%	No
1.0%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Found it difficult to maintain a healthy diet

209	N=
27.3%	Yes
72.7%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

d. Found it difficult to get enough rest

209	N=
47.1%	Yes
52.9%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

e. Found it difficult to exercise regularly

209	N=
42.2%	Yes
57.8%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

f. Found it difficult to take care of your household responsibilities

209	N=
40.1%	Yes
57.7%	No
2.2%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

g. Experienced problems with your health

209	N=
35.2%	Yes
64.4%	No
0.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

h. Found it difficult to find time to visit your doctor

209	N=
23.0%	Yes
75.9%	No
1.1%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

i. Felt strained financially due to your caregiving responsibilities

209	N=
32.6%	Yes
67.0%	No
0.4%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

15. How important is it to you to be able to provide care for your loved one so that they can keep living independently in their own home? Is it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

209	N=
56.1%	Extremely important
36.7%	Very important
3.7%	Somewhat important
-	Not very important
1.0%	Not at all important
2.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

16. How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for an adult loved one in the future? Is it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

209	N=
46.7%	Extremely likely
27.1%	Very likely
15.3%	Somewhat likely
4.9%	Not very likely
4.3%	Not at all likely
1.7%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

SKIP TO Q 34

QUESTIONS 17 THROUGH 32 ARE FOR FORMER CAREGIVERS AND EMULATE THOSE FOR CURRENT CAREGIVERS.

NOTE TO DATA PROGRAMMERS: DURING THE DATA PROCESSING QUESTIONS 2 THROUGH 32 NEED TO BE RUN AS IS AND ALSO COLLAPSED SO THAT THERE IS ONE SET OF DATA FOR EACH OF THESE QUESTIONS THAT AGGREGATES CURRENT AND FORMER CAREGIVERS TOGETHER.

17. Have you ever been a family caregiver who provided UNPAID care to an adult loved one?

[INTERVIEWER NOTE: IF THE RESPONDENT ASKS IF THE PERSON THEY HAVE PROVIDED CARE TO HAD TO LIVE WITH THEM THE INTERVIEWER SHOULD SAY "THIS PERSON DID NOT HAVE TO LIVE WITH YOU."]

791	N=
40.8%	Yes, I have provided care to an adult loved one in the past
59.2%	No **[SKIP TO QUESTION 33]**
-	[DO NOT READ] Not sure **[SKIP TO QUESTION 33]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 33]**

18. What was the age of the person who you most recently provided care to? **[INTERVIEWER: IF THEY ARE PROVIDED CARE TO MORE THAN ONE PERSON, ASK THEM TO ANSWER BASED ON THE PERSON THEY ARE PROVIDING THE MOST CARE TO]. [RECORD AGE IF KNOWN AND GIVEN; IF NOT KNOWN OR GIVEN, TRY TO RECORD IT IN THE RANGE BELOW.]**

323	**N=**
	_______ [RECORD AGE]
1.0%	Under age 18 **[SKIP TO QUESTION 33]**
1.8%	18-49
4.2%	50-59
2.6%	60-64
90.5%	65+
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

19. Thinking about the person you most recently provided care to, which of the following daily activities did you provide? Did you **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH H.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Assist with bathing or dressing

320	N=
61.9%	Yes
37.8%	No
0.3%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Provide transportation to appointments

320	N=
85.5%	Yes
14.5%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Take them shopping or shopping for them

320	N=
86.2%	Yes
13.8%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

d. Help them with meals

320	N=
83.6%	Yes
16.4%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

e. Help them to manage finances

320	N=
64.0%	Yes
35.6%	No
0.4%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

f. Aide with household chores

320	N=
84.8%	Yes
15.2%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

g. Oversee their medication management

320	N=
73.6%	Yes
25.9%	No
0.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

h. Being responsible for other medical or nursing tasks

320	N=
72.3%	Yes
27.1%	No
0.6%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

20. Are there any other activities that you provided?

320	N=
32.5%	Yes **[ASK Q21]**
65.1%	No **[SKIP TO QUESTION 22]**
2.4%	[DO NOT READ] Not sure **[SKIP TO QUESTION 22]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 22]**

21. What were they? **[RECORD RESPONSES]**

____

22. Have you ever been employed either full or part-time while providing care to your adult loved one?

320	N=
60.5%	Yes **[ASK Q23]**
39.2%	No **[SKIP TO QUESTION 27]**
0.3%	[DO NOT READ] Not sure **[SKIP TO QUESTION 27]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 27]**

23. Now thinking again about the adult loved one you have most recently provided care to, did you ever have to **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH D.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Go into work early or late, or take time off to provide care for a loved one

193	N=
69.0%	Yes
30.1%	No
1.0%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Take a leave of absence from your job to provide care for a loved one

193	N=
34.5%	Yes
65.0%	No
0.5%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Go from working full-time to part-time to provide care for a loved one

193	N=
15.7%	Yes
84.3%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

d. Give up working entirely to provide care for a loved one

193	N=
21.8%	Yes
78.2%	No
-	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

24. Are there any other things related to your work life that you ever had to do in order to care for your loved one?

193	N=
21.3%	Yes **[ASK Q25]**
76.9%	No **[SKIP TO QUESTION 26]**
1.8%	[DO NOT READ] Not sure **[SKIP TO QUESTION 26]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 26]**

25. What were they? **[RECORD RESPONSES]**

____

26. [IF Q23A=YES ASK]: You mentioned that you had to go into work early or late, or take time off to provide care to an adult loved one. How often would you say you had to take time away from work or adjust your work schedule to provide care for someone? Would you say **[INSERT AND READ EACH ANSWER CATEGORY.]**?

133	N=
26.2%	More than once per week
10.4%	Once per week
26.5%	Several times per month but less often than once per week
17.7%	Once per month
12.2%	Less than once per month
7.1%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

27. Now thinking again about the adult loved one you have most recently provided care to, while providing this care did you ever have to **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH C.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**

a. Use your own money to help provide care

320	N=
58.8%	Yes
40.6%	No
0.6%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

b. Make changes to your home for the loved one in your care

320	N=
42.9%	Yes
56.7%	No
0.3%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

c. Move into another home to accommodate the loved one in your care

320	N=
16.2%	Yes
83.2%	No
0.6%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

28. Are there any other things you ever had to do?

320	N=
17.6%	Yes **[ASK Q29]**
80.3%	No **[SKIP TO QUESTION 30]**
2.1%	[DO NOT READ] Not sure **[SKIP TO QUESTION 30]**
-	[DO NOT READ] Refused **[SKIP TO QUESTION 30]**

29. What were they? **[RECORD RESPONSES]**

30. As a caregiver have you ever **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH I.]**? **[RECORD A RESPONSE FOR EACH ITEM.]**?

a. Felt stressed out emotionally due to your caregiving responsibilities

320	N=
62.6%	Yes
36.9%	No
0.4%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

b. Felt stressed out in trying to balance your job and family

320	N=
51.2%	Yes
47.7%	No
0.7%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

c. Found it difficult to maintain a healthy diet

320	N=
28.6%	Yes
70.6%	No
0.7%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

d. Found it difficult to get enough rest

320	N=
51.1%	Yes
48.4%	No
0.4%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

e. Found it difficult to exercise regularly

320	N=
41.1%	Yes
58.0%	No
0.7%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

f. Found it difficult to take care of your household responsibilities

320	N=
37.7%	Yes
61.6%	No
0.5%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

g. Experienced problems with your health

320	N=
24.1%	Yes
75.1%	No
0.6%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

h. Found it difficult to find time to visit your doctor

320	N=
17.4%	Yes
82.1%	No
0.4%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

i. Felt strained financially due to your caregiving responsibilities

320	N=
23.1%	Yes
76.8%	No
-	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

31. How important was it to you to be able to provide care for your loved one so that they could keep living independently in their own home? Was it **[INSERT AND READ EACH ANSWER CATEGORY.]?**

320	N=
60.0%	Extremely important
31.0%	Very important
2.8%	Somewhat important
1.5%	Not very important
1.9%	Not at all important
2.7%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

32. How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for an adult loved one in the future? Is it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

320	N=
21.7%	Extremely likely
22.0%	Very likely
18.4%	Somewhat likely
16.8%	Not very likely
18.0%	Not at all likely
3.2%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

SKIP TO Q 34

<u>QUESTION 33 IS FOR RESPONDENTS WHO ARE NOT CURRENT OR FORMER CAREGIVERS.</u>

33. How likely do you think it is that you will provide any caregiving or assistance on an unpaid basis for an adult loved one in the future? Is it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

468	N=
7.5%	Extremely likely
14.8%	Very likely
27.5%	Somewhat likely
23.1%	Not very likely
24.7%	Not at all likely
2.3%	[DO NOT READ] Not sure
0.2%	[DO NOT READ] Refused

QUESTIONS 34 AND ONWARD ARE FOR ALL RESPONDENTS

34. In your opinion, as a current or former caregiver or as someone who may provide care in the future, how helpful would the following types of caregiving support be to you? Would **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH G]** be very helpful, somewhat helpful, or not helpful?

a. Assistance with providing transportation

1000	N=
48.7%	Very helpful
31.1%	Somewhat helpful
18.2%	Not helpful
1.6%	[DO NOT READ] Not sure
0.3%	[DO NOT READ] Refused

b. Assistance with understanding how to manage medications

1000	N=
44.0%	Very helpful
30.6%	Somewhat helpful
23.2%	Not helpful
2.1%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

c. Connecting with other caregivers in similar situations

1000	N=
35.3%	Very helpful
42.8%	Somewhat helpful
19.2%	Not helpful
2.5%	[DO NOT READ] Not sure
0.3%	[DO NOT READ] Refused

d. Information about available resources for caregivers in your community

1000	N=
58.3%	Very helpful
30.7%	Somewhat helpful
9.1%	Not helpful
1.9%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

e. Respite care or breaks from caregiving responsibilities

1000	N=
55.7%	Very helpful
29.5%	Somewhat helpful
10.4%	Not helpful
3.9%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

f. Assistance with providing meals

1000	N=
42.9%	Very helpful
35.7%	Somewhat helpful
19.4%	Not helpful
2.0%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

g. Assistance with managing household chores

1000	N=
44.3%	Very helpful
37.1%	Somewhat helpful
17.7%	Not helpful
0.8%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

INDEPENDENT LVIING

35. If you or a loved one needed help when the basic tasks of life become more difficult due to aging or illness, where would you prefer to receive that care or help for yourself or a loved one? **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH C. ACCEPT ONLY ONE ANSWER.]**

1000	N=
75.0%	At home with caregiver assistance
14.9%	In an assisted living facility or group home
5.1%	In a nursing home
4.6%	[DO NOT READ] Not sure
0.4%	[DO NOT READ] Refused

36. If you or a loved one needed help to remain independent, how important would it be to have services that would allow you or a loved one to live independently at home for as long as possible? Would it be **[INSERT AND READ EACH ANSWER CATEGORY.]**?

1000	N=
51.4%	Extremely important
34.7%	Very important
10.8%	Somewhat important
1.1%	Not very important
1.1%	Not at all important
0.8%	[DO NOT READ] Not sure
0.2%	[DO NOT READ] Refused

37. How important is it that services that help older adults live independently, such as home health care, personal care, day programs, and services so caregivers can take a break from their caregiving duties, are available in your community? Is it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

1000	N=
40.5%	Extremely important
38.1%	Very important
16.5%	Somewhat important
2.2%	Not very important
1.3%	Not at all important
1.3%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

38. Now I'm going to ask you about some community services. Please tell me how important you think it is to have the following services in your community to help people remain in their own homes as they age. How important is having **[INSERT, READ AND RANDOMIZE ITEMS A THOUGH J.]** in your community? Do you think it is **[INSERT AND READ EACH IMPORTANCE ANSWER CATEGORY.]**?

a. Senior Centers

1000	N=
24.4%	Extremely important
41.5%	Very important
25.5%	Somewhat important
3.8%	Not very important
3.2%	Not at all important
1.6%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

b. Chore or homemaker services where someone comes in to do light housekeeping or cleaning for low-income and older persons

1000	N=
26.7%	Extremely important
42.1%	Very important
23.1%	Somewhat important
4.4%	Not very important
2.5%	Not at all important
1.1%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

c. Congregate meals such as senior lunch programs

1000	N=
21.5%	Extremely important
37.7%	Very important
28.7%	Somewhat important
6.1%	Not very important
4.0%	Not at all important
1.7%	[DO NOT READ] Not sure
0.3%	[DO NOT READ] Refused

d. Home delivered meals

1000	N=
23.7%	Extremely important
37.5%	Very important
28.2%	Somewhat important
4.7%	Not very important
4.1%	Not at all important
1.6%	[DO NOT READ] Not sure
0.3%	[DO NOT READ] Refused

e. Visiting nurse services, such as an RN who comes to your home after a hospitalization

1000	N=
37.1%	Extremely important
43.9%	Very important
14.8%	Somewhat important
1.0%	Not very important
2.1%	Not at all important
1.1%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

f. Well-trained certified home health care providers

1000	N=
39.3%	Extremely important
41.5%	Very important
14.5%	Somewhat important
1.5%	Not very important
1.9%	Not at all important
1.2%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

g. Breaks for family caregivers from caregiving duties

1000	N=
35.8%	Extremely important
41.2%	Very important
18.3%	Somewhat important
2.0%	Not very important
1.7%	Not at all important
0.9%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

h. End of life or hospice services **[IF NECESSARY READ: Medication or services provided to relieve symptoms of terminal illness]**

1000	N=
45.4%	Extremely important
39.3%	Very important
11.5%	Somewhat important
1.4%	Not very important
1.0%	Not at all important
1.2%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

i. Special transportation services such as one for seniors or persons with disabilities

1000	N=
38.6%	Extremely important
42.2%	Very important
15.2%	Somewhat important
1.7%	Not very important
1.7%	Not at all important
0.6%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

j. A central place for caregivers to go to get information and resouces

1000	N=
28.6%	Extremely important
43.7%	Very important
21.7%	Somewhat important
2.9%	Not very important
1.9%	Not at all important
1.0%	[DO NOT READ] Not sure
0.2%	[DO NOT READ] Refused

39. Family caregivers help older Hawaii residents live independently by performing services like bathing and dressing as well as managing medication and paying bills. How important do you think it is to have more resources and training for family caregivers? Do you think it is **[INSERT AND READ EACH ANSWER CATEGORY.]**?

1000	N=
37.7%	Extremely important
39.2%	Very important
18.0%	Somewhat important
2.5%	Not very important
1.7%	Not at all important
0.9%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

WORKPLACE PROTECTIONS

40/41. Now I'm going to ask if you support or oppose some proposals that would provide help for working family caregivers. Do you support or oppose **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH C.]**?

a. Requiring employers to provide a limited amount of unpaid leave to employees who have to take time off for family caregiving purposes

1000	N=
56.7%	Strongly support
28.5%	Somewhat support
3.3%	[DO NOT READ] Neither support nor oppose
5.6%	Somewhat oppose
3.8%	Strongly oppose
1.9%	[DO NOT READ] Not sure
0.2%	[DO NOT READ] Refused

b. Requiring employers to provide some paid leave to all employees that can be used for family caregiving purposes

1000	N=
46.9%	Strongly support
30.0%	Somewhat support
4.4%	[DO NOT READ] Neither support nor oppose
8.5%	Somewhat oppose
6.6%	Strongly oppose
3.4%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

c. Ensuring employers cannot fire an employee for taking time off for family caregiving purposes

1000	N=
63.7%	Strongly support
22.1%	Somewhat support
3.0%	[DO NOT READ] Neither support nor oppose
5.6%	Somewhat oppose
3.2%	Strongly oppose
2.1%	[DO NOT READ] Not sure
0.3%	[DO NOT READ] Refused

CARE ACT

42/43. Now I'm going to ask if you support or oppose some proposals that would provide additional help for family caregivers. Do you support or oppose **[INSERT, READ AND RANDOMIZE ITEMS A THROUGH C.]**?

a. Requiring hospitals and care facilities to record the name of a patient's family caregiver in the medical record upon admission

1000	N=
58.0%	Strongly support
28.1%	Somewhat support
3.8%	[DO NOT READ] Neither support nor oppose
4.3%	Somewhat oppose
2.5%	Strongly oppose
3.0%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

b. Hospitals keeping a family caregiver informed of major decisions, like transferring or discharging the patient

1000	N=
75.2%	Strongly support
18.3%	Somewhat support
2.0%	[DO NOT READ] Neither support nor oppose
2.1%	Somewhat oppose
0.9%	Strongly oppose
1.1%	[DO NOT READ] Not sure
0.4%	[DO NOT READ] Refused

c. Requiring hospitals to explain and demonstrate any medical or nursing tasks family caregivers will need to perform after the patient returns home

1000	N=
78.8%	Strongly support
16.1%	Somewhat support
1.2%	[DO NOT READ] Neither support nor oppose
1.4%	Somewhat oppose
1.5%	Strongly oppose
1.0%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

RESPITE CARE

44/45. Do you support or oppose providing short-term help from a home health aide so family caregivers can take a break from their caregiving duties?

1000	N=
60.5%	Strongly support
30.3%	Somewhat support
1.9%	[DO NOT READ] Neither support nor oppose
3.1%	Somewhat oppose
1.4%	Strongly oppose
2.8%	[DO NOT READ] Not sure
-	[DO NOT READ] Refused

TAX CREDIT

46/47. Do you support or oppose providing a state income tax credit to family caregivers who incur expenses for the care and support of an older family member living with them?

1000	N=
68.2%	Strongly support
20.2%	Somewhat support
1.7%	[DO NOT READ] Neither support nor oppose
3.9%	Somewhat oppose
3.6%	Strongly oppose
2.4%	[DO NOT READ] Not sure
0.1%	[DO NOT READ] Refused

DEMOGRAPHICS

The following questions are for classification purposes only and will be kept entirely confidential.

D1. What is your current marital status? Are you **[INSERT AND READ EACH ANSWER CATEGORY.]**?

1000	N=
69.0%	Married
3.2%	Not married, living with your partner or significant other
0.8%	Separated
6.0%	Divorced
8.8%	Widowed
11.5%	Or are you currently single and never married
-	[DO NOT READ] Not sure
0.8%	[DO NOT READ] Refused

D2. **[IF D1 = 1 ASK**: "Are you or your spouse currently a member of A-A-R-P?" **IF D1 = 2 ASK**: "Are you or your partner currently a member of AARP?" **OTHERWISE ASK** "Are you currently a member of AARP?"]

1000	N=
39.7%	Yes
58.1%	No
1.7%	[DO NOT READ] Not sure
0.5%	[DO NOT READ] Refused

D3. Thinking about who lives in your household, do you currently **[INSERT AND READ ITEMS A THROUGH C BELOW.]**?

a. Have any children under age 18 living with you

1000	N=
23.9%	Yes
74.9%	No
0.5%	[DO NOT READ] Not sure
0.7%	[DO NOT READ] Refused

b. Have any children over age 18 living with you

1000	N=
27.6%	Yes
71.2%	No
0.5%	[DO NOT READ] Not sure
0.7%	[DO NOT READ] Refused

c. Have any children away at college

1000	N=
15.9%	Yes
82.8%	No
0.6%	[DO NOT READ] Not sure
0.7%	[DO NOT READ] Refused

D4. Do you own or rent your primary residence?

1000	N=
83.9%	Own
12.0%	Rent
1.7%	[DO NOT READ] Other living arrangement **[RECORD ANSWER]**
0.9%	[DO NOT READ] Not sure
1.5%	[DO NOT READ] Refused

D5. What type of home is your primary residence? **[READ EACH ANSWER CATEGORY.]**?

1000	N=
78.4%	Single family home
0.1%	Mobile home
6.0%	Town home or duplex
4.4%	Apartment
9.6%	Condominium or coop
0.2%	[DO NOT READ] Something else
0.1%	[DO NOT READ] Not sure
1.4%	[DO NOT READ] Refused

D6. What is the highest level of education that you completed? **[READ EACH ANSWER CATEGORY.]**

1000	N=
2.5%	0 to 12th grade, but with no diploma
16.2%	High school graduate or equivalent
11.7%	Post high school education, but with no degree
17.3%	2 year degree
23.9%	4 year degree
5.6%	Post graduate study, but with no degree
21.0%	Graduate or professional degree
0.3%	[DO NOT READ] Not sure
1.5%	[DO NOT READ] Refused

D7. Which of the following best describes your current employment status? **[READ EACH ANSWER CATEGORY.]**

1000	N=
6.7%	Self-employed full-time
5.9%	Self-employed part-time
35.9%	Employed full-time
7.5%	Employed part-time
35.4%	Retired and not working at all
2.6%	Unemployed and looking for work
4.4%	Or are you not in the labor force for other reasons
0.5%	[DO NOT READ] Not sure
1.2%	[DO NOT READ] Refused

D8. What race do you consider yourself? Are you **[READ AND RECORD ALL RESPONSES]**

1000	N=
37.7%	White or Caucasian
22.2%	Japanese
9.2%	Filipino
13.2%	Hawaiian
7.4%	Chinese
0.7%	Korean
0.1%	Samoan
1.3%	Black or African American
2.9%	Portuguese
1.5%	Latino/Hispanic any race
6.3%	Other Asian
5.8%	Or are you some other race? **[RECORD ANSWER]**
0.1%	[DO NOT READ] Not sure
2.0%	[DO NOT READ] Refused

D9. Thinking about your state elections for **Hawaii** Governor and Legislators in the last 10 years, which of the following best describes your voting behavior? Would you say you vote always, most of the time, about half of the time, seldom, or would you say you never vote?

1000	N=
76.8%	Always
14.8%	Most of the time
3.3%	About half of the time
2.1%	Seldom
0.7%	Never
0.5%	[DO NOT READ] Not sure
1.9%	[DO NOT READ] Refused

D10. Do you consider yourself to be a **[INSERT, READ, AND RANDOMIZE ITEMS A THROUGH D.]**?

1000	N=
45.3%	Democrat
16.2%	Republican
23.1%	Independent
0.6%	Tea Party member
3.5%	[DO NOT READ] Something else **[RECORD ANSWER]**
4.8%	[DO NOT READ] Not sure
6.5%	[DO NOT READ] Refused

D11. How would you characterize your political views? Would you say you are **[INSERT, READ, AND RANDOMIZE ITEMS A THROUGH C.]**?

1000	N=
24.7%	Conservative
43.5%	Moderate
22.6%	Liberal
1.5%	[DO NOT READ] None of these
4.3%	[DO NOT READ] Not sure
3.4%	[DO NOT READ] Refused

D12. We realize income is a private matter and so rather than ask you anything specific about your income, I'd like to ask you to please stop me when I get to the category that includes your household's income before taxes in 2013. Was it **[INSERT AND READ EACH ANSWER CATEGORY.]**?

1000	N=
3.5%	Less than $10,000
4.6%	$10,000 to less than $20,000
5.5%	$20,000 to less than $30,000
6.3%	$30,000 to less than $40,000
6.1%	$40,000 to less than $50,000
8.9%	$50,000 to less than $60,000
7.4%	$60,000 to less than $75,000
13.8%	$75,000 to less than $100,000
11.0%	$100,000 to less than $125,000
6.4%	$125,000 to less than $150,000
4.2%	$150,000 to less than $200,000
4.8%	$200,000 or more
3.1%	[DO NOT READ] Not sure
14.4%	[DO NOT READ] Refused

D13. What is your 5-digit zip code? ___ ___ ___ ___ ___

	[DO NOT READ] Not sure [DO NOT READ]
	[DO NOT READ] Refused [DO NOT READ]

That was our last question for tonight/today. Thanks you very much for taking the time to help us out. Have a great day/night!

METHODOLOGY

The 2014 AARP Survey of Hawaii Registered Voters Age 45+ on Caregiving was conducted through telephone interviews with a sample of 1,000 respondents ages 45 and older drawn from an age targeted voter list. The interviews were conducted in English by Precision Opinion, Inc. from August 28th through September 9th, 2014. The results from the study were weighted by age, gender and geographic county of residence to reflect the Hawaii population of registered voters age 45 and older. The margin of error for the complete set of 1,000 interviews is ±3.2%.

Respondents were screened to ensure that they were residents of Hawaii, age 45 or older and registered to vote in Hawaii.

The questionnaire was developed by AARP staff. In order to improve the quality of the data, the questionnaire was pretested with a small number of respondents. The pretest interviews were monitored by Precision Opinion, Inc. and AARP staff.

The response rate for this study was 17 percent and was calculated using AAPOR's response rate 3 method. The cooperation rate was 90 percent as calculated using AAPOR's cooperation rate 3 method.[1]

Throughout the report, statistics representing survey responses are reported in percentages which may not add up to 100 due to rounding and non-response. Also due to rounding, the percentages reported in the text may vary slightly from those in the annotation or in graphs.

---

[1] Calculated using AAPOR's Outcome Rate Calculator Version 2.1. May 2003

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million, that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse. We advocate for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name as well as help our members obtain discounts on a wide range of products, travel, and services. A trusted source for lifestyle tips, news and educational information, AARP produces AARP The Magazine, the world's largest circulation magazine; AARP Bulletin; www.aarp.org; AARP TV & Radio; AARP Books; and AARP en Español, a Spanish-language website addressing the interests and needs of Hispanics. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Learn more at www.aarp.org.

State Research brings the right knowledge at the right time to our state and national partners in support of their efforts to improve the lives of people age 50+. State Research consultants provide strategic insights and actionable research to attain measurable state and national outcomes. The views expressed herein are for information, debate, and discussion, and do not necessarily represent official policies of AARP.

AARP staff from the Hawaii State Office, Campaigns, State Advocacy and Strategy Integration (SASI) and State Research contributed to the design, implementation and reporting of this study. Special thanks go to AARP staff including Barbara Stanton, State Director in Hawaii, Bruce Bottorff, Associate State Director of Communications in Hawaii, Steven Tam, Associate State Director of Advocacy in Hawaii; Chryste Hall and Jodi Sakol, Campaigns; Glen Fewkes and James McSpadden, SASI; Cheryl Barnes, Aisha Bonner, Rachelle Cummins, Terri Guengerich, Angela Houghton, and Darlene Matthews, State Research; and Doris Gilliam, Office of General Counsel. Please contact Joanne Binette at 202-434-6303 for more information regarding this survey.

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For more information about this survey, please contact Joanne Binette at:

202.434.6303 or e-mail jbinette@aarp.org

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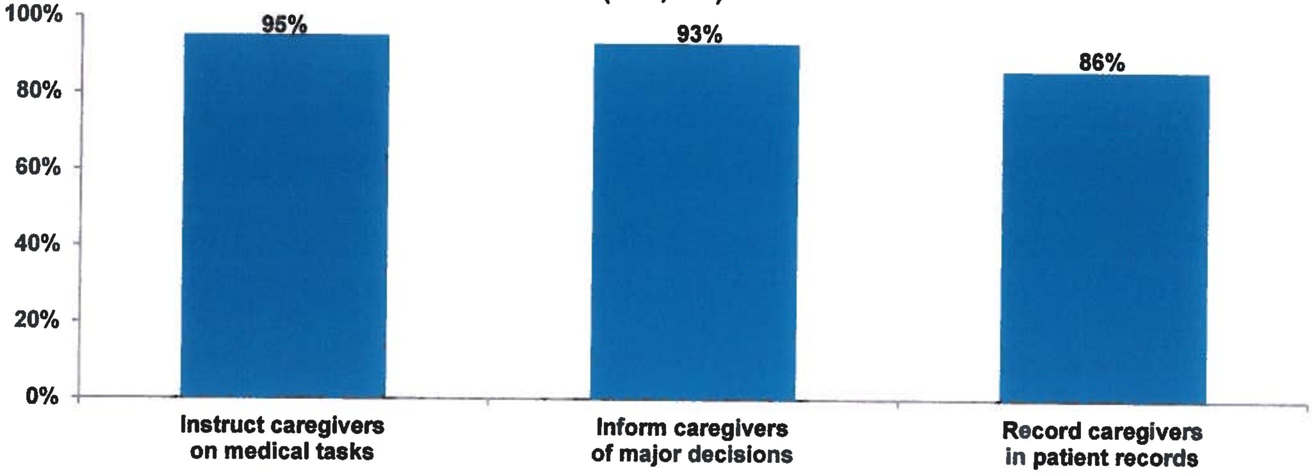
2014 AARP Caregiving Survey of Hawaii Registered Voters Age 45 and Older: Support for Family Caregivers When Loved Ones are Hospitalized

Hawaii registered voters age 45 and older strongly support proposals to help family caregivers navigate the health care system on behalf of their loved ones. Specifically, respondents support requiring hospitals and health care facilities to explain and demonstrate medical and nursing tasks that family caregivers will need to perform after the patient returns home; keep a family caregiver informed of major decisions, like transferring or discharging the patient; and record the name of a patient's family caregiver in the medical record upon admission.

Support for Proposals to Require Hospitals to Engage with Family Caregivers (n=1,000)



The average age of Hawaii caregivers is 62 years old and the majority is female (59%), married (65%), has a two year college degree or higher (66%), working either full or part-time (53%) and has an annual household income of less than $100,000 (58%).

AARP Hawaii commissioned a telephone survey of 1,000 Hawaii registered voters age 45 and older to learn about their experiences with family caregiving, as well as their opinions on proposals to support family caregivers in the state. This report highlights results from registered voters interviewed between August 28 and September 9, 2014. The data in this report has been weighted by age, gender and geographic county of residence to reflect the Hawaii population of registered voters age 45 and older. The survey has a margin of error of ±3.2 percent.

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AARP Research

For more information about this survey, please contact Joanne Binette at:
202.434.6303 or e-mail jbinette@aarp.org

Benefits of working with the Aging and Disability Resource Centers to assist Family Caregivers in coping effectively with Hospital Discharge of seniors needing care:

1. By bringing an individual connected with the ADRC into the hospital room and then into the home, there is the opportunity for the senior and family caregiver to participate in a comprehensive functional assessment that takes into consideration person-centered care, formal and informal support, options counseling to address service needs and any potential gaps, and efficient connection to appropriate Home and Community-Based Services.
2. The ADRC personnel has direct access to the Harmony database and, therefore, direct access to see what, if any, supportive services are already in place for the individual and/or family caregiver.
3. The consumer's record of hospitalizations can be directly linked to the record of HCBS thereby allowing ADRC personnel to have a more complete picture of the overall status of the individual and family caregiver.
4. MCOA utilizes Registered Nurse Coaches for program implementation. Therefore, basic instruction and assistance is readily available. For family caregivers requiring more intense assistance, the ADRC Coach can ensure that the family member receives timely assistance from the PCP and/or Home Health agency.
5. ADRC Coaches have access to an evidence-based model of program delivery that includes emphasis on patient/family empowerment and Family Caregiver assessment through the Family Caregiver Activation in Transitions Caregiver Tool.

Benefits of formalizing a working relationship statewide between the hospitals and Care Transitions Programs implemented by ADRCs are mutual: The hospital will experience reduced readmission rates, and family caregivers experience increased connectivity to HCBS.

Continued areas of concern: formalized training in areas such as wound care, tube feeding, and additional such tasks that are typically beyond the scope of family caregivers at the beginning of such a journey.

Existing Resources to implement statewide: Trainer of Trainer in Care Transitions Intervention—reduces the cost exponentially; Interest

The Kauai Care Transition Program at Kauai Veterans Memorial Hospital

Hospital Discharge Planning Grant

Final Evaluation Report

County of Kauai

Kauai Agency on Elderly Affairs

Submitted by:

Fenfang Li, PhD, Principal Investigator

Pam Arnsberger, PhD, Co-Investigator

Honolulu, Hawaii

August 29, 2013

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Executive Summary

Methods

In March 2012, the Kauai County Area Agency on Aging in conjunction with Kauai Veteran's Memorial Hospital launched the Kauai Care Transition program. The purpose of this program is to reduce hospital readmissions and assist patients to successfully transition back to home and empower them in managing their own health. The target populations are people 60 years and over who reside in West Kauai (from Koloa to Kekaha) and present one or more admitting diagnoses which include: 1) severe respiratory/pulmonary diseases (i.e. chronic obstructive pulmonary disease (COPD), pneumonia, etc.); 2) cardiac-related diseases (i.e. arrhythmias/congested heart failures); 3) sepsis; and 4) cellulitis.

Hospital admission records from April 1, 2012 to March 31, 2013 were used to evaluate the effectiveness of the Care Transition Intervention (CTI) program in preventing and reducing hospital readmission rates as well as in assisting patients with successful transition and managing their own health. Both quantitative and qualitative evaluations are conducted.

Chi-squared tests were initially used to evaluate whether readmission rates within different time period (e.g., a year, 60days, or 30 days) differed significantly between the intervention and baseline time period. Chi-squared tests were also used to evaluate whether the intervention effectively reduced readmission rates among patients with risk factors identified at baseline.

To justify whether the observed difference in the readmission rates between the intervention period and baseline is due to the intervention rather than other factors, e.g., patient characteristics, the two data sets were combined into one data set. A new variable, **Time,** was created to differentiate data between the intervention period and the baseline period. A series of tests were conducted to examine patient characteristics between those two time periods. Chi-squared tests were used to compare categorical patient characteristics between the two time period, including patient's sex, discharge sites, patient's primary insurance, and admitting medical services. Independent t-tests were used to compare continuous patient characteristics including patient's age and length of stay.

Finally, if patient populations were found to be significantly different by some patient characteristics, a multivariate logistic regression model was then used to evaluate the effectiveness of the intervention while controlling for these patient characteristics.

Qualitative evaluation of the intervention included several components: (1) Patient Activation Assessment (PAA), which evaluated patients' knowledge, understanding, and skill in medication management, red flags, medical care follow up and personal health records; (2) Care Transition Measure (CTM-3) which reflected the overall quality of the care transition; (3) Medication Discrepancy Tool, which identified and characterized medication discrepancies that have arisen when patients were making the transition between sites of care; and (4) CTI 30-day follow up survey to assess patient satisfaction.

Results

A total of 269 patients age 60 and over were included for analysis. As some of those patients were readmitted, those 269 patients contributed to a total of 329 hospital admission records. During the intervention period (March 2012 to April 2013), a total of 58 patients were referred to the program. Some of the patients were referred to the program more than once. As a result, there were a total of 61 referrals. Of those 61 referrals, 30 completed the program, 5 did not complete the program, 25 with unknown program completion status and one was still ongoing at the time the data was extracted for analysis.

Of the 269 patients that included the 58 CTI participants, **43 (16%)** were readmitted over the course of the CTI project year (March 2012 to April 2013). Among the 43 patients with any readmissions, 22 were readmitted within 60 days from their first dates of discharge from an acute bed and 13 were readmitted within 30 days from their first dates of discharge from an acute bed. Hence, **8.2% (22 over 269)** of the patients were readmitted within 60 days and **4.8% (13 over 269)** were readmitted within 30 days.

Hospital Re-Admission Rate Baseline vs. Intervention

Chi-squared tests revealed a significant difference in the readmission rate within a year. The overall readmission rate was 28.1% at baseline (calendar year 2010) and 16.0% at the intervention period (April 2012 to March 2013) (X^2=11.85, p<0.001). The CTI program reduced the readmission rate within a year by 42.8%. A significant difference was also observed in the readmission rates within 60 days at baseline (17.7) and during the intervention period (8.2%) (X^2=11.09, p<0.001). Readmission rate within 60 days was reduced by 53.6%. Similarly, there was also a significant difference in the readmission rates within 30 days at the baseline (12.5%) and the intervention period (4.83%) (X^2=10.19, p=0.001). The readmission rate within 30 days of admission was reduced by 61.4%.

Difference between Patient Characteristics

Chi-squared tests found no significant difference between baseline and intervention period in the following patient characteristics: distribution of patient discharged to different types of sites (X^2=2.53, p=.283), proportions of patients with arrhythmias as their primary admitting diagnosis, or cellulitis or COPD among any of the three diagnoses. The only significant difference observed was the distribution of various types of primary health insurance (X^2=8.592, p=.035). There was a higher percentage of Medicare patients (40.9%) and a lower percentage of HMSA/65C+ patients (23.4%) during the intervention period compared to baseline (34.7% for both Medicare patients and HMSA/65C+).

Readmission Rates among Patients with Risk Factors

No significant difference was observed in readmission rates within a year, or within 60 days, or within 30 days between patients with certain risk factors and those without. In other words, by providing KCTI services to at risk patients, the risk of readmission among high risk patients were reduced to a level equivalent to patients without such risk factors. Those risk factors examined included the following ones: discharged not to home, HMSA/65+ as the primary health insurance, arrhythmias as the primary admitting diagnosis, and cellulitis and chronic obstructive pulmonary disease (COPD) among any of the primary, secondary, or tertiary diagnosis. The only significant difference in readmission rates of any period observed was between patients with different types of health insurance. Patients with other types of health insurance, i.e., Medicare Advantage plans, such as Alohacare Advantage, Ohana/Wellcare Medicare advantage plan, Humana Medicare Advantage Plan, Medicare advantage plan by the University Health Alliance, and other types of insurance such as Veteran Affairs Department, etc., had the highest readmission rates. In contrast, at baseline, patients with HMSA/65C+ had the highest readmission rates.

The final multivariate logistic regression model predicting readmission rate within a year found that the Care Transition intervention was statistically significant in reducing readmission rates, while controlling for patients' primary health insurance, discharging sites, arrhythmias, any COPD, and any cellulitis. Readmission rates was as half as that of the baseline (OR=0.48, $p<0.001$). Similarly, the final multivariate logistic regression model predicting readmission rate within 60 days or 30 days also found that the intervention was statistically significant in reducing readmission rates within 60 days and 30 days, while controlling for patients' primary health insurance, discharging sites, arrhythmias, any COPD, and any cellulitis. Readmission rate within 60 days during the intervention period was 0.42 times as likely as that of the baseline (OR=0.42, $p<.001$). Readmission rate within 30 days during the intervention period was one third as likely as that of the baseline (OR=0.34, $p=0.003$).

Patient Activation Assessments found that the CTI program succeeded in improving patient's ability in medication management, health care follow up and the use of Personal Health Records (PHR). The overall quality of care transition was high, with mean scores of 3.4 to 3.5 out of a total score of 4. Medication Discrepancy Tool identified the most frequent discrepancies both at the patient and at the system level. The CTI 30-days follow up survey revealed that the majority of the patients improved in their understanding and skills in medication management and warning signs of worsening health conditions. Nearly two thirds of those responded agreed that CTI program helped them to better manage their health and 94% considered the CTI coaches courteous and helpful.

In summary, this study demonstrates that an educationally based intervention designed to address readmission rates can be successfully implemented in a small acute hospital setting and can reduce readmission rates for variously measured time periods even while controlling for other possible predictors of readmission. By providing CTI intervention to patients with risk factors, this study was successful in reducing risk of readmission rates among those patients and subsequently, reduced readmission rates hospital wide. The intervention was also able to empower and educate patients with better skills in managing their own health.

Background of Hospital Readmission intervention

Unplanned hospital readmission among Medicare patients within 30 to 60 days of discharge is considered to be a cardinal indicator of poor health care quality as well as costly for the health care system (O'Hare, Yost, McCorkle, 1993;   Experton, Ozminkowsk,, Pearlman, Thompson, 1999). As early as the 1980's, 22 percent of Medicare patients were readmitted within a 60 days period costing the system over 8 billion per year or 24 per cent of Medicare inpatient expenditures (Steinberg, 1984). Some more recent studies have identified readmission rates of over 50% for specific conditions when the window for readmission (or the time period) is extended beyond the 60 day period (Bravata, Ho et al 2007; Mudge Kasper Redfern Bell Baras, Dip Pachana 2011).

An April 2009 *New England Journal of Medicine* article reported that 19.6% of Medicare patients in non-managed care acute hospital settings were readmitted to the hospital within 30 days, 34.0% within 90 days, and more than half (56.1%) within one year of discharge. In addition, the Medicare Payment Advisory Commission (MedPAC) found that 17.6% of hospital admissions resulted in readmissions within 30 days of discharge. Readmissions currently remain a costly component of Medicare-covered hospital services accounting for an estimated $15 billion of Medicare spending (Jencks, Williams, and Coleman, 2009; Stone and Hoffman, 2010).

Targeting patients at risk for early readmission has been suggested as one way to reduce Medicare expenditures. Risk factors for readmission commonly include measures of health status, diagnosis, and surgery (Holloway, Thomas, Shapiro, 1988). Studies have found that advanced age, five or more medical comorbidities and a history of depression can also contribute to the likelihood readmission. Lack of patient education has also been cited as a contributing factor to this undesirable outcome (Marcantonio, McKean, Goldfinger, Kleefield, Yurkofsky, 1999).

As a result, several different types of interventions have tested in the field to determine the possibility of reducing both the likelihood and the number of readmission for older patients. These endeavors can be characterized as being on a continuum from clinical and medical interventions to social and educational efforts. Experimental programs to reduce readmission rates have targeted barriers that prevent recovery from or inhibit management of chronic illness including the relation between medications and illness, the relation between health behaviors and illness, knowledge of early signs and symptoms and methods of accessing resources. Educational interventions have focused on modifying behavioral factors such as noncompliance with medications, diet and delay in seeking preventive care (Dracup Baker, Dunbar 1994; Happ Naylor, Roe 1997).

Such interventions, generally restricted to certain diagnoses or conditions, have had mixed results. One- study focusing on the use of a geriatric consultant team for patients with hip fracture found there was no difference among readmission rates for those who received and those who did not receive the intervention (Deschodt, Braes, Broos, et al, 2010). However, another intervention (a randomized controlled trial) which included a 24 week exercise and telephone follow-up program showed significantly fewer hospital admissions for the treatment vs. the control group as well as significantly greater improvement in their quality of life (Courtney, Edwards and Chang, 2009) . A descriptive observational study that focused on improving communication gaps between patient and doctor regarding medications concluded that miscommunication over medication might have been responsible for 35% of the patients readmitted and was considered to be preventable for 61% of this group (Witherington, Pirzoda and Avery, 2008).

Patient education has been a significant component of many of these interventions. A study that focused on a nursing intervention demonstrated that a brief education and support intervention by a nurse could increase self-care behaviors among patients who had been hospitalized with heart disease but found no significant change in resource utilization (Jaarsma, Halfens, Huijer, 1999). A randomized trial of an educational and supportive intervention for patients with a diagnosis of heart failure was focused on increasing compliance with medication and treatment protocols through education patients to manage their own disease. Results indicated that the intervention was associated with a 39% decrease in the total number of readmissions. After adjusting for clinical and demographic characteristics, the intervention group had a significantly lower risk of readmission compared with the control group (Krumholz, Amatruda, Smith, Mattera, Roumanis, Radford, et al,1997) . Finally, Rich et al., conducted a randomized trial utilizing a nurse-directed multidisciplinary intervention This intervention included intensive education in the medical management of the patients, including home visits, with a resulting 56% reduction in readmission rates. (Rich Beckham Wittenberg, Leven Freedland, Carney, 1995)

Home based methods including multidisciplinary teams composed of physicians, nurses, social workers and pharmacists are often an essential component of these interventions. For instance, Australian investigators reported that a home-based intervention that reported a 40% reduction in readmissions and appeared to most effective in reducing the frequency of multiple readmissions (Stewart, Marley, Horowitz, 1999).

The Care Transition Intervention

Based on the promising but inconclusive findings from these and other similar studies, the County of Kaua`i Agency on Elderly Affairs (KAEA) in partnership with Kaua`i Veterans Memorial Hospital (KVMH) initiated the *Kaua`i Care Transition Program* designed to help patients with complex chronic conditions with their transition from hospital to home, and manage their health conditions and recovery successfully at home. Patient education and empowerment were the signature components of the intervention.

The goal of the program, implemented over a 12- month period from April 1, 2012 to March 31, 2013, was to empower and educate high risk elderly patients to effectively manage their health through increasing their knowledge of self-care skills. The targeted outcome was a reduction in both the likelihood of hospital readmission within 30 days and a reduction in the number of total re-hospitalizations over the study period.

Methods and Materials

Study settings and populations

KVMH is a 45 bed hospital which includes 15 acute, and 30 Acute/SNF Swing and ICF beds, located at the county of Kauai. The target population was composed of people 60 years and older, who resided in West Kauai in the State of Hawai'i. Preliminary analysis of hospital admission data for people 60 and over in the year 2010 succeeded in identifying several high risk groups of patients. These included those with severe respiratory/pulmonary diseases (i.e. COPD, pneumonia etc), cardiac-related diseases (i.e. arrhythmia/congestive heart failure), sepsis, and cellulitis**.** Patients discharged/transferred to facilities such as intermediate care facilities, skilled nursing facilities, or other acute hospitals were also associated with increased likelihood of readmission. Alternatively, several groups of patients were specifically excluded from the study including cognitively-impaired patients who lacked a primary caregiver**;** active substance-abusers not in treatment or recovery programs**;** patients with acute mental illness (not in treatment or taking medication) and long term nursing home residents.

The Kauai Care Transition program was based on the Care Transition Intervention (CTI), a patient-centered intervention designed by Dr. Eric Coleman (Coleman, Parry, Chalmers, et al., 2006). Known as the Coleman model, it is a 4 week intervention program which utilizes a trained coach who follows the patients upon discharge from the hospital. In the Kauai Care Transition program, the coach was a board certified occupational therapist. Referrals to the program were made by a physician or any member of the hospital multidisciplinary team and were coordinated by the hospital social services department. Initial contact between the patient and coach was made in the hospital and a home visit, to provide continuity during the transition and to ensure that patients would take a more active role in managing their care. The first home visit generally occurred within 24-72 hours after the patient was discharged. During this visit, the coach reviewed with patients their discharge plan and ensured that they were adhering to the treatment protocol, complying with medication instructions scheduling follow up appointments with their primary care physician, and recognizing warning signs and symptoms of worsening conditions. As part of this process, the patient received a Personal Health Record (PHR) to record his/her medical history, medications and allergies, a list of red flags or warning signs and other critical information. They were encouraged to bring this record along to physician office visits so that they could record any updates on their medical information as needed.

The coach also role-played effective communication strategies with the patient to prepare him/her to clearly articulate his/her needs with the primary physician or other health care professionals. After the initial home visit the coach called once a week to monitor the patient's progress and address any questions or concerns. The coach also referred patients, if interested, to the Kauai Agency on Elderly Affairs or other agencies for an array of home and community based programs that might further assist in their care at home. Overall, the care transition program followed the patient for up to 4 weeks with three additional telephone calls. If they wished to, patients could also initiate contact with the coach. There was a one month follow-up mailed client survey and/or phone call from the coach to monitor their progress.

Evaluation of the intervention

The evaluation of the program was multifaceted. It included both qualitative and quantitative evaluation. The qualitative evaluation utilized four tools: (1) The Patient Activation Assessment (PAA), (2) Care Transition Measure (CTM-3); (3) Medication Discrepancy Tool, and (4) CTI 30-day follow up survey.

PAA provides the transition coaches a method of tracking patients' progress in skill transfer and activation along the Four Pillars during their participation in the Care Transitions Intervention program (PAA, 2013). PAA itself has a total of 4 components: (1) Medication Management, which assesses patients' ability to demonstrate effective and reliable use of medication management approach, to understand the purpose, when and how to take each medication, to accurately update medication list, to share medication list with PCP and/or specialist; (2) Red Flags, which assesses patients' understanding of Red Flags and ability to articulate how to respond to Red Flags; (3) Medical Care Follow Up which assess patients' ability to schedule and follow through on appointment and to write a list of questions for PCP; and (4) Personal Health Record (PHR), which assesses patients' understanding of the purpose of PHR and the importance of updating PHR as well as patients' agreement to bring PHR to every health encounter.

As a result, PAA has a total of 10 items. For each of the 10 item, if the patient demonstrates the ability, or understanding, or presence of characteristics that item is expecting, that item is then scored 1; otherwise, it is scored 0. PAA is expected to be done at 4 times: (1) the first assessment measure of the patient's activation before having received any coaching; (2) three other assessments at the subsequent encounters (home visit and three phone calls). The final PAA forms the basis for an overall determination of activation.

Care Transition Measure (CTM-3) measured the overall quality of the care transition using the following 3 questions: (1) The hospital staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left the hospital; (2) When I left the hospital, I had a good understanding of the things I was responsible for in managing my health; and (3) When I left the hospital, I clearly understood the purpose for taking each of my medications. Responses of each of the 3 questions are scored on a 4-point Likert Scale: Strongly Disagree =1; Disagree =2; Agree =3; Strongly Agree =4. Total scores are the sum of the response across those 3 items, with lower scores indicating a poorer quality transition, and higher scores indicating a better transition (CTM-3, 2013).

The Medication Discrepancy Tool identified and characterized medication discrepancies that arose when patients were making the transition between sites of care, as well as the causes of any such discrepancies at both the patient and systematic level. Total number of medication discrepancies was reported during the intervention period.

The CTI 30-days follow-up survey assesses a total of 8 items. The first 3 items assess patients' knowledge of medications prescribed, patients' confidence in asking questions to doctor or pharmacist, patients' knowledge of warning signs of worsening health conditions. The following two questions asked the patients whether they had went to ER, or readmitted within the last 30 days. It also asked the patients about the CTI program and CTI coaches and finally a question asked whether the patient has any questions for further assistance.

Quantitative Evaluation

An in-depth data analysis was undertaken to determine if hospital readmission rates were reduced between baseline and the intervention period. Hospital readmission rates within a year, within 60 days, and within 30 days were examined respectively. Further examinations included where the intervention effectively reduced readmission rates among patients with risk factors identified at baseline as compared to those without such risk factors and whether patients completed the CTI program had lower readmission rates compared to those who did not complete the program.

To justify that any detected reduction of hospital admission rate is due to the intervention rather than other factors, the two data sets were combined into one data set. A new variable, **Time,** was created to differentiate data between the intervention period and the baseline period. A series of tests were conducted to examine patient characteristics between those two time periods. If patient populations were found to be significantly differed by some patient characteristics, a multivariate logistic regression model was then used to evaluate the effectiveness of the intervention while controlling for these patient characteristics.

Hospital data from April 1, 2012 to March 31, 2013 were submitted as an Excel spreadsheet for data analysis. Only patients age 60 and older were included in the analysis. Information regarding referral to the intervention and whether a patient completed the intervention program were coded by different colors. After importing the data to SAS$^{©}$, codes were created to correspond to the various color designations and a variable, ***Referral*** was first created with 3 categories: referred, not referred, and ineligible referral. Another variable, ***Completion,*** was also created with 4 categories: complete, incomplete, ongoing, and unknown.

As done in the baseline analysis, two variables were created to serve as dependent variables in the analysis: (1) ***Readmission (Readmitted within a year)***, referring to whether the patient was readmitted or not within a year from the first discharge date from an acute hospital bed and (2) ***Read30days (Readmitted within 30 days),*** referring to whether the patient was readmitted or not within 30 days from the first discharge date from an acute hospital bed**.** In addition, another variable, ***Read60days (Readmitted within 60 days)***, referring to whether the patient was readmitted or not within 60 days from the first discharge date from an acute hospital bed, was also created.

Only admissions to acute beds, including medical, surgical, or intensive care unit are considered for the determination of whether a patient is readmitted and the total number of admissions. Transfers of patients from acute beds to skilled nursing facility (SNF) beds or intermediate care facilities (ICF) beds were not considered as meeting the definition of readmission. To determine whether a patient is readmitted within a year, or 30 days, or 60day, another variable, ***FirstReadDays*****,** was created to determine the days between the patient's first discharge date and first readmission date. Even though a patient can be readmitted more than once, only the very first readmission was used.

A number of other variables were also created or otherwise assigned codes for the analysis. Age at admission was calculated as the difference in years between the date of first admission to an acute bed and the date of birth. Other variables discussed in the literature as possibly having an effect on early readmission included for further analysis included length of stay, gender, the medical services codes, and patients' primary insurance codes. Primary insurance was reduced to four main groups: HMSA/65C+, MEDICARE, HMSA, and all other insurances combined.

Frequencies run for the discharge site code indicated that there were 12 different discharge sites. These discharge sites were regrouped into three major categories: home (with or without home health), skilled nursing facility (including swing beds and ICF placement), and all other sites (Oahu or various acute hospitals). Tables 1a and Table 1b provides descriptive statistics of the study sample based on those variables.

The next step in the process was to code the ICD-9 codes for primary, secondary, and tertiary diagnosis. Table 2 lists the top 10 diagnosis for primary, secondary and tertiary diagnosis for the sample data. The baseline data analysis found that primary diagnosis of arrhythmias, any of the three admitting diagnosis of COPD or cellulitis were risk factors of readmission. To determine whether those factors remained risk factors of readmission during the intervention period, the following three new variables were created: (1) Arrhythmias, if the patient's primary diagnosis is arrhythmias; (2) Cellulitis, if the patient has cellulitis among either one of those 3 diagnoses, and (3) COPD, if the patient has COPD among either one of those 3 diagnoses.

Statistical Analysis

Descriptive statistics

Descriptive analysis on patient characteristics included mean age of patients, average length of stay, major types of admitting medical services, discharging sites, and primary health insurance. Frequency counts of patients' primary, secondary and tertiary admitting diagnosis were provided. Main outcome variables examined included readmission rates within a year, within 60 days and within 30 days.

Other information examined included number of referrals to the intervention program and whether the patient completed the program or not. Summary statistics of the qualitative evaluation including PAA, CTI-3 score, medication discrepancy, and CTI 30 days follow-up were also provided.

Inferential statistics

Chi-squared tests were initially used to evaluate whether readmission rates within different time periods (e.g., within a year, or 60 days or 30 days) differed significantly between intervention period and baseline. To further test whether the intervention effectively reduced readmission rates among patients with risk factors identified at baseline, chi-squared tests were also used to compare readmission rates between patients with those risk factors and patients without those risk factors. Risk factors examined including the following ones: discharged not to home, HMSA/65+ as the primary health insurance, arrhythmias as the primary admitting diagnosis, and cellulitis and chronic obstructive pulmonary disease (COPD) among any of the primary, secondary, or tertiary diagnosis. When the sample size requirement was not meet, e.g., sample data includes small and/or zero cell counts, Fisher’s exact test was then applied.

In addition, we examined whether a particular component of the intervention contributed to its general effectiveness. Chi-squared tests were used to examine readmission rates between those referred to the program and completed the program, and those referred to the program but did not complete the program, or their status of completion was unknown.

To justify whether the observed difference in the readmission rates between the intervention period and baseline is due to the intervention rather than other factors, e.g., patient characteristics, the two data sets were combined into one data set and a new variable, **Time,** was created to differentiate data between the intervention period and the baseline period. Any record from intervention period was assigned a value of 2 and any record from baseline was assigned a value of 1. A series of tests were conducted to examine patient characteristics between those two time periods. Chi-squared tests were used to compare categorical patient characteristics between the two time period, including patient's sex, discharge sites, patient's primary insurance, and admitting medical services. Independent t-tests were used to compare continuous patient characteristics including patient's age and length of stay. If the hospital patient populations were found to be significantly differ by some patient characteristics, a multivariate logistic regression model was then used to evaluate the effectiveness of the intervention while controlling for these patient characteristics.

Results

Information on referral to the program

The total hospital data included 517 records, with a total of 329 records belong to patients age 60 and older. Those 329 records were from a total of 269 patients, which includes readmissions. During the intervention period, a total of 64 patients were referred to the program, of which 58 were patients 60 and over.

Of these 58 patients, 49 were referred to the program at their first admission to the hospital. Among those 49 patients, 2 had a second referral. A total of 6 patients were referred at their second admission; 2 patients were referred at their third admission to the hospital and one of them had another referral at his/her fifth admission. One patient was referred at his fourth admission to the hospital. As a result, there were a total of 61 referrals made from those 58 patients.

Among those 49 patients referred at their first admissions, 24 completed the program. One patient is still in the program at the time when the data set is submitted for analysis. Another 4 did not complete the program and the 20 patients were of unknown status of program completion. Those with unknown status and those did not complete the program were later combined into one group and were compared to those completed the program on readmission rates, including readmission rates within a year, within 60 days and within 30 days.

Patient characteristics

A total of 269 patients age 60 and older were included in the analysis. This included the 58 CTI participants. The age of the sample ranged from 60.1 to 105.4 with the mean age being 77.5 years. Slightly over half (50.9%) of the sample were male and 49.1% were female. 88.5% of the patients received medical services, with 9.3% receiving ICU , and another 2.2 % receiving surgery or emergency services. In terms of health insurance, Medicare insured 40.9%, of the patients. HMSA 65plus insured about a quarter (23.4%). HMSA itself insured an additional 11.2% with the remainder spread out over 19 other insurance plans (Table 1a).

Septicemia was the top primary diagnosis, constituting 18.4% of the study sample. The second most frequent primary diagnosis was pneumonia (10%), followed by chronic heart diseases (5.1%), then chronic bronchitis (3.6%), and then cellulitis (3%). Table 2 lists the top 10 primary, secondary, and tertiary diagnosis of the study sample. Among the 260 patients, a total of 14 patients have the primary diagnosis as arrhythmias, a total of 10 patients have cellulitis among any of the 3 diagnoses, and a total of 16 patients have COPD among any of the 3 diagnoses. Appendix 1 lists the frequency counts of the primary, secondary, and tertiary diagnosis of the study sample.

Readmission rates

A total of 269 patients were included in the analysis. Among those 269 patients, 226 were admitted only once, 32 admitted twice, 6 admitted 3 times, 4 admitted 4 times, and 1 admitted 5 times. The number of admissions ranged from a minimum of 1 to a maximum of 5 over the course of the year, with a mean number of admissions of 1.5. The length of hospital stay in days ranged from 1 to 21 days with the mean length of stay being 3.6 days.

Of the 269 patients, **43 (16%)** were readmitted over the course of the year. Among the 43 patients with any readmissions, 13 were readmitted within 30 days from their first dates of discharge from an acute bed and 22 were readmitted within 60 days from their first dates of discharge from an acute bed. Hence, **4.8% (13 over 269)** of the patients were readmitted within 30 days, and **8.2% (22 over 269)** were readmitted within 60 days.

Comparing readmission rates between intervention and baseline period

Chi-squared tests revealed a significant difference between the readmission rate within a year at baseline (28.1%) and during the intervention period (16.0%) (X^2=11.85, p<0.001). When compared to baseline readmission rates, the intervention reduced the readmission rate by 42.8% percent. A significant difference was also observed in the readmission rates within 60 days at baseline (17.7) and during the intervention period (8.2%) (X^2=11.09, p<0.001). Readmission rate within 60 days was reduced by 53.6%. There was also a significant difference in the readmission rates within 30 days at baseline (12.5%) and during the intervention period (4.83%) (X^2=10.19, p=0.001). The readmission rate within 30 days of admission was reduced by 61.4%.

Did patient population changed between baseline and intervention period?

To justify that the reduction in the readmission rates within a year and reduction of readmission rate within 30 days were due to the intervention rather than other factors, patient population changes (chi-squared tests or independent t-tests) were used to compare distributions of selected patient characteristics. Most of those selected patient characteristics are those identified as risk factors at baseline for readmission either within a year or within 30 days. Chi-squared tests found that there were no significant difference in distribution of patient discharged to different types of sites (X^2=2.525, p=.283). There was no significant difference in the gender distribution between the two time periods (X^2=0.299, p=.585). No significant difference in the proportion of patients with arrhythmias as their primary admitting diagnosis, or cellulitis among any of the three diagnoses, or COPD among any of the three diagnoses (Table 3).

In addition, independent t-tests also found no significant difference in the mean age of patients between intervention and baseline periods, nor was there significant difference in the mean length of hospital stay (Table 3). Nevertheless, there was significant difference in the distribution of different categories of patients' primary health insurance (X^2=8.592, p=.035; Table 3).

Did the intervention reduce readmission rates among those with high risk factors?

The intervention reduced risk of readmission rates among high risk patients to a level equivalent to patients without risk factors. This is reflected by the fact that no significant difference was observed in the readmission rates within a year among those discharged to home (with or without home health care) (16%), those discharged to ICF or SNF (15.6%), and those discharged to other sites (e.g., acute hospital bed or other acute hospitals)(14.3%) (X^2=0.1093, p=0.947, Table 3). Fisher's exact test revealed no significant difference in the readmission rates between those with arrhythmias (28.6%) and those without (15.3%) (p=.250), or between those with cellulitis (20%) and those without (15.8%) (p=.664) or between those with COPD (25%) and those without (15.4%) (p=.298, Table 4). Nevertheless, significant difference in the readmission rates were found among patients with different types of health insurance (X^2=10.18, p=.017), with patients of other types of insurance (non-Medicare, non-HMSA patients) having the highest readmission rate (27.3%), followed by patients of Medicare (15.5%), then HMSA/65C+ (9.5%) and HMSA(6.7%) (Table 4).

Similar patterns of results were found when comparing the admission rates within 30 days and admission rates within 60 days. No significant difference was observed in the readmission rates within 30 days and 60 days among patients discharged to different sites, or between patients with and without the specific disease. Nevertheless, significant difference was observed among patients with different types of health insurance. Patients with other types of health insurance had the highest readmission rates within 30 days or 60 days (12.1% and 18.2% , respectively), followed by Medicare patients (3.6% and 5.5%, respectively), then HMSA/65C+ (1.6% and 4.8%, respectively), and HMSA (0% and 3.3%, respectively).

Is there a difference between those enrolled and completed the CTI program and CTI enrollees who did not complete the program?

A total of 58 patients were enrolled into the intervention program. 49 of the 58 were enrolled at their respective first hospital admissions. Among those 49 patients, 24 completed the program, 24 did not complete the programs (4 incomplete and 20 with unknown status of program completion), and 1 with ongoing status at the time the data was submitted for analysis. Fisher's exact test found no significant difference in the readmission rates between the 24 patients (25%) who completed those program and the other 24 who did not or with unknown status of completion (12.5%) (p=.461). Meanwhile, there was no significant difference in readmission rates between those completed (25%) and those did not complete (25%).

Using multivariate logistic regression to control for patient characteristics

As patient population between the two periods were found significantly different in the distribution of various types of health insurance, a multivariate logistic regression model was run to examine the effectiveness of the intervention while controlling for patient characteristics, in particular, patients' primary health insurance.

Table 5 showed the results of the final multivariate logistic regression model predicting readmission rate within a year. The intervention was found statistically significant in reducing readmission rates (within a year), while controlling for patients' primary health insurance, discharging sites, arrhythmias, any COPD, and any cellulitis. Readmission rates was as half as that of the baseline (OR=0.48, p<0.001). Although the odds of readmission were higher among those discharged to ICF or SNF or other sites as compared to those discharged to home, they are not statistically significant. Compared to HMSA/65C+, patients with regular HMSA were only 0.36 times as likely to be readmitted (p<0.001), while patients with other types of health insurance were at increased risk of admission (OR=1.10, p=0.06). No statistically significant difference was found between patients with HMSA/65C+ and Medicare patients. No significant difference was found between those having arrhythmias as the primary diagnosis and those not having, or between those with any cellulitis among the primary, second, and tertiary diagnoses and those without. Nevertheless, readmission rates among those with COPD were 3 times higher than those without (OR=3.20, p<0.01).

Table 6 shows the results of the final multivariate logistic regression model predicting readmission rate within 30 days. Intervention was found statistically significant in reducing readmission rates within 30 days, while controlling for patients' primary health insurance, discharging sites, arrhythmias, any COPD, and any cellulitis. Readmission rate within 30 days during the intervention period was one third as likely as that of the baseline (OR=0.34, p=0.003). Although the odds of readmission were higher among those discharged to ICF or SNF or other sites as compared to those discharged to home, they are not statistically significant. No significant difference was found among patients with different types of health insurance. However, readmission rates within 30 days were over 3 times higher among patients with arrhythmias as the primary diagnosis compared to those without (OR=2.96, p=0.047), and among those with cellulitis among any of the primary, secondary or tertiary diagnosis, compared to those without (OR=3.27, p=0.03). No significant difference was found between those having COPD among the primary, secondary, and tertiary diagnoses and those without.

Table 7 shows the results of the final multivariate logistic regression model predicting readmission rate within 60 days. Intervention was found statistically significant in reducing readmission rates within 60 days, while controlling for patients' primary health insurance, discharging sites, arrhythmias, any COPD, and any cellulitis. Readmission rate within 60 days during the intervention period was 0.42 times as likely as that of the baseline (OR=0.42, p<0.001). Although the odds of readmission were higher among those discharged to ICF or SNF or other sites as compared to those discharged to home, they are not statistically significant. No significant difference was found among patients with different types of health insurance. However, readmission rates within 30 days were nearly 3 times higher among patients with arrhythmias as the primary diagnosis compared to those without (OR=2.93, p=0.025), and among those with cellulitis among any of the primary, secondary or tertiary diagnosis, compared to those without (OR=2.68 p=0.052). No significant difference was found between those having COPD among the primary, secondary, and tertiary diagnoses and those without.

Results of the qualitative evaluation

Of the 58 patients referred to the CTI program, a total of 30 completed the program and another patient is still in the program when the data was extracted and submitted for analysis. Patient Activation Assessment was done among those 31 patients. Among those 31 patients, only one patient had a total of 4 assessments, with the rest 30 patients having only 2 assessments. The majority of these patients had the two assessments done within a 30-day period, with only a few exceptions (n=4) where the two assessments were done over a 30-day period. Among the 30 patients with only 2 assessments, 22 patients had the same scores of the 10 items between the 2 assessments. Of the remaining 8 patients, all patients experienced improvement in PAA on at least one of the 10 items, with scores changed from 0 to 1. The patient with 4 assessments had all 10 times scored 1 for all the 4 assessments. Table 8 summarizes the results of PAA during the intervention period.

A total of 17 patients participated in the medication discrepancy assessment. Out of the 17 patients participated, 10 had 1 discrepancy, 5 had 2 discrepancies, and 2 had 3 discrepancies. As a result, a total of 26 medication discrepancies were identified. The most frequently identified discrepancy at the patient level was non-intentional non-adherence (e.g., knowledge deficit), i.e., I don’t understand how to take this medication (n=12), followed by not filling prescription (n=5), and then the patient did not think that he/she needs the prescription (n=3). The most frequently identified medication discrepancies at the system level was conflicting information from different informational sources (e.g., discharge instructions indicating one thing while pill bottle saying another thing) (n=13), followed by incomplete or inaccurate or ineligible discharge instructions (n=5), and then incorrect dosage (n=4). The most frequently used resolution was encouraging patient to call PCP/specialist about the problem (n=21), followed by discussion potential benefits and harm that may result from non-adherence (n=7), and then encouraging patient to schedule an appointment with PCP/specialist to discuss problems identified at the next visit (n=4).

A total of 48 patients completed the Overall Quality of Care Transition Score during the intervention period. Mean scores of the 3 questions ranged from 3.37 to 3.46. A total of 16 patients answered the CTI 30-days follow-up survey. Among those 16 patients, the majority (81.3%) indicated that they understand the medication prescribed and were confident in asking question to doctor or pharmacist. Slightly over half (56.3%) of those 16 patients knew the warning signs of worsening health conditions. 81.3% did not visit ER for urgent conditions within the last 30 days and none of them was readmitted to the hospital within the last 30 days. Nearly two thirds (62.5%) thought CTI helped to better manage their health and 93.8% considered the coaches were courteous and helpful. Slightly over a third (37.5%) indicated they had questions for further assistance.

Discussion and conclusions

These findings indicate that the intervention was successful in reducing readmission rates within a year period, and within 30 days or 60 days. Such reductions remained true even after controlling for other factors identified as risk factors in the literature as being likely to affect readmission. Furthermore this study contributes to the literature by identifying that type of health insurance may be one factor that influences readmission. For example, this study found that patients with all other types of other health insurance had increased odds of readmission rate within a year compared to those with HMSA/65C+, while patients with regular HMSA had decreased odds of readmission rate. No significant difference was observed between Medicare patients and HMSA/65C+. This supports work done by researchers where Medicare without any additional insurance was identified as reducing the risk for readmission(Silverstein, Qin, Mercer, Fong and Haydon, 2008) and where socioeconomic factors such as race and lack of insurance influenced readmission status (Wiley and Blackwell, 2010).

In addition, this study identified multiple diagnoses as risk factors at baseline to be targeted for the intervention, a unique approach compared to most studies where a single diagnostic group is identified. By providing CTI intervention to patients with risk factors, this study was able to reduce readmission rates among those at risk to a level equivalent to those without such risk factors. As a result, readmission rates were reduced hospital wide. **This study demonstrated the value of careful targeting in implementing such an intervention.**

An additional merit of this study is the opportunity to compare those who completed the intervention with those who did not complete it or whose completion status was unknown. Findings of no difference between these two groups helps establish that there was no bias in sample mortality, another major threat to internal validity when there is no control group. Finally this is a prospective study, as opposed to a retrospective study which pulls from medical records, which increases study validity.

One study limitation is that there was no randomization at the patient level and subsequently, there was no equivalent comparison or control group for the study, which is a threat to internal validity. This was somewhat mitigated by the evaluation of patient characteristics between baseline and intervention period. The findings revealed that patient characteristics remained same among most of the identified risk factors, such as proportion of patients discharged not to home, proportions of patients with cellulitis, or COPD, or arrhythmias. The only difference identified was the distribution of various types of health insurance, with a slightly higher percentage of Medicare patients (40.9%) and a slightly lower percentage of HMSA/65C+ patients (23.4%) during the intervention period as compared to baseline (34.7% Medical patients and HMSA/65C+ both). Nevertheless, the effectiveness of the intervention remained true even after controlling for patient’s primary health insurance in the multivariate logistic model.

Patient Activation Assessments found although the majority of patients had already possessed the characteristics of expectation at the first (baseline assessment) across the 10 items, the CTI program succeeded in improving patient’s ability in medication management, health care follow up and the use of Personal Health Information. The overall quality of care transition was high, with mean scores of 3.4 to 3.5 out of a total score of 4.

The CTI 30-days follow up survey revealed that the majority of the patients improved in their understanding and skills in medication management and warning signs of worsening health conditions. Nearly two thirds of those responded agreed that CTI helped them to better manage their health and 94% considered the CTI coaches courteous and helpful. Finally, identified most frequent medication discrepancies will help in targeting future intervention efforts if CTI program is going to be adopted by other health care facilities.

Overall this study demonstrates that an educationally based intervention designed to address readmission rates can be successfully implemented in a small acute hospital setting and can reduce readmission rates for variously measured time periods even while controlling for other possible predictors or readmission. By providing CTI intervention to patients with risk factors, this study was able to reduce readmission rates among those at risk to a level equivalent to those without such risk factors. This study demonstrated the value of careful targeting in implementing such an intervention. Finally, the intervention was also able to empower and educate patients with better skills in managing their own health.

Table 1a. Descriptive statistics of the study sample based on selected variables for patients age 60 and over, Kauai Veteran's Memorial Hospital, April 2012 to March 2013 (n=269).

Selected Variables	**Number**	**Percent**
Readmitted within a year	**43**	**16.0**
Readmitted within 30 days	**13**	**4.8**
Readmitted within 60 days	**22**	**8.2**
Gender (female)	132	49.1
Medical service		
Medical	238	88.5
ICU	25	9.3
Other (e.g., surgical, emergency, etc.)	6	2.2
Primary health insurance		
HMSA/65C+	63	23.4
MEDICARE	110	40.9
HMSA	30	11.2
ALL OTHER	66	24.5
Discharged to what site		
HOME with or without home health	151	56.1
SNF or ICF	90	33.5
All Other*	28	10.4

*Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and other types of insurance such as Veteran Affairs Department, etc.

Table 1b. Descriptive statistics of the study sample based on continuous variables (n=269).

Continuous Variable	**Mean**	**Minimum**	**Maximum**
Number of admissions	1.5	1	5
Length of stay in days	3.6	0	21
Age at time of first admission	77.5	60.1	105.3

Table 2. List of top 10 primary, secondary, and tertiary diagnosis of the study sample, Kauai Veteran's Memorial Hospital, April 2012 to March 2013 (n=269).

Primary Diagnosis	COUNT (%)	Secondary Diagnosis	COUNT (%)	Tertiary Diagnosis	COUNT(%)
Septicemia	61(18.4%)	Pneumonia	38(12.0%)	Dehydration	27(8.8%)
Pneumonia	33(10.0%)	Chronic heart failure	21(6.6%)	Acute kidney failure	23(7.5%)
Chronic heart failure	17(5.1%)	Acute kidney failure	20(6.3%)	Diabetes	19(6.2%)
Chronic bronchitis	12(3.6%)	Encephalopathy	19(6.0%)	Cardiomyopathy	16(5.2%)
Cellulitis	10(3.0%)	Anemia	17(5.4%)	Chronic heart failure	14(4.6%)
Asthma	8(2.4%)	Respiratory failure	17(5.4%)	Atria fibrillation	13(4.2%)
Atria fibrillation	8(2.4%)	Diabetes	13(4.1%)	Cardiovascular symptoms	11(3.6%)
Cerebral artery occlusion	8(2.4%)	Dehydration	13(4.1%)	Chronic kidney failure	10(3.2%)
Choleystitis	7(2.1%)	Pressure ulcers	9(2.8%)	End Stage Renal Disease	10(3.2%)
End Stage Renal Disease	7(2.1%)	Atria fibrillation	8(2.5%)	Respiratory failure	7(2.3%)

Table 3. Comparison of patient characteristics between intervention (April 2012 to March 2013) and baseline period (2010)

Patient Characteristics	**Baseline N (%)**	**Intervention N (%)**	**Chi-square**	**p value**
Male	148 (51.4%)	132 (49.1%)	0.299	0.585
Discharging sites			2.515	0.283
Home (with or without home health)	145 (50.4%)	151(56.1%)		
ICF or SNF	115 (39.9%)	90 (33.5%)		
Other	28 (9.7%)	28 (10.4%)		
Primary diagnosis of arrhythmias	14 (4.9%)	14(5.2%)	0.034	0.853
Any diagnosis of cellulitis	13 (4.5%)	10 (3.7%)	0.223	0.637
Any diagnosis of COPD	13 (4.5%)	16 (6.0%)	0.580	0.445
Primary health insurance			**8.592**	**0.04**
HMSA	27 (9.4%)	30(11.2%)		
HMSA/65C+	100 (34.7%)	63 (23.4%)		
Medicare	100 (34.7%)	110 (40.9%)		
Other*	61 (22.2%)	66 (24.5%)		
Continuous variables	Baseline mean (sd)	Intervention mean (sd)		*P* value
Age	76.6 (10.4)	77.5 (11.3)		.323
Length of stay	5.5(23.7)	3.6 (2.6)		0.728

*Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and other types of insurance such as Veteran Administration, etc.

Table 4. Readmission rates within a year among selected patient characteristics, Kauai Veteran's Memorial Hospital, April 2012 to March 2013 (n=269).

Patient Characteristics	**Readmitted N (%)**	**Not readmitted N (%)**	**Chi-square**	**p value**
Discharging sites			0.1093	0.9468
Home (with or without home health)	25 (16.6%)	126 (83.4%)		
ICF or SNF	14 (15.6%)	76 (84.4%)		
Other	4 (14.3%)	24 (85.7%)		
Primary diagnosis of arrhythmias				0.2503*
Yes	4 (28.6%)	10 (71.4%)		
No	39(15.3%)	216 (84.7%)		
Any diagnosis of cellulitis				0.664*
Yes	2(20%)	8 (80%)		
No	41 (15.8%)	218 (84.2%)		
Any diagnosis of COPD				0.298*
Yes	4 (25.0%)	12 (75%)		
No	39 (15.4%)	214 (84.6%)		
Primary health insurance			10.1827	**0.0171**
HMSA	2 (6.7%)	28 (93.3%)		
HHSA/65C+	6 (9.5%)	57 (90.5%)		
Medicare	17 (15.5%)	93 (84.6%)		
Other**	18 (27.3%)	48 (72.7%)		

Fisher's exact test was used due to small cell counts. * Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and Veteran Admission, etc.

Table 5. Results of the final logistic regression analysis predicting readmission rate within a year, controlling for selected patient characteristics

Variable	**B value**	**Standard Error**	**Significance Level**	**Odds Ratio**	**95% confidence interval of the odds ratio**
Time (intervention period)	-1.15	0.17	**<.001**	**0.48**	0.32–0.74
Primary insurance					
HMSA	-0.73	0.34	**0.03**	**0.36**	0.14 – 0.94
Medicare	0.07	0.19	0.69	0.81	0.49 – 1.34
Other	0.38	0.20	**0.06**	**1.10**	0.64 – 1.91
Discharge sites					
ICF or SNC	0.12	0.16	0.46	1.35	0.87 – 2.10
Other*	0.06	0.23	0.81	1.26	0.63 – 2.55
Arrhythmias	0.58	0.45	0.20	1.79	0.74 – 4.31
Any COPD	1.16	0.41	**<0.01**	**3.20**	1.43 – 7.13
Any Cellulitis	0.30	0.50	0.55	1.34	0.51 – 3.57

*Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and other types of insurance such as Veteran Administration.

Table 6. Results of the final logistic regression analysis predicting readmission rate within 30 days, controlling for selected patient characteristics

Variable	**B value**	**Standard Error**	**Significance Level**	**Odds Ratio**	**95% confidence interval of the odds ratio**
Time (intervention period)	-0.52	0.17	**<.01**	**0.36**	0.18–0.70
Primary insurance					
HMSA	-0.74	0.56	0.19	0.41	0.09 – 1.92
Medicare	0.17	0.28	0.54	1.02	0.49 – 2.90
Other	0.41	0.30	0.17	1.25	0.44– 3.52
Discharge sites					
ICF or SNC	0.15	0.24	0.52	1.41	0.74 – 2.68
Other*	0.04	0.34	0.92	1.25	0.44– 3.52
Arrhythmias	1.09	0.55	**0.047**	2.96	1.02 – 8.65
Any COPD	-0.03	0.77	0.97	0.98	0.22 – 4.38
Any Cellulitis	1.19	0.55	**0.03**	3.27	1.12 – 9.59

*Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and other types of insurance such as Veteran Administration, etc.

Table 7 Results of the final logistic regression analysis predicting readmission rate within 60 days, controlling for selected patient characteristics

Variable	**B value**	**Standard Error**	**Significance Level**	**Odds Ratio**	**95% confidence interval of the odds ratio**
Time (intervention period)	-0.43	0.22	**<.01**	**0.42**	0.24–0.72
Primary insurance					
HMSA	-0.79	0.46	0.09	0.33	0.09 – 1.17
Medicare	0.08	0.24	0.72	0.79	0.43 – 1.46
Other*	0.38	0.25	0.13	1.07	0.55– 2.08
Discharge sites					
ICF or SNC	0.13	0.20	0.54	1.24	0.72 – 2.14
Other	-0.03	0.29	0.91	1.06	0.55– 2.08
Arrhythmias	1.08	0.48	**0.025**	2.93	1.14 – 7.50
Any COPD	0.31	0.57	0.59	1.37	0.45– 4.18
Any Cellulitis	0.99	0.51	**0.052**	2.68	0.99– 7.26

***Other types of insurance included Medicare Advantage plans, such as Alohacare Advantage, Ohana/ Wellcare Medicare Advantage Plan, Humana Medicare Advantage Plan, Medicare Advantage Plan provided by the University Health Alliance, and other types of insurance such as Veteran Administration, etc.**

Table 8. Summary of the Patient Activation Assessment (PAA) (n=31).

Scenarios of score change	**Total number of patients**	**Comments**
Patients with only 2 assessments (n=30)	30	
• Scored “1” (yes) to all 10 items for both assessments	20	
• Scored “1” (yes) to 9 of the 10 items for both assessments and “0” for 1 out of the 10 items	2	One patient scored “0” for demonstrating understanding of Red Flags, or warning signs that condition may be worsening and the other patient scored “0” for whether to agree to bring PHR to every health encounter for both assessments
• Changed from scoring “0” at the first assessment to scoring of “1” at the second assessment for at least 1 out of the 10 items	8	Most frequent improvements occurred at medical management regarding patients’ understanding of the purpose, when and how to take each medication (n=6), to accurately update medication list (n=5), followed by patients’ ability to schedule and follow through on appointment and patients’ agreement to bring Person Health Record at every health encounter (n=2)
• Changed from scoring “1” at the first assessment to scoring “0” at the second assessment for at least 1 out of the 10 items	1	One patient scored “1” for agreeing to bring PHR at every health encounter at the first assessment to scoring of “0” at the second assessment
Patients with 4 assessments	1	
• All 10 items were scored “1” for all of the 4 assessments.		

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Appendix 1. Frequency counts of primary, secondary, and tertiary diagnosis of the study sample, Kauai Veteran's Memorial Hospital, April 2012 to March 2013 (n=269).

List of Primary Diagnosis

Primary diagnosis	Frequency	Percent	Cumulative Percent
Abdominal pain	1	0.31	0.31
Acute MI	5	1.57	1.88
Acute Postoperation pain	1	0.31	2.19
Acute bronchitis	4	1.25	3.45
Acute gouty arthropathy	1	0.31	3.76
Acute kidney failure	2	0.63	4.39
Acute pancreatitis	6	1.88	6.27
Alveiolar pnuemonopathy	1	0.31	6.58
Anemia	2	0.63	7.21
Ankle fracture	1	0.31	7.52
Anoxic brain damage	1	0.31	7.84
Appendicitis	1	0.31	8.15
Asthma	8	2.51	10.66
Atrial fibrillation	8	2.51	13.17
Atrial flutter	2	0.63	13.79
Bradycardia	1	0.31	14.11
CHF	17	5.33	19.44
Cardiac arrest	1	0.31	19.75
Cardiac dysrhythmias	3	0.94	20.69
Cellulitis	10	3.13	23.82
Cerebral artery occlusion	8	2.51	26.33

Primary diagnosis	**Frequency**	**Percent**	**Cumulative Percent**
Cerebral embolism w infarction	1	0.31	26.65
Cerebrovascular disease	2	0.63	27.27
Cholelithiasis	3	0.94	28.21
Choleystitis	1	0.31	28.53
Chronic bronchitis	12	3.76	32.29
Chronic sinusitis	1	0.31	32.6
Closed fracture of Pelvis	1	0.31	32.92
Colon cancer	1	0.31	33.23
Conduction disorders	2	0.63	33.86
Deep vein thrombosis	1	0.31	34.17
Dehydration	1	0.31	34.48
Dementia unspecified	1	0.31	34.8
Diabetes Mellitus	4	1.25	36.05
Diverticulitis	5	1.57	37.62
ESRD	7	2.19	39.81
Encephalopathy,not else specified	1	0.31	40.13
Enteritis	2	0.63	40.75
Erythematous conditions	1	0.31	41.07
Fever	1	0.31	41.38
Flu with respiratory dis	1	0.31	41.69
Foreign body in stomach	1	0.31	42.01
Fracture femur	7	2.19	44.2
Fx humerus shaft-closed	1	0.31	44.51
GI bleed	7	2.19	46.71
Gastric ulcer with hemorrhage	4	1.25	47.96

Primary diagnosis	Frequency	Percent	Cumulative Percent
Gastritis	1	0.31	48.28
Gastroenteritis	3	0.94	49.22
Glucocorticoid deficiency	2	0.63	49.84
Grand mal status	1	0.31	50.16
Heart disease complications	1	0.31	50.47
Heart failure	1	0.31	50.78
Hip contusion	1	0.31	51.1
Hip fracture	1	0.31	51.41
Hyponatremia	3	0.94	52.35
Hypotension	1	0.31	52.66
Insitu colon cancer	1	0.31	52.98
Intermediate coronary syndrome	1	0.31	53.29
Intestinal or peritoneal adhesions w ob	5	1.57	54.86
Intracerebral hemorrhage	2	0.63	55.49
Ischemic heart disease	2	0.63	56.11
Leg injury	1	0.31	56.43
Lumbar fracture	1	0.31	56.74
Malignant neoplasm of ascending colon	1	0.31	57.05
Malignant neoplasm of bone and bone marrow, secondary	1	0.31	57.37
Malignant neoplasm of liver, secondary	1	0.31	57.68
Mal-union of fracture	1	0.31	57.99
Metabolic Encephalopathy	1	0.31	58.31
Multiple rib fracture	1	0.31	58.62

Primary diagnosis	**Frequency**	**Percent**	**Cumulative Percent**
Myoclonus	1	0.31	58.93
Oral disease	2	0.63	59.56
Osteoarthritis	4	1.25	60.82
Other alteration of consciousness	1	0.31	61.13
Other digestive system complications	2	0.63	61.76
Other disorders of neurohypophysis	1	0.31	62.07
Other postoperative infection	3	0.94	63.01
Paralytic ileus	2	0.63	63.64
Pericardial Disease	1	0.31	63.95
Pleural Effusion	1	0.31	64.26
Pneumonia	25	7.84	72.1
Pneumonitis due to solids and liquids	7	2.19	74.29
Poisoning	1	0.31	74.61
Pulmonary Embolism	1	0.31	74.92
Pyleonephritis	4	1.25	76.18
Rectal bleeding	2	0.63	76.8
Respiratory Failure	2	0.63	77.43
Rotator cuff(capsule)sprain	1	0.31	77.74
Septicemia	54	16.93	94.67
Skin cancer	1	0.31	94.98
Stomach cancer	1	0.31	95.3
Subdural hemorrhage	1	0.31	95.61
Transcient cerebral ischemia	4	1.25	96.87
UTI	3	0.94	97.81
Unspecified disease of respiratory	1	0.31	98.12

Primary diagnosis	Frequency	Percent	Cumulative Percent
system			
Unspecified infectious and parasitic diseases	1	0.31	98.43
Unspecified osteomyelitis, ankle and foot	1	0.31	98.75
Vascular insufficiency of intestine	3	0.94	99.69
Ventral hernia w/obst	1	0.31	100

List of Secondary Diagnosis

Secondary diagnosis	Frequency	Percent	Cumulative Frequency
Atrial fibrillation	8	2.53	2.53
CHF	21	6.65	9.18
COPD	1	0.32	9.49
CV disease	1	0.32	9.81
CV symptoms	2	0.63	10.44
Cellulitis	3	0.95	11.39
Chronic Kidney Disease	3	0.95	12.34
Diabetes	13	4.11	16.46
ESRD	6	1.9	18.35
ETOH withdrawal	1	0.32	18.67
Foreign body in intestine and colon	1	0.32	18.99
GI bleed	1	0.32	19.3
NSTEMI	3	0.95	20.25
PBSO	1	0.32	20.57

Secondary diagnosis	Frequency	Percent	Cumulative Frequency
SBE	1	0.32	20.89
SIRS	2	0.63	21.52
TIA	2	0.63	22.15
UTI	6	1.9	24.05
VSD	1	0.32	24.37
abdom aneurysm	1	0.32	24.68
abdominal pain	1	0.32	25
acute MI	5	1.58	26.58
acute kidney failure	20	6.33	32.91
acute pancreatitis	6	1.9	34.81
alignant neoplasm of pancreas	1	0.32	35.13
anemia	17	5.38	40.51
asthma	5	1.58	42.09
bacteremia	1	0.32	42.41
benign neo of colon	1	0.32	42.72
bronchitis	5	1.58	44.3
candidiasis	1	0.32	44.62
capillary dis	1	0.32	44.94
cardiomyopathy	4	1.27	46.2
cerebral art occ	1	0.32	46.52
chest pain	1	0.32	46.84
cholethiasis	3	0.95	47.78
cirrhosis of liver	1	0.32	48.1
colon cancer	1	0.32	48.42
contusion	1	0.32	48.73

Secondary diagnosis	Frequency	Percent	Cumulative Frequency
cystic kidney dis	2	0.63	49.37
dehydration	13	4.11	53.48
dementia	6	1.9	55.38
depression	1	0.32	55.7
dis lipoid metabolism	8	2.53	58.23
dis magnesium metabolism	1	0.32	58.54
diverticulitis	2	0.63	59.18
encephalopathy	19	6.01	65.19
fever	1	0.32	65.51
fx femur	1	0.32	65.82
h pylori	1	0.32	66.14
hemiplegia	2	0.63	66.77
hypertension	2	0.63	67.41
hyponatremia	1	0.32	67.72
hypotension	2	0.63	68.35
hypothyroidism	1	0.32	68.67
inflam br dis	1	0.32	68.99
intest inf	2	0.63	69.62
ischemia	1	0.32	69.94
liver cancer	1	0.32	70.25
low platelets	1	0.32	70.57
lumbar fx	1	0.32	70.89
malignant neoplasm of lymph nodes	1	0.32	71.2
malignant neoplasm of respiratory and digestive	1	0.32	71.52

Secondary diagnosis	**Frequency**	**Percent**	**Cumulative Frequency**
systems			
malunion fx	2	0.63	72.15
myocarditis	1	0.32	72.47
nerv sys inj	1	0.32	72.78
old MI	1	0.32	73.1
pancytopenia	2	0.63	73.73
pleural eff	1	0.32	74.05
pneumonia	38	12.03	86.08
postop inf	3	0.95	87.03
pressure ulcers	9	2.85	89.87
pulm heart dis	1	0.32	90.19
pulmonary emb	1	0.32	90.51
resp failure	17	5.38	95.89
rhabdomyolysis	1	0.32	96.2
septicemia	3	0.95	97.15
syncope	2	0.63	97.78
systemic sclerosis	1	0.32	98.1
toxic neuropathy	2	0.63	98.73
urine retention	1	0.32	99.05
vasc insuffiency	1	0.32	99.37
vit b complex def	1	0.32	99.68
vomiting	1	0.32	100

List of Tertiary Diagnosis

Tertiary diagnosis	Frequency	Percent	Cumulative Percent
Atrial fibrillation	13	4.28	4.28
CHF	14	4.61	8.88
CKD	10	3.29	12.17
COPD	3	0.99	13.16
CV symptoms	11	3.62	16.78
Caisson Disease	1	0.33	17.11
Cardiac complications, not specified	1	0.33	17.43
Cardiovascular disease	2	0.66	18.09
Diabetes	19	6.25	24.34
Diffuse diseases of connective tissue	1	0.33	24.67
ESRD	10	3.29	27.96
Filariasis	1	0.33	28.29
GI bleed	4	1.32	29.61
MRSA	3	0.99	30.59
NSTEMI	1	0.33	30.92
RA	3	0.99	31.91
SIRS	3	0.99	32.89
SVT or brady	1	0.33	33.22
UTI	4	1.32	34.54
abdom aneurysm	2	0.66	35.2
abdominal pain	5	1.64	36.84
acute kidney failure	23	7.57	44.41

Tertiary diagnosis	**Frequency**	**Percent**	**Cumulative Percent**
acute pancreatitis	4	1.32	45.72
anemia	2	0.66	46.38
aortic valve dis	2	0.66	47.04
artery dis	1	0.33	47.37
asthma	5	1.64	49.01
bacteremia	2	0.66	49.67
bone cancer	2	0.66	50.33
bronchitis	3	0.99	51.32
cardiomyopathy	16	5.26	56.58
cellulitis	2	0.66	57.24
cerebral art occ	2	0.66	57.89
chest pain	1	0.33	58.22
cholethiasis	2	0.66	58.88
chronic sinusitis	1	0.33	59.21
conduction dis	6	1.97	61.18
dehydration	27	8.88	70.07
dementia	5	1.64	71.71
dis lipoid metabolism	3	0.99	72.7
dis magnesium metabolism	1	0.33	73.03
drug dependence	1	0.33	73.36
encephalopathy	3	0.99	74.34
gastroenteritis	1	0.33	74.67
gout	1	0.33	75
head injury	1	0.33	75.33
heart failure	1	0.33	75.66

Tertiary diagnosis	Frequency	Percent	Cumulative Percent
hemarrhrosis	1	0.33	75.99
hemiplegia	2	0.66	76.64
hernia	1	0.33	76.97
hydronephrosis	1	0.33	77.3
hypertension	5	1.64	78.95
hypotension	4	1.32	80.26
ischemia	3	0.99	81.25
liver CA	1	0.33	81.58
liver abscess	1	0.33	81.91
low platelets	2	0.66	82.57
lymph node CA	2	0.66	83.22
malnutrition	5	1.64	84.87
monoplegia	1	0.33	85.2
nervous sym	2	0.66	85.86
other	2	0.66	86.51
pain	2	0.66	87.17
pancytopenia	1	0.33	87.5
pleural eff	1	0.33	87.83
pneumonia	6	1.97	89.8
postop inf	1	0.33	90.13
pressure ulcers	4	1.32	91.45
prostate CA	1	0.33	91.78
prostate dis	1	0.33	92.11
pulm heart dis	3	0.99	93.09
pulmonary emb	1	0.33	93.42

Tertiary diagnosis	Frequency	Percent	Cumulative Percent
pyleonephritis	1	0.33	93.75
resp failure	7	2.3	96.05
septicemia	1	0.33	96.38
subdural hem	1	0.33	96.71
syncope	2	0.66	97.37
tobacco	1	0.33	97.7
toxic neuropathy	4	1.32	99.01
unspec res dis	1	0.33	99.34
venous insuf	2	0.66	100

Hospital Readmission Rates

Caregivers' Working Group

November 12, 2014

House Conf. Rm.

Peter A. Sybinsky, Ph.D.

President & CEO

Hawaii Health Information Corporation

Hospital Readmission Rates: Review

- 30-day readmission measures are: “estimates of unplanned readmission. . . to any acute care hospital within 30 days of discharge from a hospitalization.” (CMS)
- Calculated by using Medicare claims and eligibility information
- Include Medicare beneficiaries aged 65+ enrolled in Fee-for-Service Medicare
- Medicare rates are the only state level hospital ratings of readmission rates currently available

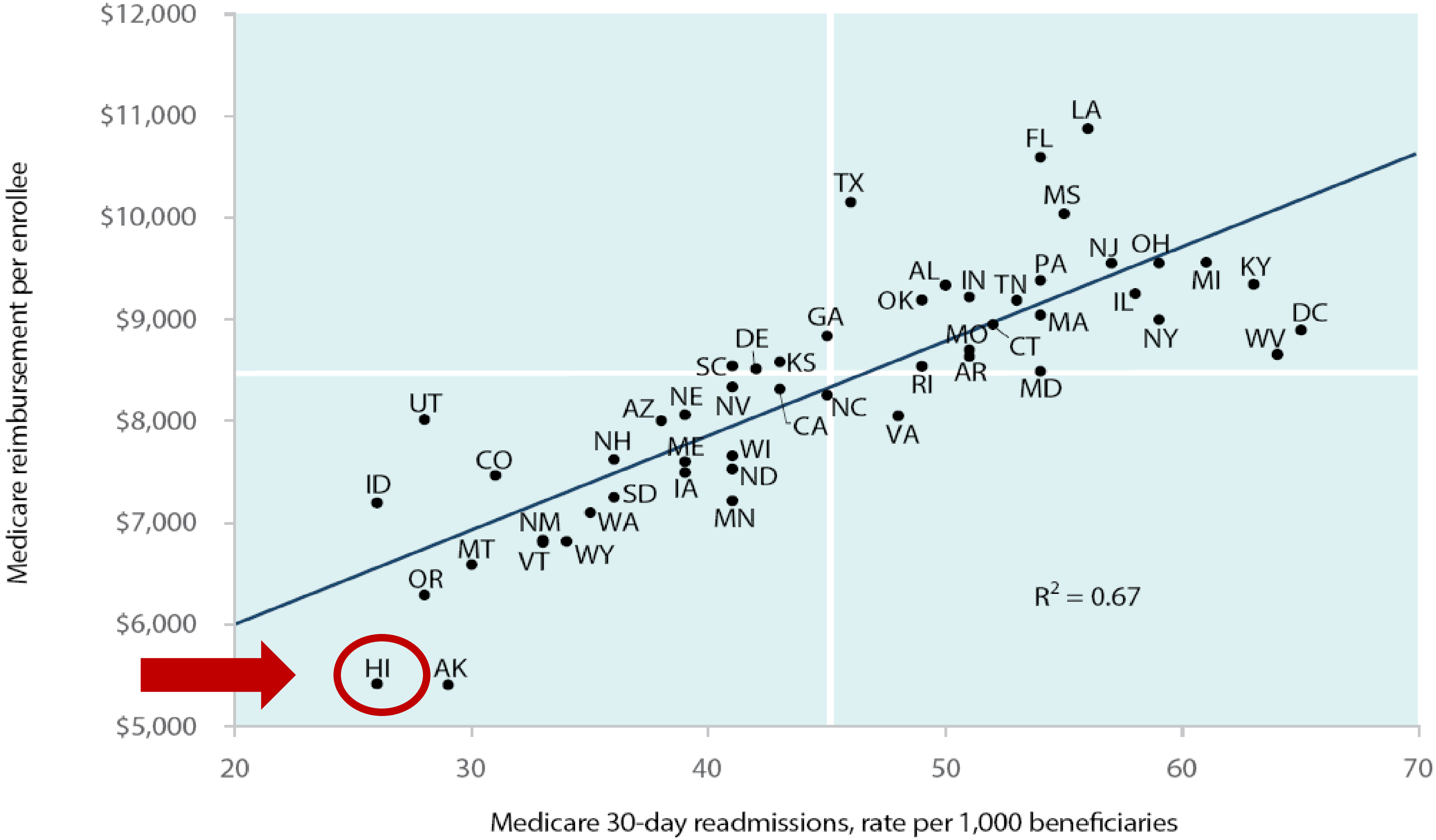
Hospital Readmission Rates: Review

- Measures are adjusted statistically for age, past medical history, comorbidities
- Currently, CMS uses five different readmission measures:
  - Heart Attack (AMI)
  - Heart Failure (HF)
  - Pneumonia
  - Hip/Knee replacements (NEW-Just Added)
  - 30 day overall rate (all conditions)

Hospital Readmission Rates: Overall (all conditions): How is Hawaii doing?

Medicare Cost per Beneficiary and 30-Day Readmissions by State, 2012

Source: The Commonwealth Fund



Hospital Readmission Rates Are Used in CMS' Hospital Readmissions Reduction Program

- Established by ACA (Section 3025)
- Incentivize hospitals to improve care
- Program also reduces Medicare costs

Hospital Readmission Rates Are Used in CMS' Hospital Readmissions Reduction Program

- Rewards/penalties based on the difference between a CMS estimate of what a hospital "should" score for a time period and what they actually do score. (If a readmission rate is higher than CMS estimate, financial penalties kick in.)

- Scores based on average of previous 3 year period. Ex. June 2012 score is based on data from previous 3 years (7/1/2008 through 6/30/2011). Penalties calculated starting with 2012 scores (Final Rule 2012).

Hospital Readmission Rates: Hospital Readmissions Reduction Program - II

- Utilizes specific rates rather than overall rate:
    - Heart Attack (AMI)
    - Heart Failure (HF)
    - Pneumonia

- Hospital must score <u>at or lower than expected on all three</u> readmission measures (AMI, CH, Pneumonia) in order <u>not</u> to be penalized.

Hospital Readmission Rates: Hospital Readmissions Reduction Program - II

- Based on data from Fee for Service Medicare patients (Does not include Medicare Advantage). In Hawaii, this is ~55% of Medicare patients
- Need minimum number of patients to get a score.

Hospital Readmission Rates: Hospital Readmissions Reduction Program: How is Hawaii doing? (2013)

- Percentage of Hospitals Statewide Penalized :

Nat’l Average	65.7%
Hawaii	66.7% (w/o HMC hospitals)
HI rank (of 50)	21st

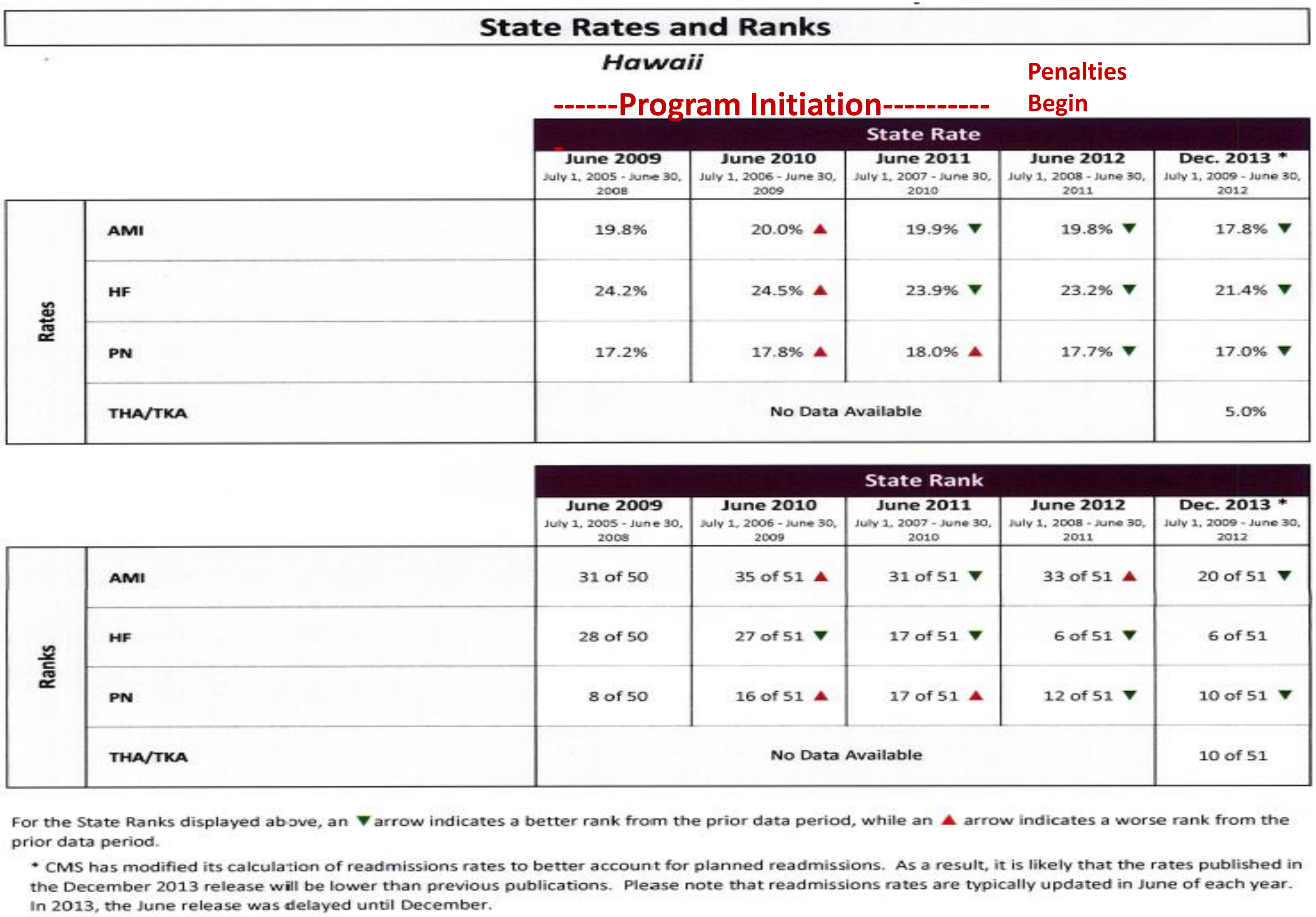
- Est. Impact on Payments (% lost due to penalties)

Nat’l Average	.27%
HI percentage	.13%
HI rank (of 50)	29th

- Total reduced in Hawaii: $430,900 (2013)
  $270,700 (2014)*

* 4(out of 12) hospitals not penalized in 2014. Data from 2013 is used for 2014 penalties.

Hospital Readmission Rates Penalties: How is Hawaii doing?



State Rates and Ranks

Hawaii

------Program Initiation----------

Penalties Begin

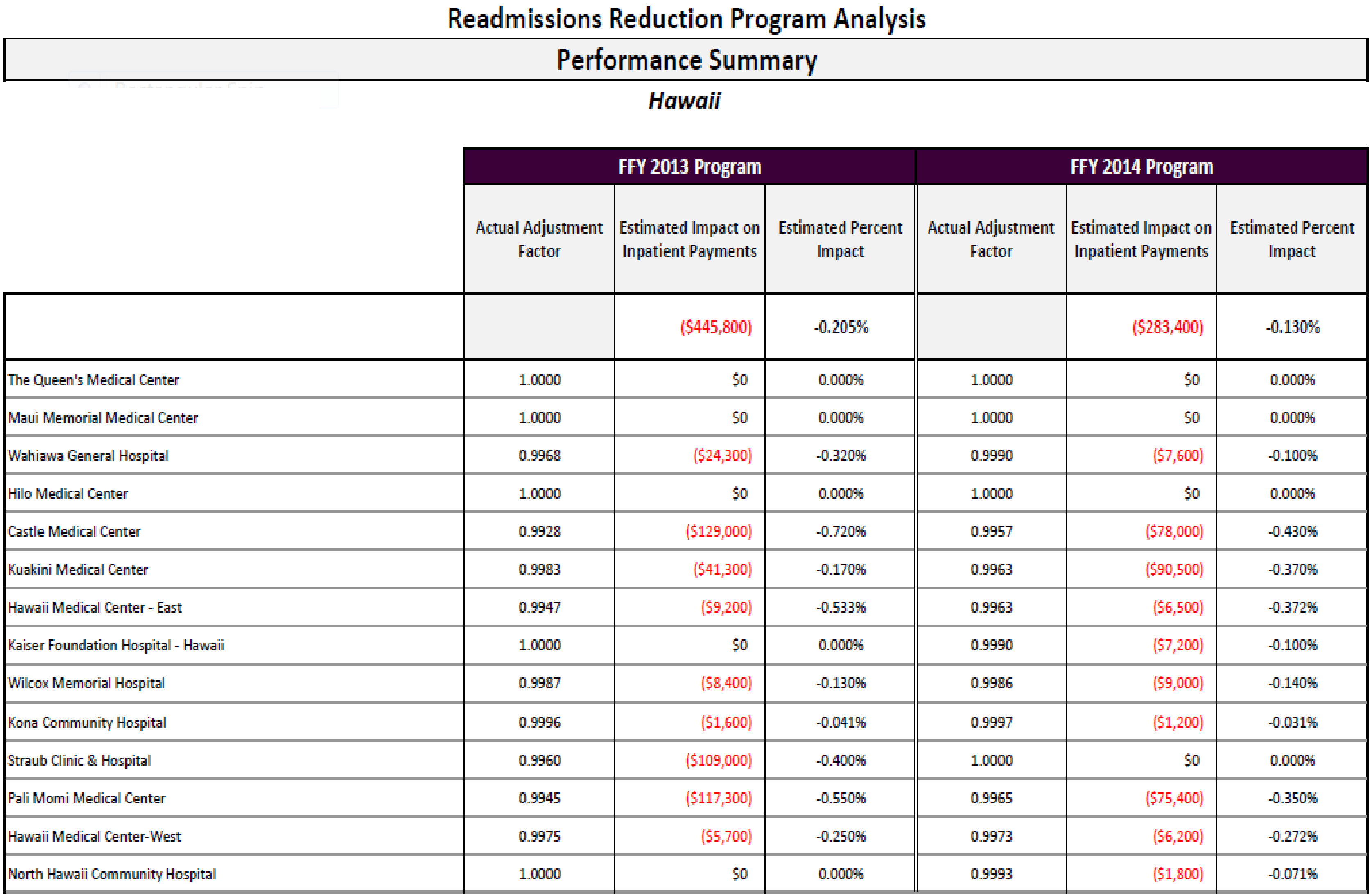
		State Rate				
		June 2009 July 1, 2005 - June 30, 2008	**June 2010** July 1, 2006 - June 30, 2009	**June 2011** July 1, 2007 - June 30, 2010	**June 2012** July 1, 2008 - June 30, 2011	**Dec. 2013 *** July 1, 2009 - June 30, 2012
Rates	**AMI**	19.8%	20.0% ▲	19.9% ▼	19.8% ▼	17.8% ▼
	HF	24.2%	24.5% ▲	23.9% ▼	23.2% ▼	21.4% ▼
	PN	17.2%	17.8% ▲	18.0% ▲	17.7% ▼	17.0% ▼
	THA/TKA	No Data Available				5.0%

		State Rank				
		June 2009 July 1, 2005 - June 30, 2008	**June 2010** July 1, 2006 - June 30, 2009	**June 2011** July 1, 2007 - June 30, 2010	**June 2012** July 1, 2008 - June 30, 2011	**Dec. 2013 *** July 1, 2009 - June 30, 2012
Ranks	**AMI**	31 of 50	35 of 51 ▲	31 of 51 ▼	33 of 51 ▲	20 of 51 ▼
	HF	28 of 50	27 of 51 ▼	17 of 51 ▼	6 of 51 ▼	6 of 51
	PN	8 of 50	16 of 51 ▲	17 of 51 ▲	12 of 51 ▼	10 of 51 ▼
	THA/TKA	No Data Available				10 of 51

For the State Ranks displayed above, an ▼ arrow indicates a better rank from the prior data period, while an ▲ arrow indicates a worse rank from the prior data period.

* CMS has modified its calculation of readmissions rates to better account for planned readmissions. As a result, it is likely that the rates published in the December 2013 release will be lower than previous publications. Please note that readmissions rates are typically updated in June of each year. In 2013, the June release was delayed until December.

Hospital Readmission Rates Penalties By Hospital



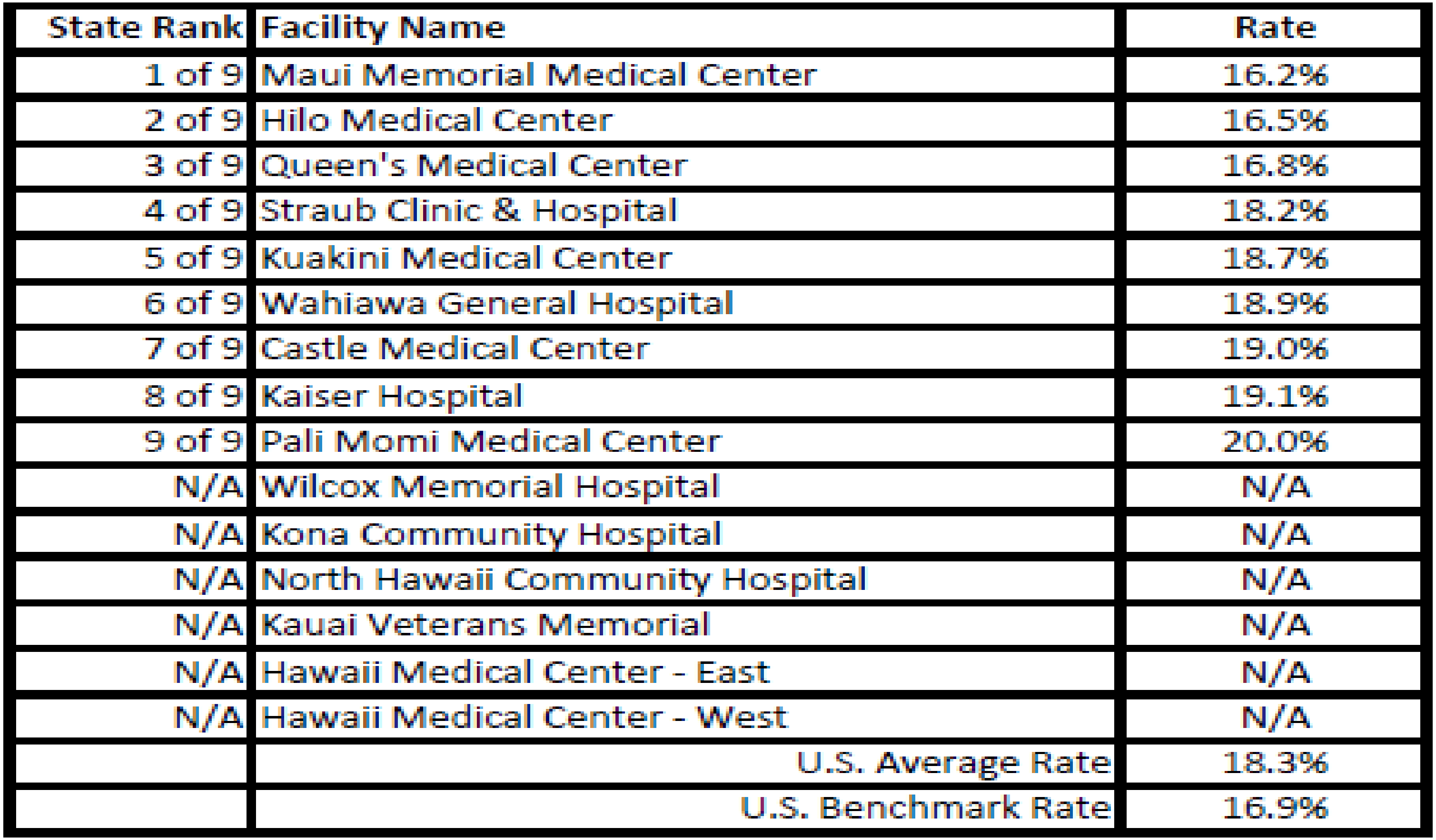
Readmissions Reduction Program Analysis

Performance Summary

Hawaii

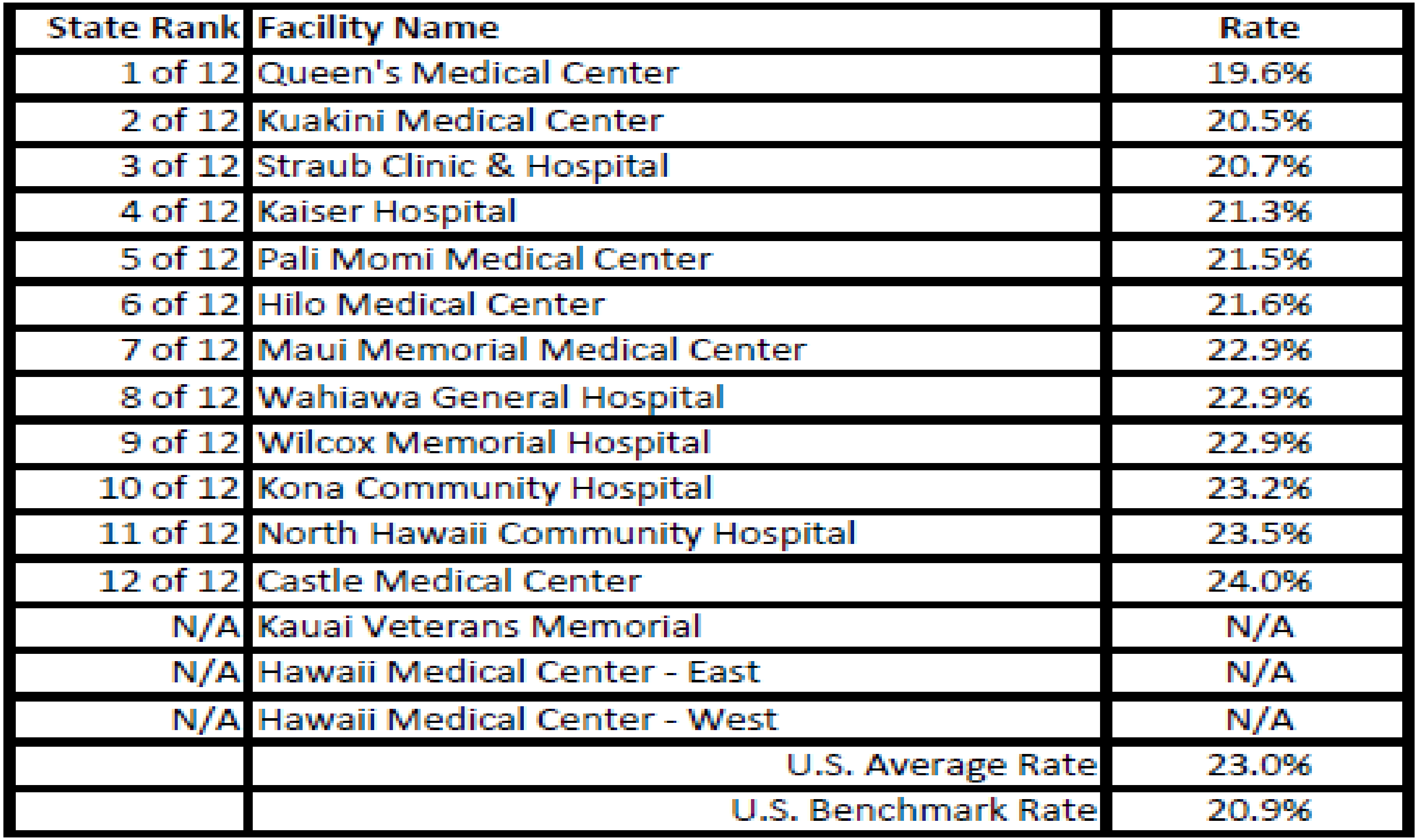
	FFY 2013 Program			FFY 2014 Program		
	Actual Adjustment Factor	Estimated Impact on Inpatient Payments	Estimated Percent Impact	Actual Adjustment Factor	Estimated Impact on Inpatient Payments	Estimated Percent Impact
		($445,800)	-0.205%		($283,400)	-0.130%
The Queen's Medical Center	1.0000	$0	0.000%	1.0000	$0	0.000%
Maui Memorial Medical Center	1.0000	$0	0.000%	1.0000	$0	0.000%
Wahiawa General Hospital	0.9968	($24,300)	-0.320%	0.9990	($7,600)	-0.100%
Hilo Medical Center	1.0000	$0	0.000%	1.0000	$0	0.000%
Castle Medical Center	0.9928	($129,000)	-0.720%	0.9957	($78,000)	-0.430%
Kuakini Medical Center	0.9983	($41,300)	-0.170%	0.9963	($90,500)	-0.370%
Hawaii Medical Center - East	0.9947	($9,200)	-0.533%	0.9963	($6,500)	-0.372%
Kaiser Foundation Hospital - Hawaii	1.0000	$0	0.000%	0.9990	($7,200)	-0.100%
Wilcox Memorial Hospital	0.9987	($8,400)	-0.130%	0.9986	($9,000)	-0.140%
Kona Community Hospital	0.9996	($1,600)	-0.041%	0.9997	($1,200)	-0.031%
Straub Clinic & Hospital	0.9960	($109,000)	-0.400%	1.0000	$0	0.000%
Pali Momi Medical Center	0.9945	($117,300)	-0.550%	0.9965	($75,400)	-0.350%
Hawaii Medical Center-West	0.9975	($5,700)	-0.250%	0.9973	($6,200)	-0.272%
North Hawaii Community Hospital	1.0000	$0	0.000%	0.9993	($1,800)	-0.071%

Hospital Readmission Rates: AMI 2013



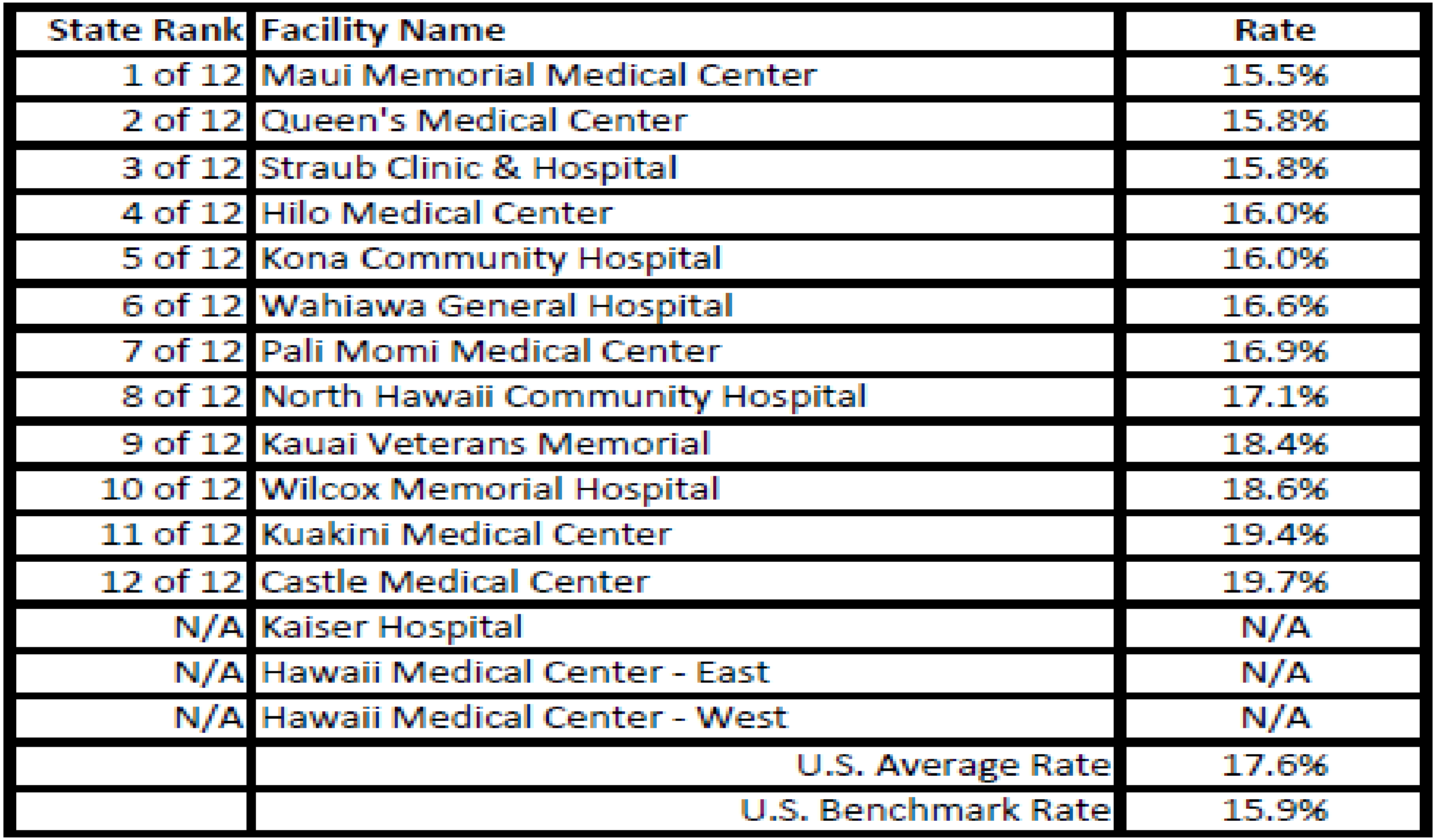
State Rank	Facility Name	Rate
1 of 9	Maui Memorial Medical Center	16.2%
2 of 9	Hilo Medical Center	16.5%
3 of 9	Queen's Medical Center	16.8%
4 of 9	Straub Clinic & Hospital	18.2%
5 of 9	Kuakini Medical Center	18.7%
6 of 9	Wahiawa General Hospital	18.9%
7 of 9	Castle Medical Center	19.0%
8 of 9	Kaiser Hospital	19.1%
9 of 9	Pali Momi Medical Center	20.0%
N/A	Wilcox Memorial Hospital	N/A
N/A	Kona Community Hospital	N/A
N/A	North Hawaii Community Hospital	N/A
N/A	Kauai Veterans Memorial	N/A
N/A	Hawaii Medical Center - East	N/A
N/A	Hawaii Medical Center - West	N/A
	U.S. Average Rate	18.3%
	U.S. Benchmark Rate	16.9%

Hospital Readmission Rates: Heart Failure 2013



State Rank	Facility Name	Rate
1 of 12	Queen's Medical Center	19.6%
2 of 12	Kuakini Medical Center	20.5%
3 of 12	Straub Clinic & Hospital	20.7%
4 of 12	Kaiser Hospital	21.3%
5 of 12	Pali Momi Medical Center	21.5%
6 of 12	Hilo Medical Center	21.6%
7 of 12	Maui Memorial Medical Center	22.9%
8 of 12	Wahiawa General Hospital	22.9%
9 of 12	Wilcox Memorial Hospital	22.9%
10 of 12	Kona Community Hospital	23.2%
11 of 12	North Hawaii Community Hospital	23.5%
12 of 12	Castle Medical Center	24.0%
N/A	Kauai Veterans Memorial	N/A
N/A	Hawaii Medical Center - East	N/A
N/A	Hawaii Medical Center - West	N/A
	U.S. Average Rate	23.0%
	U.S. Benchmark Rate	20.9%

Hospital Readmission Rates: Pneumonia 2013



State Rank	Facility Name	Rate
1 of 12	Maui Memorial Medical Center	15.5%
2 of 12	Queen's Medical Center	15.8%
3 of 12	Straub Clinic & Hospital	15.8%
4 of 12	Hilo Medical Center	16.0%
5 of 12	Kona Community Hospital	16.0%
6 of 12	Wahiawa General Hospital	16.6%
7 of 12	Pali Momi Medical Center	16.9%
8 of 12	North Hawaii Community Hospital	17.1%
9 of 12	Kauai Veterans Memorial	18.4%
10 of 12	Wilcox Memorial Hospital	18.6%
11 of 12	Kuakini Medical Center	19.4%
12 of 12	Castle Medical Center	19.7%
N/A	Kaiser Hospital	N/A
N/A	Hawaii Medical Center - East	N/A
N/A	Hawaii Medical Center - West	N/A
	U.S. Average Rate	17.6%
	U.S. Benchmark Rate	15.9%

Readmission Rates: To Come. . .

- System will include two new readmission rates in the Readmission Reduction program:
  - Hip/Knee replacements (2015)
  - COPD (future)

- Rates for the previous year are to be published in June of each year, however:
  - in 2014, rates were not published until December for the 2013 rates.
  - We have been notified that the new rates will be available for 2014 in December 2014 or January 2015.

Questions

HHIC Hospital Readmission Algorithm (3M)

- Definition: A subsequent hospital admission within 30 days following an original admission that is potentially preventable.
- No comparable data available at state level
- "Potentially preventable": "clinically-related to the initial hospital admission which may have resulted due to a deficiency in quality care in:
  - The initial admission
  - Discharge planning
  - Lack of post discharge follow-up or coordination in care.

Potentially Preventable Readmission Rates: 2013

Table 1. Total 30-day readmissions and aggregate charges, Hawaii, by payer, 2013

	Number of readmissions		Cost of readmissions		
Payer Type	Readmission	Readmissions as a percent of all readmissions	Readmission Charges (Excluding Initial Admission)	Readmission Charges as a Percent of Total Charges	Readmission Rate (Actual)
Dept of Defense	85	2%	$3,170,718	1%	4.92
Medicaid/Quest	1,261	23%	$52,371,428	22%	6.24
Medicare	3,033	55%	$143,540,196	60%	9.54
Miscellaneous	24	0%	$1,164,099	0%	2.80
Private Insurance	970	18%	$35,463,820	15%	3.47
Self Pay	101	2%	$3,190,765	1%	5.29
Overall:	**5,474**	**100%**	**$238,901,026**	**100%**	**6.48**

Readmission: A readmission within 30 days of initial admission. Readmission "chains" are counted which is a sequence of PPRs that are all clinically-related to the initial admission. A readmission chain may contain an initial admission and only one PPR, which is the most common situation, or may contain multiple PPRs following the initial admission.

Source: Hawaii Health Information Corporation, 2013.

HAWAII HEALTH
INFORMATION CORPORATION
Hawaii's source of healthcare data

September 2014

HHIC INSIGHT #2

Introduction

Health care reform has targeted hospital readmissions as a key area for improving care coordination and achieving potential savings. The Centers for Medicare & Medicaid Services (CMS) Hospital Readmissions Reduction Program has selected acute myocardial infarction, heart failure, and pneumonia as target areas for the Medicare population. CMS chose these conditions, in part, because of their high prevalence and their associated high costs for total admissions and readmissions among Medicare beneficiaries. In 2015, CMS will expand their assessment of readmissions to additional conditions that represent high volume and costs.

In addition, private payers have also targeted hospital readmissions in their shift to paying providers for quality. In Hawaii, the Hawaii Medical Service Association (HMSA) has adopted 3M's Potentially Preventable Readmissions (PPRs) as they work with providers to improve care coordination across the continuum to avoid preventable readmissions.

The purpose of this issue of "HHIC Insight" is to examine the top 10 reasons for readmissions by key payers in Hawaii: Medicare, Medicaid/QUEST, Private insurance. We use data from the Hawaii Health Information Corporation (HHIC) to present the conditions with the largest number of 30-day readmissions among Hawaii's hospitals and their associated estimated costs.

Readmission is defined as a subsequent hospital admission within 30 days following an original admission. Readmissions are limited to those considered potentially preventable.[1] A potentially preventable readmission is a readmission that is clinically-related to the initial hospital admission which may have resulted due to a deficiency quality care in the initial admission, inadequate discharge planning or lack of post discharge follow-up or coordination in care.

Key Insights
. In 2013, there were approximately 5,500 30-day readmissions in Hawaii, with associated charges of almost $249 million
. For Medicare patients, the three conditions with the largest 30-day readmissions were septicemia (278 readmissions), congestive heart failure (244 readmissions) and pneumonia (116 readmissions). These conditions resulted in about $33 million in hospital charges.
. For Medicaid/QUEST patients, the three conditions with the largest number of 30-day readmissions were cellulitis (70 readmissions), major depressive disorders (67 readmissions), and congestive heart failure (60 readmissions). These conditions resulted in about $8 million in hospital charges. Five of the top 10 readmissions for Medicaid/QUEST patients were mental health and substance abuse related, totaling $5.7 million in hospital charges.
. For the privately insured, the three conditions with the largest number of 30-day readmissions were septicemia (64 readmissions), major depressive disorders (35 readmissions) and cellulitis (23 readmissions). These conditions resulted in about $4.5 million in hospital charges.

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[1] Based on 3M's Potentially Preventable Readmissions (PPR) algorithm. See Definition at end for more detailed definitions.

Findings

Overview of hospital readmissions and related charges by payer

In 2013, there were over 5,400 readmissions in Hawaii across all payers (Table 1). Potentially preventable readmissions contributed $239 million in total hospital charges.

Medicare had the largest share of total readmissions (55 percent) and associated charges for readmissions (60 percent). Medicaid/QUEST had the second largest share of total readmissions (23 percent) and represented a lower share of associated charges (22 percent). Private insurance had a much smaller share of total readmissions (18 percent) and the second highest associated charges (15 percent). The uninsured represented the smallest proportion of the hospital population overall, accounting for only 2 percent of total readmissions and 1 percent of charges.

Overall, Hawaii potentially preventable readmission rates ranged from 3.5 percent for the privately insured to 9.5 percent for Medicare beneficiaries.[2]

Table 1. Total 30-day readmissions and aggregate charges, Hawaii, by payer, 2013

	Number of readmissions		Cost of readmissions		
Payer Type	Readmission	Readmissions as a percent of all readmissions	Readmission Charges (Excluding Initial Admission)	Readmission Charges as a Percent of Total Charges	Readmission Rate (Actual)
Dept of Defense	85	2%	$3,170,718	1%	4.92
Medicaid/Quest	1,261	23%	$52,371,428	22%	6.24
Medicare	3,033	55%	$143,540,196	60%	9.54
Miscellaneous	24	0%	$1,164,099	0%	2.80
Private Insurance	970	18%	$35,463,820	15%	3.47
Self Pay	101	2%	$3,190,765	1%	5.29
Overall:	**5,474**	**100%**	**$238,901,026**	**100%**	**6.48**

Readmission: A readmission within 30 days of initial admission. Readmission "chains" are counted which is a sequence of PPRs that are all clinically-related to the initial admission. A readmission chain may contain an initial admission and only one PPR, which is the most common situation, or may contain multiple PPRs following the initial admission.

Source: Hawaii Health Information Corporation, 2013.

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[2] Miscellaneous payers grouping not included in comparison.

Medicare

Conditions that resulted in the most readmissions for Medicare patients, 2013

Table 2 lists the 10 conditions with the most 30-day potentially preventable readmissions for Medicare patients aged 65 years and older. Their rank order is based on the number 30-day readmissions. Together, these 10 conditions accounted for 40 percent of all Medicare readmissions (1,220 readmission chains). These conditions contributed $ 63 million in total hospital charges (44 percent of all costs for Medicare readmissions).

Three conditions currently targeted by the CMS Hospital Readmissions Reduction Program also rank among the top 10 conditions in Hawaii. These include congestive heart failure (244 readmissions; $13.1 million in total charges), pneumonia (116 readmissions; $6.3 million in total charges), and acute myocardial infarction (81 readmissions; $3.5 million in total charges).

Table 2. Ten conditions with the most 30-day readmissions for Medicare patients, by total number readmissions, 2013

Reason for Initial Hospitalization	Eligible Discharges	Readmissions	Readmission Rate	Readmission Days (Excluding Initial Admission)	Readmission Charges (Excluding Initial Admission)
Septicemia & Disseminated Infections	2,732	278	10.18	2583	$13,613,437
Congestive Heart Failure	1,388	244	17.58	2396	$13,161,063
Pneumonia	1,284	116	9.03	1330	$6,265,539
Chronic Obstructive Pulmonary Disease	862	115	13.34	1516	$8,152,999
Stroke	1,081	94	8.70	722	$3,800,814
Renal Failure	630	84	13.33	886	$5,011,172
Acute Myocardial Infarction	688	81	11.77	618	$3,491,038
Cardiac Arrhythmia & Conduction Disorders	853	74	8.68	557	$2,915,601
Major Respiratory Infections & Inflammations	589	71	12.05	647	$3,457,680
Cellulitis & Other Bacterial Skin Infections	662	63	9.52	773	$3,386,835
Overall:	**10,769**	**1,220**	**11.42**	**12,028**	**$63,256,178**

Source: Hawaii Health Information Corporation, 2013

The number one reason for readmissions in Hawaii is septicemia (278 readmission chains); $13.6 million in total charges). The top 10 conditions include additional chronic conditions such as cardiac dysrhythmias and chronic obstructive pulmonary disease.

Hawaii's top 10 conditions are identical to the top 10 nationally with the exception of the following: cellulitis and other bacterial skin infections and respiratory infections and inflammations are unique to Hawaii's top 10. In total the three infections (septicemia, cellulitis, and respiratory infections) total 412 readmissions annually and $20.4 million in hospital charges.

The average readmission rate for these 10 high-volume conditions among Medicare beneficiaries was 11.4 per 100 admissions. Readmission rates among these conditions ranged from 8.7 for cardiac arrhythmia and stroke to 17.6 for congestive heart failure.

Medicaid/QUEST

Conditions that resulted in the most readmissions for Medicaid/QUEST patients, 2013

For Medicaid/QUEST patients (Table 3), the 10 conditions with the most potentially preventable 30-day readmissions accounted for 39 percent of all Medicaid/QUEST readmissions (494 readmissions) and 35 percent of all charges for Medicaid/QUEST readmissions ($18.4 million).

Four mental health or substance use disorders were among the conditions resulting in the most all-cause, 30-day readmissions for Medicaid/QUEST patients. These conditions included depression, schizophrenia, bipolar disorders, alcohol-related disorders, and other drug abuse and dependence disorders. They resulted in a total of 231 readmissions and $5.7 million in hospital charges.

Infections (septicemia and cellulitis) among Medicaid/QUEST patients resulted in 121 readmissions and $5.7 million in hospital charges.

The average readmission rate for the 10 highest volume conditions among individuals covered by Medicaid/QUEST was 14.2 per 100 admissions. Readmission rates among these conditions ranged from 7.6 for septicemia to 18.0 for diabetes.

Table 3. Ten conditions with the most 30-day readmissions for Medicaid/QUEST, by number readmissions, 2013

Reason for Initial Hospitalization	Eligible Discharges	Readmissions	Readmission Rate	Readmission Days (Excluding Initial Admission)	Readmission Charges (Excluding Initial Admission)
Cellulitis & Other Bacterial Skin Infections	870	70	8.05	670	$2,901,768
Major Depressive Disorders & Other Psychoses	537	67	12.48	741	$1,783,056
Congestive Heart Failure	382	60	15.71	477	$2,753,461
Schizophrenia	374	60	16.04	704	$1,692,645
Septicemia & Disseminated Infections	674	51	7.57	561	$2,834,423
Diabetes	250	45	18.00	427	$1,956,498
Bipolar Disorders	253	40	15.81	431	$1,017,958
Alcohol Abuse & Dependence	224	38	16.96	228	$785,949
Chronic Obstructive Pulmonary Disease	241	37	15.35	417	$2,302,482
Other Drug Abuse & Dependence	160	26	16.25	143	$413,085
Overall:	**3,965**	**494**	**14.22**	**4,799**	**$18,441,325**

Source: Hawaii Health Information Corporation, 2013.

Private Insurance

Conditions that resulted in the most readmissions for privately insured patients, 2013

For privately insured patients (Table 4), the 10 conditions with the most potentially preventable 30-day readmissions accounted for 25.0 percent of all privately insured readmissions (244 discharges) and 26 percent of costs for all privately insured readmissions ($9 million).

Readmissions for privately insured patients spanned broadly across various body systems relative to Medicare- and Medicaid/QUEST-covered patients. Septicemia accounted for the largest share of readmissions (64 readmissions; 7 percent) among privately insured patients, followed by depression resulted in 35 readmissions (4 percent of privately insured readmissions).

Infections (septicemia and cellulitis) among the privately insured resulted in 87 readmissions and $3.9 million in charges. Three mental health related conditions are among the top 10 (depression, bipolar disorders, schizophrenia) resulting in 66 readmissions and $1.8 million in hospital charges.

The average readmission rate for these 10 high-volume conditions among the privately insured was 8 per 100 admissions. Readmission rates among these conditions ranged from 2.8 for laparoscopic cholecystectomy to 13.9 for schizophrenia.

Table 4. Ten conditions with the most 30-day readmissions for privately insured patients, by total number readmissions, 2013

Reason for Initial Hospitalization	Eligible Discharges	Readmissions	Readmission Rate	Readmission Days (Excluding Initial Admission)	Readmission Charges (Excluding Initial Admission)
Septicemia & Disseminated Infections	844	64	7.58	473	$2,410,269
Major Depressive Disorders & Other/Unspecified Psychoses	356	35	9.83	283	$673,147
Cellulitis & Other Bacterial Skin Infections	480	23	4.79	246	$1,529,666
Congestive Heart Failure	285	23	8.07	170	$987,622
Chronic Obstructive Pulmonary Disease	239	21	8.79	268	$1,283,755
Renal Failure	215	17	7.91	66	$299,595
Cardiac Arrhythmia & Conduction Disorders	361	16	4.43	49	$294,654
Bipolar Disorders	128	16	12.50	244	$565,133
Schizophrenia	108	15	13.89	174	$539,378
Laparoscopic Cholecystectomy	493	14	2.84	97	$477,906
Overall:	**3,509**	**244**	**8.06**	**2,070**	**$9,061,125**

Source: Hawaii Health Information Corporation, 2013

Data Source

Hawaii Health Information Corporation (HHIC). HHIC's databases include reliable, verified synthetic patient identifiers that can be used to track a person across hospitals within the State. HHIC's databases include all payer, all hospital visit data in Hawaii.

Definitions

Readmission: Readmission is a return hospitalization to an acute care hospital that follows a prior admission from an acute care hospital. Intervening admissions to non-acute care facilities (e.g., a skilled nursing facility) are not considered readmissions and do not impact the designation of an admission as a readmission.

Readmission time interval (e.g. 30 days): The readmission time interval is the maximum number of days allowed between the discharge date of a prior admission and the admit date of a subsequent admission in order for the subsequent admission to be a readmission.

Potentially Preventable Readmission: A Potentially Preventable Readmission (PPR) is a readmission (return hospitalization within the specified readmission time interval, as defined above) that is clinically-related (as defined below) to the initial hospital admission.

Clinically-related: Clinically-related is defined as a requirement that the underlying reason for readmission be plausibly related to the care rendered during or immediately following a prior hospital admission. A clinically-related readmission may have resulted from the process of care and treatment during the prior admission (e.g. readmission for a surgical wound infection) or from a lack of post admission follow up (lack of follow-up arrangements with a primary care physician) rather than from unrelated events that occurred after the prior admission (broken leg due to trauma) within a specified readmission time interval.

Eligible discharges At Risk (for Readmission): Discharges minus Excluded Admissions (see below).

Initial admission: The Initial Admission is an admission that is followed by a clinically-related readmission within a specified readmission time interval. Subsequent readmissions relate back to the care rendered during or following the Initial Admission. The Initial Admission initiates a readmission chain.

Readmission chain: A readmission chain is a sequence of PPRs that are all clinically-related to the Initial Admission. A readmission chain may contain an Initial Admission and only one PPR, which is the most common situation, or may contain multiple PPRs following the Initial Admission.

Excluded admission: An excluded admission is an admission that is globally excluded from consideration as both a readmission and Initial Admission due to the nature and complexity of the required follow up care (e.g., multiple trauma) or because the patient left against medical advice.

Readmission rate (actual): Number of readmission chains divided by Eligible discharges at risk for readmission.

Non-event: A Non-event is an admission to a non-acute care facility such as a nursing home or an admission to an acute care hospital for non-acute care (e.g., convalescence). Non-events during the interval between an Initial Admission and a readmission are ignored.

Payer *(insurance status)*: Payer is the expected primary payer for the hospital stay. To make coding uniform across all HCUP data sources, payer combines detailed categories into more general groups:

- Medicare: includes patients covered by fee-for-service and managed care Medicare
- Medicaid/QUEST: includes patients covered by fee-for-service and managed care Medicaid/QUEST
- Private Insurance: includes Blue Cross, commercial carriers, and private health maintenance organizations (HMOs) and preferred provider organizations (PPOs)
- Uninsured: includes an insurance status of "self-pay" and "no charge."

When more than one payer is listed for a hospital discharge, the first-listed payer is used.

Charges: Charges represent the amount a hospital billed for the case. Hospital charges reflect the amount the hospital billed for the entire hospital stay and do not include professional (physician) fees.

Community Resources Available for Caregiver Training
November 12, 2014

Caregiver Training (per the KCC Kupuna Education Center, ADRC website, and consulting with the AAAs)

Name	Description	Contact Information
1. KCC Kupuna Education Center	The KCC Kupuna Education Center has been providing Family Caregiver Training on a regular basis for the past 8 years at KCC. There are several types of training that we have provided and they are described in more detail on our website: www.kupunaeducation.com. Caregiver training is also starting to expand to McKinley Community School for Adults.	Cullen T. Hayashida, Ph.D. Kupuna Education Center Kapiolani Community College 4306 Diamond Head Road Honolulu, HI 96816 USA Phone: (808) 734-9469 Cell: (808) 781-6604 Fax: (808) 734-9128 web: www.kupunaeducation.com email: cullen@hawaii.edu
2. AARP	AARP convenes annual family caregiver conferences in each county.	Jackie Boland AARP Hawaii Community Outreach Director 1132 Bishop St Ste 1920 Honolulu, HI, 96813-2813 Office: (808) 545-6003 Fax: (808) 537-2288 Email: jboland@aarp.org Web: http://www.aarp.org/hi
3. Alzheimer's Association of Hawaii	What Now? Caregiver Orientation Series Classes are designed to provide information and allow for guided group discussion and sharing in a one hour period. The series will be scheduled	Aloha Chapter Headquarters, Oahu Office 1050 Ala Moana Boulevard, Suite 2610 Honolulu, Hawaii 96814 808.591.2771

	throughout the year so caregivers can elect to select the training that is most needed at the time and pick up the other classes later in the year, or take the complete 8-week course: • Alzheimer's Educating Yourself About the Disease: A comprehensive guide to understanding Alzheimer's disease and related disorders • Putting Legal and Financial Affairs in Order: How to begin with the legal and financial issues • Learning to Manage Challenging Behaviors: How to approach some of the more challenging care situations that arise • Taking Care of Yourself: How can I cope while I care for my loved one? • Hiring and Managing In-Home Caregivers: Introductions to homecare planning and management • When Is It Time to move Our Loved One into a Facility? Steps to take when exploring residential facilities • Communication: Tips on ways to improve communication with someone who has Alzheimer's disease or dementia. • Wandering: Causes, Coping, Strategies and Tips	
4. ORI – Anuenue Hale	Vision's Course for Caregivers (6 modules).	64-1510 Kamehameha Highway Wahiawa, Hawaii 96786

		Telephone: (808) 622-3929 FAX: (808) 621-8227 Email:helemano808@hawaii.rr.com Website:www.ori-hawaii.com
5. Queen's Foster Family - Community Care Programs	Caregiver training and case management.	1301 Punchbowl Street Honolulu, HI 96813 (808) 547-4779 http://www.queensmedicalcenter.org/ email@queens.org
6. Responsive Caregiver of Hawaii	Responsive Caregiver of Hawaii educates families about how their programs and services will improve their loved one physically and mentally, along with offering them consultation on how to take care of their child or family member with disabilities.	98-1247 Kaahumanu Street, #219B Aiea, HI 96701 Phone: 808-488-7391 Fax: 808-488-6952 Email: info@rcoh.org
7. Child & Family Service – Kauai	‘Ohana Care Promoting caregiver well-being to enable them to continue helping our kūpuna. Services include: • Case Management • Supportive Counseling • Support Groups • Caregiver Education • Powerful Tools for Caregivers	2970 Kele Street, Suite 203 Līhu‘e, HI 96766 Phone: (808) 245-5914
8. UH Maui College, Intergenerational	Powerful Tools for Caregivers is a six-week education program for family and friends caring for older adults.	310 Kaahumanu Ave, Bldg. 214 Kahului, HI 96732 Phone: (808)244-3242 x222
9. Hawaii Island Adult Care (Big Island)	One-on-One Caregiver Support, Hands on Caregiver Skills Training, Relaxation Techniques, Networking with other Caregivers	34 Rainbow Dr, Hilo, HI 96720 Phone: (808) 961-3747

General training and education are available for older adults and their families, however, these resources are not necessarily training specifically for family caregivers. This list doesn't include hospice, respite, or condition-specific support groups.

1. DOH Public Health Nursing Branch
2. Hawaii Pacific Gerontological Society (HPGS)
3. Hawaii Senior Fair
4. First Hawaiian Bank's PrimeTime Senior Fair
5. Generations Magazine's Aging in Place Fair
6. Eldercare Support Group
7. Ohana Care Program
8. Koolau Caregiver Support Group
9. Queen Liliuokalani Children's Center
10. Wilson Homecare
11. Kokua Kalihi Valley Elder Services
12. Kokua Care
13. Hawaii Family Caregiver Coalition
14. Family Caregiver Foundation of America
15. Project Dana
16. Alu Like, Native Hawaiian Caregiver Support
17. CFS Gerontology Caregiver Respite Program
18. CFS Gerontology Ohana Care Program
19. Fujii Home Care
20. American Red Cross
21. Central Oahu Caregivers Support Group
22. Castle Caregiver Support Group
23. VA Caregiver Support Group
24. Paradise Home Care Cooperative (Big Island)
25. Services for Seniors (Big Island)

October 24, 2014

Kaiser Permanente (KP) Response to: Caregiver Task Force Request for Information [HCR78]

1. **Compile Hospital Discharge Policies by facility or system. Also, please include copies of the written policy in addition to summaries.**

   6020-02-27C INTERDISCIPLINARY CARE OF PATIENTS: DISCHARGE PLANNING: INTERDISCIPLINARY CARE OF PATIENTS: DISCHARGE PLANNING - Discharge Planning

   6425-05 UTILIZATION REVIEW & DISCHARGE PLANNING PROCESS FOR HOSPITALIZED PATIENTS: UTILIZATION REVIEW & DISCHARGE PLANNING PROCESS FOR HOSPITALIZED PATIENTS

   - KP policies are deemed proprietary; however, we have provided the federal law basis and a description of our process as follows:

   - Kaiser Foundation Hospital (KFH) adhere to 42 CFR Ch. IV, §482.32, Conditions of Participation: Discharge Planning. Our hospital is evaluated through The Joint Commission survey that monitors KFH compliance and was last survey April 2012 without findings associated with the Caregiver Task Force Request [HCR78].

   - In addition, to ensure patients are receiving the most appropriate and quality medical care, KP maintains internal policies to procedurally reinforce the COP requirements. Discharges are planned for timeliness and to appropriate placement.

     KP Staff work with the patient and family in planning a timely discharge. When placement into a Nursing Home or other facility is necessary, the KP assists the patient and family with those arrangements.

   - Discharge planning begins at or before admission. The physician is expected to identify the expected length of stay and begin the discharge planning at admission. The plan is updated throughout the patient stay.

   - The primary team components in the discharge planning process include:

     - Medical Staff: As part of All QHS discharges, the medical staff participates in all phases of the discharge planning process. Discharge orders are written as early as possible to day of discharge.

     - Nursing Staff: Initiate discharge planning, assist patient and family with process within 48-hrs of discharge, and begin discharge teaching upon or close to admission.

- Social work/Case Management: participate in all phases of the discharge planning, including early identification of high risk patients, involvement of family, coordination with the health care team.

2. Compile Hospital Caregiver / Designated Patient Representative Education / Training Policies, if any, by facility or system. Please include who provides caregiver/designated patient representative training such as a doctor, nurse or social worker. Also, please include copies of the written policy in addition to summaries.

Each patient's unique needs are incorporated into discharge planning and instruction. KP understands that patients and families may be overwhelmed by health care and all that may have rapidly occurred. To ensure a safe discharge, staff is trained to:

A. Provide the patient opportunities throughout the patient's stay to identify an individual to provide caregiving. This may change along the care continuum.
  1) Staff explains to the purpose of the patient's caregiver and possible limitations (i.e. Compromises safety or is medically or therapeutically contraindicated).
  2) Staff is made aware of the patient's chosen caregiver.
  3) The patient has access to the caregiver at all times.
  4) Staff asks patient if patient would like to involve chosen caregiver during rounds, patient education, and other crucial decision making or care processes. This person may or may not be the designated surrogate decision maker.
  5) This person is identified in the patient's medical records.

6070-01 PATIENT AND FAMILY EDUCATION: ENSURES THAT EDUCATION IS PROVIDED TO IMPROVE PATIENT HEALTH OUTCOMES BY TEACHING AND PROMOTING HEALTHY BEHAVIOR AND INVOLVING THE PATIENT AND FAMILY IN DECISIONS

6425-05 UTILIZATION REVIEW & DISCHARGE PLANNING PROCESS FOR HOSPITALIZED PATIENTS: UTILIZATION REVIEW & DISCHARGE PLANNING PROCESS FOR HOSPITALIZED PATIENTS

B. Communication needs are identified, including the patient's preferred language or any communication impairments; language services or auxiliary aides are arranged to facilitate discharge

1600-128C PROVIDNG LANGUAGE ASSISTANCE: DEFINE THE STANDARDS OF CARE AND PRACTICE TO ENSURE THE PATIENT'S RIGHT TO TIMELY AND PROFESSIONAL LANGUAGE ASSISTANCE SERVICES

C. Staff is trained to involve both the patient and the family/support person to design the discharge planning and instructions to the patient's needs.
  1) Patients will be asked on admission to define their “family” and other “partners in care” and how they will be involved in care and decision making.
  2) For patients without decision-making capacity, the legal surrogate’s or family’s wishes will be followed.
  3) Family and other partners in care are welcome 24 hours a day according to patient’s preference.

6425-11 PATIENT/FAMILY CONFERENCES RELATING TO DISCHARGE: PATIENT/FAMILY CONFERENCES RELATING TO DISCHARGE

- Clinical Comp PCD Patient and Family Education
- PCD – Patient and Family Education – LIP &RN

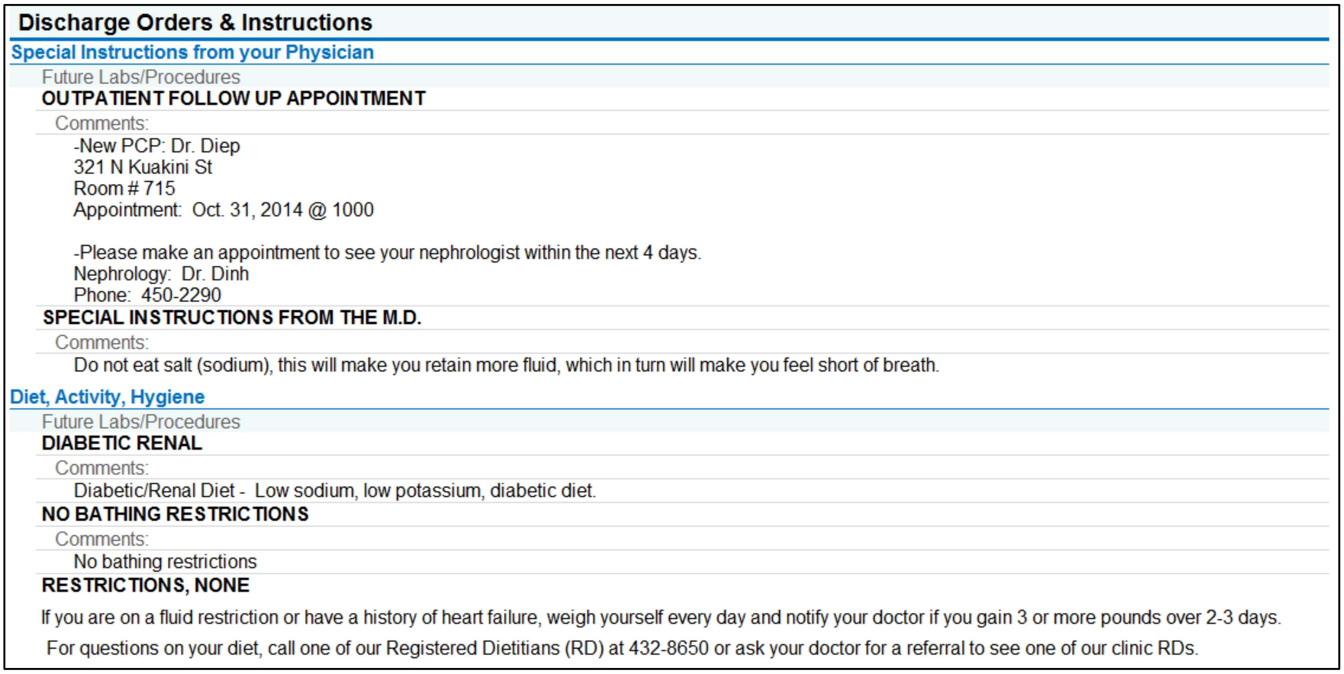
D. Discharge plans are modified to ensure the patient can understand an act on discharge plan.

1) Plain language is used
2) Visual models, pictures, and videos are used for discharge instructions
3) "Teach back" method is used to assess understanding which involves asking the patient and/or support to explain in his/her own words the information the staff shared, or ask the patient/support to demonstrate a skill that was taught.
4) Staff refrain from using the phrase 'do you understand' as many people may answer 'yes', but do not in fact understand.
5) Discharge instructions are written at a 5th grade reading level.
6) Discharge material has been translated into most frequently encountered languages.

6070-01 PATIENT AND FAMILY EDUCATION: ENSURES THAT EDUCATION IS PROVIDED TO IMPROVE PATIENT HEALTH OUTCOMES BY TEACHING AND PROMOTING HEALTHY BEHAVIOR AND INVOLVING THE PATIENT AND FAMILY IN DECISIONS

E. Follow up providers or social services are identified
   1) Patients who need follow up care are referred to a provider
   2) ID social services in the community, as needed.
   3) Ensure the ordering of durable medical equipment for patients, as needed.

Example of discharge “After Visit Summary” example for each hospital discharge individualized to the patient’s principle diagnosis.



Discharge Orders & Instructions

Special Instructions from your Physician

Future Labs/Procedures

OUTPATIENT FOLLOW UP APPOINTMENT

Comments:

-New PCP: Dr. Diep
321 N Kuakini St
Room # 715
Appointment: Oct. 31, 2014 @ 1000

-Please make an appointment to see your nephrologist within the next 4 days.
Nephrology: Dr. Dinh
Phone: 450-2290

SPECIAL INSTRUCTIONS FROM THE M.D.

Comments:

Do not eat salt (sodium), this will make you retain more fluid, which in turn will make you feel short of breath.

Diet, Activity, Hygiene

Future Labs/Procedures

DIABETIC RENAL

Comments:

Diabetic/Renal Diet - Low sodium, low potassium, diabetic diet.

NO BATHING RESTRICTIONS

Comments:

No bathing restrictions

RESTRICTIONS, NONE

If you are on a fluid restriction or have a history of heart failure, weigh yourself every day and notify your doctor if you gain 3 or more pounds over 2-3 days.

For questions on your diet, call one of our Registered Dietitians (RD) at 432-8650 or ask your doctor for a referral to see one of our clinic RDs.

3. Kaiser Moanalua Chart of top five admitting diagnoses (excluding Normal Newborns).

Data source: HHIC past two years

CY 2012 (by APR_DRG)
560 - Vaginal Delivery
720 - Septicemia & Disseminated Infections
302 - Knee Joint Replacement
194 - Heart Failure
540 - Cesarean Delivery

CY 2013 (by APR_DRG)
560 - Vaginal Delivery
720 - Septicemia & Disseminated Infections
302 - Knee Joint Replacement
194 - Heart Failure
540 - Cesarean Delivery

4. Kaiser Moanalua Chart of top five readmitting diagnoses

Data source: HHIC past two years

CY 2012 (by APR_DRG)
720 - Septicemia & Disseminated Infections
194 - Heart Failure
139 - Other Pneumonia
045 - Cva & Precerebral Occlusion W Infarct
190 - Acute Myocardial Infarction

CY 2013 (by APR_DRG)
720 - Septicemia & Disseminated Infections
194 - Heart Failure
165 - Coronary Bypass W Cardiac Cath Or Percutaneous Cardiac Procedure
045 - Cva & Precerebral Occlusion W Infarct
460 - Renal Failure

5. Kaiser Moanalua Discharge Disposition for past two year

Data source: KPHC
1) HOME
2) HOMEHEALTH
3) SNFMCR
4) EXPIRED
5) HOSPICE HOME or FACILITY
6) AMA (Against Medical Advice)

6. A breakdown of the age ranges of the patients (50-60, 61-70, 71-80, and 80 yrs +) admitted for the past two years, and readmitted within 30 days of discharge. The count of patient readmissions within 30-days of discharge for CY2012 and CY 2013, in age ranges (under 60, 60-80, and over 80 years old).

Unable to provide this data at this time, will plan to provide as follow up information at next meeting.

7. How much does each hospital currently charge the insurance companies using CPT codes 99495 and 99496 for providing patient education/training? These codes expressly include "transitional care management services" ("TCM"s) communicated to the "patient, family members, guardian or caretaker, surrogate decision makers or other qualified health care professional."

This information is proprietary and confidential. Information not provided.

THE QUEEN'S HEALTH SYSTEMS

1301 Punchbowl Street ● Honolulu, Hawaii 96813 ● Phone (808) 691-5900

September 19, 2014

HCR 78
Caregiver Task Force Request for Information

1. Compile Hospital Discharge Policies, by facility or system. Also, please include copies of the written policy in addition to summaries.

QMC policies are deemed proprietary; however, we have provided the federal law basis and a description of our process as follows:

QMC hospitals all adhere to 42 CFR Ch. IV, §482.32, Conditions of Participation: Discharge Planning. Our hospitals are evaluated through The Joint Commission survey that monitors QMC hospital compliance.

In addition, to ensure patients are receiving the most appropriate and quality medical care, QMC maintains internal policies to procedurally reinforce the COP requirements. Discharges are planned for timeliness and to appropriate placement. QMC Staff work with the patient and family in planning a timely discharge. When placement into a Nursing Home or other facility is necessary, the QMC assists the patient and family with those arrangements.

Discharge planning begins at or before admission. The physician is expected to identify the expected length of stay and begin the discharge planning at admission. The plan is updated throughout the patient stay.

The primary team components in the discharge planning process include:

Medical Staff: As part of ALL QHS discharges, the medical staff participates in all phases of the discharge planning process. Discharge orders are written as early as possible to day of discharge.

Nursing Staff: Initiate discharge planning, assist patient and family with process within 48 hrs of discharge, and begin discharge teaching upon or close to admission.

Social work/Case Management: participate in all phases of the discharge planning, including early identification of high risk patients, involvement of family, coordination with the health care team.

2. Compile Hospital Caregiver/Designated Patient Representative Education/ Training Policies, if any, by facility or system. Please include who provides caregiver/designated patient representative training such as a doctor, nurse or social worker. Also, please include copies of the written policy in addition to summaries.

Each patient's unique needs are incorporated into discharge planning and instruction. QMC understands that patients and families may be overwhelmed by health care and all that may have rapidly occurred. To ensure a safe discharge, staff is trained to:

1) Provide the patient opportunities throughout the patient's stay to identify an individual to provide caregiving. This may change along the care continuum.
    a) Staff explains to the purpose of the patient's caregiver and possible limitations (ie. Compromises safety or is medically or therapeutically contraindicated).
    b) Staff is made aware of the patient's chosen caregiver.
    c) The patient has access to the caregiver at all times.
    d) Staff asks patient if patient would like to involve chosen caregiver during rounds, patient education, and other crucial decision making or care processes. This person may or may not be the designated surrogate decision maker.
    e) This person is identified in the patient's medical records.
2) Communication needs are identified, including the patient's preferred language or any communication impairments; language services or auxiliary aides are arranged to facilitate discharge
3) Staff is trained to involve both the patient and the family/support person to design the discharge planning and instructions to the patient's needs.
    a) Staff encourages family/support to ask questions and participate in process.
    b) If the patient has a primary caregiver at home, staff asks for that person to be involved.
4) Discharge plans are modified to ensure the patient can understand an act on discharge plan.
    a) Plain language is used
    b) Visual models, pictures, and videos are used for discharge instructions
    c) "Teach back" method is used to assess understanding which involves asking the patient and/or support to explain in his/her own words the information the staff shared, or ask the patient/support to demonstrate a skill that was taught.
    d) Staff refrain from using the phrase 'do you understand' as many people may answer 'yes', but do not in fact understand.
    e) Discharge instructions are written at a 5th grade reading level.
    f) Discharge material has been translated into most frequently encountered languages.
5) Follow up providers or social services are identified
    a) Patients who need follow up care are referred to a provider
    b) ID social services in the community, as needed.
    c) Ensure the ordering of durable medical equipment for patients, as needed.

Additionally, QMC provides Transitional Case Management Program.

a) TCMP is a service provided by the hospital to ensure that identified patients have a smooth transition from hospital to home and to avert inappropriate readmissions
b) Attempts made to contact patient by phone within 3 days of discharge, every 3-4 days for the first fifteen days then 7-10 days for the last fifteen days (30 days total). Patient participation is voluntary.
c) TCMP services provide the following:
    - Ensure that physician follow-up appointments are met
    - Medication Reconciliation and Management
    - Education to manage health condition
    - Education to manage symptoms
    - Coordination of services (ex. DME orders, transportation etc)
    - Support for patient and/or family members

3. Chart of top five admitting diagnoses for the past two years

<u>CY 2012</u> (by APR-DRG)
Vaginal Delivery
Septicemia & Disseminated Injections
Cesarean Delivery
Heart Failure
Cva & Precerebral Occlusion W Infarct

<u>CY 2013</u> (by APR-DRG)
Vaginal Delivery
Septicemia & Disseminated Injections
Cesarean Delivery
Heart Failure
Cellulitis & Other Bacterial Skin Infections

4. Chart of top five readmitting diagnoses (within 30 days of discharge) for the past two years

<u>CY 2012</u>
Septicemia & Disseminated Injections
Heart Failure
Renal Failure
Schizophrenia
Other Pneumonia

<u>CY 2013</u>
Septicemia & Disseminated Injections
Heart Failure
Schizophrenia
Major Depressive Disorders & Other Psychoses
Cellulitis & Other Bacterial Skin Infections

5. Identification of top discharge destinations (nursing homes, care home, residential care) (i.e. home, skilled care/rehab facilities, adult residential care home, other) Indicate by percentage or breakdown – i.e. what percentage among the pts are discharged directly to home, transferred to skilled nursing facilities or rehab facilities

1) Home
2) Nursing Home or Rehab – Skilled Nursing Care (SNF)
3) Expired
4) Another Facility, not otherwise specified
5) Rehab Acute Facility
6) Against Medical Advice

6. A breakdown of the age ranges of the patients (50-60, 61-70, 71-80, and 80yrs +) admitted for the past two years, and readmitted within 30 days of discharge

Admitted

	CY 2012	%	CY 2013	%
Under 60 years old	14,716	54%	15,015	55%
60 – 80 years old	8,339	31%	8,432	31%
Over 80 years old	4,049	15%	3,678	14%
		100%		100%

The count of patient readmissions within 30-days of discharge for CY2012 and CY2013, in age ranges (under 60, 60-80, and over 80 years old).

Due to technical difficulties, we are unable to provide this information at this time. We hope to be able to provide this for the next meeting.

7. How much does each hospital currently charge the insurance companies using The CPT codes 99495 and 99496 for providing patient education/training? These codes expressly include "transitional care management services" ("TCM"s) communicated to the "patient, family members, guardian or caretaker, surrogate decision makers or other qualified health care professional."

This information is proprietary and confidential. We are unable to provide this information to the task force.

Policy Name:	Discharge Planning/ Multi-Disciplinary Discharge Planning Process
Department:	Case Management
Effective Date:	02/2012
Revised Date(s):	01/06, 06/09
Replaces:	

Policy & Procedure

The reader is cautioned to refer to the Central Policy Database for the most current version of this document and not rely on any printed version.

Approval Signature: ______________________________

Name: ____________________ **Title:** ____________________

Approval Signature: ______________________________

Name: ____________________ **Title:** ____________________

Scope:

This policy applies to Case Management, the Attending Physician, Nursing, Medical Social Services, Dietary, Infection Control, Rehabilitation Services, Respiratory Care Services, Financial, Pharmacy Services, and Other disciplines as appropriate within XXXXX.

Policy Statement:

Discharge Planning provides for comprehensive, quality patient care via a coordinated, interdisciplinary process to ensure a plan for continuing care for each patient post discharge.

Definitions:

A. Discharge Planning High Risk: Patients who have met pre-established criteria for necessity of case management and/or social services intervention to coordinate a comprehensive, interdisciplinary discharge plan.

B. Pharmacy Definition of High Risk: Patients who will be imminently harmed if continuation of medications, that were initiated while inpatient, were not available by an outside Retail Pharmacy.

Policy/Procedure:

I. The discharge planning process begins upon admission by the attending physician and members of the interdisciplinary team.

II. High risk screening of patients will be performed utilizing the high risk screening criteria and referral will be made to Case Management.

III. High risk patients will include:

   A. Residence in Skilled Nursing Facility (SNF), Intermediate Care Facility (ICF), Residential Adult Community Care Program (RACCP), or Care Home facility

    B. Expected need for Residence in SNF, ICF, RACCP, or Care Home facility

    C. Lives alone/no support system

    D. Homeless

    E. Possible victim of abuse, neglect or exploitation

    F. Respiratory failure and/or tracheostomy

    G. Chronic wound

    H. Renal failure

    I. Coma

    J. Psychiatric or behavior disorder

    K. No insurance

    L. HIV/Aids

    M. End of life needs/issues

IV. Medium risk patients will include:

    A. Readmission within 30 days

    B. Tourist

    C. Family crisis

    D. Age over 70 with debilitating disease

    E. Multiple chronic diseases

V. The attending physician is responsible for the discharge plan and projected discharge date.

VI. Department Profile:

    A. Patient Services

        1. The discharge planning process is initiated upon admission. Case Managers will review all admissions within three business days.

        2. The discharge planning goals will be evaluated and updated on a continuing basis. Factors to consider in the identification of patients requiring complex discharge planning:

            a. Clinical course of illness which may require continuing care needs from multiple community resources.

            b. Indications that a patient and/or family are unable to accept or cope with required care of the patient.

            c. Evidence of need for reinforcement and clarification of instruction.

        d. The expressed need of a patient or family.

        e. Ability to pay for continued medical services (i.e., medications, supplies, etc.)

    3. When interdisciplinary patient care conferences are held, discharge planning will be discussed.

B. Case Management

    1. Discharge Planning:

        a. Identify as early as possible the expected post discharge care needs of patients utilizing high risk screening and utilizing the interdisciplinary team approach.

        b. A Case Manager is assigned for the coordination of discharge planning.

        c. The Case Manager will coordinate and develop a multi-resource plan that considers the medical, social, and financial needs of the patients and provides continued quality care after hospital discharge.

        d. An initial case management discharge planning assessment will be performed on patients admitted to the facility within three working days of admission. The assessment will focus on the following factors:

            i. Initial Admission Diagnosis

            ii. Functional Level

            iii. Living Environment

            iv. Health Care Resource Utilization

            v. Financial Situation

            vi. Family and Social Support

        a. The initial case management discharge planning assessment results will be utilized to assist the RN Case Manager in prioritization of patients case management needs.

        b. Patients identified to be at high and medium risk for complex case management needs will have a detailed initial discharge planning assessment documented in EPIC.

C. Medical Social Services:

    1. Identifies patients with high-risk social needs, which affects discharge planning. Coordinates with the RN Case Manager accordingly. Such patients may be encountered in the course of routine coverage or referrals for presenting problems other than identified discharge planning.

    2. Assesses and attempts to individual psychosocial and family problems which threaten to delay discharge or impair coping at home.

    3. Assists the health care team in understanding the psychosocial, economic, religious, spiritual, cultural, and family factors that interact with discharge planning needs.

4. Serves as a resource and referral source to community agencies which may be able to meet patient's needs outside the hospital.

5. Serves as liaison to the social services community with special attention to supporting the development of plans and interventions that will resolve repetitive discharge problems.

D. Rehabilitation Services:

1. Rehabilitation Services provide a functional assessment of the patient's ability to perform age appropriate post discharge. The areas evaluated and treated include developmental levels, physical limitations and the resultant deficits, mobility in self-care skills; cognitive and perceptual skills; speech, swallowing and hearing abilities for communication. Specifically, each discipline will assess and treat the following:

    a. Physical Therapy will determine safety in mobility and delays/limitations in development/functions presence of pain and provide recommendations for adaptive devices needed therapeutic modalities.

    b. Occupational Therapy will determine patient's developmental/fine motor skills and safety needs in self-care activities. Provide recommendations for adaptive equipment needed by the patient such as feeding, dressing and hygiene aids. Will also assess the patient's cognitive and perceptual skills and treat any deficits. Provides splinting and hand rehabilitation where appropriate.

    c. Speech Pathology/Audiology will provide an assessment of the patient's communication abilities and screen for any hearing difficulties. Will provide recommendations for any adaptive devices needed. Also will assess patient's cognitive abilities prior to discharge and treat any deficit. Will provide recommendation for any swallowing/aspiration precautions.

2. A physician referral is needed for ordering any of the above therapies.

3. When continuing rehabilitation services are needed, post discharge recommendations will be made for appropriate follow-up referrals.

E. Respiratory Care Services will provide discharge assistance for:

1. Home Aerosol Therapy Instruction (updraft, metered dose inhaler)

2. Instruction on Chest Physiotherapy and Breathing Exercises

3. Instruction on Tracheostomy Care and Airway Suction

4. Instruction on Humidity Therapy or Bland Aerosol Therapy

5. Smoking Cessation Counseling

6. Evaluation for participation in Outpatient Respiratory Rehab Program (education and physical reconditioning)

7. Home Mechanical Ventilation

F. Dietary/Nutritional Services:

1. Provides information to interdisciplinary team members regarding nutritional status, intervention and progress during hospitalization and for discharge.

2. Communicates nutrition intervention, progress, and recommendations to families/care takers.

3. Coordinates referrals to other community nutrition programs/agencies.

4. Provides nutrition education/counseling to patient/families/caretakers.

5. Instructs patient on diet or formula preparation as indicated.

6. Provides basic nutrition or diet information on current diet.

7. Provides information on adequacy of diet/tube feedings and recommends supplements as indicated.

8. Provides food/drug interaction education as informed by pharmacy or nursing.

9. Provides follow up services as indicated by referral from physician, insurance companies or agencies on fee-for-service basis.

G. Patient Financial Services

1. Patient Financial Services falls under the umbrella of Business Services. One of the services available is the storage of the patient valuables during the hospitalization and the release of the valuables on the day of the discharge.

2. The department also has insurance verifiers who will contact the insurance carriers to verify the insurance coverage and obtain the benefits and ensure all of the third party requirements have been met.

3. Once the insurance coverage has been confirmed, the account is forwarded to the financial counselors. The financial counselors will provide the patient and/or the patient's representative with appropriate financial alternatives and financial guidance. The financial counseling will include arranging monthly payment plans, informing the patient about their insurance coverage, completing credit applications and also assisting the patient in applying for state welfare assistance. The financial counselors handle the account from the time the patient is admitted to the day of discharge.

H. Pharmacy Services

1. All original discharge prescriptions should be sent to the Outpatient/Retail Pharmacy within twenty-four (24) hours of anticipated discharge.

    a. In order to avoid delay in service, the discharge prescription should be sent with a current face sheet and any allergies should be indicated on the prescription.

2. The Outpatient/Retail Pharmacy will coordinate third party billing for the patient.

    a. Pharmacy staff will notify the department that the prescription is ready for pick up and the exact amount due at the time of pick up. If valid picture ID is necessary, the pharmacy staff will also notify the department.

3. If the Outpatient/Retail Pharmacy is closed prior to any discharge medications being picked up:

   a. Outpatient/Retail Pharmacy will communicate to the department that the patient or patient's representative may pick up the prescription from the Inpatient Pharmacy.

   b. Outpatient/Retail Pharmacy will notify the department of the exact amount due at the time of pick and if a valid ID is necessary.

4. If discharge medication is necessary when the Outpatient/Retail Pharmacy is closed:

   a. Inpatient Pharmacy will assess the discharge order and coordinate with the department to determine if the patient is qualified as a "high risk".

   b. If the patient is qualified, the Inpatient Pharmacy will request that the floor send the original discharge order.

   c. Inpatient Pharmacy will provide up to a 72-hour supply of medication and attach a note to remind the patient that if additional medication is needed, he/she must follow up with the Attending Physician.

Standard / Reference & Year:	PC.04.01.01, PC.04.01.03, PC.04.01.05, PC.04.02.01 TJC 2012
Rationale for Revision:	☐ New ☐ Update ☐ Consolidation
Author(s) & Department(s):	Director Case Management
Reviewer(s) & Department(s):	Director Case Management, Chief Nurse Executive, Rehabilitation, Dietary, Respiratory, Pharmacy, Financial

January 16, 2015

MEMO

To: The Honorable Suzanne Chun Oakland, Chair
The Honorable Gregg Takayama, Chair
Family Caregivers Working Group Members

From: George Greene, Esq., President & CEO, Healthcare Association of Hawaii

RE: Clarifying Information Related to Draft Family Caregivers Working Group Report: Findings 10-12

Thank you for the opportunity to provide this information as requested at the Caregivers Task Force meeting on Monday, January 12, 2015. It is meant to clarify Findings 10,11 and 12 of the Draft Report, particularly:

- Finding 10: relating to Centers for Medicare and Medicaid Services (CMS) Conditions of Participation on Discharge Planning
- Finding 11: relating to The Joint Commission (JC) accreditation guidelines
- Finding 12: relating to Hawaii Hospital Readmissions

1) CMS Conditions of Participation (CMS §482.43) on Discharge Planning

CMS develops Conditions of Participation (CoPs) that health care organizations must meet in order to begin and continue participating in the Medicare and Medicaid programs. The following are parts of Section 482.43 that pertain to discharge planning:

A. Settings of Care Requiring Discharge Planning:

Inpatient admissions only.

> "Accordingly, under the regulation, hospitals are required to have a discharge planning process that applies to all inpatients; discharge planning is not required for outpatients." *Interpretive Guidelines §482.43*

B. Timeframes for Initial Assessment for Discharge Planning:

Identification of high-risk patients who need discharge planning must occur at least 48 hours in advance of the patient's discharge.

> "The identification of patients must be made at an early stage of the patient's hospitalization. This is necessary in order to allow sufficient time to complete discharge planning evaluations and develop appropriate discharge plans, for those patients who need them. Ideally the identification process will be completed when the patient is

> admitted as an inpatient, or shortly thereafter. However, no citations will be made if the identification of patients likely to need discharge planning is completed at least 48 hours in advance of the patient's discharge…" *Interpretive Guidelines §482.43(a)*

C. Assessment of a Patient's Ability for Self-Care:

The Medicare CoP requires that the evaluation include assessment of the patient's capacity for self-care or, alternatively, to be cared for by others in the environment, i.e., the setting, from which the patient was admitted to the hospital.

D. Documentation of Discharge Planning:

> "The hospital … must discuss the results of the evaluation with the patient or individual acting on his or her behalf. The results of the discharge planning evaluation must be discussed with the patient or the patient's representative. Documentation of this communication must be included in the medical record, including if the patient rejects the results of the evaluation. It is not necessary for the hospital to obtain a signature from the patient (or the patient's representative, as applicable) documenting the discussion." *Interpretive Guidelines §482.43(b)(6)*

> "The hospital must document in the patient's medical record the arrangements made for initial implementation of the discharge plan, including training and materials provided to the patient or patient's informal caregiver or representative, as applicable." *Interpretive Guidelines §482.43(c)(3) & §482.43(c)(5)*

E. Education / Training:

> "The hospital is required to arrange for the initial implementation of the discharge plan. This includes providing in-hospital education/training to the patient for self-care or to the patient's family or other support person(s) who will be providing care in the patient's home. The education and training provided to the patient or the patient's caregiver(s) by the hospital must be tailored to the patient's identified needs related to medications, treatment modalities, physical and occupational therapies, psychosocial needs, appointments, and other follow-up activities, etc. Repeated review of instructions with return demonstrations and/or repeat-backs by the patient, and their support persons will improve their ability to deliver care properly. This includes providing instructions in writing as well as verbally reinforcing the education and training." *Interpretive Guidelines §482.43(c)(3) & §482.43(c)(5)*

> "The evaluation must consider what the patient's care needs will be immediately upon discharge, and whether those needs are expected to remain constant or lessen over time. If the patient was admitted from his/her private residence, the evaluation must include an assessment of whether the patient is capable of addressing his/her care needs through self-care. The evaluation must include assessment of whether the patient

> will require specialized medical equipment or permanent physical modifications to the home, and the feasibility of acquiring the equipment or the modifications being made. <u>If the patient is not able to provide some or all of the required self-care, the evaluation must also address whether the patient has family or friends available who are willing and able to provide the required care at the times it will be needed, or who could, if willing, be trained by the hospital sufficiently to provide the required care.”</u> *Interpretive Guidelines §482.43(b)(1), §482.43(b)(3) & §482.43(b)(4)*
>
> “If neither the patient nor the patient’s family or informal caregiver(s) are able to address all of the required care needs, then the evaluation must determine whether there are community-based services that are available to meet the patient’s needs while allowing the patient to continue living at home.” *§482.43(b) (3)*

F. <u>Discharge Delays:</u>

> “The hospital personnel must complete the evaluation on a timely basis so that appropriate arrangements for post-hospital care are made before discharge, and to avoid unnecessary delays in discharge.” *§482.43(b)(5)*

G. <u>Patient / Caregiver Engagement in Discharge Plan:</u>

The Medicare CoP requires ongoing consultation with the patient and his or her family on the discharge process.

> “The patient or the patient’s representative must be actively engaged in the development of the plan, so that the discussion of the evaluation results represents a continuation of this active engagement.” *Interpretive Guidelines §482.43(b)(6)*
>
> “The patient has the right to participate in the development and implementation of his or her plan of care. The patient or his/her representative (as allowed under State law) has the right to make informed decisions regarding his/her care and the patient’s rights include...being involved in care planning and treatment. Accordingly, hospitals are expected to engage the patient, or the patient’s representative, actively in the development of the discharge evaluation, not only as a source of information required for the assessment of self-care capabilities, but also to incorporate the patient’s goals and preferences as much as possible into the evaluation.” *§482.13(b)*
>
> “The discharge planning process is a collaborative one that must include the participation of the patient and the patient’s informal caregiver or representative, when applicable. In addition, other family or support persons who will be providing care to the patient after discharge need to be engaged in the process. Keeping the patient, and, when applicable, the patient’s representative and other support persons informed throughout the development of the plan is essential for its success. Providing them with information on post-discharge options, what to expect after discharge and, as

> applicable, instruction and training in how to provide care is essential. The patient needs clear instructions regarding what to do when concerns, issues, or problems arise, including who to call and when they should seek emergency assistance." *Interpretive Guidelines §482.43(c)(3) & §482.43(c)(5)*
>
> "As needed, the patient and family members or interested persons must be counseled to prepare them for post-hospital care**."** *§482.43(c) (5)*

Additionally, CMS requires inpatient hospitals to administer HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) Surveys as part of their Hospital Value-Based Purchasing program (Hospital VBP), which links a portion of inpatient hospitals' payment from CMS to their performance on a set of quality measures. The HCAHPS Survey is the basis of the Care Domain component of the Hospital VBP program, and accounts for 30% of a hospital's total performance score.

Simplified, this means that there is another level of CMS requirements and oversight that pertains to the current role hospitals have in discharge planning and training of the patient and family or caregiver via the HCAHPs Survey. A hospital's scores are directly tied to their reimbursement (or penalties, dependent upon their performance), which are also publicly reported. Hospitals are currently finding that they must come up with additional human resources that are solely dedicated to improving their HCAHPS scores to keep up with these increased requirements and also avoid penalties.

The following are the pertinent questions found in the survey:

- "During this hospital stay, did doctors, nurses or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?"
- "During this hospital stay, did you get information in writing about what symptoms or health problems to look out for after you left the hospital?"
- "During this hospital stay, staff took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left.
- "When I left the hospital, I had a good understanding of the things I was responsible for in managing my health."
- "When I left the hospital, I clearly understood the purpose for taking each of my medications.

2) JC Accreditation Guidelines

HAH exchanged correspondence with The Joint Commission (the national hospital accreditation and regulatory agency) specifically about the issue of caregiver training and discharge. The correspondence is below; full JC standards relating to discharge are attached.

AARP assertion about JC

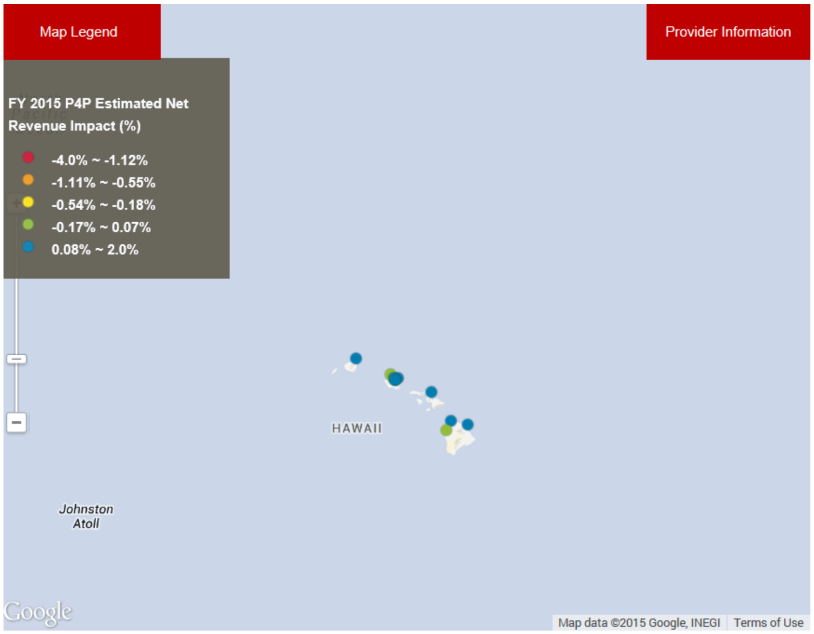
> *"The Joint Commission has no requirement for caregiver designation and inclusion in medical record, only inclusion of the legal representative is required. TJC has no requirement of caregiver notification upon discharge, but rather this is based upon hospital discretion. TJC has no requirement for in-person caregiver training. Hospitals inform family members (caregiver optional) about post-discharge care options, and are to provide written discharge instructions."*

Response from The Joint Commission (Received on January 13, 2015)
Mark A. Crafton, Executive Director, Communications and External Relations
Division of Business Development, Government & External Relations

> *"Thank you for your request for our assessment of the accuracy of the statement below you attribute to the local Hawaii AARP chapter. The statement is confusing because the terms "family" and "caregiver" may or may not be synonymous. As noted in the glossary of the 2015 Joint Commission Comprehensive Accreditation Manual for Hospitals (CAMH), a caregiver can be a "family member, significant other, friend, volunteer or individual employed by the patient to provide services in the home." Conversely, we define family as "a person or persons who play a significant role in an individual's life. Family may include persons not legally related to the individual (such as a caregiver) whom the individual personally considers to be family."*
>
> *In the AARP statement, they indicate that "The Joint Commission has no requirement of caregiver notification upon discharge, but rather this is based upon hospital discretion." This statement is not accurate if the caregiver is a family member (which as noted may or may not be a blood relative) involved in the patient's care, as PC.04.01.05 EP 2 requires that family involved in ongoing care must be informed of the need for continuing care. In addition,* ***The Joint Commission requires hospitals to 1) educate family on how to obtain continuing care, 2) notify family of discharge needs, and 3) include family in planning the discharge.*** *Our requirements also require a discharge summary be provided to the patient/family, including the provisions for any follow-up care to be provided by family/caregivers who will be involved in continuing care for the patient."*

3) Hawaii Hospital Readmissions

Readmissions rates in Hawaii are among the lowest in the country. According to Hawaii Health Information Corporation (HHIC), Hawaii has a 6% readmission rate compared to a national average of 10.7%. Several hospitals in Hawaii are among the top 10 percent (percentile) in the country for the conditions tracked that result in preventable readmissions.



This map shows estimated pay-for-performance (P4P) penalties by CMS for hospitals in FY 2015. The penalties will be based on how well/poor hospitals perform in CMS' programs for readmissions, value-based purchasing, and hospital-acquired conditions (HACs).

Each hospital has 5.5% of their inpatient Medicare reimbursement potentially at risk in FY 2015.

As you'll see, there are more blue dots for Hawaii, which shows that our state has a much lower risk for negative financial impact in comparison to other regions. As a result, Hawaii hospitals are estimated to have fewer penalties imposed by CMS in FY 2015.

In closing, we thank you for the opportunity to provide this information on behalf of our membership on Findings 10, 11 and 12 of the Family Caregivers Working Group Draft Report. In the meantime, if you have any questions, please don't hesitate to reach me at ggreene@hah.org.

GG:ag
Enclosure: Joint Commission Standards of Discharge

The Joint Commission Standards Relating to Discharge

Source: 2015 Joint Commission Comprehensive Accreditation Manual for Hospitals (CAMH)

Program: Hospital
Chapter: Provision of Care, Treatment, and Services
Standard: PC.04.01.01: The hospital has a process that addresses the patient's need for continuing care, treatment, and services after discharge or transfer.
Rationale: (None)
Element(s) of Performance (EPs):
1 The hospital describes the reason(s) for and conditions under which the patient is discharged or transferred.

2 The hospital describes the method for shifting responsibility for a patient's care from one clinician, hospital, program, or service to another.

3 The hospital describes the mechanisms for external transfer of the patient.

4 The hospital agrees with the receiving organization about each of their roles to keep the patient safe during transfer.

22 For hospitals that use Joint Commission accreditation for deemed status purposes: The hospital informs the patient or the patient's family of his or her freedom to choose among participating Medicare providers and, when possible, respects the patient's and family's preferences when they are expressed. The hospital does not limit the qualified providers that are available to the patient.

23 For hospitals that use Joint Commission accreditation for deemed status purposes: When the discharge planning evaluation indicates a need for home health care, the hospital includes in the discharge plan a list of participating Medicare home health agencies (which have requested to be on the list) that are available and serve the patient's geographic area. For patients enrolled in managed care organizations, the hospital lists home health agencies that have a contract with the managed care organization.

24 For hospitals that use Joint Commission accreditation for deemed status purposes: When the discharge planning evaluation indicates a need for posthospital extended care services, the hospital includes in the discharge plan a list of participating Medicare skilled nursing facilities that are available and in the geographic area requested by the patient. For patients enrolled in managed care organizations, the hospital lists skilled nursing facilities that have a contract with the managed care organization.

25 For hospitals that use Joint Commission accreditation for deemed status purposes: The hospital documents in the patient's medical record that the list of home health agencies or skilled nursing facilities was presented to the patient or to the individual acting on the patient's behalf. The discharge plan identifies disclosable financial interests between the hospital and any home health agency or skilled nursing facility on the list.

> Note: Disclosure of financial interest is determined in accordance with the provisions in 42 CFR 420.206.

26 For hospitals that use Joint Commission accreditation for deemed status purposes: The hospital has written discharge planning policies and procedures applicable to all patients.

Standard: PC.04.01.03: The hospital discharges or transfers the patient based on his or her assessed needs and the organization's ability to meet those needs.
Rationale: (None)
EPs:
1 The hospital begins the discharge planning process early in the patient's episode of care, treatment and services.

2 The hospital identifies any needs the patient may have for psychosocial or physical care, treatment, and services after discharge or transfer.

3 The patient, the patient's family, licensed independent practitioners, physicians, clinical psychologists, and staff involved in the patient's care, treatment, and services participate in planning the patient's discharge or transfer.

> Note 1: The definition of "physician" is the same as that used by the Centers for Medicare & Medicaid Services (CMS) (refer to the Glossary).
>
> Note 2: For psychiatric hospitals that use Joint Commission accreditation for deemed status purposes: Social service staff responsibilities include, but are not limited to, participating in discharge planning, arranging for follow-up care, and developing mechanisms for exchange of information with sources outside the hospital.

4 Prior to discharge, the hospital arranges or assists in arranging the services required by the patient after discharge in order to meet his or her ongoing needs for care and services.

5 For hospitals that use Joint Commission accreditation for deemed status purposes and have swing beds used for long term care: Except when specified in the CoP from 42 CFR 483.12(a)(5)(ii), the written notice of transfer or discharge required under paragraph 42 CFR 483.12(a)(4) must be made by the hospital at least 30 days before the resident is transferred or discharged.

> Note: Notice may be made as soon as is practical before transfer or discharge when the safety of the individuals in the facility would be endangered; the health of the individuals in the facility would be endangered; the resident's health improves sufficiently to allow a more immediate transfer or discharge, and immediate transfer or discharge is required by the resident's urgent medical needs; or a resident has not resided in the facility for 30 days.

6 For hospitals that use Joint Commission accreditation for deemed status purposes and have swing beds used for long term care: The written notice before transfer or discharge specified in the CoP from 42 CFR 483.12(a)(4) includes the following:

- The reason for transfer or discharge
- The effective date of transfer or discharge
- The location to which the resident is transferred or discharged
- A statement that the resident has the right to appeal the action to the state
- The name, address, and telephone number of the state's long term care ombudsman
- For a resident who is developmentally disabled, the mailing address and telephone number of the agency responsible for the protection and advocacy, established under Part C of the Developmental Disabilities Assistance and Bill of Rights Act
- For a resident who is mentally ill, the mailing address and telephone number of the agency responsible for the protection and advocacy, established under the Protection and Advocacy for Mentally Ill Individuals Act

10 For hospitals that use Joint Commission accreditation for deemed status purposes: The hospital conducts reassessments of its discharge planning process within its established time frames for reassessment.

11 For hospitals that use Joint Commission accreditation for deemed status purposes: The reassessment of the discharge planning process includes a review of discharge plans to determine if the discharge plans meet the needs of patients.

Standard: PC.04.01.05: Before the hospital discharges or transfers a patient, it informs and educates the patient about his or her follow-up care, treatment, and services.
Rationale: (None)
EPs:

1 When the hospital determines the patient's discharge or transfer needs, it promptly shares this information with the patient, and also with the patient's family when it is involved in decision making or ongoing care.

2 Before the patient is discharged, the hospital informs the patient, and also the patient's family when it is involved in decision making or ongoing care, of the kinds of continuing care, treatment, and services the patient will need.

3 Before the patient is discharged or transferred, the hospital provides the patient with information about why he or she is being discharged or transferred.

5 Before the patient is transferred, the hospital provides the patient with information about any alternatives to the transfer.

7 The hospital educates the patient, and also the patient's family when it is involved in decision making or ongoing care, about how to obtain any continuing care, treatment, and services that the patient will need.

8 The hospital provides written discharge instructions in a manner that the patient and/or the patient’s family or caregiver can understand. (See also RI.01.01.03, EP 1)

Standard: PC.04.02.01: When a patient is discharged or transferred, the hospital gives information about the care, treatment, and services provided to the patient to other service providers who will provide the patient with care, treatment, or services.
Rationale: (None)
EPs:

1 At the time of the patient’s discharge or transfer, the hospital informs other service providers who will provide care, treatment, or services to the patient about the following:

- The reason for the patient’s discharge or transfer
- The patient’s physical and psychosocial status
- A summary of care, treatment, and services it provided to the patient
- The patient’s progress toward goals
- A list of community resources or referrals made or provided to the patient

(See also PC.02.02.01, EP 1)

HAWAII HEALTH INFORMATION CORPORATION
Hawaii's source of healthcare data

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January 22, 2015

Senator Suzanne Chun-Oakland, Co-chair
Representative Greg Takayama, Co-chair
Family Caregivers Task Force
Hawaii State Legislature
State Capitol
Honolulu, HI 96813

Dear Co-Chair Chun-Oakland and Co-Chair Takayama,

At the January 12 meeting of the Task Force, HHIC was asked to put the new Finding # 12 of the draft Task Force report into context. We appreciate this opportunity and recommend the following highlighted information be added to the wording of the new Finding #12, if the finding is retained in the final report:

"The cost of hospital readmissions in Hawaii is significant~~.~~ According to the Hawaii Health Information Corporation ("HHIC")'s Insight No. 2 (released in September 2014), there were approximately 5,500 thirty-day hospital readmissions in Hawaii in 2013, with associated charges of almost $239 million. These are borne by all payers in the healthcare system (Medicare, private insurance, self-pay, etc.), but over $52 million are ~~paid by~~ charged to the state's Medicaid/QUEST program."

To place these figures in context, HHIC data show that there were 119,002 hospital discharges, generating overall charges of $3.7 billion in 2013. Readmissions thus made up 4.6% of all hospital discharges and 6.4% of all hospital charges in 2013. HHIC Insight #2 was written to describe the major illnesses affecting readmissions, not to analyze readmissions' costs or impact. These figures, therefore, do not differentiate how great a proportion of the charges displayed relate to discharges in which family members are involved, or how charges might be affected by any policy approach the legislature may take.

Readmissions, as used in the report cited, are potentially preventable return hospitalizations within the specified readmission time interval (30 days) that is clinically-related to the initial hospital admission. This index is not the same statistic used by CMS in its preventable readmissions program and the data developed is not comparable with either the CMS statistic or methods that might be used in other jurisdictions. This index is used by HMSA and the hospitals in HMSA's value-based purchasing program to incentivize hospitals to reduce readmissions. It does not differentiate by payer and rewards hospitals for their total effort to reduce readmissions, not just those insured by HMSA."

We also recommend the relocation of the new Finding #12 to placement after the old Findings 13—16, since such relocation would put the findings within the context of the other data on hospital readmissions.

We would be glad to discuss these recommended changes with you as needed and appreciate the opportunity to put the figures from our Insight Report #2 in context.

Sincerely,

Peter A. Sybinsky, Ph.D.
President and CEO

Care Transition Program

John T. Berthiaume M.D.
Vice President, Medical Director, Quality Management
Hawaii Medical Service Association
October 27, 2014

Advanced Hospital Care Program

- Initiated in 2010, Pay for Quality Program for all HMSA network hospitals
- Twenty percent of program weighted to discharge planning and readmission reduction
- Year one hospitals paid for process
  - Appoint discharge planning Champion
  - Develop Multidisciplinary team
  - Develop Data capture methodology
  - Develop a written protocol and program to make outbound calls to high risk patients
  - Develop a process to notify all physicians involved in the care of the discharged patient, a discharge summary

Advanced Hospital Care Program

- Year two and to date, reward points for improvement in Potentially Preventable Readmission Reduction
- Observed to Expected ratio used to “risk adjust” patient population
- Ten top service lines used
- Hospitals paid for performance and improvement

Top 10 PPR Initial Service Lines

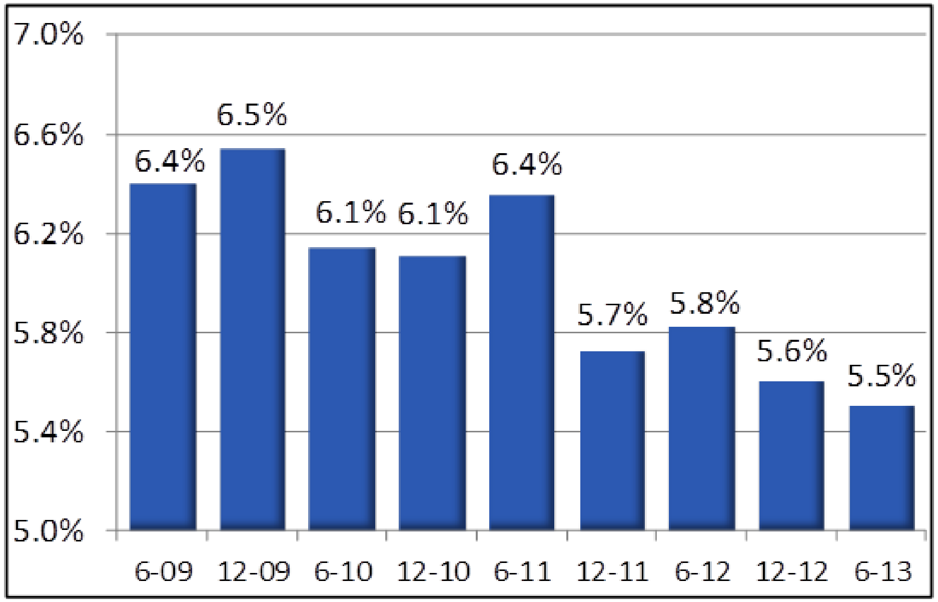
AHC Hospitals

PPR Initial Service Line	Eligible Dcs At Risk (for Readmission)	Actual to Expected Ratio (Goal =<1)
Obstetrics/Delivery	14,019	1.00
Neonatology	13,033	1.05
General Surgery	6,319	0.97
Infectious Disease	6,172	0.94
Orthopedic Surgery	5,536	0.96
Pulmonary	5,416	0.92
Gastroenterology	5,219	0.91
Cardiology	4,674	0.99
Neurology	4,068	0.90
Psychiatry	3,215	1.17

Improvement Over Time

HMSA began measuring **<u>Preventable Readmissions</u>** in 2010. Between the first and last periods shown below, the weighted average readmission rate has dropped by about 14%.

Trend in risk-adjusted readmission rate



Source: HHIC. All-payer 30-day readmission rate for six-month periods ending in months shown.

Reduction in readmissions produced substantial savings

- Savings measured by hospital production costs, covering all payers
- 13.5% cumulative reduction in readmission rate
- 640 admissions avoided per year
- $8.2 million saved in hospital costs per year

Source: HHIC: 2012 average cost per discharge = $12,784

Healthways Care Model

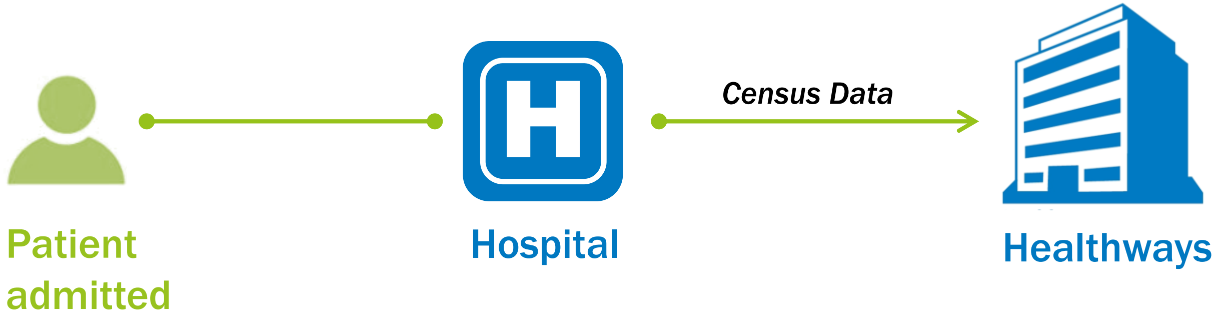
- Initiated midyear 2014

- Four Components
  - Short Term Case Management
  - Complex Case Management
  - Readmission Reduction Program
  - Late Stage Disease Management Program

- For the Readmission Reduction Program, a nurse is embedded into hospital to help with Care Transitions for patients that meet criteria

The Care Model In The Hospital

Step 1: Identify Patients at Risk for Re-Admission



Patient admitted

Hospital

Census Data

Healthways

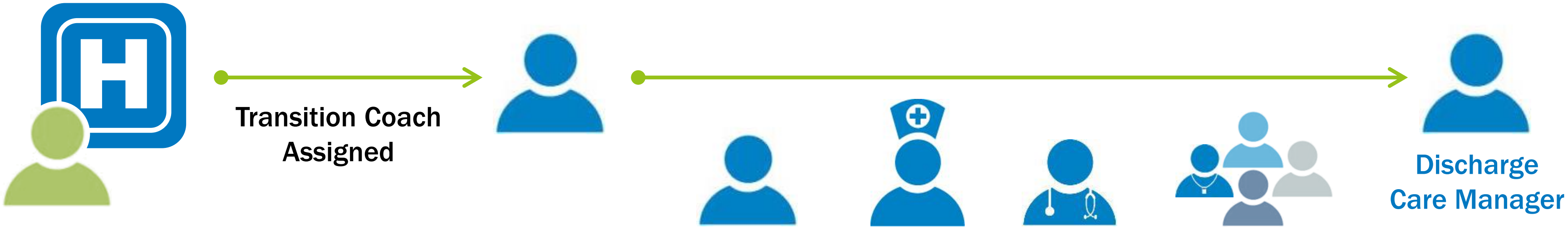
Predictive model runs on admitted patient data. Results rank patients by priority for intervention based on probability of readmitting.

RRI* Results	
John Doe	504-1
Jane Smith	302-1
Mary Long	210-2

* Re-hospitalization Risk Index

The Care Model In The Hospital

Step 2: Evaluate and Intervene



Transition Coach Assigned

At-risk Patient Targeted in Hospital

Caregiver

Nurse

PCP

Ancillary Services (e.g., pharmacy, nutrition services)

Discharge Care Manager

The Transition Coach assists the patient and/or caregivers in preparing for discharge.

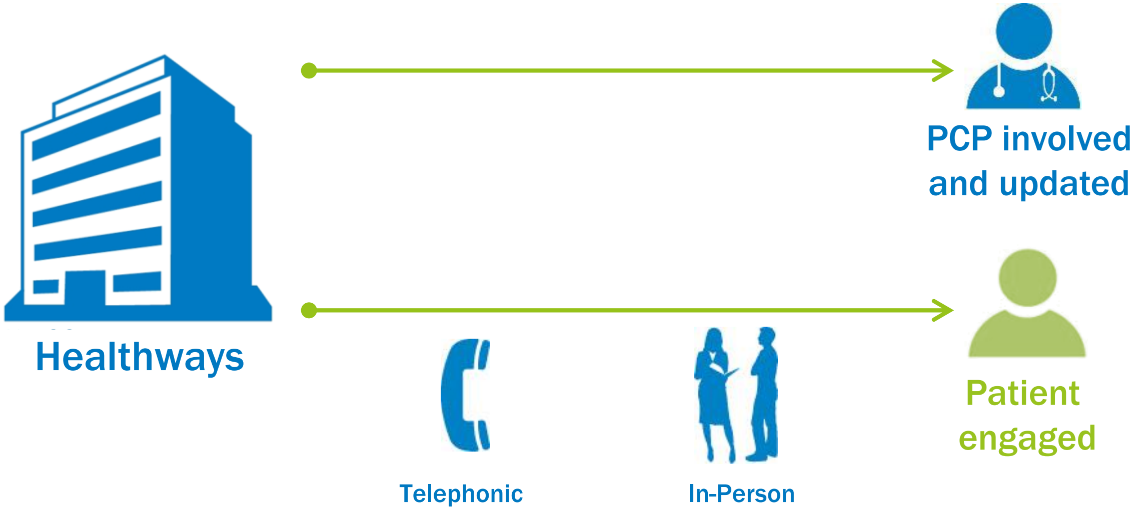
- Conducts a comprehensive assessment of the patient
  - Functional status
  - Social support
  - Health literacy
  - Cognitive deficits
  - Medication knowledge and adherence
  - Depression screening

Interventions

- Assists with medication reconciliation
- Collaborates with case managers
- Connects with PCP
- Delivers a tailored education plan
- Provides the patient with a Care Transition Record that includes key information from the hospitalization and guides the patient and post-discharge care providers in next steps
- Initiate in-home services
- Connects patient with community resources

The Care Model In The Hospital

Step 3: Follow Up



- Administer Discharge Plan
- Engage each patient in the most effective way for them: telephonic or in-person
- Interventions
  - ○ Follow-up appointments
  - ○ Red flags
  - ○ Medication management
  - ○ Use of Care Transition Record
- Interact with primary care physician to keep them informed and ensure they are meeting patient's discharge needs
- Work with patient as appropriate based on their location after discharge (e.g., skilled nursing facility, long-term care, home, etc.)

Care Model Update

- Now in six hospitals (Kuakini, CMC, QMC, KVMH/Mahelona, QMC West, and Hilo)
- Fully staffed for outpatient CM roles
- Cases under management

Readmit Risk	**1,306 Screened** **1,016 Enrolled** **516 Active**

Hospital Access & Integration Timeline

	Launched	Imminent	Engaged
Kuakini Hospital	5/5		
Queen's Hospital	7/7		
Castle Hospital	7/23		
KVMH/Sam Mahelona *(Kauai)*	9/12		
Queen's West	9/15		
Maui Memorial *(Maui)*		October	
Hilo Medical Center *(Hawaii Island)*		October	
HPH – Straub		November	
Kona Community Hospital *(Hawaii Island)*		November	
HPH – Pali Momi		November	
HPH – Wilcox *(Kauai)*		November	
North Hawaii Community *(Hawaii Island)*			TBD
Rehab Hospital of the Pacific			TBD

HAWAII CARE TRANSITION PROGRAM

AGENDA

- Overview of Hawaii Care Transition Program, Partners, Goals, Target Population
- Care Transition Intervention Model (aka Coleman)
- Hawaii County
- Kauai
- Maui
- Outcomes

OVERVIEW

- CMS Grant Award to Hawaii Executive Office on Aging and County AAAs
- Hospital Partners (Kauai Veterans Memorial Hospital, Hilo Medical, & Maui Memorial Medical Center)
- Care Transition Intervention Model (CTI) Protocols and 4 Pillars

GOALS

- Reduce hospital readmissions/ER visits
- Assist patients to successfully transition back to home and empower them in managing own health
- Strengthen relationships and coordination between health system and community services
- Connect Consumers to other Healthy Aging Programs and community resources via AAA/ADRC

CARE TRANSITION INTERVENTION®

- Care Transition Intervention® (CTI) – 4 week program developed by Dr. Eric Coleman
- An evidence based model using a person-centered approach
- A self management model teaching skills, providing information and tools for individuals to successfully transition across settings now and in their future

PROTOCOL

- Initial visit in the hospital by the Coach
- Home visit within 24-72 hours of discharge
- Weekly telephone contacts for the next three weeks

TRANSITION COACH

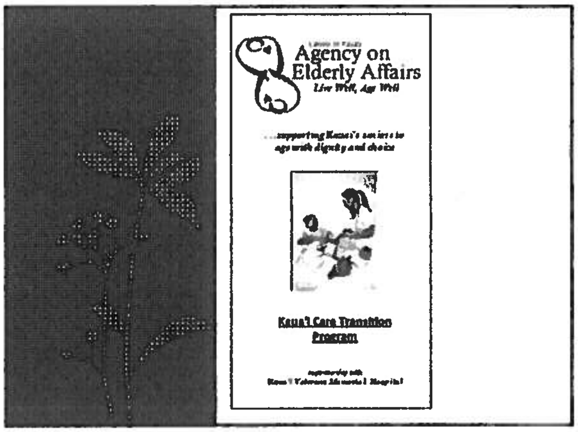
- Coach helps patients and families learn transition-specific self care management skills
- Not required to be a registered nurse or clinical social worker

CTI FOUR PILLARS

- Medication Self Management
- Patient-Centered Personal Health Record
- Follow-Up with Primary Physician
- Recognizing Red Flags

HAWAI'I COUNTY'S TRANSITION PROJECT

- Hilo Medical Center
- Competition with Project Hope
- Collaborated with Ohana Health Plan
- Enrolled 17 Ohana Health Plan clients with successful results



Agency on Elderly Affairs

Live Well, Age Well

...supporting Kauai's seniors to age with dignity and choice

Kaua'i Care Transition Program

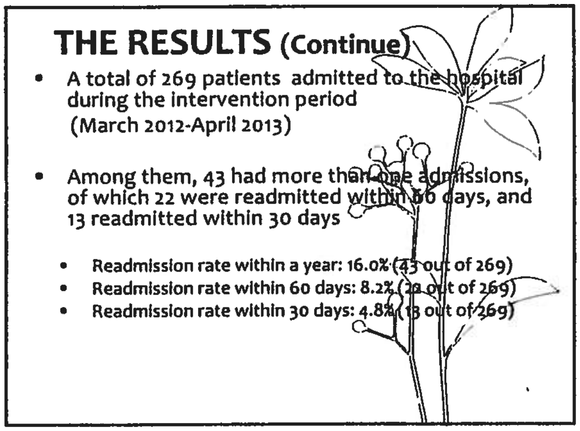
KAUAI CARE TRANSITION PROGRAM

- Kauai Veterans Memorial Hospital (KVMH)
  - ➢ Target Population (60 y.o and older)
  - ➢ Health Conditions (admitting diagnoses)

High Risk: Severe pulmonary/respiratory, cardiac-related diseases/ conditions, sepsis, and cellulitis

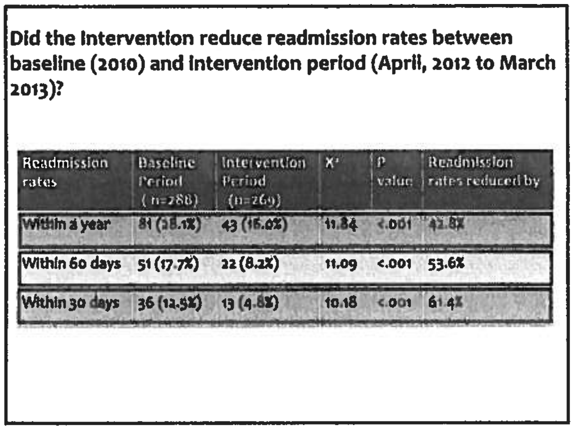
THE RESULTS (2012-13)

- **Referral to CTI:** A total of 58 high risk patients (age 60 and over) were referred to CTI program.
- A total of 269 patients (age 60 and over) admitted to the hospital during the intervention period.



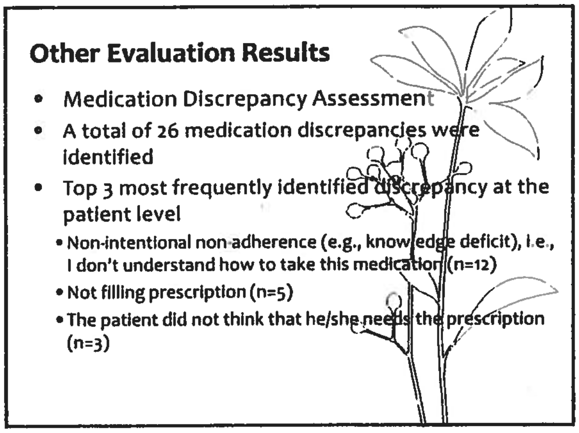
THE RESULTS (Continue)

- A total of 269 patients admitted to the hospital during the intervention period (March 2012-April 2013)
- Among them, 43 had more than one admissions, of which 22 were readmitted within 60 days, and 13 readmitted within 30 days
  - Readmission rate within a year: 16.0% (43 out of 269)
  - Readmission rate within 60 days: 8.2% (22 out of 269)
  - Readmission rate within 30 days: 4.8% (13 out of 269)



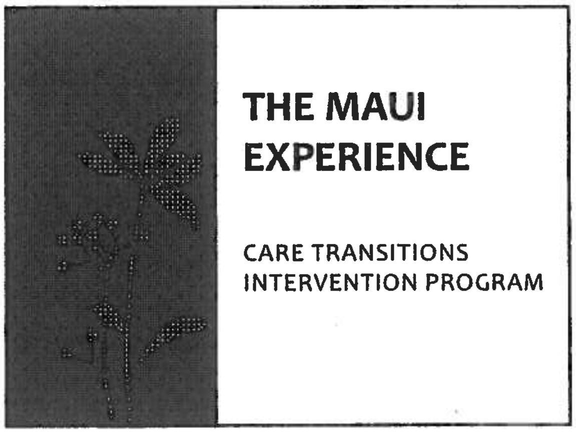
Did the intervention reduce readmission rates between baseline (2010) and intervention period (April, 2012 to March 2013)?

Readmission rates	Baseline Period (n=288)	Intervention Period (n=269)	X^2	P value	Readmission rates reduced by
Within a year	81 (28.1%)	43 (16.0%)	11.84	<.001	42.8%
Within 60 days	51 (17.7%)	22 (8.2%)	11.09	<.001	53.6%
Within 30 days	36 (12.5%)	13 (4.8%)	10.18	<.001	61.4%



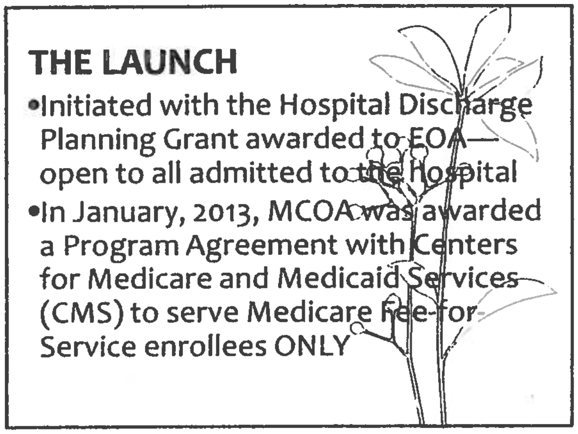
Other Evaluation Results

- Medication Discrepancy Assessment
- A total of 26 medication discrepancies were identified
- Top 3 most frequently identified discrepancy at the patient level
  - Non-intentional non-adherence (e.g., knowledge deficit), i.e., I don't understand how to take this medication (n=12)
  - Not filling prescription (n=5)
  - The patient did not think that he/she needs the prescription (n=3)



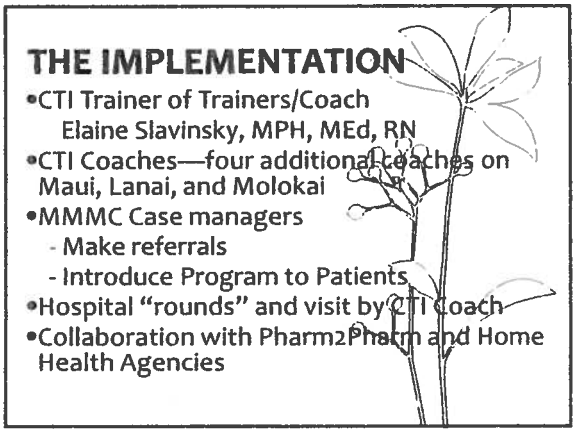
THE MAUI EXPERIENCE

CARE TRANSITIONS INTERVENTION PROGRAM



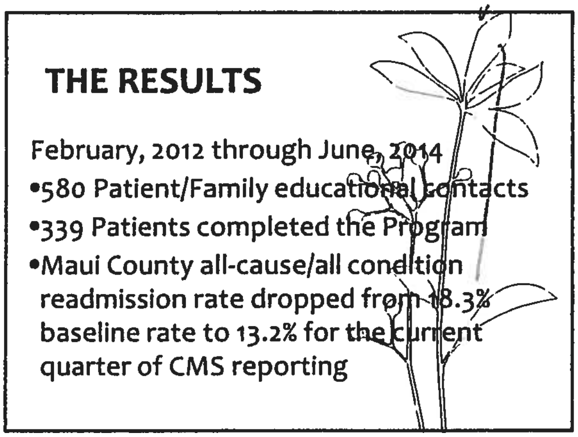
THE LAUNCH

- Initiated with the Hospital Discharge Planning Grant awarded to EOA—open to all admitted to the Hospital
- In January, 2013, MCOA was awarded a Program Agreement with Centers for Medicare and Medicaid Services (CMS) to serve Medicare Fee-for Service enrollees ONLY



THE IMPLEMENTATION

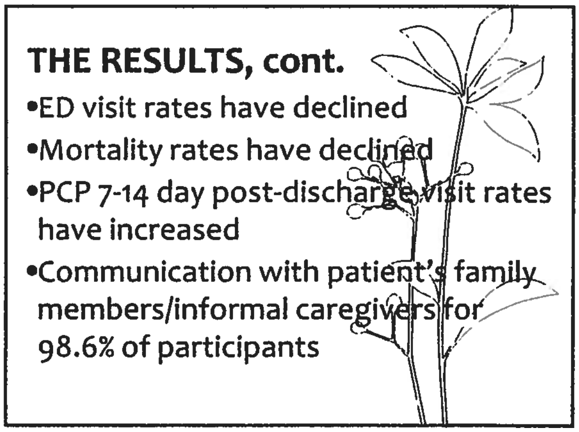
- CTI Trainer of Trainers/Coach
  Elaine Slavinsky, MPH, MEd, RN
- CTI Coaches—four additional coaches on Maui, Lanai, and Molokai
- MMMC Case managers
  - Make referrals
  - Introduce Program to Patients
- Hospital "rounds" and visit by CTI Coach
- Collaboration with Pharm2Pharm and Home Health Agencies



THE RESULTS

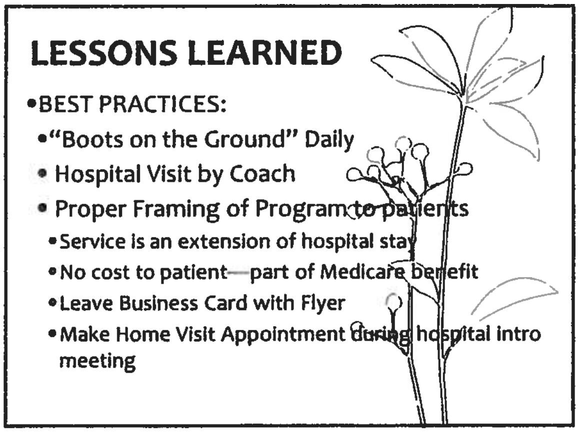
February, 2012 through June, 2014

- •580 Patient/Family educational contacts
- •339 Patients completed the Program
- •Maui County all-cause/all condition readmission rate dropped from 18.3% baseline rate to 13.2% for the current quarter of CMS reporting



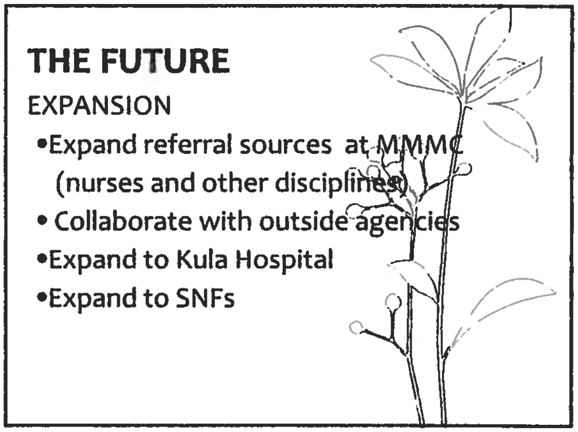
THE RESULTS, cont.

- •ED visit rates have declined
- •Mortality rates have declined
- •PCP 7-14 day post-discharge visit rates have increased
- •Communication with patient's family members/informal caregivers for 98.6% of participants



LESSONS LEARNED

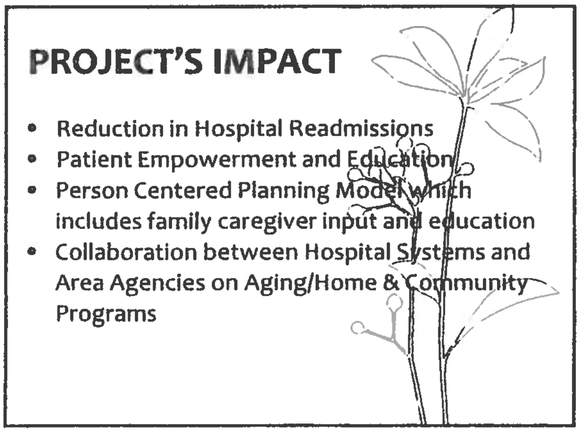
- •BEST PRACTICES:
  - •"Boots on the Ground" Daily
  - • Hospital Visit by Coach
  - • Proper Framing of Program to patients
    - •Service is an extension of hospital stay
    - •No cost to patient—part of Medicare benefit
    - •Leave Business Card with Flyer
    - •Make Home Visit Appointment during hospital intro meeting



THE FUTURE

EXPANSION

- •Expand referral sources at MMMC (nurses and other disciplines)
- • Collaborate with outside agencies
- •Expand to Kula Hospital
- •Expand to SNFs



PROJECT'S IMPACT

- Reduction in Hospital Readmissions
- Patient Empowerment and Education
- Person Centered Planning Model which includes family caregiver input and education
- Collaboration between Hospital Systems and Area Agencies on Aging/Home & Community Programs

Report on Pharm2Pharm Program
Pali Momi Medical Center

Lois Nash, B.S. Pharm, M.S., Pharmacy Administration
Director of Pharmacy, Pali Momi Medical Center

Angela Li, PharmD and Shanele Shimabuku, PharmD
Pharm2 Pharm Pharmacists 485-4276

PALI MOMI
MEDICAL CENTER
An Affiliate of Hawai'i Pacific Health

Pharm2Pharm
Pali Momi Medical Center

- **Background**
- According to Hawaii Health Information Corporation, medication-related hospitalizations in Hawaii cost over $100,000,000 in 2010
  - The elderly and those living in medically underserved areas are at particular risk for medication-related acute care admissions
- Hospital pharmacists found unexplained discrepancies between preadmission medication regimens and discharge medication orders in 49% of all general medicine patients

- **Service**
- Pharm2Pharm is a new service model that will address the common gaps in care and reduce medication-related hospitalizations and ED visits in high risk populations
  - Funding will be provided by a $14.3 million cooperative agreement between the Daniel K. Inouye College of Pharmacy and the CMS innovation center

- **Goals**
- To improve health and healthcare, while reducing overall costs

PALI MOMI
MEDICAL CENTER
An Affiliate of Hawai'i Pacific Health

Patient Eligibility

- **Extensive Inclusion and Exclusion Criteria**

Inclusion Criteria

Based on patient age, Number of medications, High risk medications, Diagnosis (ACS, Afib, COPD, HF, DM), Admission for medication related problems, Recurrent admissions for uncontrolled chronic condition

Exclusion Criteria

Not a full time county resident, No reasonable expectation of discharge to site for follow up, Severe dementia, Active psychosis, Hospitalization for suicide/homicide attempt, Leaves AMA, Hospice patient, Aggressive cancer, Current drug abuse

Hospital Pharmacist

- Identify eligible patients
- Medication education prior to/upon discharge
- Coordinate with nursing and case management to assist with discharge
- Provide Pharm2Pharm pharmacist with patient information and identified medication-related issues to follow-up with after discharge
- Follow-up phone call after discharge

Hospital Pharmacist

Pharm2Pharm Pharmacy

Patient's Pharmacy

Pharm2Pharm Community Pharmacist

- Coordinate with hospital/patient's pharmacy and PCP after discharge
- Monthly follow-up phone calls throughout the year
- Medication education

Patient’s Pharmacist Where Prescriptions Filled

(Might Be P2P Pharmacy Also)

- Fill Patient Prescriptions
- Coordinate with Pharm2Pharm Pharmacist and Hospital Pharmacist to assist with patient’s care

Program Results

Time Since Implementation

2 Months

Number of Patient Enrolled in Program

100 Patients

Most Common Patient Diagnoses

Cardiac Patients

Diabetic Patients

Average Number of Medications per Patient

10 – 15 Medications

Number of Readmissions within this Patient Group During 2 Months

7 Patients

OCTOBER 2012

HOME ALONE:

Family Caregivers Providing Complex Chronic Care

Susan C. Reinhard, RN, PhD
Senior Vice President and Director,
AARP Public Policy Institute

Carol Levine, MA
Director, Families and Health Care Project,
United Hospital Fund

Sarah Samis, MPA
Senior Health Policy Analyst,
United Hospital Fund

funded by

AARP

United Hospital Fund
Shaping New York's Health Care: Information, Philanthropy, Policy

The John A. Hartford Foundation 1929

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AARP's Public Policy Institute informs and stimulates public debate on the issues we face as we age. Through research, analysis and dialogue with the nation's leading experts, PPI promotes development of sound, creative policies to address our common need for economic security, health care, and quality of life.

The United Hospital Fund is a nonprofit health services research and philanthropic organization whose primary mission is to shape positive change in health care for the people of New York. We advance policies and support programs that promote high-quality, patient-centered health care services that are accessible to all. We undertake research and policy analysis to improve the financing and delivery of care in hospitals, health centers, nursing homes, and other care settings. We raise funds and give grants to examine emerging issues and stimulate innovative programs. And we work collaboratively with civic, professional, and volunteer leaders to identify and realize opportunities for change.

2012-10
October 2012

AARP Public Policy Institute
601 E Street, NW, Washington, DC 20049
http://www.aarp.org/ppi

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ACKNOWLEDGMENTS

The authors gratefully thank The John A. Hartford Foundation and the AARP Foundation for their generous support of this project. This report is part of a larger initiative, *Professional Partners Supporting Family Caregivers*, which seeks a better understanding of what family caregivers are expected to do and how health care professionals can better support them in their work. We thank Amy Berman, senior program officer at The John A. Hartford Foundation, for her thoughtful and consistent support of this project.

Both the United Hospital Fund and AARP provided substantial in-kind support for this project. We thank our project team for their expertise, enthusiasm, and careful attention to the details of this work. At the United Hospital Fund, David Gould, senior vice-president for program, directed the overall survey development, implementation, and analysis. Deborah Halper provided thoughtful suggestions and questions at key stages of the work. At the AARP Public Policy Institute, Ari Houser, quantitative methods advisor, provided methodological guidance and expert analysis on the effects on quality of life of providing medical/nursing tasks. Lynn Feinberg, Rita Choula, Enid Kassner, Rick Deutsch, and Jordan Green offered important ideas for shaping the survey, analyzing the results, and communicating the findings. Working with UHF staff, Jeffrey Nichols, Sally Sobolewski, and Cameron MacDonald reviewed sections of the survey questionnaire and responses. We also acknowledge Joe Garrett at Knowledge Networks for his guidance in constructing and fielding the survey.

We especially want to thank the family caregivers who responded to this survey for sharing their experiences in ways that can help us all better understand the work they do so we can advance solutions to help them.

HOME ALONE:
Family Caregivers Providing Complex Chronic Care

EXECUTIVE SUMMARY

This study challenges the common perception of family caregiving as a set of personal care and household chores that most adults already do or can easily master.

Family caregivers have traditionally provided assistance with bathing, dressing, eating, and household tasks such as shopping and managing finances. While these remain critically important to the well-being of care recipients, the role of family caregivers has dramatically expanded to include performing medical/nursing tasks of the kind and complexity once provided only in hospitals.

To document this major shift, the AARP Public Policy Institute and the United Hospital Fund undertook the first nationally representative population-based online survey of 1,677 family caregivers to determine what medical/nursing tasks they perform. Both organizations contributed to this report. We present a brief overview in this executive summary, followed by more detailed key findings and the full research report.

Highlights of Survey Results

- **Almost half (46 percent) of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.** These tasks include managing multiple medications, helping with assistive devices for mobility, preparing food for special diets, providing wound care, using monitors, managing incontinence, and operating specialized medical equipment.
- **Many family caregivers managed many different kinds of medications.** Three out of four (78 percent) family caregivers who provided medical/nursing tasks were managing medications, including administering intravenous fluids and injections. Almost half were administering five to nine prescription medications a day. Medication management was reported to be difficult because it took so much time, it created anxieties about making a mistake, and some care recipients were uncooperative.
- **Most family caregivers learned how to manage at least some of the medications on their own.** Despite frequent emergency department visits and overnight hospital stays, few family caregivers reported receiving assistance and training from health care professionals.
- **Caregivers found wound care very challenging, and many wanted more training.** More than a third (35 percent) of family caregivers who provided medical/nursing tasks reported doing wound care. While fewer caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as difficult because of fear of making a mistake. More than a third (38 percent) would like more training.
- **Family caregivers of chronically ill persons frequently served as care coordinators.** More than half (53 percent) of family caregivers who performed medical/nursing tasks coordinated care—twice the rate of those who mainly provided personal care.

- **Family caregivers performing medical/nursing tasks reported both positive and negative effects on their quality of life.** Family caregivers who performed five or more medical/nursing tasks were most likely to believe they were making an important contribution, primarily preventing nursing home placement. Compared with those who performed one to four tasks, they were also most likely to report feeling stressed and worried about making a mistake. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health
- **More than half of family caregivers performing medical/nursing tasks said they did not feel they had a choice because there was no one else to do it or insurance wouldn't cover a professional's help.** A small percentage (12 percent) reported pressure from the care recipient.
- **Family caregivers reported very few home visits by health care professionals.** Sixty-nine percent of the care recipients did not have any home visits by health care professionals. Of those who did have home visits, roughly seven in ten were visited by a nurse.
- **Most family caregivers who provided help with five or more medical/nursing tasks believed they were helping their family member avoid institutionalization.** Those who provided these tasks and reported they had training were more likely to say they were able to help their family member avoid nursing home placement. These significant relationships are important on both the individual and public policy levels.

Major Recommendations

- **A consensus-building body should revisit measures of activities of daily living (ADLs) and instrumental activities of daily living (IADLs).** The measures commonly used for a half-century no longer adequately capture what family caregivers do. The Institute of Medicine is particularly well suited to this kind of consensus-building effort.
- **Individual health care professionals must fundamentally reassess and restructure the way they interact with family caregivers in daily practice.** Every health care clinician and social service professional must feel personally responsible for ensuring that patients and families in their care understand how to perform the challenging tasks outlined in this report.
- **Health care provider organizations (hospitals, rehabilitation centers, home care agencies, nursing homes, and hospices) must support health care professionals in their efforts through adequate resources and strong leadership.** Every provider should have clear expectations, protocols, and support for clinicians who interact with family caregivers, especially caregivers who are taking on complex medical/nursing tasks. Payment policies should be structured to make this happen.
- **Professional organizations should lead and support professionals in their efforts to improve communication and training for family caregivers.** Some organizations have already begun this process. But much more needs to be done.

- **Leaders in medical, nursing, social work, allied health professional training and continuing education should examine their curricula to determine where and how the importance of acknowledging, supporting, and training family caregivers can be added or strengthened.** New approaches are needed that blend technical and communication skills. Training must be adapted to respond to changes in the family member's condition or the family caregiver's needs and capabilities.
- **Accrediting and standard-setting organizations must take seriously their evaluation of how well institutions incorporate family caregiver needs and require corrective steps to address deficiencies.** The Joint Commission accredits and certifies more than 19,000 health care organizations and programs in the United States and has criteria for assessing patient and family participation in decision making and other aspects of quality care. But these criteria are not generally given high priority in ratings, and many institutions see them only as ideals. The Joint Commission should ensure that surveyors are trained to assess family caregiver training and support. The National Quality Forum, which endorses national consensus standards for measuring and publicly reporting on performance, should specifically define and promote standards that include the role of family caregivers.
- **Federal policymakers should proactively consider family caregivers in developing new models of care that focus on coordination and quality improvement.** Explicitly including family caregivers in federal funding requirements for new models of care focused on care coordination and quality improvement is an essential first step.
- **State policymakers should proactively consider family caregivers in funding and policy development.** State governments should incorporate family caregiver assessments in publicly funded programs, including the new demonstrations for people eligible for both Medicare and Medicaid. States should enable registered nurses to delegate medical/nursing care tasks to qualified direct care workers who serve people in their homes.
- **Caregiver advocacy and support organizations should include in their service and policy agendas resources that address the needs of family caregivers who have taken on the triple burden of personal care, household chores, and medical/nursing tasks.** Caregiver organizations have used ADLs and IADLs in describing their constituents and in advocating for funding and services. They, like their health care professional colleagues, must expand their view to include the special needs of family caregivers who perform medical/nursing tasks.
- **Academic and government researchers should conduct further studies to understand medical/nursing tasks performed by different types of family caregivers and their needs for training and support.** Further research is needed in diverse populations, particularly ethnic minorities, family caregivers whose primary language is not English, and other groups whose experiences may differ from a national sample. More research is also needed on training methods and interactions between professionals and family caregivers. Foundations should support these studies.

HOME ALONE:
Family Caregivers Providing Complex Chronic Care

KEY FINDINGS

It is well known that family caregivers perform activities of daily living (ADLs) like bathing and dressing, as well as instrumental activities of daily living (IADLs), such as shopping, cooking, and preparing meals. But little is known about the complex health-related activities they perform. This report focuses on family caregivers' responsibility for "medical/nursing tasks" that can "make nursing students tremble."[1] [2] The AARP Public Policy Institute and the United Hospital Fund collaborated on the first national survey devoted specifically to medical/nursing tasks to further explore the complexity of the "new normal" that family caregivers face.[3] We present detailed key findings here, followed by the full research report.

The findings are derived from an online survey of a nationally representative sample of 1,677 caregivers who provided unpaid care to a relative or friend age 18 or older in the preceding 12 months. Overall, the demographic characteristics of caregivers and care recipients are comparable to those of other national surveys and described in detail in the report. Most of the care recipients had multiple chronic conditions and had frequent visits to emergency departments (EDs) and overnight hospital stays. The key findings outlined here focus on the medical/nursing tasks that family caregivers performed and the general lack of training and support they received.

Almost half of family caregivers performed "medical" or "nursing" tasks for care recipients with multiple physical and chronic conditions.

In this survey , 777 of the 1,677 family caregivers (46 percent) performed medical/nursing tasks. They reported performing a variety of activities that some call "nursing," others call "medical," and still others call "health-related." Here we call them "medical/nursing tasks," which include the following:

- Managing medications, including injections and intravenous therapy (78 percent)
- Helping with assistive devices (canes and walkers) for mobility (43 percent)
- Preparing food for special diets (41 percent)

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[1] S. C. Reinhard, *Caregiving and Loss: Family Needs, Professional Responses: Nursing's Role in Family Caregiver Support* (Hospice Foundation of America, Washington DC 2001).

[2] We decided to use the term "medical/nursing tasks" for several reasons. We wanted to use a term that survey respondents would relate to, not what professionals understand by the term. Other terms, such as "health-related," suggest activities related to food and exercise rather than the kinds of interventions we were targeting. Some terms, such as "complex medical care," have more currency in the medical world than among family caregivers. Family caregivers respond to "medical tasks" as a broader term than "nursing tasks," which they think of as something that only a licensed professional nurse can do. We chose the combined term "medical/nursing" to give survey respondents the broadest understanding of what we were asking of them. Consensus on language that captures this crucial family caregiving work would be helpful for future research and policy development.

[3] L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (Washington, DC: AARP Public Policy Institute, 2011.

- Doing wound care, such as ostomy care, treatment of pressure sores, and application of ointments and prescription drugs and bandages for skin care (35 percent)
- Using meters or monitors, including glucometers to test blood sugar levels, oxygen and blood pressure monitors, test kits, and telehealth equipment (32 percent)
- Administering enemas and managing incontinence equipment and supplies (25 percent)
- Operating durable medical equipment, such as lifts to get people out of bed, hospital beds, and geri-chairs (21 percent)
- Operating medical equipment, including mechanical ventilators, tube feeding equipment, home dialysis, and suctioning (14 percent)

Almost all (more than 96 percent) of these family caregivers also provided ADL or IADL assistance.

Family caregivers found some tasks more difficult than others, with some surprises for health care professionals.

When asked to select two medical/nursing tasks that are "hard to do," family caregivers reported a range of tasks, including some that are conventionally not thought of as difficult. Two out of three (67 percent) of those who performed incontinence support found this very hard to do. This kind of task involves more than "help with toileting," which is measured as an ADL, and it often involves intimacy with a parent or other family member in ways that would ordinarily be proscribed. Similarly, more than half (53 percent) of those who prepared food for special diets found this work hard to do because it involves more than "help with meals," typically classified as an IADL.

> *"The constant monitoring of blood sugar levels and the need to balance diet to match blood sugar levels"…affects my quality of life.*

It is less surprising that half (49 percent) of family caregivers who needed to operate mechanical equipment, such as mechanical ventilators, feeding tubes, or home dialysis equipment, found this work hard to do. And one in three (36 percent) of those who used meters, monitors, or durable medical equipment reported these activities as difficult.

Managing medications was very challenging and little training was reported.

More than three out of four (78 percent) family caregivers who provided medical/nursing tasks managed medications, including administering intravenous fluids and injections. Almost all of these family caregivers also helped with ADLs, IADLs, or both. And the majority (81 percent) provided at least one additional medical/nursing service.

"I constantly monitor drugs."

These family caregivers were not just helping with a pill or two a day, which may have been the case decades ago when IADL measures included "help with medications." Almost half (46 percent) helped chronically ill people who took between five and nine medications a day. Close to one in five (18 percent) family caregivers helped care recipients who took ten or more prescription medications daily; seven in ten (69 percent) care recipients also took between one and four over-the-counter medications or supplements.

More than 60 percent of family caregivers asked a health care professional (doctor, nurse, or pharmacist) questions about the care recipient's medication or looked up information on the Internet about the medication's risks and benefits. Close to a third (31 percent) actively monitored their care recipient for potential side effects of medication, a task that requires caregivers to be knowledgeable about the medications.

Almost two-thirds (61 percent) of the family caregivers who found medication management difficult cited the following main reasons:

- Forty-two percent cited the time and inconvenience; 18 percent reported having to administer medications several times a day or night and 38 percent daily.
- Twenty-nine percent reported being afraid of making a mistake and harming their family member.
- Twenty-four percent reported that the care recipient was resistant and did not cooperate.

The majority of these medication caregivers (more than 60 percent) learned how to manage at least some of the medications on their own:

- Close to half (47 percent) said they never received training from any source.
- Thirty-two percent received training in an outpatient setting from a doctor or nurse.
- Sixteen percent received training from a hospital nurse or doctor.

When asked what would help them in medication management, many family caregivers commented, "Fewer medications." Almost a third (29 percent) said another person to help would be good. One in four (24 percent) would appreciate more training, and 22 percent said they would like more cooperation from the care recipient.

Performing wound care was also very challenging, and many family caregivers received training.

More than a third (35 percent) of medical/nursing caregivers reported doing wound care, and almost all (92 percent) of these family caregivers performed other medical/nursing tasks in addition to wound care. While fewer family caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as hard.

Of these family caregivers, close to half (47 percent) felt that wound care was challenging because they were afraid of making a mistake and/or harming their family member. Other reasons included the following:

- Takes time or is inconvenient (34 percent)
- Emotionally difficult for caregiver (33 percent)
- Family member resists or has cognitive or behavioral problems (14 percent)

Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management. More than a third (36 percent) were trained by a hospital nurse or physician, and a quarter received training from a home care nurse. A substantial percentage of family caregivers (38 percent) thought more training in wound care would help them, compared with 24 percent citing training in medication management as potentially helpful.

Family caregivers felt pressured to perform medical/nursing tasks, but most pressure was self-imposed.

Family caregivers reported that they often felt pressured to take on medical/nursing tasks that they considered difficult. More than half (57 percent) said they did not feel they had a choice in assuming a hard task. Many of these (43 percent) felt they had a personal responsibility (there was no one else to do it, or insurance would not cover it). And some cited external pressure from the care recipient (12 percent) or another family member.

Family caregivers who perform medical/nursing tasks are more likely to be care coordinators than those who perform only ADL or IADL tasks.

Most family caregivers acted as care coordinators, but those who performed medical/nursing tasks were more than twice as likely to do so as those who performed only ADL/IADL tasks (57 percent vs. 24 percent). Very few family caregivers (3–4 percent) reported working with a care manager from an insurance company or government program or hiring a private geriatric care manager.

The greater the number of medical/nursing tasks family caregivers perform, the greater the effects on their quality of life.

Family caregivers who performed five or more medical/nursing tasks were most likely to feel close to the person they are helping. They also believed that they were gaining new skills and were making an important contribution. Compared with those who performed one or two tasks, they were also most likely to report the following:

- Depression (51 percent vs. 33 percent)
- Feeling the need to constantly watch out for something to go wrong (51 percent vs. 21 percent)
- Feeling stressed about talking to many professionals (40 percent vs. 16 percent)
- Feeling worried about making a mistake (36 percent vs. 12 percent)

These highly involved family caregivers appeared to understand how important they are to the person who needs such substantial medical/nursing care, but they were stressed and depressed by their significant health management role.

The greater the number of medical/nursing tasks family caregivers performed, the more likely they were to report that they were helping the care recipient avoid nursing home placement.

Three out of four family caregivers who provided help with five or more medical/nursing tasks believed they were helping their family member avoid institutionalization. The same was true of family caregivers who were caring for people with five or more chronic conditions. Two out of three caregivers who helped with medical/nursing tasks for family members with five or more chronic conditions reported that this support helped avoid nursing home placement. Family caregivers who provided medical/nursing tasks and reported they had training were more likely to say they were able to help their family member avoid nursing home placement. These significant relationships are important on both the individual and public policy levels.

"How has doing these medical/ nursing tasks affected your own quality of life?

One caregiver's answer:

"What life?"

Another family caregiver's answer:

"In the last year and a half I have developed high blood pressure, diabetes, and weight gain so now I have sleep apnea."

HOME ALONE:
Family Caregivers Providing Complex Chronic Care

INTRODUCTION

In recognition of the crucial role of family caregivers as the foundation of long-term care, a national panel of experts recently identified family caregiving as one of five key dimensions in a high-performing system of long-term services and supports.[4] Many studies have repeatedly cited family caregivers as the "backbone," "bulwark," or "mainstay" of care of older people and adults with disabilities.

Despite this recognition, the family caregiver's role in primary, acute, and chronic care is typically invisible. Family caregivers are the main care coordinators, trying to tie together the fragmented pieces of their family member's care with several different clinicians, hospitals stays, and transitions between settings, as well as dealing with social service agencies and other community services. Recent efforts to reduce hospital readmissions and improve transitional care have to varying degrees included family caregivers as critical partners,[5] but the models are still focused mainly on the patient, or at best, the patient/family.

The United Hospital Fund's Next Step in Care campaign is the only effort specifically addressing the needs of family caregivers during care transitions. In its Transitions in Care-Quality Improvement Collaborative (TC-QuIC), none of the 37 participating hospitals, home care agencies, rehabilitation programs, or hospices had a systematic way of identifying the actual (rather than the assumed) family caregiver. Even in the vast literature on family caregiving, there is scant attention to the complex medical/nursing tasks that caregivers are expected to take on to help people with multiple chronic conditions.

Donelan and colleagues[6] at the Harvard School of Public Health, United Hospital Fund, and the Visiting Nurse Service of New York explored this issue more than a decade ago. Family caregivers reported receiving little training in how to manage wound care, pumps and machines at the bedside, and medications, although survey limitations did not permit more detailed analysis of their experiences in performing these medical/nursing tasks. Other studies have looked at these tasks in the context of specific populations. To our knowledge, only two books have been devoted to this subject: *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care*,[7] which focuses on pediatric and human immunodeficiency virus (HIV) care, and *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*.[8]

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[4] S. C. Reinhard, E. Kassner, and A. Houser, "How the Affordable Care Act Can Help Move States Toward a High-Performing System of Long-Term Services and Supports," *Health Affairs* 30, no. 3 (2011): 447–53.

[5] Mary Jo Gibson, Kathleen Kelly, and Alan K. Kaplan, "Family Caregiving and Transitional Care: A Critical Review, www.caregiver.org; C. Levine and L. Feinberg, "Transitions in Care: Are They Patient- and Family-Centered?" *Generations* (Winter 2012–13), forthcoming.

[6] K. Donelan, C. A. Hill, C. Hoffman, K. Scoles, P. Hollander Feldman, C. Levine, and D. Gould, "Challenged to Care: Information Caregivers in a Changing Health System," *Health Affairs* (2002): 222–31.

[7] John D. Arras, *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care* (Baltimore, MD: Johns Hopkins University Press, 1995).

[8] Levine, C., S. C. Reinhard, L. Feinberg, S. Albert, and A. Hart, *Family Caregivers on the Job: Moving Beyond ADLs and IADLs* (New York, NY: United Hospital Fund of New York, 2004).

Review of this scant literature on home care nursing and family caregiver tasks found no standard list of tasks, and often no discussion of the differences between tasks performed in institutional and home settings or between the performance of the task by a nurse or other professional and a family member. There seems to be an implicit assumption either that the formal health care system provides these medical/nursing services, or that they are so simple that any untrained family member can do them. Neither assumption is true.

Methodology

Survey questions were based on a review of other national family caregiver surveys, literature on caregiver tasks, review of tasks delegated by registered nurses to unlicensed direct care workers,[9] and the authors' experiences interviewing family caregivers and health care professionals. Knowledge Networks (KN), a survey research firm, was engaged to field the survey. KN maintains a large, nationally representative panel of survey respondents randomly recruited through probability-based sampling. Households are provided with access to the Internet and hardware if needed. KN fielded the survey in December 2011.

The initial screening question was, "In the past 12 months, have you provided unpaid care to a relative, partner, or friend age 18 years or older to help them take care of themselves because of a chronic illness or disability?" Family caregivers of people permanently living in nursing homes were excluded. About 18 percent of the respondents answered "Yes" to this question, a response rate slightly lower than, but consistent with, other survey results. A total of 1,677 valid responses made up the full panel.

These respondents were then asked, "Beyond emotional support and companionship, caregiving may include many different types of specific help. Did you help with:

- **Personal care tasks** (such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet);
- **Household tasks** (such as shopping, managing personal finances, arranging for outside services, or providing transportation); or
- **Medical or nursing tasks** (such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks)?"

The first two types of tasks corresponded respectively to the conventional ADL and IADL scales. The third category—medical/nursing tasks—included activities that are clearly in that realm, such as wound care and monitoring of medical equipment. Because of the complexity of medication management and the number of medications, both prescription and over-the-counter (OTC) drugs, that individuals with chronic illnesses take, medication management was included in the medical/nursing category rather than in the IADL category.

For this analysis, survey respondents were divided into two groups: (1) those who did any medical/nursing task in addition to ADL or IADL tasks, or both, which included 777 people; and (2) those who provided only ADL or IADL tasks, as defined in the survey question above, which included 900 people.

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[9] S. C. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Rising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2011.

For all survey questions with fill-in options, written responses were analyzed and assigned to the appropriate response categories whenever possible.

All information in this report comes from family caregiver responses to survey questions. No independent verification of care recipients' chronic conditions or other factors was undertaken.

Table 1
Characteristics of Family Caregivers
(percent)

		All	M/N Tasks	ADL/IADL
		N=1677	N=777	N=900
Gender	Male	42	38	45
	Female	58	62	55
Age	18–34	15	14	16
	35–39	19	19	19
	50–64	40	40	40
	65–79	23	24	22
	80+	3	3	3
	Mean Age	53	54	53
	Median Age	56	57	55
Race	White	73	71	75
	Black	10	12	9
	Hispanic	9	9	9
	Other	7	8	7
Marital Status	Married	67	68	66
	Single	33	32	34
Education	< High school	9	10	8
	High school	30	32	29
	Some college	31	29	32
	BA or higher	30	29	32
Work Status	Working	47	46	49
	Not working	17	18	16
	Retired	27	27	27
	Disabled	9	9	8
Household Income	< $25K	23	23	23
	25–49	25	26	25
	50–74	19	18	20
	75–99	13	13	12
	100–124	9	7	10
	125+	11	12	10

All- Total Caregivers

M/N Tasks- Those Performing Medical/Nursing Tasks

ADL/IADL- Those Performing Only Activities of Daily Living and/or Instrumental Activities of Daily Living

Columns may not sum to 100 percent due to rounding.

Who Are the Family Caregivers?

The general profile of family caregivers in this study is quite similar to those described by other caregiver surveys, such as those by the National Alliance for Caregiving and AARP[10] and the U.S. Bureau of Labor Statistics.[11] Using KN's basic demographic information on survey respondents and responses to additional questions on their caregiving relationships, this study carefully examined these characteristics to see if there were any differences between the family caregivers who performed medical/nursing tasks and those who assisted only with ADL/IADLs, which could affect comparisons between the two groups.

Table 1 summarizes key sociodemographic data for the survey's 1,677 respondents. In addition to displaying the information for the full panel, it compares the 900 caregivers who provided only ADL/IADL tasks with the 777 who provided medical/nursing tasks (almost

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[10] National Alliance for Caregiving and AARP, "Caregiving in the U.S." (Washington, DC, 2009), retrieved from http://assets.aarp.org/rgcenter/il/caregiving_09_fr.pdf.

[11] U.S. Bureau of Labor Statistics, "American Time Use Survey Summary" (last modified June 22, 2012), retrieved from http://www.bls.gov/news.release/atus.nr0.htm.

always in addition to ADL/IADL tasks). In table 1 and subsequent tables, M/N Tasks stands for medical/nursing tasks.

Consistent with other family caregiving surveys,[12] we found that a modest majority of family caregivers (55 percent) were females, although a greater proportion of the caregivers performing medical/nursing tasks were female. There is a broad age distribution, with one-third younger than age 50, 40 percent age 50–64, and more than a quarter age 65 and older. A preponderance of the panel was white (73 percent). Two-thirds were married. Almost half (47 percent) were working, and more than half (61 percent) had attended or graduated from college. Household income distribution was broad, but not skewed toward the high end, with just 20 percent over $100,000.

There were no significant differences in any of these sociodemographic characteristics between the two groups of family caregivers.

Adult children caring for their parents were the largest group of family caregivers (38 percent) (see table 2). Another 27 percent cared for other relatives. A large number (20 percent) were spousal or partner caregivers. Spousal caregivers were almost twice as likely to be doing medical/nursing tasks; 65 percent of spousal caregivers performed medical/nursing tasks compared with 35 percent who performed only ADL/IADL tasks. The relationship of intimacy/family ties holds steady, as significantly smaller proportions of caregivers for other relatives (23 percent) and friends (12 percent) performed medical/nursing tasks.

The length of time that a family caregiver cared for the family member did not appear to differ by the type of caregiving tasks. Close to a third of all family caregivers had spent less than a year in their caregiving role, close to a quarter had spent between one and two years, and an additional quarter had spent more than five years. Survey respondents had somewhat fewer longer-term caregivers than the 2009 survey by the National Alliance for

Table 2

Relationship to Care Recipient and Duration of Caregiving

(percent)

		All	M/N Tasks	ADL/ IADL
Relationship with Care Recipient	Child	38	37	38
	Other relative	27	23	31
	Spouse or partner	20	28	13
	Friend or neighbor	15	12	18
Length Providing Care	< 1 year	32	31	34
	1–2 years	24	24	23
	3–5 years	20	19	20
	> 5 years	24	26	22

Columns may not sum to 100 percent due to rounding.

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[12] A 2009 national survey by the National Alliance for Caregiving and AARP (http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf) found that caregivers are predominantly female (66 percent), 48 years of age on average, with a third (36 percent) taking care of a parent. Data from the 2004 National Long-term Care Survey found that spouses and children continue to be the primary family caregivers and that gender disparities persist (http://assets.aarp.org/rgcenter/ppi/ltc/2010-09-caregiving.pdf). The National Health and Aging Trends Study, the successor to the National Long-term Care Survey, will release its first data in spring 2013.

Caregiving and AARP, which found that 31 percent had spent five years or more.

Who Are the Care Recipients?

Care recipients in this survey looked similar to those in other surveys.[13] The majority (65 percent) of the care recipients were female. The mean age was 71; 88 percent were over age 50, of whom 40 percent were over age 80 (table 3). Almost all (88 percent) had some health insurance. Since this was generally an older adult population, most people had some form of Medicare coverage, and many had additional supplemental coverage. Sixteen percent of family caregivers reported that the care recipient had Medicaid coverage, suggesting that this group was not predominantly low income. There were no notable differences in these sociodemographic characteristics between the group that received medical/nursing services and the group that did not.

Table 3
Characteristics of Care Recipients
(percent)

		All	M/N Tasks	ADL/ IADL
Gender	Male	35	41	30
	Female	65	59	70
Age	18–34	5	5	5
	35–39	7	6	7
	50–64	20	20	19
	65–79	29	31	28
	80+	40	38	41
	Mean Age	71	71	71
	Median Age	75	74	76
Same House	Yes	38	52	26
	No	62	48	74
Health Insurance*	Medicare	58	59	57
	Medicare Advantage	13	14	11
	ESI	23	23	22
	Medicaid	16	15	17
	Direct Pay	15	15	15
	Tricare or CHAMPVA	6	5	6
	NA	2	2	2

*Columns do not sum to 100 percent because respondents could select multiple options.

Differences between the two groups are probably related to spousal caregiving. Care recipients receiving medical/nursing services were far more likely to be men (41 percent of men vs. 30 percent of women). They were also twice as likely to be living with the family caregiver; half (52 percent) of all medical/nursing recipients lived with their family caregiver, compared with one in four (26 percent) receiving ADL/IADL assistance only.

What Are Care Recipients' Health Problems?

As suggested by their frequent use of acute care, care recipients in this survey had multiple health problems (table 4). Almost all family caregivers (85 percent) reported that recipients had chronic physical health conditions such as stroke/hypertension, musculoskeletal conditions (arthritis, osteoporosis), cardiac conditions, and others. Some family caregivers (10 percent) reported "old age" as a problem.

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[13] In the National Alliance for Caregiving and AARP survey (http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf), the typical care recipient was female (62 percent), and 70 percent of the caregivers cared for someone 50 years of age or older.

Table 4
Care Recipient Chronic Conditions
(percent)

		All	M/N Tasks	ADL/ IADL
Physical Health	Stroke, hypertension	38	44	33
	Musculoskeletal (arthritis, osteoporosis, etc.)	38	38	37
	Cardiac disease (heart attack, angina, congestive heart failure, etc.)	25	29	21
	Diabetes	22	25	20
	Cancer	14	15	12
	Lung disease	12	16	9
	Kidney disease	8	9	6
	Movement disorder (Parkinsons, etc.)	4	4	3
	Trauma	3	3	3
	Neurological disorders (ALS, epilepsy, Epstein Barr, etc.)	2	2	2
	Congenital conditions (CP, autism, Downs, etc.)	2	2	2
	Traumatic brain injury	2	2	2
	Gastro-intestinal problems	2	2	2
	Paralysis	2	3	1
	Multiple sclerosis	1	2	1
	Transplant (kindey, liver, stem cell)	1	1	1
	HIV/AIDS	<1	<1	<1
Cognitive	Memory problems, including dementia or Alzheimer’s	30	34	27
Behavioral Health	Depression	22	25	19
	Mental Illness	4	4	4
Sensory	Hearing problems	20	22	18
	Vision problems	20	22	18
No Specific Condition, Just Old Age		10	7	13
Other		<1	3	3

Columns do not sum to 100 percent because respondents could select multiple options.

What Conditions Complicate the Performance of Medical/Nursing Tasks?

The survey also explored the incidence of other conditions that would likely complicate the provision of services by grouping health conditions into four domains: physical health conditions; cognitive conditions such as dementia, memory problems, and Alzheimer’s; sensory impairments such as vision and hearing and behavioral conditions such as depression and mental illness. There was a notable incidence of confounding domain conditions for both groups; close to a quarter had at least one behavioral health condition, and 30 percent had at least one cognitive condition (table 5). For all four domains, care recipients whose family caregivers performed medical/nursing

Table 5
Chronic Conditions by Domain
(percent)

	All	M/N Tasks	ADL/ IADL
Physical Health	85	89	80
Cognitive	30	34	27
Sensory	30	33	27
Behavioral	23	26	20

Care recipients can have more than one condition per domain.

Columns do not sum to 100 percent because respondents could select multiple options.

tasks were more likely than recipients with only ADL/IADL assistance to have health conditions in each domain.

While the presence of any of these confounding conditions can complicate caregiving, the presence of conditions in more than one domain can be especially burdensome for family caregivers. Table 6 displays a "piling on" effect where recipients with physical health conditions have co-occurring conditions across multiple domains. Recipients of medical/nursing services are more likely to present confounding conditions in at least one additional domain; more than half (55 percent) of medical/nursing recipients with physical health condition(s) suffer from at least one condition in a confounding domain, compared with fewer than half (43 percent) of ADL/IADL only recipients .

Table 6
Overlap in Chronic Conditions for Those Who Have Physical Conditions
(percent)

	M/N Tasks	ADL/ IADL
	N=702	N=803
Physical + Cognitive + Behavioral + Sensory	7	4
Physical + two other domains	15	11
Physical + one other domain	33	28
Physical only	45	57

N includes only care recipients with physical health conditions.

Columns may not sum to 100 percent due to rounding.

Care Recipients' Use of Acute Care Services

Consistent with other findings about recipients of long-term services and supports with serious chronic conditions, care recipients in the survey were heavy users of acute care services. According to family caregivers, more than 30 percent of the care recipients used an ambulatory care surgery setting in the past year; 63 percent went to an ED at least once in the past year. More than half (56 percent) had at least one overnight hospital stay (table 7). Care recipients who received medical/nursing services were also more likely to have had two or more

Table 7
Care Recipients' Health Service Use within the Past 12 Months
(percent)

		All	M/N Tasks	ADL/ IADL
		N=1,677	N=777	N=900
Ambulatory Surgery	None	70	66	72
	1	19	21	17
	2	8	8	8
	3+	3	4	3
ED	None	36	31	41
	1	25	25	25
	2	20	22	19
	3+	17	21	14
	No response	1	1	1
Inpatient	None	43	39	47
	1	25	24	26
	2	17	19	14
	3+	15	18	12
	No response	1	1	1

Columns may not sum to 100 percent due to rounding.

overnight hospital stays than those who received only ADL/IADL services (37 percent vs. 26 percent).

Who Coordinates Care?

Most care coordination was performed by family caregivers, care recipients, and/or their family members (table 8), which means that these family caregivers had an additional responsibility on top of their other caregiving activities. Considering that care recipients have a high incidence of multiple chronic conditions and heavy acute care use, care coordination may be challenging for family caregivers. Family caregivers who performed medical/nursing tasks were more than twice as likely to be the primary care coordinator (53 percent) as those who provided only ADL or IADL care (24 percent). Primary care doctors were less likely to be coordinating care for care recipients who received medical/nursing assistance than for those who received only ADL or IADL care (16 percent vs. 29 percent).

Table 8

Care Coordinators

(percent)

	All	M/N Tasks	ADL/ IADL
Caregiver	37	53	24
Care Recipient or Other Family Member of the Caregiver or the Care Recipient	23	16	29
Primary Care Doctor	23	16	29
Specialist Physician	5	5	5
Care Manager (geriatric, or from private insurance or government program)	3	3	4
Physician's Assistant, Nurse, or Assistant in Doctor's Office	3	3	2
Care Recipient + Caregiver/Other Family Member	1	2	1
Other	2	1	3
No Response	2	2	2

Columns may sum to 100 percent due to rounding.

Who Helps at Home—Professionals and Others

To examine additional support provided at home, family caregivers were asked whether health care professionals conducted home visits and whether they had other assistance with their caregiving activities. Most care recipients (69 percent) did not have home visits by health care professionals (table 9). For the 31 percent (521) of care recipients who did have home visits, roughly seven in ten were visited by a nurse (table 10). Medical/nursing care recipients who had home visits by professionals were more likely to have nurse visits than those receiving only

Table 9

Care Recipients with Home Visits by Health Care Professionals

(percent)

	All	M/N Tasks	ADL/ IADL
Received a Home Visit	31	36	26
No Home Visits	69	64	73
No Response	<1	<1	<1

*Columns may not sum to 100 percent due to rounding.

ADL or IADL care (74 percent vs. 66 percent). For the whole panel, about a third of care recipients with home visits had physical therapist visits, and close to 30 percent had visits by social workers. These rates were similar for both of the care groups.

Table 10
Type of Health Care Providers Making Home Visits
(percent)

	All N=521	M/N Tasks N=282	ADL/ IADL N=239
Nurse	70	74	66
Physical Therapist	33	34	31
Licensed Social Worker	28	28	27
Occupation Therapy	14	16	11
Doctor	13	16	11
Respiratory Therapist	6	8	4
Other	2	2	3

*Columns do not sum to 100 percent because respondents could select multiple options.

Table 11
Additional Help at Home
(percent)

	All N=1677	M/N Tasks N=777	ADL/ IADL N=900
Additional Family Member	54	49	58
Home Care Aide	19	23	16
Friend	12	11	13
Other	1	1	1
No Additional Assistance	27	30	25
No Response	20	21	19

*Columns do not sum to 100 percent because respondents could select multiple options.

Family caregivers were also asked whether anyone helped them to provide regular care for the care recipient at home. More than one in four (27 percent) did not have any additional assistance with caregiving (table 11). Of those who reported additional help, the most common source was from another family member; more than half of the entire panel was supported in this fashion, although family caregivers who performed medical/nursing tasks were less likely to have help from another family member (49 percent vs. 58 percent for caregivers performing only ADL or IADL tasks). Overall, about one in five households (19 percent) had a home care aide. Family caregivers performing medical/nursing tasks were more likely (23 percent) to have assistance from a home care aide than those who provided only ADL or IADL assistance (16 percent). This may be related to the former group's more frequent use of acute care services, because Medicare covers postdischarge aide service if a skilled nursing need is also identified. Because family caregivers could indicate more than one source of payment, it is not clear which payers were primary payers.

Looking at these statistics in a broader, more humanistic way, we see a population of mostly middle-aged family members taking care of a group of older relatives with many physical and cognitive problems, with very little help from health care and social service professionals. The care recipients live at home but are frequent users of acute care services, such as hospital EDs and inpatient units. Their care is generally ongoing rather than intermittent, as is the contribution of family members. This is the face of long-term services and supports in the "new normal."[14]

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[14] Feinberg L, Reinhard SC, Houser A and Choula R. "Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving." AARP Public Policy Institute (2011) Washington, D.C.

What Medical/Nursing Tasks Do Family Caregivers Perform?

Nearly half of family caregivers in the panel (46 percent, or 777) performed medical/nursing tasks. Almost all medical/nursing caregivers, more than 96 percent (747), also provided ADL or IADL supports, or both. Notably, of these family caregivers providing medical and nonmedical support, close to two-thirds (501) did all three types of tasks: medical/nursing, ADL, and IADL. Of the nonmedical family caregivers, two-thirds (605) provided only IADL assistance. Figure 1 shows the overlap in types of caregiving tasks and the number of family caregivers in each segment.

Some tasks were more obvious candidates for the medical/nursing category than others. Recent journal articles have included medication management as a medical/nursing task.[15] Wound care and operating medical equipment like feeding tubes are clearly in the medical/nursing realm. Using assistive mobility devices like walkers was included because use of these devices by people with multiple chronic conditions is far more complicated than what is generally considered "help with walking." Likewise, we included preparation of food for special diets, which can include not only meal planning and cooking but also complicated shopping for food that fits the diet, precise measurements, and careful feeding, such as for people with swallowing difficulties.

The survey presented a list of 18 possible medical/nursing tasks, which were condensed into seven categories (figure 2). The most commonly performed medical tasks were medication management (78 percent), help with assistive mobility devices (43 percent), preparing food for special diets (41 percent), and wound care (35 percent).

Which Medical/Nursing Tasks Were Hard to Do?

Family caregivers who performed medical/nursing tasks were asked to choose which two they found "hardest to do" (table 12) and asked further questions about why these tasks were difficult. If caregivers performed only one or two medical/nursing tasks, they were automatically asked the follow-up questions. When these respondents were given the opportunity to comment on whether they found these tasks difficult, the majority affirmed that these tasks were indeed difficult for them, and we have included their responses in table 12. The results were revealing and are consistent with our decision to include some tasks typically considered ADLs, as well as the more obvious clinical tasks, in the medical/nursing category.

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[15] E. R. Giovanetti, J. L. Wolff, Q. L. Xue, C. O. Weiss, B. Leff, C. Boult, T. Hughes, and C. M. Boyd constructed an eight-item health care task difficulty scale for caregivers taking care of older adults, of which difficulties managing medication accounted for four of the eight items ("Difficulty Assisting with Health Care Tasks Among Caregivers of Multimorbid Older Adults," *Journal of General Internal Medicine 2011* 27, no. 1: 37–44). Similarly, in a cohort of cancer caregivers, Van Ryn M, Sanders S, Kahn K, Van Houtven C, Griffin JM, Martin M, Atienza AA, Phelan S, Finstad D and Rowland J. "Objective Burden, Resources, and Other Stressors Among Informal Cancer Caregivers: A Hidden Quality Issue?" *Psycho-Oncology* 20 (2011): (1) 44-52.found that more than half administered medications and decided whether medication was needed, in addition to performing ADL tasks ("Objective burden, resources, and other stressor among informal cancer caregivers: a hidden quality issue," *Psycho-Oncology* 20 (2011) : 44–52.) A study of caregivers in the Cash and Counseling demonstration projects specifically included a list of tasks as "nursing care," including "giving or taking medicine" and "caring for pressure sores and other wounds" (Sara M. Moorman and Cameron Macdonald, "Medically Complex Home Care and Caregiver Strain, *TheGerontologist*, http://gerontologist.oxfordjournals.org/content/early/2012/05/04/geront.gns067.full.pdf).

Figure 1

Distribution of 1,677 Caregivers by Task: Medical/Nursing, ADL, IADL

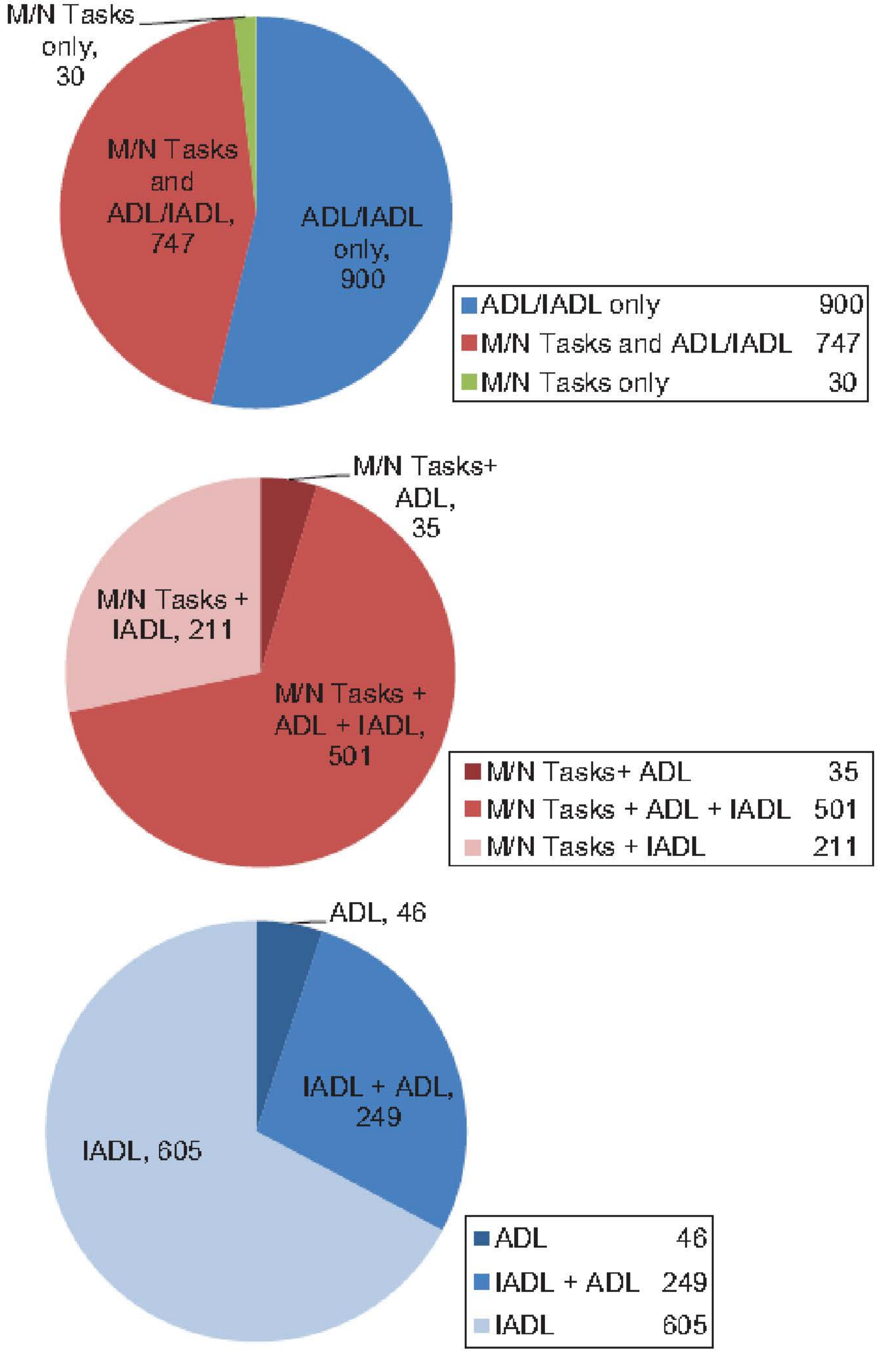
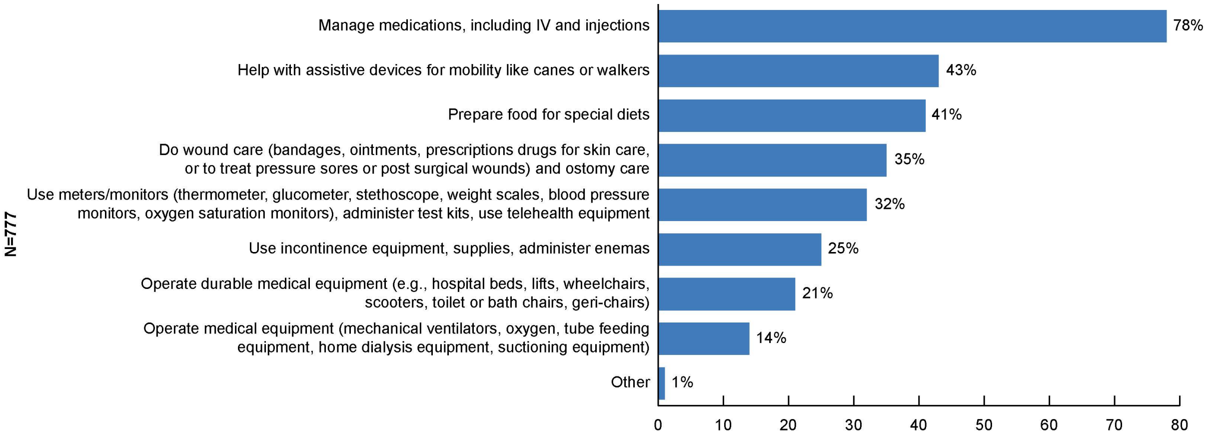


Figure 2

Medical/Nursing Tasks



Columns do not sum to 100 percent because respondents could select multiple options.

Table 12

Difficult Medical/Nursing Tasks

	# Performing Task	# Reported Hard Task	% Reported Hard Task
Use incontinence equipment, supplies, administer enemas	194	130	67
Do wound care (bandages, ointments, prescription drugs for skin care, or to treat pressure sores or post-surgical wounds) and ostomy care	275	181	66
Manage medications, including IV and injections	607	373	61
Prepare food for special diets	319	170	53
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	111	54	49
Help with assistive devices for mobility like canes or walkers	333	129	39
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	275	100	36
Operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)	162	58	36
Other	7	5	71

MacDonald[16] classified “medically complex care tasks” along four dimensions: operation of technological equipment, sophisticated diagnostic skills, exposure to bodily fluids, and substantial risk to care recipients. The results confirm that family caregivers perceived tasks with these characteristics as difficult. Two-thirds of family caregivers engaged in wound care found it difficult, and more than 60 percent who managed medications said that this was emotionally difficult and frightening. Even though the number of family caregivers saying that they operate medical equipment, such as mechanical ventilators and tube feeding systems, was small (14 percent), 49 percent reported it as hard to do. These family caregivers are performing tasks that in the recent past would have been done only in hospitals or nursing homes.

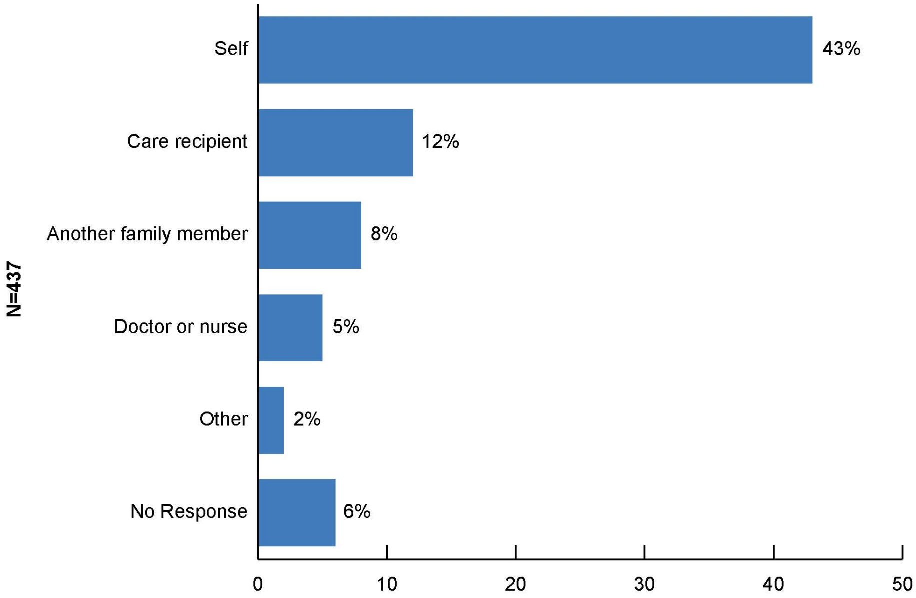
Some tasks that health care professionals might not consider hard are seen differently by family caregivers. For example, two out of three (67 percent) family caregivers reported that managing incontinence, which is different from the ADL of “helping someone go to the toilet,” is hard to do. Managing incontinence involves adult diapers and an intimate level of personal care for someone with whom the family caregiver has a long-standing personal relationship and for whom this task may impinge on familial or societal norms. Similarly, “preparing food for special diets,” as already noted, involves more than making a tuna sandwich for lunch. The degree of difficulty differs by situation and person, but all tasks can be challenging for some family caregivers.

Did Family Caregivers Feel They Had a Choice in Taking on These Tasks?

Family caregivers who did difficult tasks (N = 770) were asked whether they felt they had a choice in taking on these tasks (figure 3) More than half (57 percent) reported that they did not have a choice, but most of this pressure was self-imposed. For

Figure 3

Sources of Pressure for Those Who Reported No Choice in Taking on M/N Tasks



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[16] C. MacDonald, “High-Tech Home Care: Family Caregivers and Consequences.” Plenary Session Meeting of American Sociological Association, Boston, MA, 2008. http://gerontologist.oxfordjournals.org/content/early/2012/05/04/geront.gns067.full.pdf+h

these family caregivers, the most frequently cited reason (43 percent) was feelings of personal responsibility (no one else to do it, insurance would not cover payment for a professional), while 12 percent said that the pressure came from the care recipient, and 8 percent said it came from another family member.

Medication Management: Further Analysis

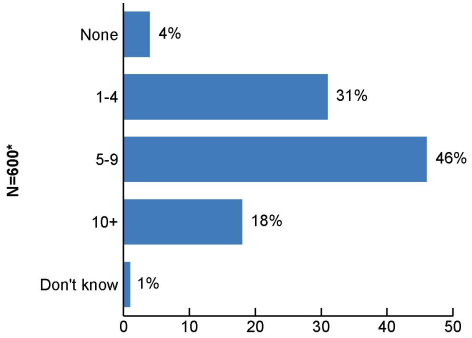
Further analysis focused on two tasks that in today's world most clearly fit into the medical/nursing category: medication management and wound care. These are two of the four tasks most commonly reported by family caregivers in the survey and are clearly in the medical/nursing realm. In addition, large majorities of family caregivers doing medication management and wound care called these tasks difficult. Finally, these tasks merit a closer look because they can require specialized training, and they have been linked to preventable health care spending, such the costs of inpatient admissions due to medication errors and infections.[17] Performing these tasks incorrectly can have adverse impacts on the care recipient's health status and quality of life.

More than three-quarters (78 percent) of medical/nursing family caregivers managed medications, including administering intravenous fluids and injections. Because medication management is such an important element in managing care at home and preventing hospital readmissions, several additional questions were asked about this task.

Most care recipients took several medications: 46 percent took between five and nine different prescription medications; close to one in five (18 percent) took ten or more prescription medications (figure 4). In addition to multiple prescription medications, care recipients also took OTC medications and supplements; more than three-quarters of caregivers reported that the person they cared for took one or more OTC medications or supplements.

Figure 4

Number of Prescription Medications Taken



*Seven respondents did not complete this question.

Columns may not sum to 100 percent due to rounding.

Family caregivers helped with medications in a variety of ways (figure 5). More than 90 percent ordered, picked up, and/or paid for the care recipient's medication. More than 80 percent of family caregivers helped care recipients take oral medications—either by giving pills or other drugs at the right time or by preparing a pillbox for recipients to take the pills independently. Thirty percent of family caregivers performed other forms of medication administration, including injections, inhalers or nebulizers, eye/ear drops, and using an infusion pump.

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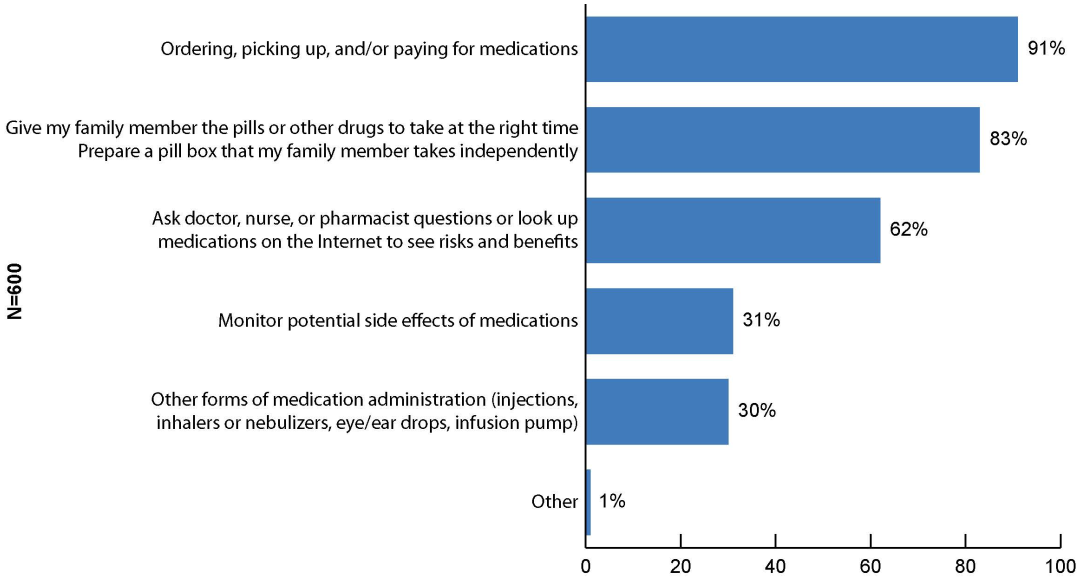
[17] D. C. Classen, L. Jaser, and D. S. Budnitz, "Adverse Drug Events Among Hospitalized Medicare Patients: Epidemiology and National Estimates," *Joint Commission Journal of Quality and Patient Safety* 36, no. 1 (2010): 12–21; G. Piazza, T. N. Nguyen, D. Cios, M. Labreche, B. Hohlfelder, J. Fanikos, K. Fiumara, and S. Z. Goldhaber, "Anticoagulation-Associated Adverse Drug Events," *The American Journal of Medicine* 124 (2011): 1136–42.

Figure 5

How Family Caregivers Help with Medication



*Seven respondents did not complete this question.

Columns do not sum to 100 percent because respondents could select multiple options.

These "medication managers" also gathered information and became familiar with possible adverse effects of the medications. More than 60 percent of family caregivers asked a health care professional (doctor, nurse, or pharmacist) questions about the care recipient's medication or looked up information on the Internet about the medication's risks and benefits. Close to a third of family caregivers (31 percent) actively monitored their care recipient for potential side effects of medication, a task that requires them to have considerable knowledge about the medications.

These "medication managers" also were responsible for a significant number of other caregiving tasks. Fully four in five (81 percent) provided at least one additional medical/ nursing service, and almost all (97 percent) also provided ADL or IADL supports, or all three to their care recipients.

Why Was Medication Management Hard to Do?

Medication management is often a difficult and time-consuming task. Family caregivers who considered it hard to do (N = 373) most frequently cited the time and inconvenience required (42 percent) (table 13). More than half of family caregivers (56 percent) who cited medication management as hard reported that they engaged in this activity at least once a day, if not several times a day or night. Other notable reasons were fear of making a mistake and causing harm (29 percent), which may be related to the number of medications being taken or the different ways in which they had to be administered (e.g., with food or on an empty stomach). Close to 60 percent of family caregivers (223) who identified medication management as hard reported that their care recipient took five or more medications. Lack of cooperation by care recipients (24 percent) was another common reason, and a repeated refrain in the comments. Many care recipients refused to take their medications as prescribed, or at all, adding to the family caregivers' stress and frustration.

Some family caregivers who completed this section of the survey describing the difficulties of performing the selected tasks nevertheless commented that "this is my mother," or "we have been married 51 years," as if simply stating that this relationship superseded the difficulties. It is an important reminder of the reason family caregivers take on this role.

Table 13
Reasons Why Medication Management Was Hard

N=373	#	%
Takes Time and/or Is Inconvenient	157	42
Afraid of Making Mistake and/or Causing Harm	110	29
My Family Member Resists or Has Cognitive or Behavioral Problems	89	24
Emotionally Difficult for Caregiver	59	16
Other	10	3
I Don't Understand What to Do	7	2
Involves Lifting or Other Physical Effort	6	2
No Response	49	13

Columns do not sum to 100 percent because respondents could select multiple options.

The survey asked about difficulties in medication management in different ways, and with different results. When all family caregivers who responded that they managed medication were asked early in the survey whether they "understood" the reason medications were prescribed, why they should be taken at specific times, and whom to call with questions, 95 percent said that they understood these factors. Almost as many (93 percent) said that they understood what adverse reaction symptoms to look for in their care recipient. Only 3 percent said they had made a medication error that resulted in a hospitalization. These findings differ from those of other surveys and anecdotal reports, in which medication mishaps are a leading cause of rehospitalization.[18]

Despite their high reported confidence in managing medications, 61 percent of the family caregivers considered it a hard task. (As noted earlier, some may have responded in this way because they only performed one or two types of task, although most confirmed that it was difficult.) There are several possible reasons for this discrepancy. The family caregivers in the survey were not in the midst of a transition or crisis; they may have learned how to manage medications, although they still find it hard. They may distinguish between "understanding" what the medication regimen should be and what to look out for, and actually fitting it into a busy schedule, especially when the care recipient is uncooperative. Or it may simply be that these family caregivers, when asked a general question about "understanding," gave what they considered to be the responsible answer.

Who Trains Family Caregivers to Manage Medications?

Given the multiple chronic health conditions of care recipients and their frequent use of acute care services, it is notable that the majority of these family caregivers (more than 60 percent) learned at least some part of how to manage on their own, and close to half (47 percent, 176) said they have never received training from any source (figure 6).

The fact that some family caregivers who responded that they learned on their own also reported that they received training from other sources may indicate that their formal

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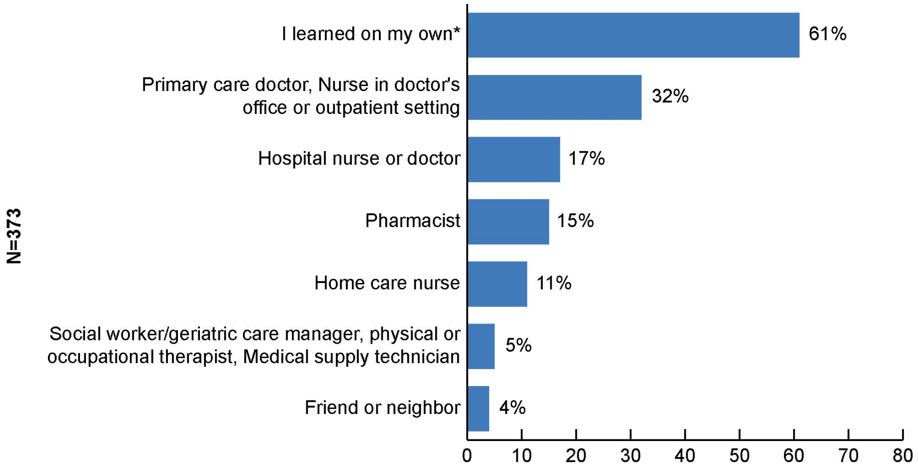
[18] Institute of Medicine- Committee on Identifying and Preventing Medication Errors. *Preventing Medication Errors: Quality Chasm Series*. Washington, DC: The National Academies Press, 2007.

A. J. Forster, H. J. Murff, F. Peterson, T. K. Gandhi, and D. W. Bates, "The Incidence and Severity of Adverse Events Among Medical Patients After Discharge from the Hospital," *Annals of Internal Medicine* 138 (2003): 317–23.

Figure 6

Sources of Training for Medication Management



*Some people who selected "I learned on my own" also selected other sources of training.

Columns do not sum to 100 percent because respondents could select multiple options.

training was inadequate. While more than half (58 percent, 213) of medical/nursing caregivers who found medication management difficult reported that their care recipient was hospitalized overnight at least once in the past 12 months, only one in five of those caregivers (21 percent, 45) received training from hospital staff. Similarly, about one in five (22 percent) of medical/nursing caregivers who identified medication management as hard had a home care aide helping them to provide care. Yet fewer than a third of these family caregivers (30 percent) received training from a home care nurse.

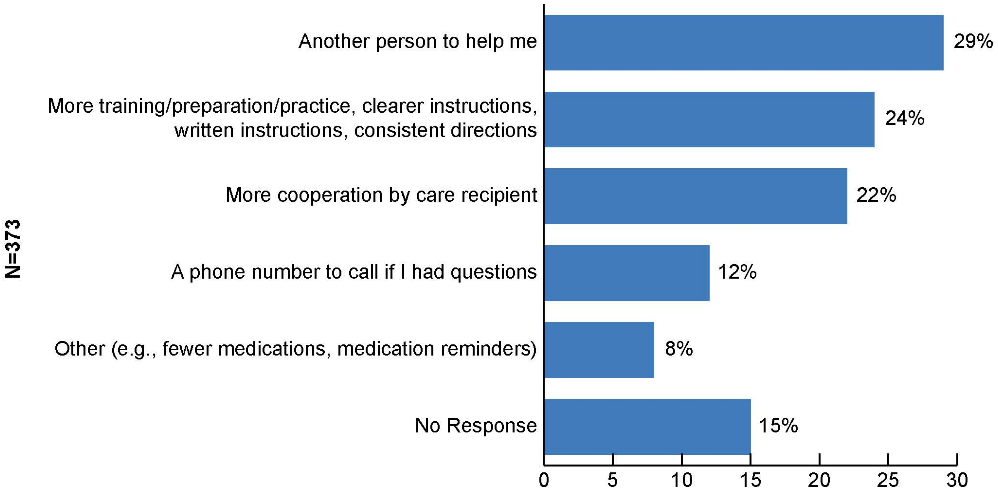
If family caregivers received training from a health care professional—a doctor or nurse—it was most likely in an outpatient community setting. Family caregivers who learned on their own, but who also had some outside training, received it from an outpatient provider. Since most care recipients in the study were taking five or more medications, it is striking that pharmacists are not a more common resource; only 15 percent report receiving training from a pharmacist.

Looking at a group of family caregivers with significant medication responsibilities—multiple medications, often resistant care recipients, likelihood of hospitalizations, and spotty training from the formal care system—it is notable that only a quarter (24 percent) thought that more training and preparation would ease their burden (figure 7). Two other possible responses—having another person or family member help with medication management and better cooperation by the care recipient—received roughly comparable positive answers (29 percent and 22 percent, respectively). No response was considered helpful by a large percentage of family caregivers.

Many of the written comments suggest that it would help if the care recipient took fewer medications. This may seem like a facetious comment, but it is well known that older people are often overprescribed medications, in addition to the OTC substances that they take on their own. In these personal responses, family caregivers have identified a more general problem in geriatric care.

Figure 7

Making Medication Management Easier



Columns do not sum to 100 percent because respondents could select multiple options.

One in four responded that more training would help. This relatively low response may reflect family caregivers' dissatisfaction with the training that they did receive, either in the hospital or in the community, as indicated in their responses to "I learned on my own" and "I received some training." Better training might well be a source of support. When staff in hospitals, nursing homes, and home care agencies participating in the United Hospital Fund's TC-QuIC were surveyed about their own performance in communicating with and training family caregivers, they were generally quite positive. By contrast, family caregivers who had recently been through a discharge in these settings had very negative responses about the same items. Clearly, the training that is being provided—usually hastily and at the last minute—is not satisfying family caregivers' needs.

Overall, family caregivers' primary complaints regarding medication management pertained to the time-consuming and complex nature of simultaneously administering several prescription medications to a vulnerable person.

Wound Care: Further Analysis

The analysis of wound care performed by family caregivers illustrates how different medical/nursing caregiving tasks present discrete challenges for caregivers. When family caregivers perform multiple tasks simultaneously, they face numerous stresses that may amplify each other.

Like medication management, wound care is a diverse set of tasks that includes preparation and application of bandages, ointments, and prescription drugs for skin care, or treating pressure sores or postsurgical wounds, including colostomy (after removal of part of the colon) and urostomy (after removal of the bladder) care. Family caregivers almost always performed other medical/nursing tasks in addition to wound care; 92 percent of family caregivers engaged in wound care were responsible for additional medical/nursing tasks. As with medication management, almost all family caregivers who found wound care to be hard (96 percent) also provided ADL or IADL supports, or all three.

While fewer family caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as hard (table 14). Wound care is so specialized that in hospitals and home care agencies it is often assigned to a wound care nurse.

Table 14
Reasons Why Wound Care Was Hard

N=181	#	%
Afraid of Making Mistake and/or Causing Harm	84	47
Takes Time and/or Is Inconvenient	60	34
Emotionally Difficult for Caregiver	59	33
My Family Member Resists or has Cognitive or Behavioral Problems	25	14
Involves Lifting or Other Physical Effort	21	12
Other	15	8
I Don't Understand What to Do	3	2
No Response	16	9

Columns do not sum to 100 percent because respondents could select multiple options.

For these family caregivers (N = 181), close to half (47 percent) felt that wound care was challenging because they were afraid of making a mistake and harming their family member. While the time and inconvenience associated with wound care were also top reasons, a third of these family caregivers cited emotional difficulties on their part, twice the rate that said this about medication management. Comments provided by family caregivers cited the "ick" factor of dealing with wounds. These results are in keeping with the fact that wound care requires more intimate physical contact and personal risk than many medication management activities.

Table 15
Frequency of Wound Care

N=181	#	%
Several Times a Day or Night	12	7
Daily	49	27
Frequently	42	23
Occasionally	74	41
No Response	2	1

Columns may not sum to 100 percent due to rounding.

Wound care was performed less frequently than medication management, although a significant share of family caregivers reported engaging in wound care daily (table 15). Two-thirds (64 percent) of family caregivers who said wound care was challenging performed the activity less than once each day; roughly one-third (27 percent) completed wound care activities daily or more frequently.

Who Trains Family Caregivers to Do Wound Care?

Given the intimate physical nature of wound care and the fact that many family caregivers may not be familiar with the skills required to perform this task, wound care is a medical/nursing task that requires training. Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management (table 16). More than a third (36 percent) were trained by a hospital nurse or physician, and a quarter received training from a home care nurse. Roughly a quarter learned from an outpatient health provider. As with medication management, many family caregivers (42 percent) taught themselves how to care for wounds, although about half of these family caregivers also received training from other sources (47 percent).

What Would Make Wound Care Easier?

A larger share of family caregivers (37 percent vs. 24 percent for medication management) thought that having more training could ease their burden with wound care (table 17). Similar to medication management, family caregivers experiencing difficulty with wound care reported that having another person or family member to help would make the task easier, as would better cooperation by the care recipient. Notably, family caregivers felt more strongly that assistance with wound care would be beneficial; larger shares of caregivers said that something could be done to make wound care easier than said so with regard to medication management.

Table 16
Sources of Training for Wound Care

N=181	#	%
I Learned on My Own*	76	42
Hospital Nurse or Doctor	64	36
Home Care Nurse	45	25
Primary Care Doctor, Nurse in Doctor's Office or Outpatient Setting	41	23
Friend or Neighbor	11	6
Social Worker/Geriatric Care Manager, Physical or Occupational Therapist, Medical Supply Technician	8	4
No Response	3	2

*Some people who selected "I learned on my own" also selected other sources of training.

Columns do not sum to 100 percent because respondents could select multiple options.

Table 17
Responses to Making Wound Care Easier

N=181	#	%
More Training/Preparation/Practice, Clearer Instructions, Written Instructions, Consistent Directions	66	37
Another Person to Help Me	62	35
More Cooperation by Care Recipient	34	19
Other	20	11
A Phone Number to Call if I Had Questions	20	11
No Response	21	12

Columns do not sum to 100 percent because respondents could select multiple options.

What Is the Effect on Quality of Life for Family Caregivers Who Perform Medical/Nursing Tasks?

Recognizing the complexity of the medical/nursing tasks they are performing, we sought to explore the effect of performing these medical/nursing tasks on family caregivers' quality of life. The analysis considered the effects of caregiving on the family caregiver's physical and mental health, as well as other possible effects. These potential effects were drawn from the broad caregiving literature and the expertise of the research team.

To the question "How has doing these medical/nursing tasks affected your own quality of life?" family caregivers responded in several ways, as summarized in table 18.

In terms of positive response, almost half (44 percent) indicated that providing this care eased their worries about their family member's condition. The same was true for feeling closer to the person (44 percent). Some family caregivers (24 percent) felt they had gained new skills they could apply in other areas of their life, and more than half (57 percent) felt they were making an important contribution.

With regard to negative effects, 14 percent said that performing these tasks had affected their employment, for example, by making it necessary for them to take time off from work. Almost one in four (23 percent) felt that these responsibilities added stress because they had to talk to so many professionals and suppliers. This source of stress is seldom recognized. And almost one in five (19 percent) worried about making a mistake. Nearly one-third (32 percent) felt that performing these tasks made them feel they had to be constantly watching out for something to go wrong.

Table 18

Positive and Negative Effects on Quality of Life for Family Caregivers Who Perform Medical/Nursing Tasks

N=777		#	%
Positive Effects	Eased/less worry	342	44
	Feeling closer	344	44
	Gaining new skills	190	24
	Making important contribution	440	57
Negative Effects	Employment/taking time off	110	14
	Dealing with many suppliers/professionals	179	23
	Making a mistake	146	19
	Constantly watching for something to go wrong	245	32
Physical and Mental Health	Fair or poor physical health	245	32
	Feeling down depressed or hopeless	349	40

Columns do not sum to 100 percent because respondents could select multiple options.

In terms of health status, nearly a third of family caregivers (32 percent) reported fair or poor physical health. Perhaps most concerning, 40 percent of the caregivers performing medical/nursing tasks reported feeling down, depressed, or hopeless in the last two weeks. While it is not possible to link these findings directly to caregiving, they suggest that family caregivers performing medical/nursing tasks are a vulnerable group at risk for serious physical and mental health consequences.

Tables 18, 19, and 20 summarize significant relationships between these effects on family caregivers' quality of life and three important aspects of their experience: the number of medical/nursing tasks performed, the number of chronic conditions the care recipient has, and whether the family caregiver received training from anyone other than a neighbor or friend. Training included any training other than that provided by a neighbor or a friend.

Table 19

Relationship between Number of Medical/Nursing Tasks Performed and Effects on Quality of Life for Family Caregivers

Effects		Number of Tasks 1–2 (N=366)	3–4 (N=237)	5+ (N=172)
Positive	Less worry	43%	46%	42%
	Feeling closer*	40%	46%	51%
	Gaining new skills**	20%	25%	34%
	Making important contribution**	48%	65%	65%
Negative	Employment**	9%	14%	26%
	Stress of talking to many**	16%	22%	40%
	Worry about making mistakes**	12%	17%	36%
	Constantly watching**	21%	34%	51%
Physical and Mental Health	Fair/poor health	31%	30%	35%
	Depressed in last 2 weeks**	33%	42%	51%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

First, the more medical/nursing tasks the family caregiver performed, the greater the effects in all areas, except for reports of less worrying and poor physical health (table 19). Family caregivers who performed five or more medical/nursing tasks were more likely to feel closer to the person they were helping. They were also more likely to feel they were gaining skills and making an important contribution. On the other hand, the more tasks family caregivers were responsible for performing, the more negative the responses. Those who performed five or more tasks were more likely to report depression (51 percent) than those who performed one or two tasks (33 percent). The same was true for feeling the need to constantly watch out for something to go wrong (51 percent vs. 21 percent), feeling stressed about talking to many professionals (40 percent vs. 16 percent), and worrying about making a mistake (36 percent vs. 12 percent). These family caregivers appear to value the role they have taken on to provide such substantial medical/nursing care, but they experience high stress and depression

Second, the more chronic conditions the care recipient had, the greater the negative effects on quality of life for family caregivers in all areas, particularly physical and mental health (table 20). More than half (54 percent) of family caregivers providing medical/nursing tasks for family members with five or more chronic conditions reported depression, and 44 percent reported fair/poor health. Although there is a relationship between chronic conditions and feeling closer to the family member, family caregivers of people with five or more chronic conditions reported the least close relationship.

Finally, family caregivers who had reported they had received training[19] were also more likely to feel that they were gaining new skills and making an important contribution than those who reported no training (table 21). Those receiving training

Table 20

Relationship between Number of Chronic Conditions and Quality of Life for the Family Caregiver

Effects		**0**	**Number of Chronic Conditions**		
		(N=80)	1 (N=151)	2–4 (N=367)	5+ (N=179)
Positive	Less worry	46%	45%	43%	44%
	Feeling closer*	43%	54%	44%	39%
	Gaining new skills	24%	26%	24%	25%
	Making important contribution	43%	58%	59%	58%
Negative	Employment**	8%	11%	13%	23%
	Stress of talking to many**	9%	13%	23%	37%
	Worry about making mistakes**	10%	13%	20%	25%
	Constantly watching**	18%	21%	32%	45%
Physical and Mental Health	Fair/poor health**	27%	28%	28%	44%
	Depressed in last 2 weeks**	33%	29%	39%	54%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

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[19] For the purpose of this report, "training" is defined as receiving training from a professional (e.g., doctor, nurse, technician, social worker) for either of the two most difficult tasks performed by the caregiver. It is possible that some caregivers performing multiple medical/nursing tasks classified as "not having training" received some training for tasks other than the two most difficult.

Table 21

Relationship between Training and Quality of Life for the Family Caregiver

Effects		Training	
		No (N=320)	Yes (N=457)
Positive	Less worry	42%	45%
	Feeling closer	41%	47%
	Gaining new skills**	16%	30%
	Making important contribution*	52%	60%
Negative	Employment	12%	16%
	Stress of talking to many**	18%	27%
	Worry about making mistakes*	15%	21%
	Constantly watching*	27%	35%
Physical and Mental Health	Fair/poor health	35%	30%
	Depressed in last 2 weeks	40%	40%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

were also more likely to report negative consequences—feeling stressed about talking to many professionals, worrying about making a mistake, and constantly watching out for something to go wrong. It is unlikely that these were a consequence of training; the results may suggest that caregivers seek out training in response to these impacts.

What Is the Effect on the Care Recipient of Family Caregiver Help with Medical/Nursing Tasks?

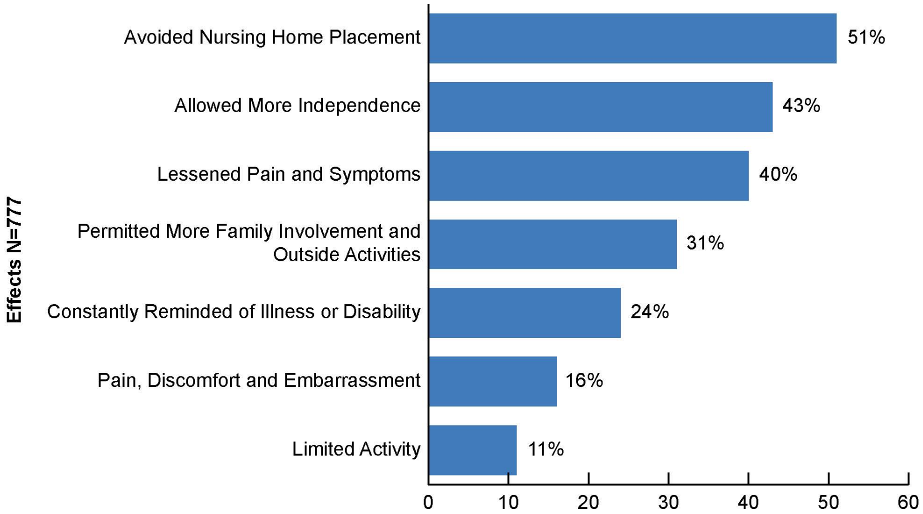
Family caregivers who provided help with medical/nursing tasks experienced significant consequences, but what about the consequences for the care recipients? To explore this question, family caregivers who provided medical/nursing tasks were asked, "How have these medical/nursing tasks affected your family member's quality of life?" Several potential responses were offered, again based on the literature and research team's expertise: Lessened pain and symptoms; permitted more involvement in family and outside activities; allowed more independence; allowed him/her to avoid nursing home placement; limited activity because of medication side effects or treatment schedule; been a constant reminder of illness or disability; and involved pain, discomfort, and embarrassment.

Figure 8 reports overall findings on care recipient effects. Most notable are family caregiver reports that the help they provided with medical/nursing tasks lessened their family member's pain and symptoms (40 percent), allowed more independence (43 percent), and avoided nursing home placement (51 percent).

Tables 22–24 summarize significant relationships between several effects on care recipients' quality of life and three factors: the number of medical/nursing tasks the family caregiver performed, the number of chronic conditions the care recipient had, and whether or not the family caregiver received training from anyone other than a neighbor or friend.

Several significant relationships are observed. For example, helping care recipients with up to four tasks allowed that family member more independence, but helping with five or more tasks is significantly related to less independence. The same pattern is shown

Figure 8
Family Caregiver Help with Medical/Nursing Tasks and Effect on Care Recipients' Quality of Life



in the relationship between help with tasks and care recipients' limited activity. Most likely, once people reach the level of need for help with five or more specialized tasks, they are more dependent for help in ADLs. There are significant relationships between the number of medical/nursing tasks the family caregiver performed and reports that the care recipient had more pain, discomfort, and embarrassment. And having the family caregiver perform many tasks was likely to constantly remind the care recipient of his/her illness or disability.

The most important finding, which has direct implications for both family caregivers and public policy, is that the more tasks family caregivers performed, the more likely they were to report that these efforts allowed the care recipient to avoid nursing home

Table 22
Relationship between the Number of Tasks Family Caregivers Performed and Care Recipient's Quality of Life

Effect on Family Member	Number of Tasks 1–2 (N=366)	3–4 (N=237)	5+ (N=172)
Lessened Pain	37%	41%	43%
More Involvement in Family	28%	34%	31%
More Independence*	45%	48%	34%
Avoid Nursing Home**	35%	59%	73%
Limited Activity**	7%	12%	16%
Constant Reminder**	17%	24%	40%
Pain, Discomfort, Embarrassment**	10%	16%	30%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

placement. Three out of four family caregivers who provided assistance with five or more medical/nursing tasks reported that they were helping their family member avoid institutionalization. The same was true for family caregivers who were caring for people with five or more chronic conditions (table 23). Two out of three caregivers who helped with medical/nursing tasks for family members with five or more chronic conditions reported that this support helped avoid nursing home placement.

Table 23

Relationship between the Number of Chronic Conditions and Effect on Care Recipients' Quality of Life

	Number of Chronic Conditions			
Effect on Family Member	0 (N=80)	1 (N=151)	2–4 (N=367)	5+ (N+179)
Lessened Pain	40%	37%	37%	47%
More Involvement in Family	26%	25%	32%	37%
More Independence	45%	36%	47%	40%
Avoid Nursing Home**	24%	36%	56%	66%
Limited Activity	9%	9%	11%	12%
Constant Reminder*	13%	25%	24%	30%
Pain, Discomfort, Embarrassment	13%	13%	17%	17%

Columns do not sum to 100 percent because respondents could select multiple options.

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

Finally, table 24 summarizes the relationship between whether the family caregiver received training and several consequences for the care recipient. Family caregivers who provided medical/nursing tasks and had some training were more likely to say they were able to help their family member avoid nursing home placement.

Table 24

Relationship between the Family Caregiver's Training and Effects on the Care Recipient

	Training	
Effect on Family Member	No (N=390)	Yes (N=387)
Lessened Pain	38%	41%
More Involvement in Family	29%	33%
More Independence	42%	44%
Avoid Nursing Home*	47%	55%
Limited Activity*	8%	13%
Constant Reminder	24%	25%
Pain, Discomfort, Embarrassment	17%	16%

Columns do not sum to 100 percent because respondents could select multiple options.

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

CONCLUSION AND RECOMMENDATIONS

This report describes the hidden world of family caregivers who perform medical/nursing tasks, such as medication management and wound care for adults with multiple chronic conditions. Almost half of family caregivers take on these tasks, in addition to doing personal care and household management. The report reveals the complexity and difficulty of specific tasks, the lack of support and training family caregivers receive, and the effects on their quality of life.

In a fragmented health care system, it is often difficult to pinpoint individual or institutional responsibility for action. As a result, people with chronic conditions and their family caregivers too often move from the care of one professional to another or from one care setting to another without a clear sense of who is in charge. All too often, no one is in charge. Expecting family caregivers to perform the medical/nursing tasks described in this report without substantial professional involvement is unrealistic and unacceptable. There are all sorts of explanations for this situation but no justification. A health care system that relies on untrained and unpaid family members to perform skilled medical/nursing tasks, but does not train and support them, has lost sight of its primary mission of providing humane and compassionate care to sick people and their families.

The report findings highlight an urgent need for both individual and collective action. No single profession or health care provider is solely responsible for ensuring that family caregivers who take on these daunting responsibilities are trained and supported. This effort requires the coordinated efforts of all sectors—hospitals, home care agencies, community agencies, nursing homes, hospices, and physician and other clinician practices—and a level of teamwork that challenges attitudes and behaviors so firmly entrenched in the current system. Yet collective action will not be effective without individual commitment.

Based on the findings in this report, we offer 10 recommendations for action.

1. A consensus-building body should revisit ADL and IADL measures.

As this report has shown, the ADL and IADL measures developed and commonly used for a half-century no longer capture what family caregivers do as they provide a range of services and supports to people with chronic illness and disabilities.[20] As a result, family caregiving is typically mismeasured and misunderstood by health care professionals and policymakers as a fairly simple, easily learned set of responsibilities.

In order to identify, assess, and support family caregivers, we need to know who they are, what they are doing (or are expected to do), and what training and support they need. Therefore, we recommend a full review of existing measures, and the construction of a new measure that encompasses the kinds of tasks described in this report. The review should also look at the existing ADL and IADL measures in terms of their complexity, timing, and duration. The first challenge will be to arrive at a consensus about terminology. As we have noted, different researchers have used different terms to describe the same set of tasks. The terms should be clear to all (including family caregivers), appropriate for both research and practice settings, and useful in following trends.

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[20] S. C. Reinhard, "The Work of Caregiving: What Do ADLs and IADLs Tell Us?" in *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*, 181–83 (New York, NY: United Hospital Fund of New York, 2004).

Who should be responsible for this review? Although several existing bodies might take on the responsibility, we suggest that the Institute of Medicine (IOM) is particularly well suited to this kind of consensus-building effort. The IOM has already issued two reports that touch on family caregiving: Its report *Retooling for an Aging America: Building the Health Care Workforce*[21] included family caregivers as part of the workforce but did not provide in-depth discussion of what practices and policies are needed to support them. In 2010 the National Research Council of the National Academy of Sciences, the parent organization to the IOM, published a Workshop Summary on *The Role of Human Factors in Home Health Care*.[22] While this report focused on professional roles, its descriptions of the home care environment and the kinds of equipment and tasks mirror those family caregivers in our report performed

2. **Individual health care professionals must fundamentally rethink and restructure the way they interact with family caregivers in daily practice.**

Every health care clinician and social service professional must feel personally responsible for ensuring that the patients and families in their care understand how to perform the challenging tasks outlined in this report, as well as others not mentioned. Physicians, nurses, social workers, pharmacists, rehabilitation therapists, and others must encourage family caregivers to ask questions, and give them information for additional help. Professionals must embrace this responsibility and institute protocols to ensure that it is met. This responsibility can be shared with other professionals through teamwork and through collaboration with other health care and social service agencies, but there must be a clear system of accountability. One compelling demand for this kind of teamwork is addressing the numbers of medications prescribed and the complexity of the medication routine. Concerted efforts can reduce the likelihood of serious adverse reactions and costly hospitalizations, as well as ease the workload for family caregivers.

3. **Health care provider organizations (hospitals, rehabilitation centers, home care agencies, nursing homes, and hospices) must support health care professionals in their efforts through adequate resources and strong leadership.**

Individual health care professionals and interprofessional teams cannot do this work alone. They need support and resources from their provider organizations across all settings. This is not just an issue for acute care hospitals or for family caregivers coping with a transition from one setting to another, although these are sentinel events that demand sustained attention. Chronic care is by its nature long term, and the training and supports for family caregivers must be of similar duration. The need does not end with discharge from any formal service, but extends to the community, where health care clinicians and social service professionals will need to address the challenge of assessment, instruction, and support, which must become integral to routine practice. And payers must recognize the need for this crucial support of family caregivers by providing financial incentives to help make it happen.

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[21] Institute of Medicine, *Retooling for an Aging America: Building the Health Care Workforce: Consensus Report* (Washington, DC: National Academies Press, 2008).

[22] National Research Council of the National Academy of Sciences, *The Role of Human Factors in Home Health Care* (Washington, DC: National Academies Press, 2010).

4. Professional organizations should lead and support professionals in their efforts to improve communication and training for family caregivers.

Some organizations have already begun this process, but much more needs to be done. Supported by The John A. Hartford Foundation and the Jacob and Valeria Langeloth Foundation, a broad panel of experts has identified the urgent need for health care professionals to better support family caregivers through evidenced-based information and tailored support.[23] In response, the National Association of Social Workers created the first *Standards for Social Work Practice with Family Caregivers of Older Adults*.[24] To reach practicing nurses, the New York University/Hartford Institute for Geriatric Nursing is leading a pilot with nurses in five hospitals to incorporate better communication, support, practical tools, and training for family caregivers. The goal is to expand this work with more than 300 hospitals nationwide that participate in NICHE (Nurses Improving Care of HealthSystem Elders).[25] A group of physician organizations (American College of Physicians, Society of General Internal Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society of Academic Emergency Physicians) issued a transitions of care consensus policy statement that suggested specific elements that include family caregivers.[26] These organizations should follow up with their membership to see how well their recommendations are being implemented.

5. Leaders in medical, nursing, social work, and allied health professional training and continuing education should examine their curricula to determine where and how the importance of family caregivers and their ongoing needs for training and support can be added or strengthened.

Recognizing the need to train and support is an essential first step in education. But training is too often provided on the professional's schedule, not the family caregiver's, and in a manner that does not meet the family caregiver's learning style or health care knowledge. Professionals often forget that family caregivers are learning to do something that is difficult, embarrassing, or painful for the care recipient, with whom they have a long-standing, intimate relationship. Evidence on the best methods for training should be reviewed for applicability to family caregivers, and new approaches should be developed that blend technical and communication skills training. Good training is not a hurried demonstration on the day of discharge or a reassuring comment that "I explained everything to your mother." Training must be repeated and reinforced to be responsive to changes in the patient's condition or the family caregiver's own needs and capabilities.

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[23] S. C. Reinhard, A. Brooks-Danso, and K. Kelly, "State of the Science: Professional Partners Supporting Family Caregivers," *American Journal of Nursing* 108 (2008): 9.

[24] National Association of Social Workers, "NASW Standards for Social Work Practice with Family Caregivers of Older Adults" (Washington, DC, 2010), Retrieved from http://www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf.

[25] E. Capezuti, M. Boltz, D. Cline, V. Vaughn Dickenson, M. Rosenberg, L. Wagner, J. Shulk, and C. Nigolian, "Nurses Improving Care for Healthsystem Elders—A Model for Optimizing the Geriatric Nursing Practice Environment," *Journal of Clinical Nursing* (2012).

[26] V. Snow, D. Beck, T. Budnitz, D. Miller, J. Potter, R. Wears, K. Weiss, and M. Williams, "Transitions of Care Consensus Policy Statement American College of Physicians-Society of General Internal Medicine-Society of Hospital Medicine-American Geriatrics Society- American College of Emergency Physicians-Society of Academic Emergency Medicine," *US National Library of Medicine, National Institutes of Health* 24, no. 8 (2009): 971–76.

Hospital residency training is a particularly important area for enhanced attention. A recent study found that there is no formal curriculum or organized teaching about how to develop competency to perform a high-quality discharge. Resident physicians said that they learned by default, leading to substantial variation.[27] The Accreditation Council for Graduate Medical Education should review its training requirements to include discharge planning that assists family caregivers. The new Medicare Graduate Nurse Education Demonstration pilot that will for the first time invest $200 million in Medicare funding to train more advanced practice registered nurses should mandate a strong focus on interventions to support family caregivers.

6. **Accrediting and standard-setting organizations must take seriously their evaluation of how well institutions incorporate family caregiver needs and require corrective steps to address deficiencies.**

The Joint Commission has many criteria for assessing patient and family participation in decision making and other important aspects of quality care. But these criteria are not generally given high priority in ratings, and many institutions see them as ideals, not standards on which they will be judged. The Joint Commission should ensure that surveyors are trained to assess family caregiver training and support. In setting standards for the delivery of high-quality health care, the National Quality Forum could specifically address the need to define and promote standards that include the role of family caregivers to follow up on its goal statement: "Healthcare should guide patients and families through their healthcare experience, while respecting patient choice, offering physical and psychological supports, and encouraging strong relationships among patients and the healthcare professionals accountable for their care…." Broad statements like these need to be followed by specific measures and tools.

7. **Federal policymakers should proactively consider family caregivers in developing new models of care that focus on coordination and quality improvement.**

As the United States aggressively develops new financing and care delivery models focusing on the integration and coordination of care—such as patient-centered medical homes, bundled payments, accountable care organizations, and managed care programs for people dually eligible for Medicare and Medicaid—it is essential to recognize that for many chronically ill people, *family caregivers are the primary care coordinators*. They cannot be expected to do more, and to play an integral role in these new models, with too little training and support. Without creatively addressing these needs, new systems of care and financing run serious risk of failure.

Now is a time ripe with opportunity. Overwhelming concerns with costs and quality of care—shared across the political spectrum—point directly to family caregivers, especially those taking on medical/nursing tasks. The federal Center for Medicare & Medicaid Innovation has the funding and visibility to stimulate new ways to assess and address the needs of family caregivers, who must be critical partners with health care professionals and provider organizations. Including family caregivers explicitly in federal requirements for funding new models of care is an essential first step. Proposals

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[27] S. R. Greyson, D. Schilla, L. Curry, E. H. Bradley, and L. I. Horwitz, "Learning by Doing: Resident Perspectives on Developing Competency in High-Quality Discharge Care," *Journal of General Internal Medicine* 27, no. 9 (2012): 1188–94.

for funding for Community Care Transitions Programs and programs for dually eligible beneficiaries are two immediate targets. Innovator organizations will need technical and financial assistance because very few existing organizations have developed adequate capacity to identify family caregivers, assess their needs, and provide training and support.

8. State policymakers should proactively consider family caregivers in funding and policy development.

The federal government leads and sets standards, but state governments set local policies and fund long-term services and supports. These efforts should incorporate family caregiver assessments in publicly funded programs,[28] including the new demonstrations for people who are eligible for both Medicare and Medicaid. States should also ensure that their state nurse practice acts and regulations permit registered nurses to delegate medical/nursing care tasks to direct care workers who demonstrate competence to perform these tasks for specific individuals in their homes. Whether paid to provide care to individuals through public funds or private payers, these workers can also relieve the demands on family caregivers who would otherwise have to perform tasks such as medication management, often leaving their job sites to do so. The State Scorecard on Long Term Services and Supports[29] will monitor progress in both caregiver assessment and nurse delegation by 2014.

9. Caregiver advocacy and support organizations should include in their service and policy agendas resources that address the needs of family caregivers who have taken on the triple burden of personal care, household chores, and medical/nursing tasks.

Caregiver organizations have used ADLs and IADLS in describing their constituents and in advocating for funding and services. They, like their health care professional colleagues, must expand their view to include the special needs of family caregivers who perform medical/nursing tasks. Caregiver organizations have drawn attention to the needs of family caregivers whose family members have Alzheimer's disease or other dementias. As this report shows, many of these individuals also have concurrent medical/nursing needs, and the combination presents particular difficulties for family caregivers. Understanding the full spectrum of family caregiver needs is essential for future program development.

10. Academic and government researchers should conduct further studies to understand medical/nursing tasks performed by different types of family caregivers and their needs for training and support.

One of the strengths of this survey is its national scope and its portrayal of a representative group of family caregivers. However, that representativeness also limited its ability to document and explore the experiences of specific subgroups and specific tasks. We encourage further research in these areas:

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[28] L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, 2012).

[29] Reinhard Kassner E, Houser A and Mollica R. "Rising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers." AARP Public Policy Institute (2011) Washington, D.C.

- Diverse populations, particularly ethnic minorities, family caregivers whose primary language is not English, and other groups whose experiences may differ from a national sample
- Spousal caregivers, who are likely to be of the same age as the care recipient and at risk for chronic health conditions
- Family caregivers of people with cognitive or behavioral conditions that may make performing medical/nursing tasks more difficult

More qualitative research is also needed about, for example, the interactions between family caregivers performing medical/nursing tasks and health care professionals in different settings.

Many academic and other research organizations can take on parts of this agenda. Foundations that have supported family caregiving in the past can sponsor a valuable new series of projects. Other foundations can provide new leadership. At the federal level, the Agency for Healthcare Research and Development, which already has consumer issues on its agenda, could focus specifically on family caregivers.

Summary

At a time when federal and state health policy is driving changes to reduce hospitalizations and nursing home admissions, it is critical to consider who will care for people with multiple chronic conditions who need substantial help with tasks that are often considered "nursing" or "medical" care. The default is the family, ready or not. Family caregivers agree to what has been called an "invisible contract"[30] when they take on the complex care of a person with multiple chronic conditions. It is time to change the terms of the contract to clearly spell out the respective responsibilities of health care providers, payers, and family caregivers with transparency and accountability.

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[30] Dow B, McDonald J. "The Invisible Contract: Shifting Care from the Hospital to the Home." Australian Health Review. 2007. 31 (2): 193-202.

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HCR 078 (notes from 7.28.14 meeting for approval at 8.25.14 meeting)

- Medicare information was used by Hawaii Health Information Corporation (Peter Sybinsky)

  55%-Medicare fee for services

  45%- Medicare advantage
- Does not include Medicare advantage
- Hospital compare website
- 10/1/12-beginning of reduction in compensation for more re-admissions
- Dartmouth
  - Medicare distribution per enrollee is lowest in Hawaii
- Emergency room rates are not included in readmission rates

1st part of mtg

What do we needs in terms of data?

- Policies and procedures for discharge planning of hospitals
- Policies and procedures for caregiver training
- Emergency rooms-readmissions to hospitals occur through ERs
- Inventory of community-based programs to assist patient population
- Discharge destinations
- Home health
- OASIS-home health agencies transferred
  - West Oahu transition gp-

- Medication reconciliation is important
- Hired pharmacists-Pali Momi

2009-2012-person-centerd hospital discharge model

ADRC

(Malia)

Kauai 43% reduction in readmissions discharged

(Audrey)

- Workshops-use technology and use websites-caregiver training

Cullen Hayashida

Health Information

Pharm to Pharm

Adv. Directive

POLST

- Consistent discharge planning and caregiver training
- Policies and procedures for discharge planning and caregiver training in hospitals
- Medicare advantage programs do not cover care transition
- Discharge disposition
- Readmission from home health/homebase

Initiatives to reduce admissions and readmissions

- Care transitions program (Coleman model) (Norma Circle, Deborah Stone-Walls)
- MCC training (Kristian Stone)
- KCC training (Cullen Hayashida)

- Network of care (Dr. Fridovich)
- Pharm to Pharm (Kristian)
- ADRC-Kauai, Maui
  - (Wes Lum) Hawaii person-centered hospital discharge model
- Behavioral health education (Dr. Fridovich)
- Adv. Directives
- POLST

Financial and time commitments of family caregivers

Logistical barriers

Discharge and caregiver training

Review other states that passed legislation

Oklahoma

New Jersey

QIO=Mountain Pacific Health

Medicare Contractor

Dee Dee Nelson

2013-Mike Robinson

Kaiser

Queens

Straub

Pali Momi

HCR078
Notes from Meeting on 08.25.2014

Meeting opened about 9:00 a.m.

First part of meeting

- Item III of Agenda

Jeremy Lakin of the Healthcare Association of Hawaii: Any data requested has costs associated with it. Private hospitals have concerns with releasing private data and policies for two of the seven questions regarding discharge planning.

- Top five readmission areas and codes may be considered proprietary information.

- Trying to ascertain what is the practice and policy in hospitals?

- Questions 4 and 7 submitted to the Healthcare Association of Hawaii

Data regarding hospital readmissions from Mountain Pacific states

- The Joint Commission standards on hospital discharge

Hospital-discharge standards required by the Centers for Medicare & Medicaid Services

- Perhaps information could be obtained from Mountain Pacific Quality Health Hawaii

- Presentations by Audrey Suga-Nakagawa and Deborah Stonewalls-Arensdale

- Castle Medical Center also participated on its own in the Hawaii Care Transition Program (despite the City and County of Honolulu's not participating in the Program)

- Presentation by Lois Nash of Pali Momi Medical Center regarding the Pharm2Pharm program

Pharm2Pharm pharmacies (Times, Foodland) at which the pharmacy coaches are located also receive federal funds to follow up with patients (10 contacts per year) as part of their responsibilities

However, patients do not need to obtain their prescription medications from Times or Foodland

- Presentation by Cullen Hayashida of Kapiolani Community College

Family Caregiver Training offered by the Kupuna Education Center

Classes are funded by state general-fund moneys; however, not many individuals seem interested in taking these classes, which is kind of troubling

Multi-step articulated (graduated) training for paid caregivers (e.g., Level I: Elder Pal; Level II: Personal Care Assistant; Level III: Home Care Assistant). Objective is to train lower-cost yet high-quality workers to provide care for patients.

Second part of meeting

- Item V of Agenda

Question was presented to the Working Group: Establish working sub-groups? One of the responses was that five working sub-groups was a "non-starter." Also, HCR78 appears to place hospitals at odds with patients and their caregivers.

- Request to follow the Healthcare Association of Hawaii's suggestion to have hospital-discharge administrators appear for a roundtable at the next meeting of the Working Group on September 22 → Jeremy Lakin agreed to arrange such an appearance.

- Question from a member of the Working Group on the value of anecdotal stories vs. release of hospital policies regarding hospital discharges

- Announcement that further information and resources would be circulated to the members of the Working Group

- Statement that hospitals are penalized two percent, which is a large amount, of their Medicare reimbursements if they experience unacceptably high rates of hospital readmissions

- No other requests for additional information

- Next meeting announced for September 22, 2014.

Meeting adjourned about 10:40 a.m.

HCR078
Notes from Meeting on 9.22.14

Meeting opened about 9:00 a.m.

Item III of Agenda

A. Presentation by Steve Tam, Director of Advocacy AARP

The CARE Act: What It Means for Hawaii

In 2012, Hawaii had oldest population in the nation for people age 85 and older at 39,000. In 2050, that number is projected to increase three times as many, approximately 117,000 people age 85 and older.

In Hawaii, 247,000 people serve as caregiver and provide $1.99 billion worth of services.

The job of the caregiver is unlike any other job in that it is 24/7, there is no vacation time, must maintain another job in addition, and must provide assistance with medical procedures with no prior training.

It is estimated that these jobs are equivalent to those with pay of $25 an hour, yet most are family members and work without pay.

As population ages, situation will be more critical as more Hawaii residents will be admitted and discharged from hospitals, and many family members will be tasked with caregiving.

In 2012, 23 percent of Hawaii home health clients were hospitalized, according to AARP. (Request number of discharges by Hawaii hospitals).

AARP's Home Alone Report: Family caregivers perform complicated medical/nursing tasks and medication management; training is limited; most care recipients do not receive home visits by health professionals; performing medical/nursing tasks may prevent nursing home placement; caregiver quality of life affected.

Training of family caregivers is a cost effective solution to improving care at home.

Nationwide, one of every eight Medicare beneficiaries who leave the hospital is readmitted in 30 days. (Request Hawaii readmission numbers).

Medicare reports spending $17.8 billion a year on patients whose return trips to the hospital could have been avoided. Under Affordable Care Act (ACA), hospitals are penalized with a cut to their Medicare payments if these avoidable readmissions continue to occur.

Average Medicare hospital 30-day readmission rates for heart failure, heart attack, and pneumonia (July 2009-June 2012) is 19.22 percent; national average is 19.89 percent.

Purpose of C.A.R.E. Act is to ensure that hospitals include the caregiver in discharge planning and provide necessary training (designation, notification, consultation, and training).

No Hawaii statute relating to requirement for caregiver designation, notification, or training.

AARP recommends stronger requirements for caregiver involvement that are not purely at discretion of hospitals.

AARP emphasizes that it is an issue of consistency. They recognize that some hospitals are thorough in their discharge plans, it's just that some are not. AARP wants consistency across the board, and the only thing they can currently fall back on are the admission numbers. AARP wants to see where the inconsistency lies and reduce the number of readmissions for all.

AARP said Oklahoma model for family caregiving is not adequate.

Discussion on Hospital Discharge Planning Project. The study said family caregivers are not adequately informed; hospitals try to engage caregivers, but this engagement is not consistently being done.

Item IV of Agenda

Discussion of Admission and Readmission Diagnoses and Hospital Discharge Policies

A. Cynthia Gaddy, Judy Suzuki; Straub Clinic & Hospital

Cynthia Gaddy:

Discharging a patient starts at admission. All preferences and information about a patient is written on their admissions forms within 24 hours of admission.

Patient education and care plans reviewed every 24 hours.

8.67 percent readmissions across board.

Staff performs teach-back method with medications. Other hospitals use this method also. Staff teaches patient about medications and patient requested to demonstrate back to staff. This method helps to involve the patient and the family. Senator Chun Oakland asked about performing additional teach-back involving caregivers.

At the end of 2014, Straub will have a case manager dedicated to each floor.

Straub also provides wound ostomy nurses, burn coordinators, cardiac care and 24/7 diabetes specialists.

Judy Suzuki:

Discharge plan is determined based upon who the designated caregiver is.

When patient is readmitted we identify the cause and then categorize it. The highest percentages for re-admittance were due to 1. Separate DRG's (separate ailment/unconnected) and 2. Disease progression.

If readmission is unwarranted, Utilization Management Committee is notified and an educational letter is sent to patient's physician.

Senator Chun Oakland inquires if there is communication across all hospitals.
Tells personal story of mother passing out and having to take her to another hospital in Wahiawa. By chance Sen. Chun-Oakland personally knew the doctor, who inquired about her mother's medication. If she had not known the doctor, they probably wouldn't have inquired about her mother's medical history because medical information does not seem to be shared hospital to hospital.

In relation to this, Cynthia Gaddy notes that there is a “care everywhere” tab for electronic transfer of patient information.

"Care everywhere" tab uses a program called "Epic". Hospitals partaking in this program include Queens, Kaiser and four HPH Hospitals.

B. Donna Sheather; The Queen's Medical Center

Discharge planning starts at admission, sometimes discharge planning starts before admission. Identify high-risk patients. Identify caregivers, family members; provide and exchange contact numbers.

Staff tries to engage family members on caregiving. Many family caregivers are busy working so staff adjusts schedule to accommodate instruction for caregivers.

Upon discharge, transitional case management program initiated 2-3 days after. Contact family caregivers within two days with key instructions, such as follow-up appointments.

C. June Drumeller, Cheryl Tanaka; Kuakini Medical Center

75 percent are Medicare patients; 10 percent readmission rates across board; readmissions usually are due to chronic illness, or unrelated.

Transition of care meetings. Meeting with physicians, patient, families, case manager, and other essential parties. Helps coordinate with care planning. Special emphasis is placed on patients readmitted within 30 and 90 days.

Staff engages with families as best as they can with caregiving instructions and support, however some families have difficulty engaging back with staff.

Usual readmission is due to 1. Chronic illness and 2. Unrelated illness.

D. Karen Schmaltz, Lara Westfall; Castle Medical Center

Castle Medical Center's case management department is comprised of RN's and social workers.

Overall assessment performed upon admittance. Look at home situation, identify caregiver(s), needs care and learning; any barriers to discharge.

Partnered with hospitalists and meet formally once a day to discuss current patients.

Once patient is discharged, they leave the hands of the hospitalist and are put back in care of primary physician.

Careboards/whiteboards. Important information displayed for patients and family, such as hospitalists, important phone numbers, and discharge plan information; updated regularly.

Utilize teach-back method.

Care transition coordinators. Identifies patients with highest risk for readmission. Transition coaches work with patients and provide important information and reminders, such as follow-up visits. Care transition coaches also assist with medications, make sure patients attend appointments, and identify barriers at home.

Coalition, Windward Partners. Hospital partners with health care agencies on Windward side; staff meets once every two months with health care agencies; candid talks about transitional care problems; identify needs and initiates follow through on solutions. Very successful.

Pharm2Pharm. Program through UH Hilo pharmacy students allows pharmacists to help high-risk patients with medications; this in-house pharmacist follows up with patients.

HMSA's transitional care program. HMSA patients followed by care transition coaches, who assist patients in obtaining proper care after discharge.

Five-minute pharmacy. Assists patients in blister pack organizing, refilling, and delivery of medications. Free service.

E. Joanne Bates, Maui Memorial Medical Center

Less than 12 percent readmission rate. Readmission is usually due to COPD, diabetes, or CHF.

Care is "unit based"; case manager at every unit staffed with physical, speech and occupational therapists, smoking cessation specialists, and dietician.

Care transitions program with Maui County Office on Aging. Program helps with Medicare patients; works with case managers; credited with drop in readmissions.

Hospitalists come in every week to discuss high risk patients with nurses and physicians.

Pharm2Pharm program is utilized.

Social workers and Salvation Army are utilized to do follow ups with homeless patients.

Drop-in patient readmission in less than 30 and 60 days recorded from April 2013-April 2014 was 17 percent.

HMSA Transitional care coaches are in progress and will be in effect starting the 29th of October for high risk, chronic, and simple discharge patients.

Transitional care coaches are coming from Health Ways, in conjunction with HMSA.

Challenges with Health Insurance Portability and Accountability Act law; sometimes patients request to not share information with caregivers, and this non-sharing of information becomes an obstacle.

Other discussions

Tracking of Physicians Orders for Life Sustaining Treatment (POLST).

SWANK: Distributor of healthcare curriculums and courses.

Item V of Agenda

A. Network of Care and Behavioral Health Education – Dr. Fridovich, DOH (making arrangements for designee to present material for next meeting)

Possible Future Agenda

Comparison chart for discharge policies. This may include a chart with each hospital's discharge checklist or personal checklist that is used by discharge planners.

Time for Kaiser to make similar presentation on discharge planning.

Possible HMSA transitional care presentation.

Next meeting announced for October 27, 2014.

Meeting adjourned about 11:20 a.m.

HCR078
Notes from Meeting on 10.27.2014

Meeting opened about 9:00 a.m.

First part of meeting

- Review of meeting notes from the meeting on September 22, 2014. After discussion, meeting notes were approved.

Second part of meeting

- **Presentation by Dr. John Berthiaume on HMSA's Care Transition Program**

In 2010 HMSA developed the Advanced Hospital Care Program; 20% of the points in this program were assigned to discharge planning and readmission reduction.

In year one HMSA paid the hospitals for a process to appoint a person in their hospital system to be a champion for discharge planning, asked that they develop multi disciplinary teams and provide HMSA with the minutes of those teams, that they develop a data capture methodology to understand not only their discharge planning challenges, but also their readmission rates and types of patients that were being readmitted.

HMSA asked them to write a written protocol and a program to make outbound calls to those most at high risk for readmission and then to develop a process to make sure all of the physicians involved for the care of an in-patient got a discharge summary in a timely way.

From 2011 onward, hospitals were paid per reduction in potentially preventable readmissions. This “potentially preventable readmissions” is a subset of all readmissions.

A company called 3M puts software together that picks up those readmissions that are planned, so any staged surgical procedures or readmissions that are entirely unrelated to the index submission. HMSA uses a top ten service line and in this scoring methodology pays hospitals for absolute performance relative to their peers as well as improvement year after year.

In order of admissions at risk for readmission, obstetrics and neonates were at the top of the list, but it goes down to all basic sub-specialties with psychiatry being in the tenth place.

This actual to expected ratio is a way that 3M severity adjusts these by the disease burdened and comorbidities of the patients and so it gives the hospitals their rate in comparison to a rate that would be expected for a group of patients.

640 re-admissions avoided per year with a savings of over 8.2 million.

Earlier this year HMSA asked their vendor partner, Health Ways to put together a care management program which has 4 components; complex case management, short term case management, readmission reduction program, and late stage disease management.

Importantly in the readmission reduction program a nurse is embedded into the program to help physicians for the patients that meet their algorithm and criteria for being at risk for readmission.

Daily admission info is transmitted from the hospitals to HMSA and therefor Health Ways, who puts patients through an algorithm that in rank order lists their risk for readmission.

The nurse in hospital looks at this list and conducts an assessment of the patient which can include functional status, social support, health literacy, any cognitive deficits, their medical knowledge and adherence to medication and treatment recommendation, and depression screening.

Interventions may consist of medication reconciliation, they collaborate with the case managers and discharge planners of the hospital and make sure the PCP is aware of the health care transition plan and they try to educate the member for triggers, use of medication etc. They also will connect the patient with community resources if appropriate.

If appropriate the in house nurse will hand off responsibility to a community based case manager and they do a follow up either telephonically or in home visit. Each PCP is updated. This is an important part of the overall strategy and HMSA has an outpatient medical center home program, which explicitly tries to get individual HMSA members cared for by specific PCP.

Approaching 80% of HMSA members are linked to a primary care physician.

The nurses in the community that take the handoffs from hospital nurses are fully staffed.

7 out of 13 hospitals participate in the program.

Questions/Comments:

HMSA was asked whether in the process of its identifying at-risk patients, there was a breakdown by age cohort. HMSA responded that a breakdown by age cohort was available with certain information. HMSA was asked if such information was available, and HMSA replied that it would try to obtain the information. Sen. Chun Oakland asked the Family Caregivers Working Group (Working Group) if it had any other information to request of HMSA. Sen. Chun Oakland announced that the co-chairs of the Working Group would brainstorm a few concise questions to ask HMSA. Rep. Takayama inquired if HMSA's Care Transition Program was a pilot program; HMSA seemed to indicate that it was not.

According to HMSA, Hawaii has a relatively low rate of utilization of health services.

Rep. Takayama asked HMSA if there might be reasons for a hospital not to participate in the Care Transition Program and if there might be any reluctance by a hospital to participate. HMSA replied that there did not appear to be any reluctance by a hospital to participate.

- **Presentation by Denicia on Admission and readmission diagnosis and hospital discharge policies at Kaiser Permanente**

Kaiser currently has two discharge policies that are in place, guided by condition of participation and TJC in requirements to assure that Kaiser patients are transitioned to the right setting upon discharge.

Kaiser staff work with their patients and most importantly with families to assure that the discharge is timely. When the patient may not be able to go home, making sure it’s the appropriate venue that they get to.

Discharge planning is very important—it begins either prior or at day one of admission. The physician is expected to determine the length of stay and he/she works with a multidisciplinary team to identify that, and they are updated as a team throughout the stay.

Program implemented last year at Kaiser, called IQM—Integrated Quality Management. Originally, Inpatient Quality Management. Integration is an important word change because it is a fact you need to have the integrated system in place to assure that family members are getting the right care.

The focus of IQM program is to make sure Kaiser remains integrated, and the transition continuum is met from the time patients see their PCP in the clinic till the time they may be in the hospital, and then the time they are discharged. It should be a continuum that is connected.

With IQM they have assigned one case manager to one hospitalist and they partner with the primary care team in the clinic. The education of the interdisciplinary team is also important. Everyday the physician leads a discussion with case manager, bedside nurse, social worker, physical therapist, pharmacy, financial counselors, and anyone else who would be pertinent to assuming the care of the patient.

Primary Care Clinics—all 19 Kaiser primary care clinics are PCMH Certified, to assure that the levels of these patients and their interactions of their needs are being obtained.

Kaiser is advocating and moving forward with the integration of POLST. APRN's can now participate in that and it is very important for every member to have a POLST identifier, making sure Kaiser meets their needs and doesn't assume their needs.

Education and Training—Ohana care is important in identifying whom the caregiver and their network is.

Kaiser makes sure caregivers leave with electronic discharge instructions. They are required to receive a 24-hour phone call follow up by a PCP. If the patient does not go home, a team of nurse practitioners, physicians, and case managers in the community at the facilities Kaiser partners with will make sure that the team from Kaiser is working in the facility with the family members to identify their true outcome goals.

Kaiser has internalized home health services.

Kaiser does not have an internalized hospice program, but they do partner with other community agencies.

For Inpatient Program at Kaiser they have the first Kaiser Certified Care Program, which was certified this March 2014. It's important because it identifies that Kaiser is having the discussions with the nurses and the patients to identify what their needs are upon discharge, not just making it based on assumptions.

Questions/Comments:

-Which islands does Kaiser operate?

Oahu is where our main hospital is. We also have facilities on Maui and the Big Island. We have 19 peripheral clinics

- **Presentation by Dr. Westphall on Department of Health, Behavioral Health Network of Care Report and Human Health Education**

Behavioral Health Network of Care Project, web-based project developed through Mental Health Transformation State Incentive Federal Grant started in 2009.

Veterans Administration boosted use by encouraging its use by veterans of mental health needs.

Primarily set up to engage consumers/family members in the community as a resource for mental health issues information and for individual consumers to help them in organizing their care.

It has a very extensive directory of services organized by county.

Most of the usage is outside of Oahu.

In addition to information on mental health, there are actual insurance applications and info on insurance.

There's the ability to contact legislature through this website.

Each consumer can develop their own personal health records and develop a wellness recovery action plan, almost like an electronic medical record, which is only accessible to the individual.

Very active involvement by veterans in Hawaii counties.

Length of visit by viewers on the website suggests they are really using the website making significant interactions.

The main use of the website is to find services, with information being secondary.

Health Education—accessible several different ways. Adult residential care, for adults with health and mental health needs, group housing info, info by program type, and person specific info.

Questions/Comments:

Who's promoting the usage of the website?

Lots of outreach services promote the network of care for services in their area. Community mental health centers are also promoting usage of the website.

Medical Health Transformation Grant—Veteran's website is a separate site. They promoted it because for mental health patients, they can put all their records, discharge papers, personal health info etc. on and know that they will never be lost, and it is free. It is an underutilized website. Completely paid for by the grant.

How are the veteran's services incorporated?

Part of a national network put together by Trilogy, so it is nationally updated daily. Locally, it is the Office of Veterans services and Ron Hahn, who is responsible for updating the website on a local level.

Security?

It is a secure system that can only be accessed with your email. However, there are pieces of it that you can specifically give guest preference to and delegate a specific length of time that this info will be available to the addressee.

Trilogy was paid by the federal government to develop the website and to duplicate it across the United States.

Sen. Chun Oakland requested the Department of Health to look into integrating various health information, files, and records into a single comprehensive system, so that information is not siloed. Sen. Chun Oakland asked AARP what they thought of having information in a single location, and AARP responded that there was value in such a system.

Third part of meeting

- Sen. Chun Oakland proposed December 1, 2014, as a meeting date of the Working Group.

- The Healthcare Association of Hawaii requested Dr. Peter Sybinsky of the Hawaii Health Information Corporation to return before the Working Group and discuss data regarding hospital admission and readmission rates. In addition, the Healthcare Association of Hawaii requested that AARP explain the 2014 State Scorecard on Long-Term Services and Supports for Older Adults and its significance to the Working Group. AARP responded that it would ask its national office regarding such a presentation.

- The Hawaii Health Information Corporation stated that it would make a presentation at the next meeting of the Working Group.

- A member of the Working Group felt that the group had no consensus on recommendations to the Legislature; another member disagreed with that statement.

- Rep. Takayama pointed out to the Working Group that recommendations to the Legislature do not necessarily include proposed legislation. For example, the Working Group could recommend that it be given more time to study the issue or could request that it be provided with additional information.

- A suggestion was made for members of the Working Group to email Sen. Chun Oakland and Rep. Takayama by November 7, 2014, with any recommendations that they had. Sen. Chun Oakland and Rep. Takayama would then aggregate the recommendations for the Working Group to consider at the next meeting. The members of the Working Group were reminded that their recommendations could be legislative or non-legislative (e.g., administrative, private-sector) in nature.

- The Healthcare Association of Hawaii asked if the Working Group's recommendations to the Legislature would be done by consensus. Sen. Chun Oakland expressed her hope that such recommendations would be reached by consensus.

- The Healthcare Association of Hawaii is working on a chart for the Working Group that compares and contrasts hospital-discharge policies and hospitals' responses to the seven questions regarding discharge planning.

- Next meeting announced for Wednesday, November 12, 2014, from 3:30 p.m. to 5:00 p.m., with the room yet to be determined.

Meeting adjourned about 11:20 a.m.

HCR078
Notes from Meeting on 11.12.2014

Meeting opened about 3:30 p.m.

First part of meeting

- Review of meeting notes from the meeting on October 27, 2014. After discussion, meeting notes were approved.

Second part of meeting

- Presentation by Dr. Peter Sybinsky of the Hawaii Health Information Corporation

Please see PowerPoint attachment for more details.

Medicare rates are the only state-level hospital ratings of readmission rates currently available. They are based on "all-cause" readmissions and are calculated using Medicare claims. Medicare Advantage participants are not included in this data--only Medicare fee-for-service participants. (Kaiser Permanente is largely a Medicare Advantage program.)

The federal government's "average score" requirement is impossible to meet, because "average" is a measure of centrality; therefore, there will always be many hospitals with lower-than-average scores, which are then penalized.

- Discussion

Ms. Laura Westphal of Castle Medical Center pointed out that in the area of hospital readmissions, there is only a stick (penalty), no carrot (bonus or reward), from the federal government.

With respect to hospital-readmission rates, "outpatients" (or "observational patients") are hospitalized for two nights or fewer, and "inpatients" are hospitalized for three nights or more.

Mr. Stuart Ho of AARP asked if the number of cases of individuals aged 65 and over who are non-Medicare patients could be identified. Dr. Sybinsky replied that he would try to obtain the information.

Ms. Barbara Service of Kokua Council commented that 12 percent of Medicare participants in Hawaii are under 65 years old.

Mr. Cullen Hayashida of Kapiolani Community College asked if the upshot of Dr. Sybinsky's presentation is that Hawaii is performing pretty well in terms of hospital-readmission rates.

Dr. Sybinsky remarked that there is a difference between all-cause data versus "potentially preventable readmissions", which is a more refined measure.

Mr. Hayashida noted that greater numbers of older adults now tend to live alone; as a result, they suffer from more falls. Although the empirical data suggests a downward trend, anecdotal evidence suggests otherwise, so there seems to be a contradiction.

Dr. Sybinsky remarked that the two sets of data provided in his presentation do not necessarily correlate precisely with the objective of the Family Caregivers Working Group and may be only partially related. Everyone needs to agree on questions in order to arrive at relevant, detailed data and information that is useful for the Working Group.

Sen. Suzanne Chun Oakland suggested forming a small working committee to develop questions to arrive at data for the Working Group. Should there be four or six members?

Mr. George Green of the Healthcare Association of Hawaii inquired about the objective of the Working Group.

Sen. Chun Oakland replied that she would like to focus on the population discharged to home settings with care provided by informed caregivers.

Mr. Green commented that any data set ought to be able to be benchmarked against national data so that data is not being looked at in a vacuum.

Sen. Chun Oakland responded that Hawaii might be in the vanguard in this area so that there might not necessarily be national-data benchmarks.

Ms. Phyllis Dendle of Kaiser Permanente Hawaii asked if there might be data that exists that could end the discussion, or would the Working Group move ahead regardless of the data?

Sen. Chun Oakland replied that she would still like to improve the quality of care for Hawaii's people, even if it appears that Hawaii is doing well.

Ms. Dendle asked that if data is not driving decision-making, should the Working Group keep trying to obtain data?

Rep. Gregg Takayama noted that it would not hurt to obtain data to see how Hawaii can improve.

Ms. Westphal pointed out that hospital readmissions can be caused by a number of factors, not just poor training of caregivers.

Sen. Chun Oakland mentioned that approximately 20 percent of Hawaii patients are covered by Medicaid, and some receive dual coverage under both Medicare and Medicaid. She wondered what the percentage of those who are covered by Medicare was.

Dr. Sybinsky noted that of patients who are covered by Medicare, 55 percent are covered by Medicare Fee-for-Service, and 45 percent are covered by Medicare Advantage.

Dr. Tim Roe of the Rehabilitation Hospital of the Pacific commented that hospital readmissions are multi-factorial, including age (especially patients aged 70 and over and aged 80 and over); co-morbidities; socioeconomic status (e.g., below the federal poverty line); and use of tobacco, alcohol, and drugs. The training and education of caregivers is important, but other factors need to be considered, as well.

<u>Third part of meeting</u>

- Presentation by Mr. Wes Lum of the Executive Office on Aging

Identity-change theory (e.g., an adult child who becomes a caregiver for an elderly parent; a spouse who becomes a caregiver for the other spouse) affects the level of stress that family caregivers may experience.

The TCARE (Tailored Caregiver Assessment and Referral®) model can tailor the type of care that is appropriate for a particular patient. There are over 90 categories of services that could help reduce the stress and burden encountered by family caregivers.

One goal might be simply to increase the number of resources available to family caregivers.

Mr. Lum distributed a list of Community Resources Available for Caregiver Training.

A member of the Working Group asked which resources are state-funded or receive subsidies from the State?

Mr. Lum responded that Kapiolani Community College's training program is state-subsidized; however, program participants must also pay a fee.

AARP commented that their training is funded completely by their own organization, without state funding.

Ms. Paula Yoshioka of The Queen's Health System inquired if there was a "gap analysis" between the over-90 categories of services in the TCARE model and what was provided on the Community Resources Available for Caregiver Training distributed by Mr. Lum.

A representative of AARP asked if Mr. Lum could indicate which classes on the Community Resources Available for Caregiver Training are available immediately to assist family caregivers.

Mr. Lum replied that the Community Resources Available for Caregiver Training does not really address timeliness of training.

A representative of AARP observed that the issue of timeliness of training is one of the greatest complaints that AARP receives from family caregivers.

Ms. Audrey Suga-Nakagawa mentioned that the timeliness of information for family caregivers on the first day the patient is discharged from the hospital is important.

Ms. Dendle remarked that the issue of hospital-readmission rates involves both primary care physicians and hospitals and that the responsibility cannot lie completely with hospitals.

A member of the Working Group commented that the hand-off of patients from the hospitalist to the primary care physician is very important.

Sen. Chun Oakland remarked that there seems to have been a change in the model of care. Before, a patient's primary care physician would see them in the hospital. Now, though, only a hospitalist sees a patient.

A member of the Working Group noted that many Medicare patients who are discharged from the hospital do not have a primary care physician (e.g., primary care physicians are busy).

- Next meeting announced for Tuesday, December 2, 2014, from 9:00 a.m. to 11:00 a.m. in Conference Room 325.

- Discussion

Rep. Takayama mentioned that the Healthcare Association of Hawaii that HAH had mentioned the issue of liability in its email of suggestions to the Working Group and asked if HAH wished to further discuss liability as an issue. Attorney Gary Slovin was mentioned as a possible presenter on the issue of liability at the next meeting of the Working Group.

AARP suggested that they would like to bring in legal counsel to present on the issue of liability, as well.

Ms. Dendle noted that hospitals are systems. A better system can be built, and there is always room for improvement. However, the care that a patient receives after being discharged cannot lie solely with hospitals.

Ms. Deborah Deborah Stone-Walls remarked that it would be good if there were greater opportunities for family-caregiver support, training, etc.

In the City and County of Honolulu, the Area Agency of Aging ("AAA") is the Elderly Affairs Division.

Sen. Chun Oakland asked if hospitals can contract with Aging and Disability Resource Centers (ADRCs) to fund transition coaches and the care-transition process. Ms. Stone-Walls responded that that might be the swiftest process.

AARP reiterated the importance of handing off a patient to a trained caregiver upon discharge from a hospital.

Mr. Green remarked that statutorily requiring a lay caregiver to provide a clinical level of care exposes hospitals to a greater risk of legal liability.

Meeting adjourned about 5:30 p.m.

HCR78, HD1, SD1: Caregiver Taskforce Working Group

Wednesday, November 12, 2014, Meeting Attendees:

Audrey Suga-Nakagawa, AARP
Stuart Ho, AARP
Phyllis Dendle, Kaiser Permanente
Laura Westphal, Castle Medical Center
Michael Robinson, HPH
Emilie Smith, Castle Home Care
Danny Cup Choy, Ohana Health Plan
Paula Yoshioka, Queens
Tina Donkervoet, Queens
Malia Espinda, Queens
George Greene, HAH
Keith Ridley, DOH
Deborah Stone-Walls. Maui County Office on Aging
Jeanette Koijane, Kokua Mau
Keith Ridley, DOH
Gerry Silva, AARP
Barbara Kim Stanton, AARP
Cullen Hayashida, KCC
Wes Lum, EOA
Barbara J. Service, Kokua Council
Mark Oto, HMSA
Nick Hughey, Maui Memorial Medical Center
Tim Roe, Rehabilitation Hospital of the Pacific
Joel Nakamura, Elderly Affairs Division
Rebecca, Drake, Elderly Affairs Division
Mihoko Ito, Ashford & Wriston
Senator Suzanne Chun Oakland
Representative Gregg Takayama
Tyrell Ma'ae, Senator Chun Oakland's office
Steven Lum, HMSO
Karen Kawamoto, Representative Takayama's office

HCR078
Notes from Meeting on 12.02.2014

Meeting opened about 9:05 a.m.

First part of meeting

- Review of meeting notes from the meeting on November 11, 2014. After discussion, meeting notes were approved.

Second part of meeting

- Discussion on written report to the 2015 Legislature

Rep. Gregg Takayama announced that the next meeting of the Family Caregivers Working Group will be held on December 11, 2014, at which time a draft report, prepared with the assistance of Keith Ridley of the Department of Health, will be circulated.

Sen. Suzanne Chun Oakland introduced and discussed the additional written materials (e.g., community-resource books) that were distributed to attendees prior to today's meeting of the Working Group.

Third part of meeting

- Presentation by Ms. Deborah Stone-Walls on Aging and Disability Resource Centers (ADRCs)

Members of Maui County Office of Aging recently returned from Centers for Medicare & Medicaid Services (CMS) training in Baltimore, Maryland. There used to be 102 cohorts in the United States to plan for Medicare discharge planning; now, only 79 remain. Among cohorts participating in the CMS program, Maui County ranked first in the nation for hospital-readmission-reduction rates, with a rate of 17.4 percent. The second-ranked cohort was a large hospital in New York, with a hospital-readmission-reduction rate of 13.9 percent.

It seems that all participants in the Working Group want better connectedness between hospitals and at-home caregivers.

ADRCs make contact with patients when they are still hospitalized and then follow up and support them after they return home. This is one aspect in which ADRCs can elevate their performance.

Ms. Stone-Walls discussed the Discharge Preparation Checklist, which contains 10 questions that can be used to assist patients when they leave the hospital.

A significant issue that needs to be addressed is how non-medically trained persons can be trained to perform more medical tasks.

There needs to be a closer connection between ADRCs and hospitals.

Ms. Stone-Walls mentioned that everything that ADRCs do is Health Insurance Portability and Accountability Act-compliant.

If an ADRC notices that an individual has multiple hospital readmissions, they can work with the family to try to reduce such readmissions.

Ms. Stone-Walls emphasized the importance of empowering patients to manage their own care.

One area that could be further improved is to have ADRC nurses (who are registered nurses) to train family caregivers with wound cleaning, tube cleaning, and other more-technical tasks. Thus, if a registered nurse is unavailable to perform these tasks, a family caregiver will be able to do them.

Ms. Elaine Slavinsky is a "trainer of trainers" and works as a contracted coach. It cost approximately $5,000 to train Ms. Slavinsky, but the initial investment has paid off, because she can now train others in Hawaii. Ms. Slavinsky not only trains coaches but also continues to monitor the coaches that she has trained.

It is important for coaches to seek an "empowerment stance" rather than an "instructive stance." Coaches cannot tell patients what to do. Coaches must work together with patients to empower them to manage their own care and make the right choices.

Sen. Chun Oakland asked what percentage of patients do not have primary care physicians.

A member of the Working Group noted that many indigent patients do not have primary care physicians. ADRCs try hard to find primary care physicians for patients who do not have them. About December 2013, HMSA reached out to the Maui County Office on Aging to try to have them be serve as HMSA's Community-based Care Transitions Program (CCTP) on Maui.

A member of the Working Group commented that approximately 55 percent of Medicare participants are Medicare Fee-for-service patients and that this population seems most appropriately served by ADRCs. The other 45 percent of Medicare participants are Medicare

Advantage patients, who receive care through other CCTP protocols. In Hawaii, approximately 225,000 Medicare participants are Medicare Fee-for-service patients, of whom approximately 36,000 to 37,000 are state retirees and 10,000 to 15,000 are federal retirees. Approximately 105,000 Medicare participants in Hawaii are Medicare Advantage patients, and approximately 28,000 individuals are dual-eligible (i.e., they are covered under both Medicare and Medicaid).

Sen. Chun Oakland remarked that there is a need to look at data to try to compare the effectiveness of CCTPs.

Mr. Stuart Ho remarked that there appeared to be no commonality among the data collected by different entities, thereby making it difficult to draw comparisons. Sen. Chun Oakland commented that there appeared to be positive, downward trends in the data collected. Ms. Audrey Suga-Nakagawa mentioned that the commonality seems to be empowerment and training.

Congestive heart failure, chronic obstructive pulmonary disease, and diabetes are the most commonly encountered health problems among CMS cohorts nationwide.

Ms. Suga-Nakagawa inquired which person completes the Discharge Preparation Checklist--the patient or the caregiver? Ms. Stone-Walls replied that either the patient or the caregiver can complete the Discharge Preparation Checklist.

Ms. Stone-Walls mentioned that about 70 percent of family caregivers are willing to work with ADRCs.

Ms. Stone-Walls mentioned that CMS only reimburses Maui ADRCs for Medicare Fee-for-service patients.

Sen. Chun Oakland pointed out that all counties, except Oahu, have a physical ADRC. Sen. Chun Oakland would like to provide full funding for an ADRC on Oahu and feels that a fully-funded ADRC on Oahu could potentially work with every hospital on the island.

Ms. Stone-Walls stated that Ms. Slavinsky is in the hospital every weekday doing rounds. Hospitals have also given her access to patients' electronic medical records. Like the other coaches, Ms. Slavinsky is also a certified community case manager. In addition, Ms. Stone-Walls mentioned that it is recommended that coaches work only with about 30 to 40 patients per month. "Lead coaches" assess hospital patients for their needs and then coordinate with the other community coaches. All coaches are independent contractors (e.g., they provide their own vehicles and laptop computers). Procurement complies with Chapter 103F, Hawaii Revised Statutes.

Medicare Advantage programs are incentivized to reduce hospital readmissions and to reduce gaps in care.

Sen. Chun Oakland remarked that if Hawaii is already doing well, then there should be an acceleration of these good practices and sharing of knowledge so that more patients can be helped sooner rather than later. It is very important that patients have appointments with primary care physicians.

Mr. Ho commented that if all the entities with hospital-discharge models could meet together and have a discussion, perhaps they could develop an ideal model.

Ms. Phyllis Dendle responded that it would be appropriate for members of the health care industry to meet together to discuss their hospital-discharge models.

Fourth part of meeting

- Presentation by Mr. Gary Slovin, representing the Health Healthcare Association of Hawaii

Mr. Slovin briefly described his professional background, including his work in tort law.

Mr. Slovin discussed his work with and experiences regarding S.B. No. 2264 (2014) (Relating to Caregiving). According to Mr. Slovin, in his discussions with Senate Judiciary staff and Attorney General David Louie, all agreed that there would be no effective way to provide immunity and protection for hospitals under the provisions of the bill.

Mr. Slovin described Hawaii as among the top two or three (if not the top) states in the nation that are most plaintiff-friendly.

Mr. Slovin raised the example of a recent case in which the Hawaii Supreme Court found a second surgeon legally liable for not informing a patient of the risk of surgery--even though the second surgeon had not performed the surgery and had had no further contact with the patient.

According to Mr. Slovin, the Hawaii Supreme Court tends to want to find a remedy for an injured patient. Ninety percent of cases in Hawaii are settled out of court, placing tremendous pressure on defendants to reach settlements. One of the main reasons is because courts in Hawaii do not have the capacity to keep trying cases. Defense counsel often advise their clients to settle and not to take cases to trial. When an individual suffers a bad result, Hawaii courts will try to find a remedy. For instance, in a potential situation in which a patient is discharged from the hospital and suffers injury afterwards, the patient will likely be perceived as innocent and the family caregiver as sympathetic. In that case, the only party left is the institution (e.g., the hospital), which has the resources to pay a settlement. This is a matter of policy, and many in Hawaii tend to support this view. The general philosophy is that an injured plaintiff needs resources to have his or her situation remedied, and institutions have deep pockets. When a plaintiff is significantly injured, defendants do not want to run the risk of not settling.

Mr. Slovin continued by stating that the tort system in the United States is not based on statutory law but on common law. The right of an individual to sue and be compensated for injury has been viewed as a constitutional right. Although a statute may provide that there is no private right of action, common law still allows a plaintiff to sue. A plaintiff's attorney will find a way to circumvent the statute and find a way to sue.

Mr. Ho remarked that he felt that there seemed to be two separate worlds--the legal world and the world of family caregiving. Mr. Ho commented that S.B. No. 2264 (2014) did not contain a private right of action. It is understandable that hospitals must assess the risk of liability. According to Mr. Ho, a law similar to S.B. No. 2264 passed unanimously in the New Jersey Legislature and was signed into law by Governor Chris Christie in November 2014. Mr. Ho stated that if New Jersey, the most litigious state in the nation, can arrive at a compromise measure, then Hawaii can, as well. Mr. Ho said that he felt that it was ironic that many health-care providers try to address the matter of hospital-readmission reduction through methods that go beyond what AARP proposed (e.g., AARP's proposal goes only as far as hospital discharge, while HMSA and Kaiser Permanente have post-discharge contact with the patient).

Via conference call, Mr. Glen W. Fewkes, Esq., who is based in Washington, D.C., and works for AARP, expressed the following:

- It has been helpful to hear the concerns of the Healthcare Association of Hawaii regarding liability and it is still our hope that legislators, hospitals, AARP Hawaii and others can work to strengthen the liability protections.
- The progress made by the hospitals and others in New Jersey is encouraging and we owe it to the quarter million family caregivers in Hawaii to try to do the same.
- The CARE Act, as it was introduced in Hawaii earlier this year, is not incredibly detailed, but we understand that it allows for rules to be promulgated to fill in some of those details. One approach might be to do more to clearly state the standard of care in the bill itself, so that the hospitals can be more comfortable with what exactly is being asked of them. We would look to the hospitals for input on what would be appropriate here.
- To the extent that negligence actions can already be brought against hospitals relating to discharges, we don’t believe that the CARE Act changes the liability landscape in a meaningful way.
- I know that AARP Hawaii is very passionate about this issue and I look forward to hearing more from them about progress in this area.

Ms. Dendle remarked that in her view, there were not two separate worlds. In practical terms, doctors need malpractice insurance. Sometimes, health providers make mistakes. To minimize mistakes, there are steps that health providers can take. When hiring employees, health providers can look at professional licenses, accreditation, qualifications, etc. After employees are hired, health providers can try to provide good systems for their employees. Ms. Dendle expressed concerns that hospitals cannot select the individuals who will serve as family caregivers for patients. Hospitals' inability to select family caregivers is all right, because patients usually prefer someone whom they know and with whom they feel comfortable.

However, if the family caregiver is not brought into the "health care system," they will continue to remain outside the system.

Mr. Cullen Hayashida commented that he felt confused by some of what had been stated earlier. To him, it sounded like if standards were set, exposure to liability is increased. However, standards are very much needed. Health care organizations are presently and will be relying in the future more and more on family caregivers. They cannot depend so heavily on professionals anymore, because there are simply not enough of them.

Rep. Takayama asked to what extent is there liability for ADRCs, coaches, or even Kapiolani Community College's training program?

Mr. Slovin responded that everyone involved in the line of providing treatment or services can be sued. However, a lawsuit is not likely unless the plaintiff can recover funds (i.e., the judgment-proof are not likely to be sued).

Meeting adjourned about 10:55 a.m.

HCR78, HD1, SD1: Caregiver Taskforce Working Group

Tuesday, December 2, 2014, Meeting Attendees:

Sharlene Chun-Lum, Papa Ola Lokahi
Audrey Suga-Nakagawa, AARP
Stuart Ho, AARP
Bruce Bottorff, AARP
Glen Fewkes, AARP (via conference call)
Phyllis Dendle, Kaiser Permanente
Michael Robinson, Hawaii Pacific Health
Emilie Smith, Castle Home Care
Francine Wai, Disability and Communication Access Board
Paula Yoshioka, The Queen's Health Systems
Dave Heywood, Hawaii Association of Health Plans
Keith Ridley, Department of Health
Norma Circle, Maui County Office on Aging
Deborah Stone-Walls, Maui County Office on Aging
Jeannette Koijane, Kokua Mau
Danny Cup Choy, Ohana Health Plan
Cullen Hayashida, Kapiolani Community College/Kupuna Education Center
Alisa Racelo, Ohana Pacific Management Company
Bob Ogawa, HLTLA
Rebecca Drake, Elderly Affairs Division
Gary Slovin, Healthcare Association of Hawaii and Ashford & Wriston
Tiffany Yajima, Ashford & Wriston
Ashley Studerus, Alzheimer's Association
Bonnie Castonguay, Hookele Health Navigators
Peter Sybinsky, Hawaii Health Information Corporation
Joanne Bates, Maui Memorial Medical Center
Beth Hoban, Prime Care Services Hawaii
Freddie Woodard, Hawaii Health Systems Corporation
Senator Suzanne Chun Oakland
Representative Gregg Takayama
Tyrell Maʻae, Senator Chun Oakland’s office
Steven Lum, HMSO
Karen Kawamoto, Representative Takayama’s office

HCR078
Notes from Meeting on 12.11.2014

Meeting opened about 1:05 p.m.

First part of meeting

- Review of meeting notes from the meeting on December 2, 2014. After discussion, meeting notes were approved.

Second part of meeting

- Mr. Keith Ridley of the Department of Health briefly introduced the draft report, prepared by DOH, of the Family Caregivers Working Group to the Legislature.

Mr. Ridley discussed the "Findings" section, which began on page 4 of the draft report. According to Mr. Ridley, the "Findings" were based on his own notes as well as the meeting notes adopted by the Working Group.

Third part of meeting

- The members of the Working Group reviewed and discussed each "Finding" of the draft report. If necessary, changes or adjustments were made to each "Finding." (Please see the revised draft report--emailed on December 16, 2014--for the changes or adjustments made.)

- The members of the Working Group reviewed and discussed the "Conclusion" and "Recommendation" sections of the draft report.

- AARP stated its disagreement with page 8 of the draft report.

- It was suggested that items #2 and #4 under the "Recommendation" section be expanded to include at-risk populations.

Fourth part of meeting

- Mr. Cullen Hayashida stated that he spoke on behalf of Mr. Wes Lum regarding the establishment of basic minimum standards--that there might be a need to establish a committee with hospital and community representation to look at basic minimum standards.

- Sen. Suzanne Chun Oakland commented that a discussion was needed concerning hospital standards, what actually happens, and issues of enforcement.

- The Healthcare Association of Hawaii remarked that each hospital has its own way of complying with requirements regarding discharge policies and that one size cannot fit all, because different hospitals serve different communities.

- Announcement that the next meeting of the Working Group would be held on January 12, 2015, at 12:00 noon.

Meeting adjourned about 2:20 p.m.

HCR78, HD1, SD1: Caregiver Taskforce Working Group

Thursday, December 11, 2014, Meeting Attendees:

Audrey Suga-Nakagawa, AARP
Stuart Ho, AARP
Barbara Kim Stanton, AARP
T.J. Davies, AARP, HARA, Kokua Council
Bruce Bottorff, AARP
Gerry Silva, AARP
Violet Medeiros, AARP
Frank Medeiros, AARP
Midori Kiso, AARP
Yuriko Vaughn, AARP
Elienne Yoshida, AARP
Dennis Bunda, AARP
Aletia Point Du Jour, AARP
Kathy Jaycox, AARP
Sophie Tang, AARP
Naomi Kimoto, AARP
Masato Inaba, AARP
Jackie Boland, AARP
Phyllis Dendle, Kaiser Permanente
Michael Robinson, Hawaii Pacific Health
June Drumeller, Kuakini Medical Center
Virginia Walker, Kuakini Medical Center
Laura Westphal, Castle Medical Center
Emilie Smith, Castle Home Care
George Greene, Healthcare Association of Hawaii
Barbara J. Service, Kokua Council
Debbie Jackson, Disability and Communication Access Board
Paula Yoshioka, The Queen's Health Systems
Keith Ridley, Department of Health
Norma Circle, Maui County Office on Aging
Deborah Stone-Walls, Maui County Office on Aging
Jeannette Koijane, Kokua Mau
Cullen Hayashida, Kapiolani Community College/Kupuna Education Center
Bob Ogawa
Rebecca Drake, Elderly Affairs Division
Mihoko Ito, Ashford & Wriston
Tiffany Yajima, Ashford & Wriston
Beth Hoban, Prime Care Services Hawaii

Timothy J. Roe, M.D., Rehabilitation Hospital of the Pacific
Ken Zeri, Hospice Hawaii
Scott McFarland, Hawaii Health Systems Corporation - Kauai
Nick Hughey, Maui Memorial Medical Center
Joel Nakamura, Elderly Affairs Division, City and County of Honolulu
Rose Nakamura, Project Vision
Senator Suzanne Chun Oakland
Representative Gregg Takayama
Tyrell Maʻae, Senator Chun Oakland’s office
Steven Lum, HMSO