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# **Covering Caregiving: Background & Strategies for Reporters**

**Kaiser Health News Webinar**

**December 2, 2015**

**Susan C. Reinhard, RN, PhD, FAAN**

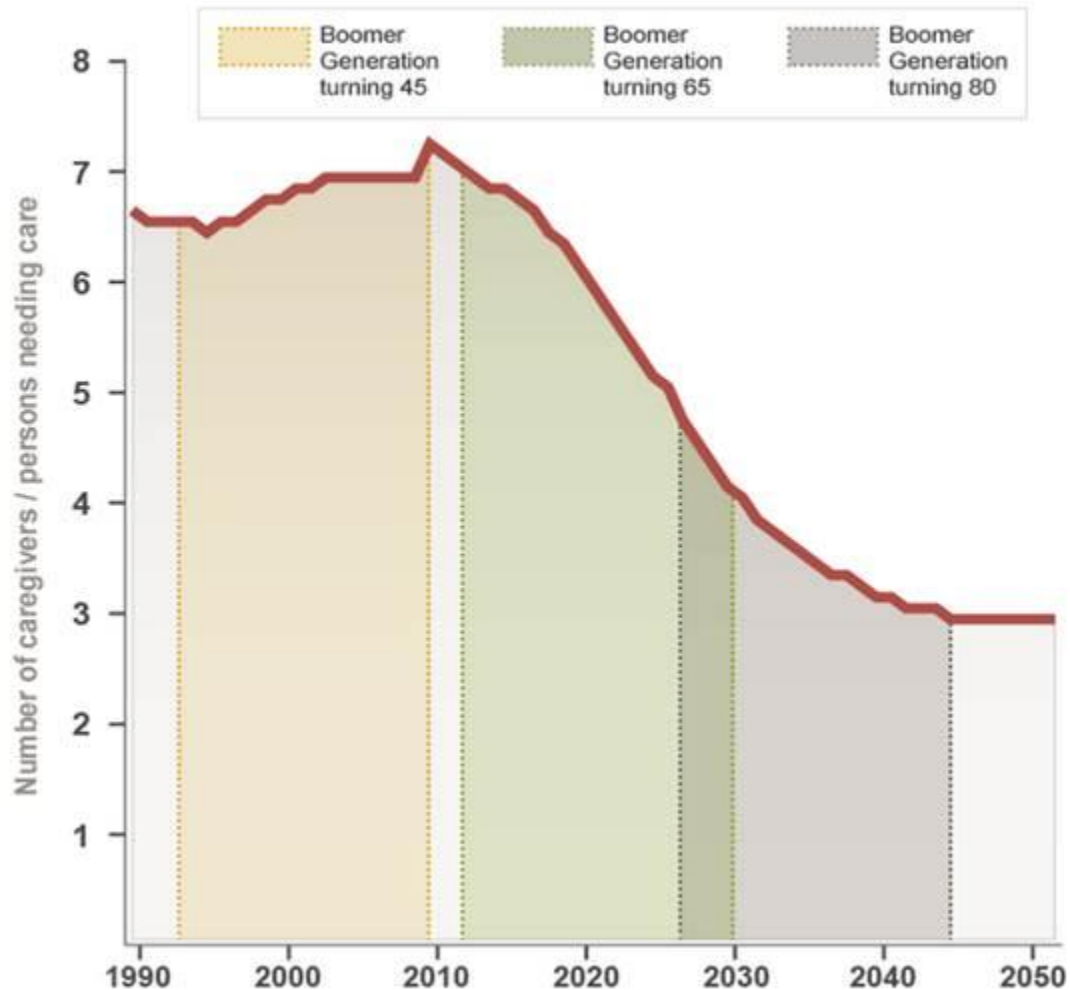


Real Possibilities

**Public Policy  
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# Caregiver Support Ratio

Caregiver Support Ratio



# Valuing the Invaluable

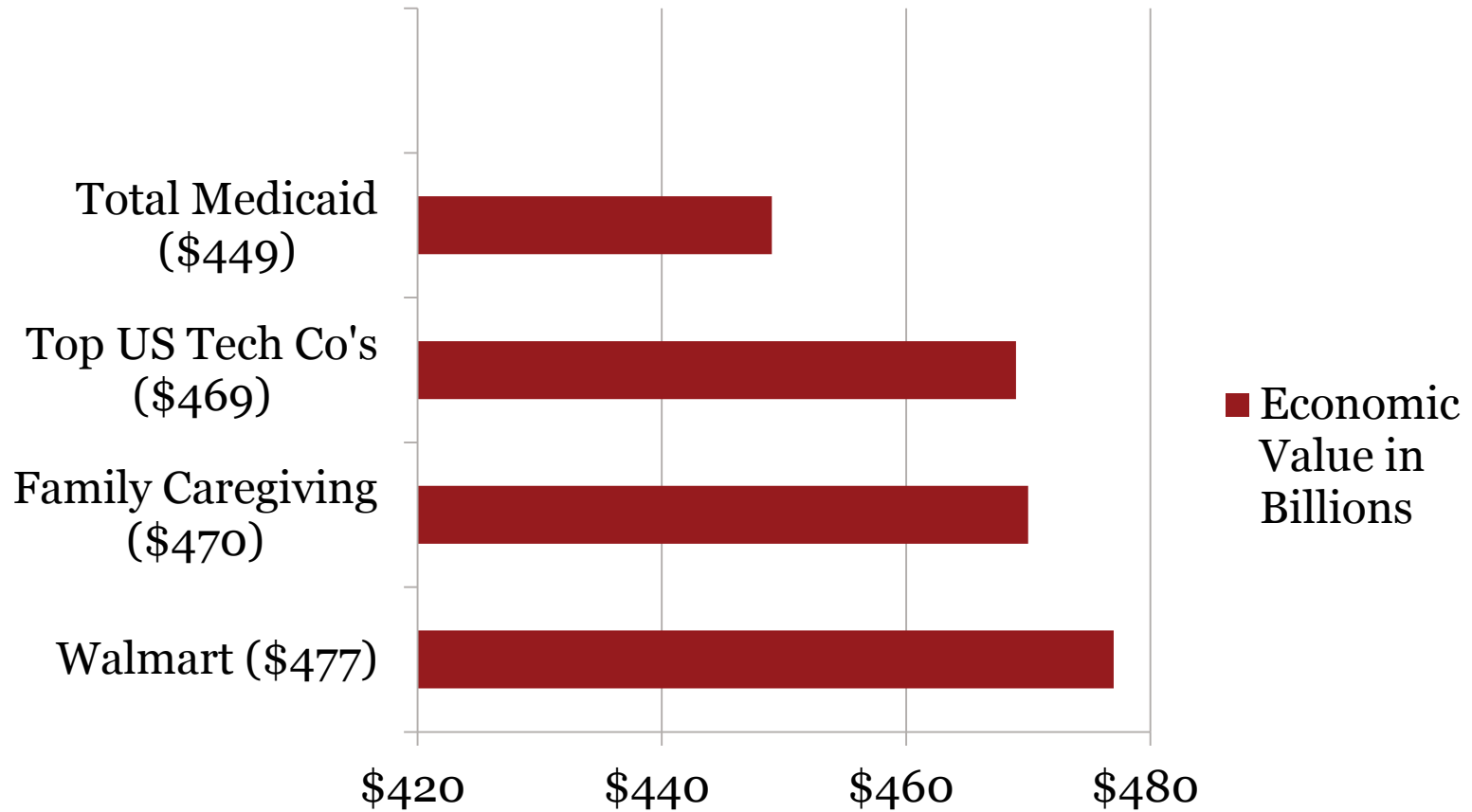
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- In 2013, about **40 million** family caregivers in the U.S. provided care to an adult with limitations in daily activities
- The estimated economic value of their unpaid contributions was about **\$470 billion in 2013**
  - **↑** from an estimated **\$450 billion in 2009**

*Source: Reinhard, Feinberg, Choula & Houser (2015). Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain, Washington, DC: AARP Public Policy Institute.*

# How Much is \$470 Billion?

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# Growing Complexity of Family Care

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**First emerging trend...**



Family caregivers now do  
medical/nursing tasks in the home

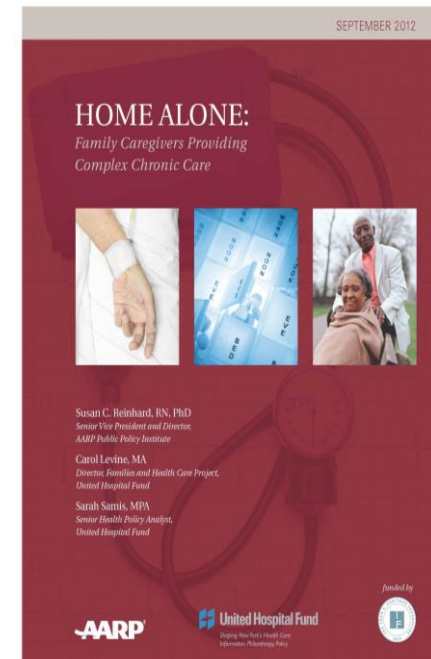
# Home Alone Research

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- AARP Public Policy Institute and United Hospital Fund collaborated on **first in-depth national survey** of family caregivers in this area

This report documents:

- What **medical/nursing tasks** family caregivers do;
- What they find difficult;
- **Who trains/guides them;** and
- Impact on their quality of life.



# Medical/Nursing Tasks

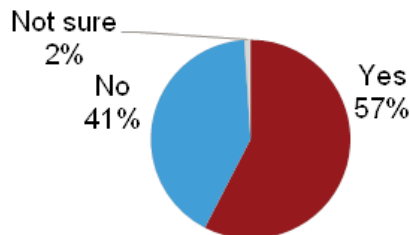
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- Managing complex medications (Poly meds, Injections)
- Prepare special food diets
- Wound care
- Changing catheters
- And more...



# Medical/Nursing Tasks

Base: Caregivers of Recipient  
Age 18+ (n=1,248)



% Yes	
Hours Caregiving per Week	
0-20 (n=826)	21+ (n=416)
45%	83%*

In addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform. Known now as medical/nursing tasks, these skilled activities include:

- injections,
- tube feedings,
- catheter and colostomy care, and
- many other complex care responsibilities.

**Higher-hour caregivers are more often performing these tasks.**

**Breakout of Higher-hour caregivers by Ethnicity:**

White: 28%, AAPI: 37%,  
African American: 39%,  
Hispanic: 40%



# CARE Act

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- Opportunity for patient to identify a family caregiver to include in the patient- and family- centered care process...in the record
- Notification of discharge
- Teaching/anticipatory guidance for family caregiver expected to perform medical/nursing tasks

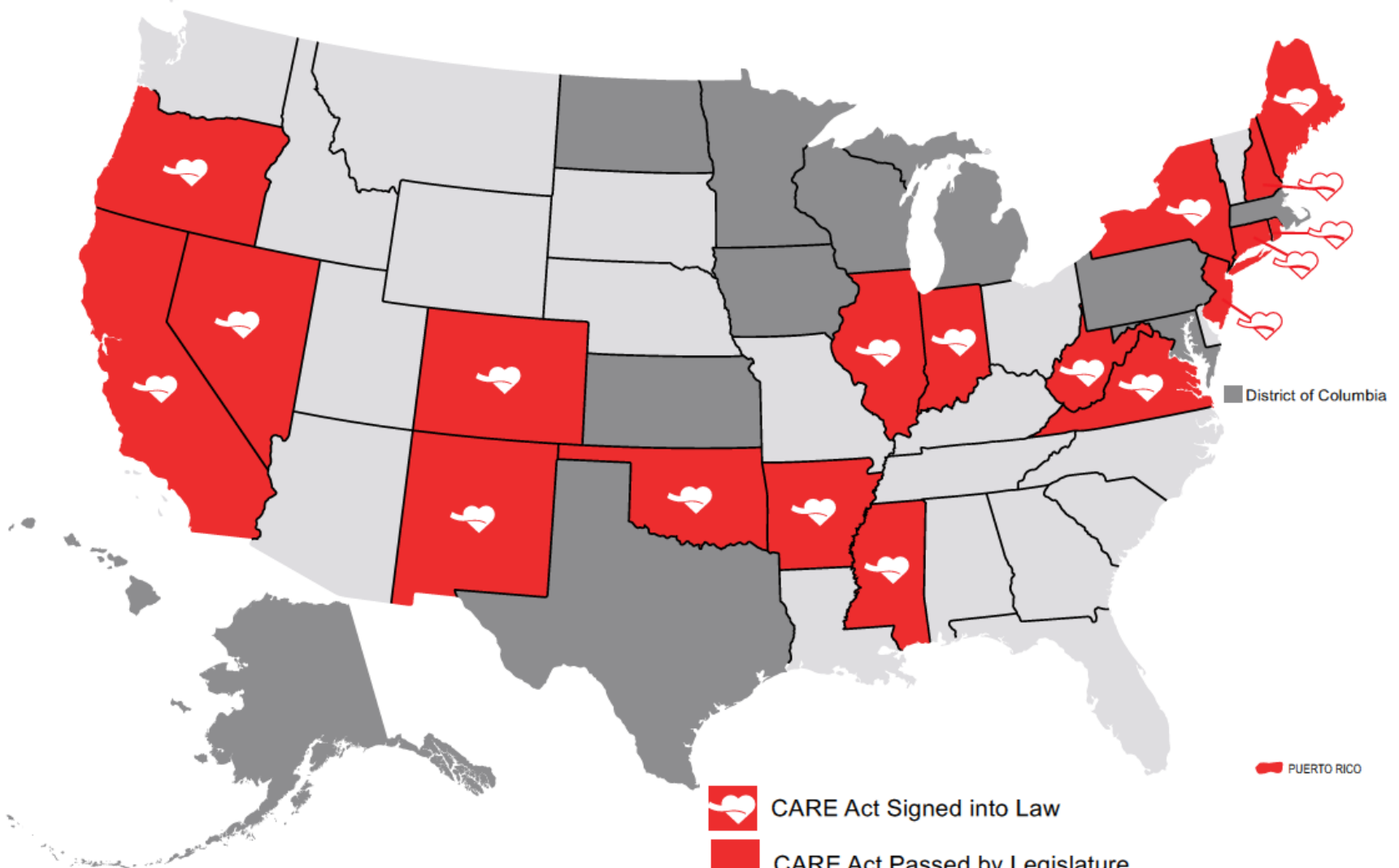
# CARE Act

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- Give support to nurses and other health and social service professionals to do what their professional standards of practice require them to do
- Stimulate new thinking on how to anticipate patient and family questions and pro-actively support them
- Reduce hospital re-admissions

# The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.



## CARE Act goes into effect:

Oklahoma, 11/5/14; Colorado, 5/8/15; New Jersey, 5/12/15; West Virginia, 6/8/15; New Mexico, 6/17/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 10/1/15; Maine, 10/15/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Rhode Island, 3/1/16; New York, 4/23/16

\*\*Updated on 11/16/2015

**I Heart Caregivers**  
AARP Real Possibilities

[aarp.org/iheartcaregivers](http://aarp.org/iheartcaregivers)

# Home Alone Alliance

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- Alliance of private, non profit, and academic organizations
- Change the field, change the culture
- Provide quality instructional videos for family caregivers performing complex tasks

# Family Caregiver Instructional Videos

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- Provide instructional vehicle on performing medical/nursing tasks
- Audience: Family Caregivers and Nursing Students
- First series focusing on medication management

# Growing Complexity of Family Care

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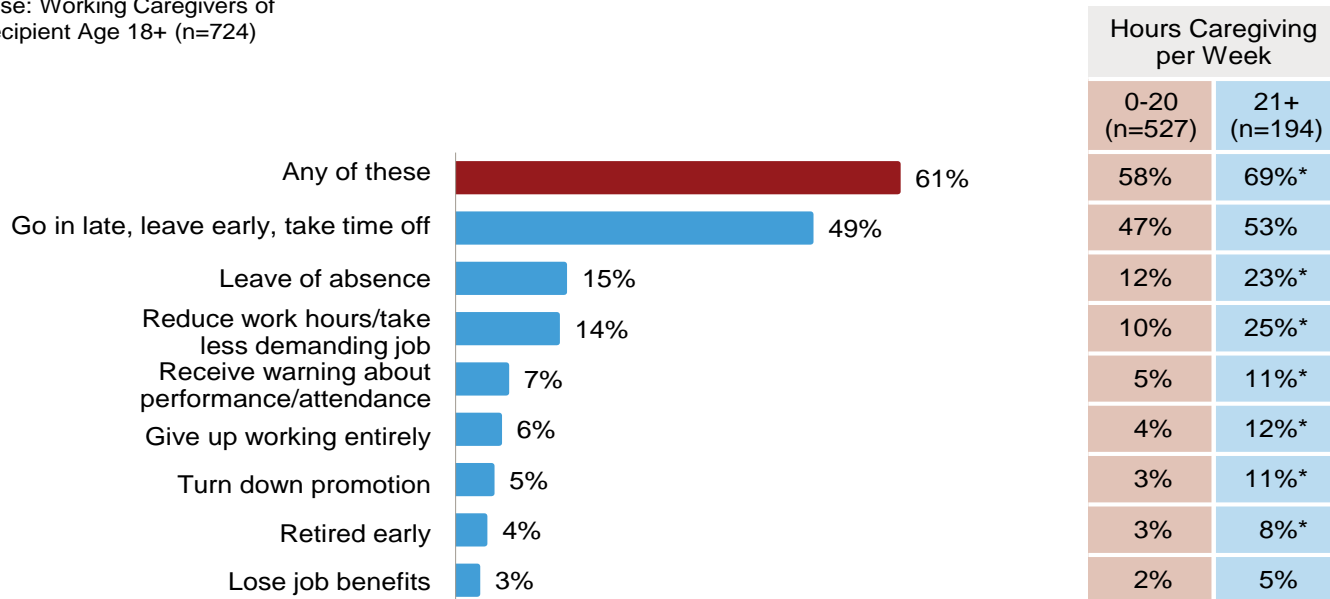
**Second emerging trend...**



More family caregivers are in the labor force, juggling demands of work, caregiving and other family responsibilities

# Balancing Caregiving and Work

Base: Working Caregivers of Recipient Age 18+ (n=724)



60% of caregivers were employed at some point in the past year while also caregiving. Higher-hour caregivers were more likely to report experiencing nearly all of these work impacts.

*Source: National Alliance for Caregiving and AARP Public Policy Institute, Caregiving in the U.S. 2015.*

# Other Impacts on Work/Caregiving Balance

- 70% of caregivers who perform medical/nursing tasks reported that caregiving impacted their job
- Of those who left their jobs:
  - 39% quit to have more time to provide care
  - 34% quit due to lack of job flexibility
  - 11%--an estimated 2.6 million workers—quit their jobs because they couldn't afford paid care.

*Source: National Alliance for Caregiving and AARP Public Policy Institute, Caregiving in the U.S. 2015.*





# Working Caregivers Need Help: Growing National Momentum

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- Strengthen “family-friendly” workplace flexibility policies
- Increase the reach of the FMLA
  - Expand coverage for in-laws, grandparents, siblings, other relatives, and protect workers in small businesses (fewer than 50 employees)
- Promote access to paid family leave
  - 3 states: CA, NJ, RI
- Promote access to paid sick days (3 to 9 days/yr.)
  - 3 states and DC: CA, CT, MA (OR’s law effective Jan. 2016)
- Protect workers with family caregiving responsibilities from discrimination in the workplace.

# Additional Resources

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## **AARP Public Policy Institute**

[www.aarp.org/ppi](http://www.aarp.org/ppi)

## **Home Alone: Family Caregivers Providing Complex Chronic Care**

<http://www.aarp.org/home-family/caregiving/info-10-2012/home-alone-family-caregivers-providing-complex-chronic-care.html>

## **Valuing the Invaluable 2015 Update**

<http://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>

## **Caregiving in the U.S. 2015**

<http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html>

## **AARP Caregiver Resource Center**

[www.aarp.org/caregiving](http://www.aarp.org/caregiving)

## **AARP I Heart Caregivers**

[www.aarp.org/iheartcaregivers](http://www.aarp.org/iheartcaregivers)

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