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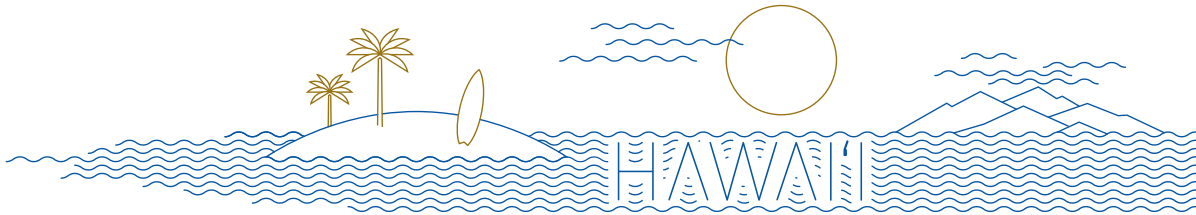
CHI 2024 Surfing the World 11-16 May 2024



Artificial Intelligence Systems for Supporting

Informal Caregivers

# of People Living with Alzheimer's Disease or Related Dementias: A Systematic Review

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Motivation-Background

Time- and resource-consuming caregiving activities for informal caregivers of people living with Alzheimer's disease or related dementias (PLWD)

The Needs of Informal Caregivers of PLWD

1. **Caregiving tasks**
   Physical/nursing care; Household work; Supervision/support; Coordination; Help received from others (informal & formal)
2. **Relationships with formal service providers**
3. **Housing**
4. **Juggling responsibilities**
5. **Financial costs**
6. **Personal health**
   Physical health; Emotional health
7. **Family relationships**
   With care recipient; With family
8. **Planning**
   Crises planning; Future planning; Information about dementia and dementia care; Information about professional support and formal services; Information about legal regulation in caring

Queluz, F. N., Kervin, E., Wozney, L., Fancey, P., McGrath, P. J., & Keefe, J. (2020). Understanding the needs of caregivers of persons with dementia: a scoping review. *International psychogeriatrics*, *32*(1), 35-52.

Motivation-Goal

To understand how artificial intelligence (AI) technology has been and can be better applied and designed to support informal caregivers of PLWD

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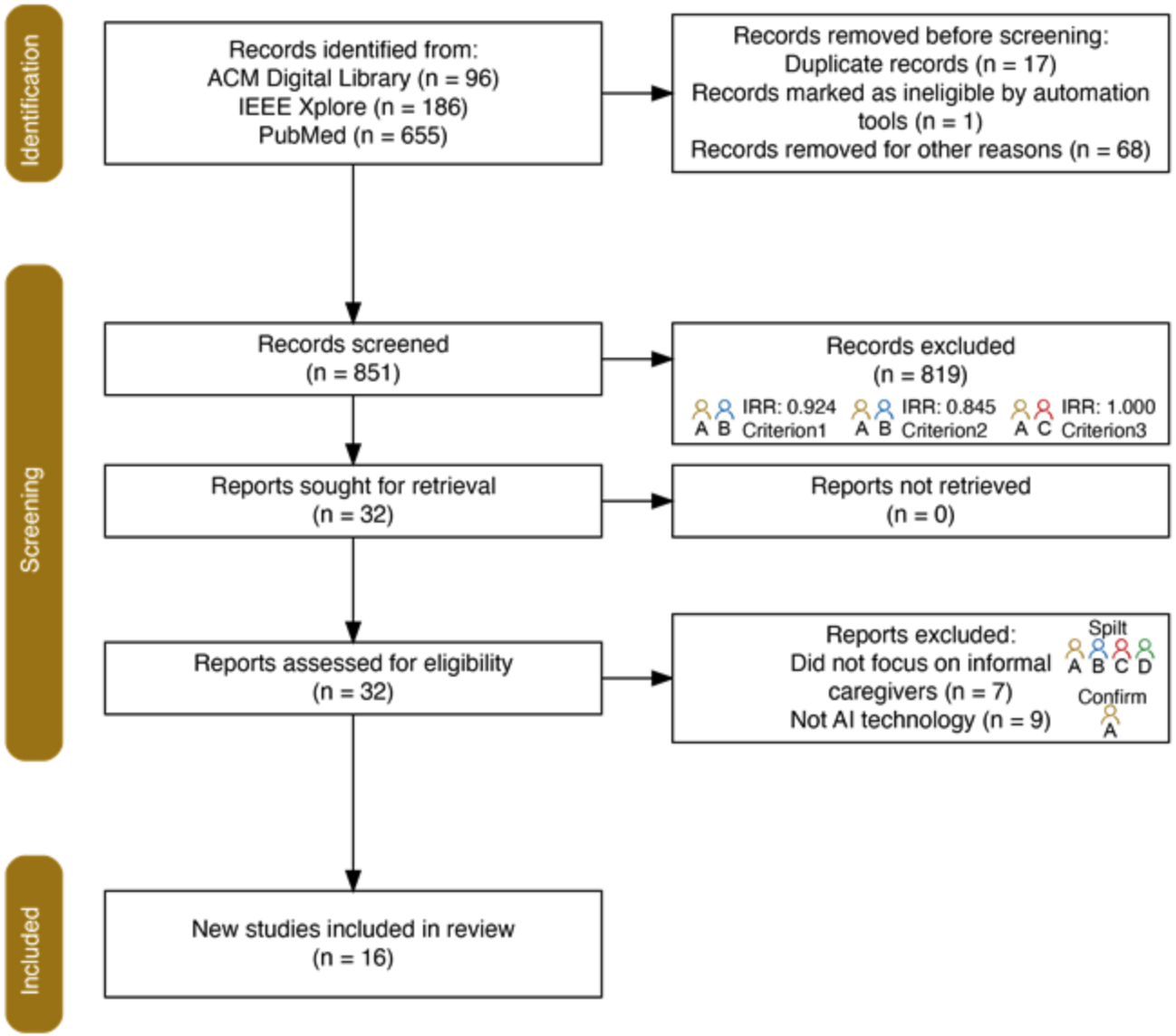
Methods



Research questions:

RQ1: What needs of informal caregivers of PLWD have or have not been investigated by AI solutions?

RQ2: What are the contexts of AI solutions for supporting the needs of informal caregivers of PLWD in terms of interfaces, data, and algorithms?

RQ3: What are the effectiveness, challenges, and limitations of these AI solutions?

Findings-Needs of Informal Caregivers of PLWD Investigated and Uninvestigated by AI Solutions

An Overview of Investigated and Uninvestigated Needs Based on the Framework of Needs of Caregivers of PLWD

Themes	Needs	#01	#02	#03	#04	#05	#06	#07	#08	#09	#10	#11	#12	#13	#14	#15	#16	Total
Caregiving Tasks	Physical/nursing care						■			■								2
	Household work			■														1
	Supervision/support	■	■				■		■		■	■	■		■		■	9
	Coordination																	0
	Help received from others																	0
Relationship with Formal Service Providers																		0
Housing																		0
Juggling Responsibilities							■											1
Financial Costs																		0
Personal Health	Physical health																	0
	Emotional health				■	■	■							■				4
Relationships	With care recipient						■											1
	With family						■											1
Planning	Crises planning																	0
	Future planning							■										1
	Info: dementia and dementia care			■	■													2
	Info: professional support/services															■		1
	Info: legal regulation in caring																	0

Findings-Contexts of AI Solutions to Support the Needs of Informal Caregivers of PLWD

An Overview of Interfaces Developed by the Studies

Themes	Needs	Software Applications	Wearable Devices	Smart Devices at Home	Smart Homes	Not Reported
Caregiving Tasks	Physical/nursing care	#06	#06, #09	#06		
	Household work			#03		
	Supervision/support	#01,#02, #06, #10, #12, #14	#01,#02, #06, #08, #10	#06	#11	#16
Juggling Responsibilities		#06	#06	#06		
Personal Health	Emotional health	#06	#06	#04, #06		#05, #13
Relationships	With care recipient	#06	#06	#06		
	With family	#06	#06	#06		
Planning	Future planning					#07
	Info: dementia and dementia care			#03, #04		
	Info: professional support and formal services	#15				

Findings-Contexts of AI Solutions to Support the Needs of Informal Caregivers of PLWD

An Overview of Data Acquired by the Studies

Themes	Needs	Sensors Data	Self-reports	Camera videos	Trusted resources	Frames of soap opera	Simulated data
Caregiving Tasks	Physical/nursing care	#06		#09			
	Household work				#03		
	Supervision/support	#01,#02, #06, #08, #10, #11, #14	#01,#02,#10	#10		#16	#12
Juggling Responsibilities		#06					
Personal Health	Emotional health	#06,#13	#05,#13		#04		
Relationships	With care recipient	#06					
	With family	#06					
Planning	Future planning		#07				
	Info: dementia and dementia care				#03, #04		
	Info: professional support and formal services		#15		#15		

Findings-Contexts of AI Solutions to Support the Needs of Informal Caregivers of PLWD

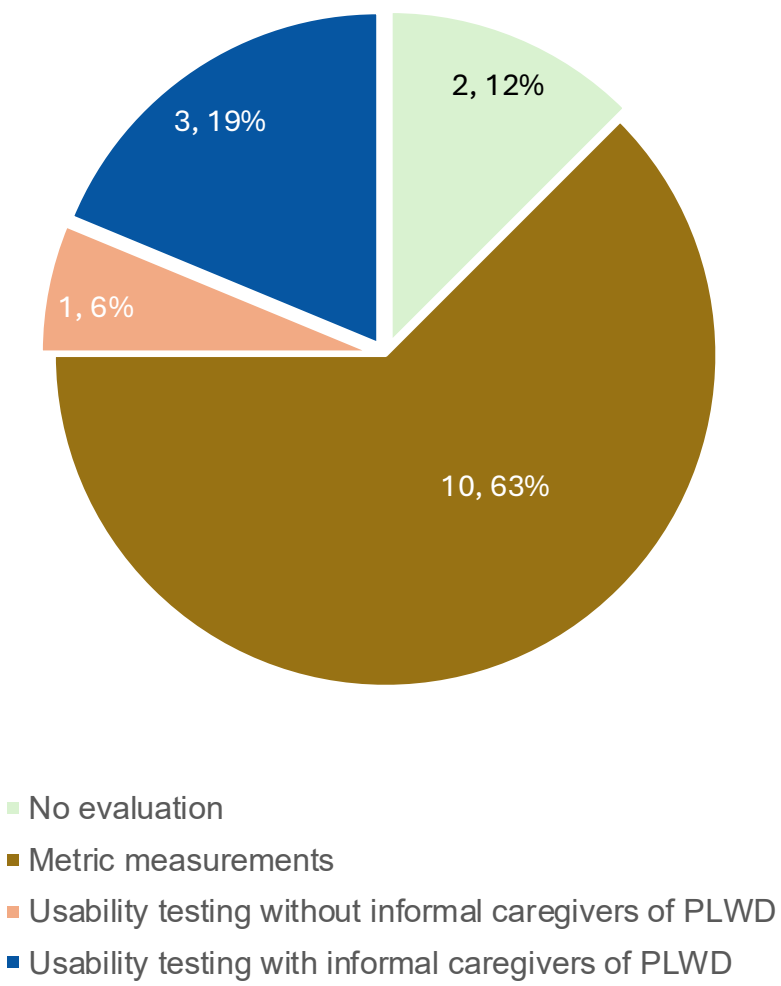
An Overview of Algorithms Applied by the Studies

Themes	Needs	Algorithms
Caregiving Tasks	Physical/nursing care	OpenFace Library [#09] Amazon Rekognition [#09] Adaptive Network-based Fuzzy Inference System [#06] CNN [#09] LSTM [#09] PCA [#09]
	Household work	Amazon Alexa [#03]
	Supervision/support	Android Activity Recognition API [#14] LSTM [#01] Axis-parallel Rectangle-based MIL [#02] Boosting Bag-level Decision Stumps (MIL-Boost) [#02] XGBoost Model [#08] Adaptive Network-based Fuzzy Inference System [#06] Multi-layered Perceptron network [#10] Decision Tree [#10] Random Forest [#11] Finite State Machine [#11] CNN [#16] SVM [#02, #10, #16] Dirichlet Process Mixture Model [#11] Dynamic Bayesian Network [#11] N-gram Model [#11] NR (OpenFaas Computing Framework) [#12]
Juggling Responsibilities		Adaptive Network-based Fuzzy Inference System [#06]
Personal Health	Emotional health	Scaled Conjugate Gradient Backpropagation Neural Network [#05] Neural Network Models proposed to be used [#13] Adaptive Network-based Fuzzy Inference System [#06] NR (AI-embedded Humanoid Social Robot) [#04]
Relationships	With care recipient	Adaptive Network-based Fuzzy Inference System [#06]
	With family	Adaptive Network-based Fuzzy Inference System [#06]
Planning	Future planning	Decision Tree [#07]
	Info: dementia and dementia care	Amazon Alexa [#03] NR (AI-embedded Humanoid Social Robot) [#04]
	Info: professional support and formal services	Hybrid Filtering Approach with a Content-based Algorithm and Rule-based Filtering [#15]

Note: NR - Algorithm Not Reported; CNN - Convolutional Neural Network; LSTM - Long Short-term Memory Network; SVM - Support Vector Machine; PCA - Principal Component Analysis; MIL - Multiple-Instance Learning

Findings-Effectiveness, Challenges, and Limitations of AI Solutions in Supporting Informal Caregivers of PLWD

Evaluation Methods for the Effectiveness



Challenges:

1. Model developing and running:
   Computing diverse data, getting ground truth data, developing standardized algorithms, real-time running and computing
2. User recruitment and ethical issues:
   Recruiting older adults, and collecting personal data and health information

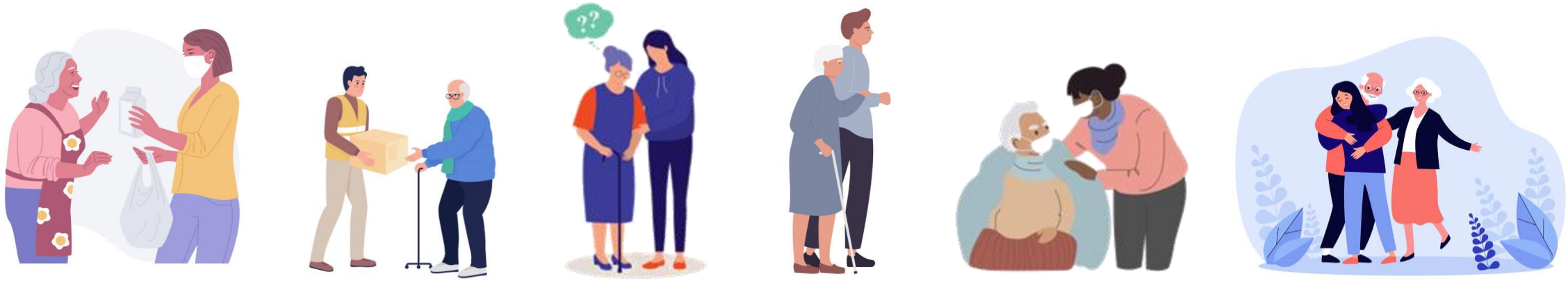
Limitations:

1. User needs:
   Lack of support for informal caregivers of PLWD in late stages and older adults
2. Performance:
   Limited accuracy, limited interaction capabilities, trade-offs in recommendation strategies
3. Research:
   Limited generalizability of the study findings

Future Work

Caregiver-centered AI solutions:

- Having a deeper understanding of the nuanced needs of caregivers across different demographics and PLWD at various stages;
- Exploring the yet uninvestigated needs of informal caregivers;
- Involving caregivers in the design and evaluation process of AI solutions;
- Overcoming the limitations of current AI applications, addressing identified challenges, and ensuring that they not only meet practical needs but also resonate ethically and empathically with their users.



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