

The Dementia Assessment of Service Needs (DEMAND): Development and Validation of a Standardized Needs Assessment Instrument

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Abstract.

Background: Dementia is one of the main triggers for care dependency among older adults who are predominantly cared for at home by relatives. To provide support in the care situation, health systems need valid information about the central needs of the affected people.

Objective: The present study aimed to develop a research instrument to assess the most important needs of people with dementia and their family caregivers.

Methods: The development of the 'Dementia Assessment of Service Needs (DEMAND)' took place within the project 'Digital Dementia Registry Bavaria (digiDEM Bayern)'. A focus group and an online survey with dementia experts were conducted to identify the most relevant support services and to develop the design of the instrument. The questionnaire was deployed in the digiDEM baseline data collection. Participants were asked to evaluate the comprehensibility of the questionnaire. Readability was assessed using the Flesch reading ease score.

Results: Seventeen experts participated in the focus group and 59 people in the online survey. The final questionnaire included 13 support services. One hundred eighty-three participants (50 people with dementia and 133 family caregivers) completed the questionnaire at baseline. The mean comprehensibility score was 3.6 (SD = 2.3). The Flesch reading ease score result was 76.

Conclusion: A research instrument could be developed, enabling people with dementia and family caregivers to directly express their individual needs for specific support services. Results show that the DEMAND is easy to understand and short in execution. Therefore, supply gaps can be identified and transformed into a specific health care plan.

Keywords: Demand, dementia, digiDEM, health services research, needs, resource use

INTRODUCTION

Dementia is one of the main triggers for care dependency among older adults [1]. Most of the people with dementia are cared for at home by relatives [2, 3], which are at increased risk for burden, stress,

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and health-related problems [4–6]. In order to provide a health care policy that is beneficial for people with dementia and their family caregivers, health care decision-makers need valid information about the central needs of those people and how to meet them.

Hitherto, there is no theoretical conceptualization of the needs of dementia family caregivers [7]. However, Stirling et al. developed a typology of need in a mixed-methods study, referring to Bradshaw's sociological typology of need [8]. The typology distinguishes between *normative need* (professionally identified caregiver burden), *felt need* (need for a service articulated by service users), *expressed need* (service usage), and *comparative need* (comparison between groups of service users with groups of non-service users). Within the specific care situation, the needs and burden of dementia family caregivers are highly linked to the needs and service use of the people with dementia [9]. Hence, the identification of *felt* and *expressed needs* of people with dementia affects the entire care situation and consequently the situation of the family caregiver as well. In this respect, the utilization of care services of people with dementia can provide relief for family caregivers [9].

Studies and research instruments that examine *felt needs*, often assess those needs on a problem-centered level, irrespective of specific support services to meet such needs [10]. In this respect, the existence of a need is derived from participants' expression of having problems in certain (care-related) areas or from specific disease-related symptoms of the people with dementia. This can be problematic, as needs derived from a problem- or symptom-centered perspective may not be met sufficiently by the offered services [10].

Thus, the aim of the present study was to develop a short and practical assessment instrument in order to assess the most important needs of people with dementia and their family caregivers by directly asking about the need after specific support services. As *felt needs* and *expressed needs* have a strong interdependence, the instrument aims to identify both *expressed needs* by asking about the former utilization of services and *felt needs* by asking about the demand of using support services in the future.

METHODS

Development of the assessment instrument

The development of the Dementia Assessment of Service Needs (DEMAND) (Fig. 1) took place

in the frame of the project 'Digital Dementia Registry Bavaria – digiDEM Bayern'. digiDEM is a multicenter, prospective, longitudinal register study including people with mild cognitive impairment (MCI) and mild to moderate dementia in Bavaria. All participants will undergo dementia screening prior to study inclusion, using Mini-Mental State Examination (MMSE) [11] and Montreal Cognitive Assessment (MoCA) [12]. The methodology of the project is described elsewhere [13]. Following the concept of Multi-criteria Decision Analysis (MCDA) [14], the development of the DEMAND was realized in close cooperation with experts from the field of dementia. In this respect, one focus group and one online survey were conducted.

Recruitment of experts

The definition of experts and the process of experts' recruitment is based upon various methodological sources [15–18]. In the project, experts were recruited who are involved in dementia care in specific background and that dealt with dementia care informally for at least two years or professionally for at least ten years. In this respect, for participating in the focus group, informal caregivers and patient representatives were recruited in order to include the perspective of the affected people as well as professional caregivers, medical staff, consultants for dementia care, and scientists. Experts were identified and chosen on dementia-specific events, past cooperation in former projects, and existing dementia networks.

Focus group

A focus group was conducted as a basis for the design of the data collection instrument, as focus groups are suitable for addressing multiple facets of and including multiple perspectives on an issue [19, 20]. Experts were asked to discuss two aspects. First, experts should identify all existing and imaginable support services for people with dementia and their family caregivers. Therefore, participants decided to distinguish support services according to the target group (people with dementia and family caregivers) and severity of dementia. The identified services were recorded on index cards and subsequently discussed with the experts in a moderated discussion. In a second step, experts should discuss the design of the

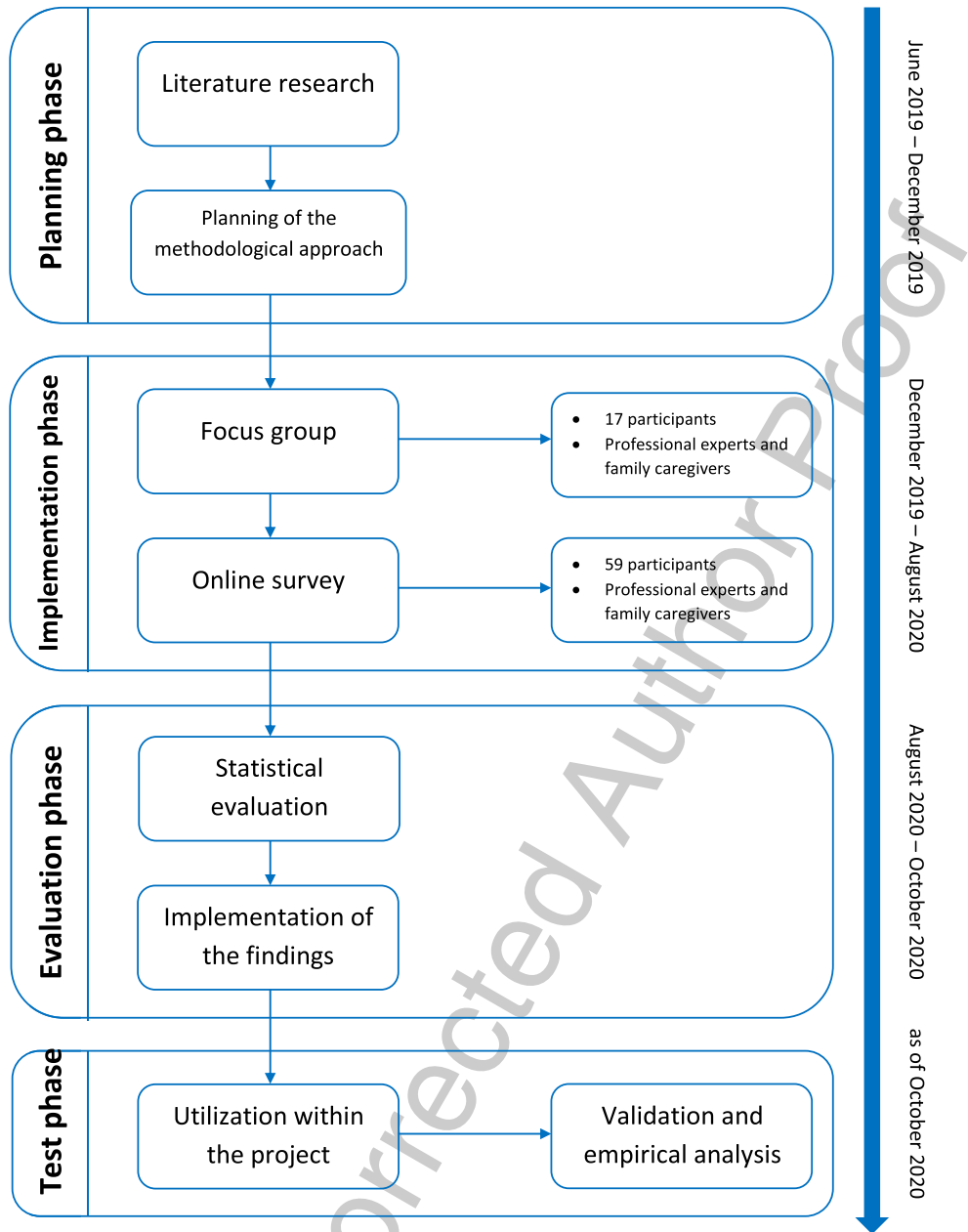


Fig. 1. Development process of the DEMAND

132 different question items. Therefore, a predesigned
 133 pattern was presented and discussed in the focus
 134 group. The conversations were recorded with a digital
 135 recording device and subsequently transcribed. The
 136 content was evaluated according to the qualitative
 137 content analysis of Mayring [21], using MAXQDA
 138 2018 (VERBI Software, 2017) [22]. The analysis of
 139 the interviews was performed according to the sum-

140 marizing content analysis technique, following an
 141 iterative, inductive approach in order to identify the
 142 central categories of the transcribed conversations.
 143 The identification of the categories and the assign-
 144 ment of the content to the categories were performed
 145 independently by two authors. In cases of discrep-
 146 ancy, a consensus was reached discursively within
 the research group.

RESULTS

Development of the assessment instrument

Focus group

Seventeen experts participated in the focus group. Four informal caregivers, two professional caregivers, two medical practitioners, two patient representatives, three consultants for dementia care, and four scientists were included. The experts could identify 74 different support services in total. In the following qualitative evaluation process, the 74 support services could be summarized to 44 support services, which built the fundament for the subsequent online survey. Lists with all identified and summarized support services from the focus group are provided as Supplementary Material.

Online survey

Fifty-nine people finished the online survey. Participants were 30 informal caregivers, four professional caregivers, nine medical practitioners, one patient representative, eight consultants for dementia care, six scientists, and one citizen volunteer. Participants had on average 13 years of experience in dementia care (informal caregivers: 5.9 years; professional experts: 20.3 years). 66.0% of the participants were female. The five highest-rated services were primary care by a general practitioner, prevention care, short-term care, adult daycare, and palliative care.

Structure and content of the instrument

The instrument consists of 13 care services. Additionally, the category "other service" is included in order to provide the option to mention the use of and need for services that are not part of the 13 care services. Each care service is provided with a formal definition in order to avoid different understandings of the care service and assessed according to the same structure. The first question assesses if a specific care service was used in the past 30 days. The time frame of 30 days was chosen in order to get valid information about frequently used services by simultaneously diminishing a possible recall bias of participants. Participants can reply that they did or did not use the service. Dependent on the answer, the interview follows two different paths.

If there was a utilization, participants should express how often the service was used and if there is a met or unmet need. Therefore, participants were

asked if the utilization of the service was sufficient and satisfying (met need), if the utilization of the service was not satisfying (unmet need), or if there was a desire to use the service more often (unmet need).

In case there was no utilization of the service, participants were asked about the reasons for not using the care service. At this point, participants have the options to express that they did not know the service before the interview (no knowledge), that they do not need the service currently (no need), or if they wish to use the service but cannot do so due to certain reasons (unmet need). The prescribed answer options, in this case, are 'The service is not available (e.g., no places available or the service doesn't exist)'; 'I cannot finance the service'; 'Due to the distance I cannot reach the service or the service cannot come to me.'; 'I am afraid that if I use the service the disease will become public'; 'The utilization is not possible due to personal (e.g., cultural) aspects' or other reasons (free text field). Thus, changes in the availability and eligibility of services over time that result in a non-utilization of the services can be investigated. The answer 'no knowledge' could also be a hint at an unknown unmet need, as a specific yet unknown service might be useful in a specific situation for the respective people with dementia and their family caregivers.

For the investigation of timely changes in service use, the questionnaire should be repeated frequently every six months or annually as indicated by the International Consortium for Health Outcomes Measurement (ICHOM) for follow-up periods in research [26]. The duration of the instrument does not exceed 15 minutes on average.

Validation

One hundred eighty-three participants (50 people with dementia and 133 family caregivers) completed the DEMAND questionnaire at baseline. Additionally, 40 people with MCI completed the DEMAND questionnaire at baseline for sensitivity analysis. Baseline characteristics are summarized in Table 1. On average, participating people with dementia were 83.6 years old and predominantly female (68.0%). The mean MMSE score was 20.5 (SD = 2.3). Participating family caregivers were on average 65.1 years old and predominantly female (69.2%).

The most frequently used services were primary care by a general practitioner (GP) (55.7%), outpatient care (53.6%), and housekeeping assistance (44.3%) (Table 2). The services Caregiver Training

Table 1
Baseline characteristics

Variable	People with dementia (n = 50)		Family caregivers (n = 133)	
	mean / number	SD / %	mean / number	SD / %
Age	83.6	6.4	65.1	12.8
Female	34	68%	92	69.2%
Education				
No school-leaving qualification	3	6.0%	2	1.5%
Lower secondary school leaving certificate (Volksschulabschluss)	30	60.0%	29	21.8%
Lower secondary school leaving certificate (Hauptschulabschluss)	4	8.0%	28	21.1%
Secondary school certificate (Mittlere Reife)	12	24.0%	46	34.6%
Advanced technical college certificate (Fachhochschulreife)	0	0%	13	9.8%
Higher education entrance qualification (A-levels) (Abitur)	1	2.0%	15	11.3%
Caregiving time in hours per day				
Assistance with ADL (n = 108)		2.8	3.3	
Assistance with IADL (n = 105)		3.2	2.8	
Supervision (n = 99)		1.8	3.2	
MMSE	20.5	2.3		
Diagnosis confirmed by further diagnostic measures	23	46.0%	83*	62.4%*
Type of dementia				
Dementia in Alzheimer disease (F00.*)	10	43.5%	46	55.4%
Vascular dementia (F01.*)	0	0%	14	16.9%
Dementia in other diseases classified elsewhere (F02.*)	0	0%	3	3.6%
Unspecified dementia (F03)	13	56.5%	20	24.1%

ADL, activities of daily living; IADL, Instrumental activities of daily living; MMSE, Mini-Mental State Examination; MoCA, Montreal Cognitive Assessment; SD, standard deviations. *Diagnosis of the person with dementia that is cared for by the family caregiver.

Table 2
Utilization of support services

Support Service	Cases	Used (%)	Not used (%)
Outpatient care	183	98 (53.6%)	85 (46.4%)
Acquisition of aids	183	47 (25.7%)	136 (74.3%)
Primary care by a GP	183	102 (55.7%)	81 (44.3%)
Housekeeping assistance	183	81 (44.3%)	102 (55.7%)
Short-term care	183	4 (2.2%)	179 (97.8%)
Palliative care	183	1 (0.5%)	182 (99.5%)
Provision of psychosocial interventions	183	58 (31.7%)	125 (68.3%)
Nursing home	183	0 (0%)	183 (100%)
Adult daycare	183	32 (17.5%)	151 (82.5%)
Respite care	132	10 (7.6%)	122 (92.4%)
Counseling services	183	38 (20.8%)	145 (79.2%)
Caregiver Training Programs for family caregivers	132	4 (3.0%)	128 (97.0%)
Supported living and alternative housing services	183	15 (8.2%)	168 (91.8%)

330 Programs for family caregivers, short-term care, and
 331 palliative care were used by less than 5.0%. The ser-
 332 vice nursing home was not used at all as caused by
 333 exclusion criteria of the project digiDEM.

334 Information concerning the need for services and
 335 reasons for non-utilization are presented in Tables 3
 336 and 4.

337 Content validity

338 In order to ensure that the construct ‘need for
 339 support service’ is matched by the items investigat-
 340 ing the construct, experts were asked to identify all
 341 existing and imaginable support services. As afore-
 342 mentioned, 74 different support services could be

343 identified, encompassing the content of the construct
 344 ‘need for support service’. The identified services
 345 were then compared to scientific literature in order to
 346 ensure no important service was missed. The results
 347 of the subsequent online survey determined the items
 348 necessary to assess the construct ‘need for support
 349 service’.

350 Face validity

351 Comprehensibility

352 The mean comprehensibility score in the study
 353 sample was 3.6 (SD=2.3; people with demen-
 354 tia: 3.8, SD=2.3; family caregivers: 3.5, SD=2.2)
 355 and thereby above the middle value of the scale

Table 3
Need for support services (if service was not used)

Support Service	Cases	Service was unknown (%)	Need of service (%)	No need of service (%)
Outpatient care	85	5 (5.9%)	3 (3.5%)	77 (90.6%)
Acquisition of aids	136	11 (8.1%)	4 (2.9%)	121 (89.0%)
Primary care by a GP	81	3 (3.7%)	1 (1.2%)	77 (95.1%)
Housekeeping assistance	102	8 (7.8%)	8 (7.8%)	86 (84.3%)
Short-term care	179	30 (16.8%)	3 (1.7%)	146 (81.6%)
Palliative care	181	50 (27.6%)	0 (0%)	131 (72.4%)
Provision of psychosocial interventions	125	22 (17.6%)	10 (8.0%)	93 (74.4%)
Nursing home	183	10 (5.5%)	0 (0%)	173 (94.5%)
Adult daycare	151	32 (21.2%)	11 (7.3%)	108 (71.5%)
Respite care	122	28 (23.0%)	2 (1.6%)	92 (75.4%)
Counseling services	145	41 (28.3%)	5 (3.4%)	99 (68.3%)
Caregiver Training Programs for family caregivers	128	34 (26.6%)	5 (3.9%)	89 (69.5%)
Supported living and alternative housing services	168	51 (30.4%)	2 (1.2%)	115 (68.5%)

Table 4
Reasons for non-utilization of support services (multiple answers were possible)

Support Service	Service is not available	Service is not financeable	Too far distance	Fear of public disclosure of dementia	No use because of personal aspects
Outpatient care	2	0	0	0	1
Acquisition of aids	0	1	1	1	1
Primary care by a GP	0	0	1	0	0
Housekeeping assistance	7	1	0	0	0
Short-term care	3	0	0	0	0
Palliative care	0	0	0	0	0
Provision of psychosocial interventions	9	1	1	0	0
Nursing home	0	0	0	0	0
Adult daycare	5	0	1	1	6
Respite care	0	0	0	0	2
Counseling services	5	0	0	0	0
Caregiver Training Programs for family caregivers	4	0	0	0	2
Supported living and alternative housing services	1	1	0	0	0

(5.5), indicating that the questionnaire was fairly comprehensible for both people with dementia and family caregivers. Sensitivity analysis for people with MCI showed a mean comprehensibility score of 2.3 (SD = 1.5, $n = 40$) proving that the DEMAND is well comprehensible for people with MCI as well.

Readability

The Flesch reading ease score result was 76, which indicates that the written content is fairly easy to read according to the classification of the score [25].

Objectivity

Objectivity was ensured by providing training for the performance of the DEMAND and access to the manual (including the instruction for performing the instrument in an interview situation and for analyzing the results) on the project home-

page (<http://www.digidem-bayern.de>). The manual includes the paper-based and digital performance of the DEMAND using REDCap [27, 28].

DISCUSSION

The specific feature of the DEMAND is that it is directly assessing the utilization of and need for care services instead of being based upon a problem-centered level. Thereby, two important and highly interdependent areas of health outcomes research are combined in one data collection instrument. Moreover, unlike other instruments, the assessment instrument is investigating the reasons for not using a service. By doing this, the DEMAND can provide essential information for improving the care situation of people with dementia and their family caregivers. Another important element is that the DEMAND is considering the needs of both people

389 with dementia and their family caregivers. Therefore,
 390 the questionnaire implies elements concerning the
 391 care situation, which is relevant for both people with
 392 dementia and family caregivers, but also elements
 393 specifically targeting the family caregivers. In this
 394 respect, the DEMAND was specifically developed for
 395 and validated in a population of people with demen-
 396 tia and their family caregivers, ensuring its validity in
 397 the respective target population. A further important
 398 aspect is that the DEMAND is easy to understand
 399 and short in execution so that the application will not
 400 be overwhelming. Results of the comprehensibility
 401 assessment indicate that the questionnaire was fairly
 402 comprehensible for both people with dementia and
 403 family caregivers. The Flesch reading ease score of
 404 76 indicates that the questionnaire is fairly easy to
 405 read. For comparison, the Camberwell Assessment of
 406 Need for the Elderly (CANE) reports a Flesch read-
 407 ing ease score of 71.8 [29]. Processing time does not
 408 exceed 15 minutes on average. Finally, due to his
 409 practical usability, the DEMAND aims to be applied
 410 in both scientific and clinical/consultation contexts.

411 *Relevance of needs assessment*

412 Support services have the potential to develop
 413 positive effects on both people with dementia and
 414 family caregivers [9]. However, international litera-
 415 ture shows that utilization rates are low despite there
 416 is often a range of offered care services [30–32]. In
 417 this respect, low utilization rates can be a hint of a mis-
 418 match between the offered services and the demanded
 419 services of the people with dementia and their fami-
 420 ly caregivers [31]. Moreover, studies discussed a
 421 lack of knowledge about services themselves, their
 422 availability, and a lack of orientation in the complex
 423 systems as main reasons for non-utilization [31, 33,
 424 34]. The DEMAND questionnaire is designed to dis-
 425 play changes in the utilization of and need for support
 426 services and can provide important information when
 427 applied in longitudinal settings.

428 In a systematic review, Schmid et al. identified
 429 17 needs assessment instruments. The instruments
 430 varied highly in several domains such as level of
 431 assessment, target group, validation measures and
 432 sample, duration, and application [10]. Novais et al.
 433 [35] included 70 studies in their review concerning
 434 the identification of needs of informal caregivers.
 435 However, not in all the studies, standardized research
 436 instruments were used. Mansfield et al. [36] could
 437 identify 4 studies in their review about the quality
 438 of needs assessment measures. In a recent review,

Kipfer et al. [37] included 18 articles that reported
 psychometric measures and results for needs assess-
 ment instruments for informal caregivers.

Level of assessment

Unlike many existing assessment instruments [10],
 the DEMAND is directly assessing the utilization of
 and need for care services, avoiding the problems
 of concluding needs indirectly from a problem- or
 symptom-centered level.

By assessing needs on the problem- or symptom-
 centered level, services may not meet the needs
 sufficiently compared to an assessment of needs
 based upon the direct addressing of services [38,
 39]. This may result from the fact, that it often
 remains unclear, which particular aspect of a problem
 is meant, and which specific intervention should be
 applied in order to solve this (aspect of the) problem
 [10].

In order to get a deeper understanding of the needs
 of family caregivers and a possible gap between
 offered and used services, the DEMAND is more-
 over investigating the reasons for not using a service.
 In this respect, the DEMAND is not only asking, if
 there is a need for a service but, inter alia, also if the
 service is existent and if there is knowledge about the
 service. Thus, besides the need for specific services,
 even barriers to resource use can be identified.

Target group

The DEMAND questionnaire is conceptualized for
 interviewing people with dementia and/or their fami-
 ly caregivers, as *felt* and *expressed needs* affect the
 entire care situation. However, the instrument also
 includes services uniquely relevant for informal care-
 givers.

In this respect, some of the existing instruments
 predominantly or only deal with the needs of people
 with dementia without referring to family caregivers
 as well [10, 35]. Yet, the needs and care situation
 of the people with dementia is strongly interdepend-
 ent with the situation of the family caregivers [9].
 Despite focusing on the needs of people with demen-
 tia, the CANE [29], the Johns Hopkins Dementia Care
 Needs Assessment (JHDCNA) [40], and the Care
 Needs Assessment Pack for Dementia (CarenapD)
 [41] assess the specific needs of family caregivers by
 several questions as well. The Carers' Needs Assess-
 ment for Dementia (CNA-D) [42] only refers to the
 needs of family caregivers, and the Partnering for

487 Better Health - Living with Chronic Illness: Dementia
 488 (PBH-LCI:D) [43] assesses the needs of family
 489 caregivers of people with dementia only indirectly.

490 *Sample for validation*

491 Both instruments dealing with the needs of people
 492 with dementia and instruments specifically address-
 493 ing the needs of informal caregivers, often lack
 494 sufficient validation, either in general or for the
 495 specific population of people with dementia and
 496 their family caregivers [10, 35–37]. Therefore, the
 497 DEMAND was specifically developed with experts
 498 from the field of dementia and validated in a pop-
 499 ulation of people with dementia and their family
 500 caregivers.

501 There are a couple of assessment instruments
 502 already addressing the needs of people with demen-
 503 tia and their family caregivers [10, 35–37]. However,
 504 some of the instruments used in the context of demen-
 505 tia are not specifically developed for people with
 506 dementia or their family caregivers [10]. Despite
 507 being widely used in the context of dementia the
 508 CANE was not developed specifically for people with
 509 dementia but older adults in general. Nonetheless,
 510 people with dementia were included in the validation
 511 sample [29]. The CarenapD [41] and the CNA-D [42]
 512 are instruments, developed specifically for people
 513 with dementia respectively their family caregivers.

514 *Duration*

515 Dementia family caregivers are at an increased
 516 risk for experiencing a high caregiver burden [4, 44].
 517 Needs assessment measures should take the burden
 518 and time consumption of care into account. There-
 519 fore, the DEMAND needed to be easy to understand
 520 and short in execution so that the application is not
 521 overwhelming and that the instrument can be applied
 522 in different contexts. In this respect, the processing
 523 time of the DEMAND does not exceed 15 minutes on
 524 average and is therefore feasible in several settings
 525 without overwhelming participants.

526 Some of the existing instruments are time-
 527 consuming and might affect the attention of the
 528 interviewed people. According to Reynolds, the
 529 CANE should be feasible within 30 minutes [29].
 530 Therefore, Stein et al. recommend the development
 531 of a shorter version of the CANE [45]. The applica-
 532 tion time of the CarenapD is about 90 minutes [10]. In
 533 practical application, the duration for completing the
 534 CNA-D is about 50 minutes due to its complex struc-

ture [42]. For most of the other existing instruments,
 duration time ranges between 10 and 30 minutes [10].

Application

Due to his practical usability, the DEMAND
 aims to be included in both scientific and clinical/
 consultation contexts.

Many other existing instruments are either used for
 clinical or research use [10, 35, 36]. The CANE can
 be applied in both clinical and research contexts [29].
 The CarenapD was solely developed for clinical use
 [41]. The CNA-D is an instrument specifically and
 solely designed for research purposes [42].

Limitations

The data basis for the development of the
 DEMAND is predominantly based upon people liv-
 ing in Bavaria. Therefore, the external validity is
 limited, as Bavarian-specific care situations cannot be
 ruled out. Moreover, the data for validation were col-
 lected within the project digiDEM. digiDEM reflects
 the population of the southern part of Germany so that
 the results may be difficult to transfer to other health
 care settings and jurisdictions. There were no peo-
 ple with dementia participating in neither the focus
 group nor the online survey. Thus, in the develop-
 ment process, the perspective of people with dementia
 themselves was only represented by patient represen-
 tatives and family caregivers as their proxy. In order
 to develop a brief instrument, the 13 highest-rated
 support services of both informal caregivers and pro-
 fessional experts were included. However, through
 the exclusion of further support services, comprehen-
 sive information about the entire service landscape
 cannot be obtained, which might lead to some imbal-
 ances.

Conclusion

The care of people with dementia is a time and
 resource-consuming process that can result in a high
 caregiver burden of family caregivers. External sup-
 port services are important measures for effectively
 reducing caregiver burden and enabling people with
 dementia to remain in their home environment as long
 as possible. In order to do so, the identification of
 the utilization of and need for services of the people
 with dementia and their family caregivers is crucial.
 The DEMAND can make an important contribution
 by providing data that are underlying for effective

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health care planning by health decision-makers. By using the DEMAND, supply gaps can be identified and transformed into a specific regional health care policy. In addition, the DEMAND can foster health outcomes research by being implemented in research projects.

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SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <http://dx.doi.org/10.3233/JAD-220363>.

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