Developing a Digital Assistive Tool for Dementia Patients and their Caregivers: A Qualitative Study on Needs, Potential Functions, User Acceptance, and Ethical Considerations

Lenka J. Wichmann, MSc, Nele Reiff, BSc, Sophie Zintl, BSc, Prof. Matthias Berking, PhD (2021)

Department of Clinical Psychology and Psychotherapy, Friedrich-Alexander-University Erlangen-Nürnberg (FAU)
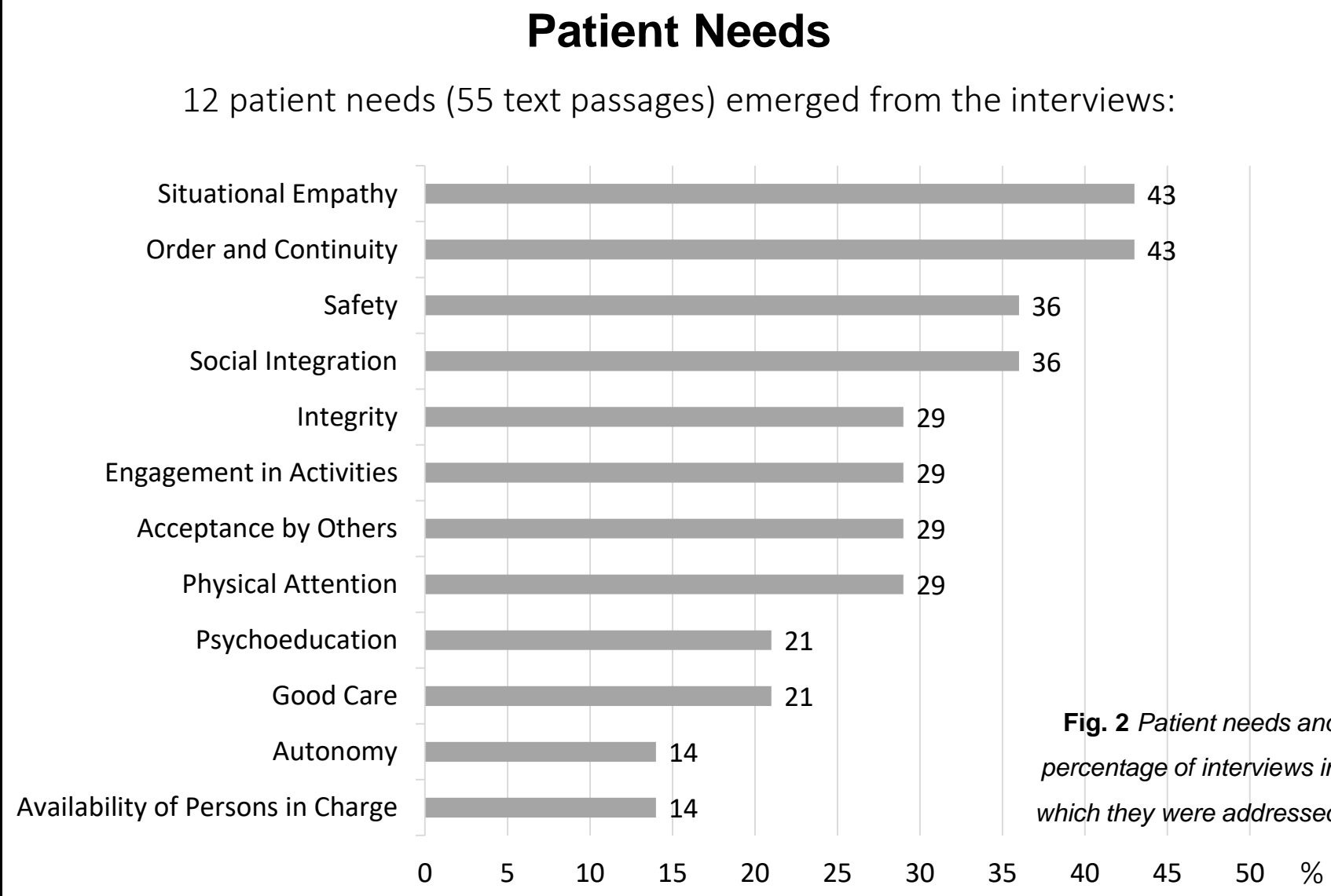
Background & Aims

- Assistive mobile applications (i.e. smartphones and tablets) for the healthcare of people with dementia (PwD) and the support of their caregivers have shown great potential to help with daily life stressors and improve subjective well-being [1].

- The accessability and wide availability of smartphones and tablets and a growing number of users aged above 65 underline the potential of applying these technologies for PwD and their caregivers.

- Research so far has concentrated on applications that:
  – include only a narrow range of functions (e.g. focus exclusively on cognitive training, monitoring, or tracking [1])
  – target only one particular stakeholder group (e.g. usage exclusively by patients, caregivers, or relatives [1]).

- This qualitative interview study was the first step in a co-creative process with a user-centered, participatory approach aimed at developing an integrative and multifunctional mobile assistant for PwD, their caregivers and their relatives.
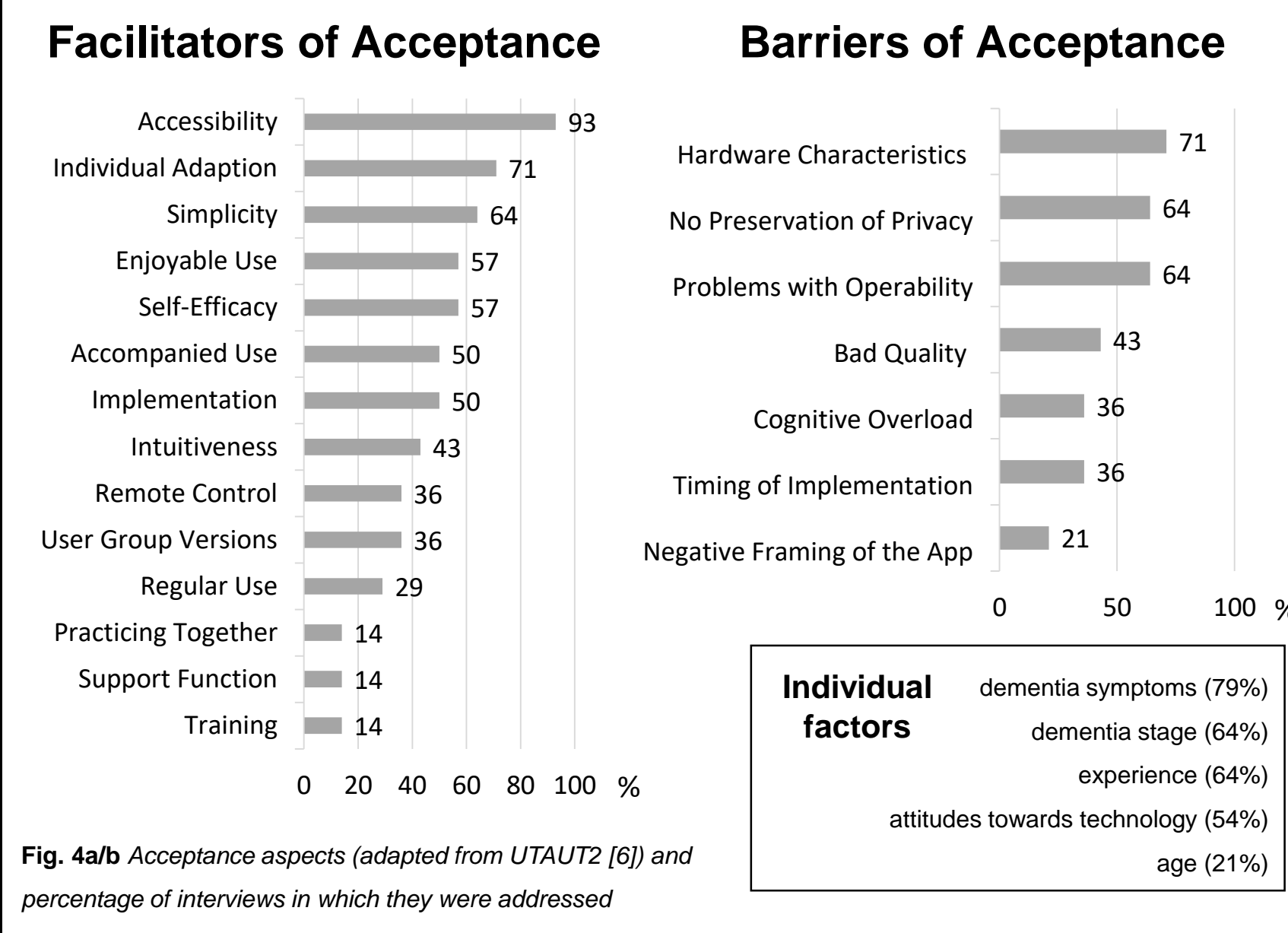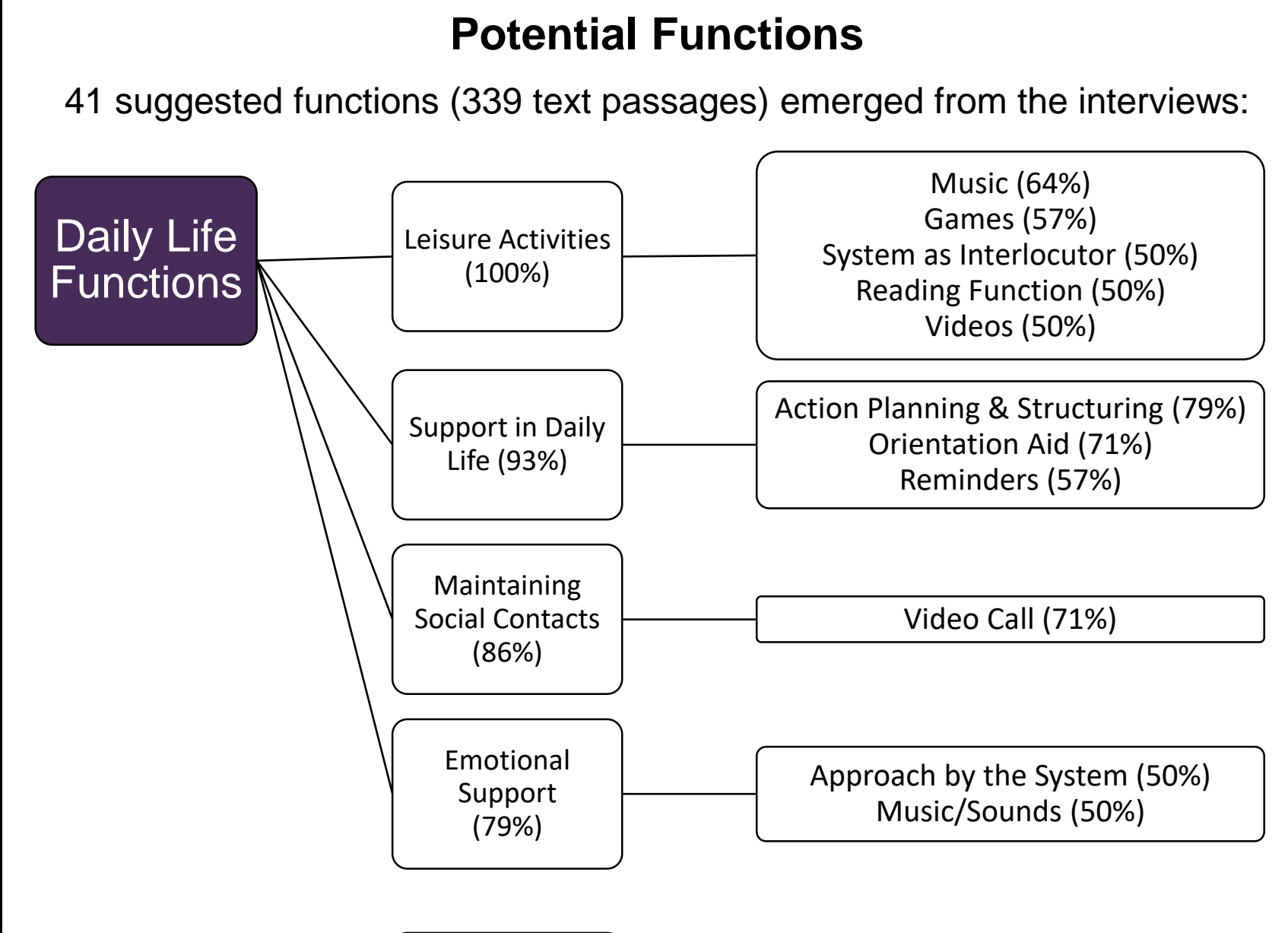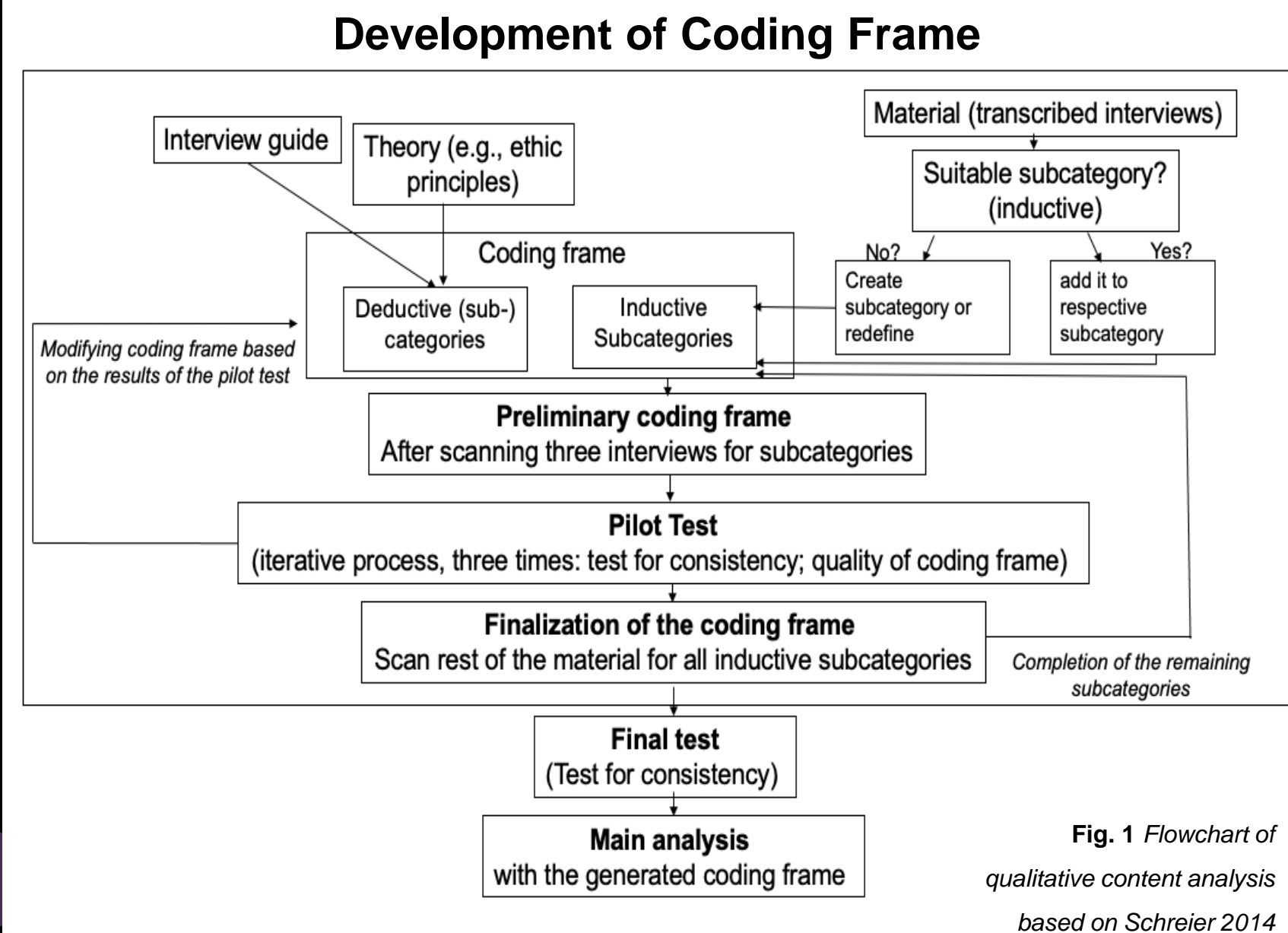
Methods

- 14 semi-structured interviews were conducted via video conferences (*Jitsi Meet*) with 15 participants (60% female, age: mean$_{age}$=49.67, SD$_{age}$=10.44)

- Groups: n = 6 relatives, n = 6 professional caregivers, n = 3 psychologists

- An interview guide was developed theory-based and covered the themes: a) background information and living situation, b) stresses and strains in dealing with dementia, c) needs of the patients and the respective interviewed group, d) potential functions and areas of application of a digital assistant, e) acceptance aspects, and f) ethical considerations

- Post-questionnaires on demographics & acceptance (TUI [2], questions rating suggested functions for acceptability), technological affinity (TA-EG [3])

- Transcribed interviews (verbatim via audio-recordings) were analysed using qualitative content analysis [4] in MAXQDA. A coding frame was developed (mixed inductive/deductive) summarizing the emerging interview themes (see Fig. 1).

Results

Development of Coding Frame

Fig. 1 *Flowchart of qualitative content analysis based on Schreier 2014*

Patient Needs

12 patient needs (55 text passages) emerged from the interviews:

Need	Value
Situational Empathy	43
Order and Continuity	43
Safety	36
Social Integration	36
Integrity	29
Engagement in Activities	29
Acceptance by Others	29
Physical Attention	29
Psychoeducation	21
Good Care	21
Autonomy	14
Availability of Persons in Charge	14

Fig. 2 *Patient needs and percentage of interviews in which they were addressed*

Potential Functions

41 suggested functions (339 text passages) emerged from the interviews:

Daily Life Functions

- Leisure Activities (100%) → Music (64%), Games (57%), System as Interlocutor (50%), Reading Function (50%), Videos (50%)
- Support in Daily Life (93%) → Action Planning & Structuring (79%), Orientation Aid (71%), Reminders (57%)
- Maintaining Social Contacts (86%) → Video Call (71%)
- Emotional Support (79%) → Approach by the System (50%), Music/Sounds (50%)

Care-Related Functions

- Digital Care and Support (100%) → Communication Interface (86%), Dementia Information (50%)
- Training of Physical and Cognitive Abilities (93%) → Cognitive Abilities (71%), Physical Abilities (50%)
- Monitoring of Physical, Mental, and Emotional State (79%)
- Navigation and Location Monitoring (79%) → GPS-Tracking (64%)
- Monitoring Disease Progression (71%) → Diagnostics by the System (50%)

Note. *In this column, only those functions being mentioned in ≥ 50% of interviews are displayed*

Fig. 3 *Daily life and care-related functions and percentage of interviews in which they were addressed*

Facilitators of Acceptance

Facilitator	Value
Accessibility	93
Individual Adaption	71
Simplicity	64
Enjoyable Use	57
Self-Efficacy	57
Accompanied Use	50
Implementation	50
Intuitiveness	43
Remote Control	36
User Group Versions	36
Regular Use	29
Practicing Together	14
Support Function	14
Training	14

Barriers of Acceptance

Barrier	Value
Hardware Characteristics	71
No Preservation of Privacy	64
Problems with Operability	64
Bad Quality	43
Cognitive Overload	36
Timing of Implementation	36
Negative Framing of the App	21

Individual factors	
dementia symptoms	79%
dementia stage	64%
experience	64%
attitudes towards technology	54%
age	21%

Fig. 4a/b *Acceptance aspects (adapted from UTAUT2 [6]) and percentage of interviews in which they were addressed*

Ethical Considerations

- **Human Contact** main ethical concern:
  – reduction in human contact (93%)

- **Data Security** ambivalent results:
  – concern and need for strict data security regulations (50%)
  – no concerns (43%)

- **Monitoring** (79%) ambivalent results:
  – conflict with personal rights of PwD
  – contributing to security and independence of PwD

- **Beneficence** (50%), Nonmaleficence (36%), Autonomy (36%), Justice (21%)

Discussion

- The study shows that a mobile assistant adapted to the needs of users can increase independence in daily life and save care resources

- **Strength** Multidimensional (variety of groups and topics) & co-creative approach (needs and expectations of users considered – crucial for later use)

- **Limitation** PwD not interviewed (due to COVID-19 pandemic)

- **Future studies** should include PwD

References
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