



JOURNAL of AGING and LONG-TERM CARE

A New 21st Century Initiative from TURKEY

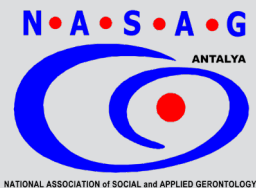
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EDITOR-IN-CHIEF:
EMRE SENOL-DURAK

EDITOR:
MITHAT DURAK

A Journal of the National Association of Social and Applied
Gerontology (NASAG) - Turkey





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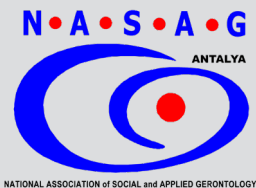
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CONTENTS

VOLUME: 5 ISSUE: 2 - 2022

SHORT REPORT

- Evaluation of Partnerships in Preparedness (PIP): A Mentorship Program for Long-Term Care Facilities in COVID-19 Crisis17
Sharon Medcalf, Matthew A. Beacom, Anna Hansen, Leslie Gunning-Scofield, Shireen S. Rajaram

REVIEW ARTICLE

- Definitions and Measurement of Engagement in Persons With Dementia: A Scoping Review27
William Matcham, Joan Thoman, Adam Sobol, Erica Sanchez, Phyllis Gaspar



Evaluation of Partnerships in Preparedness (PiP): A Mentorship Program for Long-Term Care Facilities in the COVID-19 Crisis

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ABSTRACT

Long-term care facilities (LTCF) in the U.S. rank among the most profoundly affected industries by the Covid-19 pandemic. LTCF staff faced insurmountable challenges in their attempts to contain outbreaks and mitigate transmission. Changes in workflow processes were unprecedented, increasing stress on both providers and fragile residents. LTCF facility representatives, already overwhelmed with the facility's demands, struggled to interpret the latest and ever-changing recommendations and configure guidelines for their facility operations and infrastructure. Given the isolated nature of rural (and some urban) long-term care facilities, combined with the struggling industry, a one-to-one mentorship program seemed like a viable and welcome solution. Partnerships with professional associations were established to recruit facilities interested in establishing a mentor relationship. Mentors were given a short orientation to the program and then paired with a long-term care facility representative. Daily mentor meetings were conducted in the initial weeks of the program

and then reduced to 3 times per week. Program evaluation was conducted mid-way through the program through focus groups with mentors and mentees in separate sessions. The qualitative results are the subject of this paper. Feedback from both mentor and mentees was overwhelmingly positive and concurred with systematic reviews of other published mentorship programs. Given that solutions for future planning should be based on lessons learned from previous crises, mentees in this program provided sound advice for measures that should be implemented regardless of establishing a formalized mentorship program. More comprehensive mentor orientation, mentee peer-peer interaction and engagement, consolidation of ever-evolving recommendations, and procedural templates were outcome program recommendations. This mentorship program serves as a national call to build infrastructure to provide valuable support for those who will dedicate their professional lives to protecting our vulnerable aging generation.

KEYWORDS: Long-Term Care; Mentorship; Pandemic; Preparedness.

KEY PRACTITIONER MESSAGE

1. Establish mentorship programs between long-term care facility representatives and subject matter experts in infection control and emergency preparedness.
2. Coordinate peer-to-peer mentoring support between long-term care staff in area facilities.
3. Coordinate and consolidate the sharing of concise and current information in public health emergencies.

INTRODUCTION AND BACKGROUND

Long-term care facilities (LTCF) in the U.S. rank among the most profoundly affected sectors by the Covid-19 pandemic. The infection rates among staff and residents have surprised even seasoned public health professionals, who are adept at outbreak containment and control and have a keen understanding of the vulnerability of this aging population. In the United States, there are approximately 1.3 million adults over 65 years of age living in nursing homes and approximately 1 million adults over 65 years of age living in assisted living facilities (Roy et al., [2020](#)).

At the pandemic's peak, guidance from local, state, and national experts focused on outbreak mitigation, containment, and control with little regard for the collateral consequences to residents' wholistic well-being. It was difficult for providers to access Personal Protection Equipment (PPE). To facilitate the cohorting of resident care, guidelines for Covid-19 containment in Nebraska also include the reconfiguration of workflow processes in the long-term care facilities.

The Center for Medicare and Medicaid Services (CMS) requires all LTCFs to infection prevention follow the guidance provided by the Center for Disease Control and Prevention (CDC). Shortages of PPE jeopardized the health and safety of LTCF staff and residents. They violated COVID-19 protocols set forth by the CDC and often resulted in formal deficiency tags and financial penalties (D'Adamo et al., [2020](#)). Increasing the overall challenge, some states' hospitals discharged patients to LTCFs with either positive COVID-19 tests or a lack of proof that returning residents tested negative. Other states, such as New York, implemented a moratorium on a facility's right to refuse a resident based on a positive COVID-19 test and required LTCFs to accept all patients (Ouslander & Grabowski, [2020](#)).

LTCF staff faced insurmountable challenges in their attempts to contain outbreaks and mitigate transmission. Changes in workflow processes were unprecedented, increasing stress on both providers and fragile residents. The mental health toll on LTCF industry providers was palpable during State-wide calls with facility representatives and Infection Prevention Specialists working through organized ICAP (Infection Control and Prevention) programs. LTCF facility representatives, already overwhelmed with the facility's demands, struggled to interpret the latest and ever-changing recommendations and

configure guidelines for their facility operations and infrastructure (Yen et al., [2020](#)).

According to Gavin et al. ([2020](#)), healthcare workers on the frontline of the COVID-19 response experience high rates of anxiety, depression, and distress, while simultaneously having the usual avenues of adaptive behavior such as social interaction blocked due to social distancing and other infection control mitigation measures (Gavin et al., [2020](#)). Given the isolated nature of rural (and some urban) LTCFs, combined with the struggling industry, a one-to-one mentorship program seemed like a viable and welcome solution. In a pandemic scenario, mentorship may enable the mentee to feel ready and able to use their practical knowledge and adapt as more empirical knowledge is obtained.

Mentorship programs are one way to increase social and peer-to-peer interaction (albeit limited) as positive adaptive behavior. At the same time, the mentee-mentor relationship can diminish healthcare workers' feelings of self-blame and deprecation by giving them an expert to lean on.

Professional mentorship encourages multidisciplinary collaboration and has been described as essential in personal and professional development (Burgess et al., [2018](#)). Mentorship has been shown to increase a mentee's capacity to perform certain aspects of his/her job, but overall performance also increases significantly (Ghosh et al., [2020](#)).

Additionally, a mentor can help a mentee feel important in their role in a prolonged healthcare emergency response. It can mitigate a mentee's potential feelings of loss of control and isolation by facilitating a consistent and trusting relationship. The mentee may express concerns and ask questions in a safe environment, free of judgment (Bhatti et al., [2020](#)). In turn, mentors can support LTCF providers by shouldering the responsibility of knowledge transfer and helping facility representatives remain current on guidance and mandates from the local, state, and federal levels.

In the College of Public Health at the University of Nebraska Medical Center, the Center for Preparedness Education partnered with Leading Age Nebraska and the Nebraska Health Care Association (NHCA) to recruit LTCF facilities interested in establishing Partnerships in Preparedness (PiP) mentorship program. Mentors were recruited by invitation from long-time partners of the Center

for Preparedness Education and through the Association of Healthcare Emergency Preparedness Professionals (AHEPP). Among the requirements was expertise in emergency preparedness and infection control and prevention. Mentors were given a short orientation to the program and then paired with an LCTF representative. Daily mentor meetings were conducted in the initial weeks of the program and then reduced to 3 times per week. These “huddle” sessions were used to release new guidance information and provide a forum to discuss any items that arose from the mentee/mentor interaction. Mentors established a regular schedule to meet with facility mentees, but many were available for spontaneous consultation. At the height of program participation, there were 67 long-term care facilities and 21 mentors enrolled in the program.

Program evaluation was conducted mid-way through the program through focus groups with mentors and mentees in separate sessions. The qualitative results are the subject of this paper. Our goal is to demonstrate the value and purpose of such dedicated mentorship programs and provide operational and logistical guidance to those who wish to replicate this program across disciplines.

METHOD

We used a qualitative research approach since this is a new and novel program, and there were no existing evaluation data from the perspective of the PiP mentors or mentees. Data were gathered through 2 focus groups with mentors and 2 with mentees. A total of 10 mentors and seven mentees participated in the evaluation, and each focus group had between 4-7 participants.

The semi-structured interview guide was drafted through consensus among researchers and the PiP Mentorship leadership team. Inclusion criteria were mentors and mentees in the PiP program. The University of Nebraska Medical Center’s Institutional Review Board (IRB) deemed that this study was classified as a program evaluation, and hence no further permission from IRB was needed. Focus groups were conducted via Zoom, recorded with permission from research participants, and transcribed verbatim.

Focus group sessions ranged from 45- 60 minutes, and all participation was voluntary. The main

questions focused on mentors’ and mentees’ experience with the PiP mentorship program, including suggestions for improvement. Follow-up questions were based on responses from participants and allowed flexibility for the interviewer to delve deeper into issues (Huberman & Miles, 2019).

We followed a thematic data analysis process (Braun & Clarke, 2006). Transcripts were coded to organize the data into meaningful chunks or sections. The reliability of the coding process was established by having two researchers (Shireen S. Rajaram and Sharon Medcalf) independently code the same transcript. Next, they met to discuss and develop a consensus on the codes and determine the meaning or definitions for each code (Creswell & Poth, 2016; Miles et al., 2014). They created a codebook that was used to code the rest of the transcripts using NVivo® (QSR International Pty Ltd, 2015), a software program for qualitative data analysis. As clusters of meaning developed, these codes were combined into critical themes. The coding process was both deductive or topic-driven (top-down), based on the main focus areas relating to suggestions for improvement of the program, and inductive or data-driven (bottom-up), based on the meaning that emerged through the analysis and interpretation of the data (Creswell & Poth, 2016; Miles et al., 2014).

Field notes taken following each focus group that reflected insights and impressions of the process were used to interpret the data (Miles et al., 2014). We maintained credibility or validity through peer-debriefing, prolonged engagement, and rich, thick description (Lincoln & Guba, 1985; Patton, 2014). Peer debriefing between researchers occurred in drafting the interview guide and following each focus group. The PiP leadership team had prolonged engagement over the seven months of the project, and meetings occurred almost every day. The thick description of the results with details of the context of LTCFs and CAHs (Critical Access Hospitals) helped interpret the study data (Lincoln & Guba, 1985; Patton, 2014).

A total of 10 mentors and seven mentees participated in the focus groups. The majority of mentors were female, over 55 years of age, and had a college degree. All mentors were White-Caucasian and had public health or clinical care backgrounds. Six mentors were in the field of emergency preparedness. Five mentors worked with LCTF, while five worked with LCTF and CAH. Only two mentors worked with facilities that did not experience a COVID-19 case,

while the other mentors experienced COVID-19 cases in one or more of their mentees' facilities. No personal demographic data were collected on mentees to ensure the preservation of anonymity.

RESULTS

The results of the focus groups with mentors and mentees revealed five key themes: Assured Support, Building Relationships, Perceived Role of Mentor/Mentees, Recommended Changes to the Program, and Alternative Programs. The names of people and organizations have all been redacted in the results.

Assured Support

Mentors shared that they were able to assure mentees that there would help and support them. Mentors indicated that they provided mentees with trusted advice and guidance on issues that were relevant to mentees. The support provided included informational support and esteem support that boosted the confidence and morale of mentees. Information shared mainly involved COVID-19-related issues pertaining to residents, facilities, employees, and family members.

Mentors supported with consultation in testing and screening strategies, personal protective equipment (gowns, disinfection wipes), contact tracing, documentation for CMS surveys, and more. For example, one mentor shared;

"Some of the things I've directly done to help my mentees is providing forms for like symptom tracking, how to set up their screening process... checks with the isolation placement...are they using fire doors, do they have to set up plastic screening?"

Another mentor elaborated on contact tracing;

"I have several sites who were grateful for the program since they were dealing with the COVID-19 in their facility, trying to do the contact tracing; they could just ask what was discussed to help guide them a little bit more."

Some COVID-19-related challenges involved employee HR (human relations) issues, including leave, travel, staffing exposure, and testing. One mentor shared;

"they don't have an HR department except for the director of nurses and the administrator so they don't have the ability to ask some of those

really deep questions from an HR perspective."

Mentees shared that it was difficult to get information, mainly since some of them lived in rural areas. They found mentors to be a;

"...really good line of source of what's coming down from the state level and also a way to up-channel back to the state."

Mentee:

"My mentor said that if we were surveyed and we did get a tag that was related to infection control...she would definitely be a support for our side of it and work with us on what we needed to do to correct it. And I think that that was very, very, very encouraging for me, that there was going to be somebody that was going to be helping me with a problem if we did have a tag."

Mentors shared notes from the daily/thrice weekly huddle session with their mentees. One mentee stated:

"I have any questions at all, she goes and asks anybody that might have the answer if I need it right away. Otherwise, she'll put it out into her little group, to brainstorm and get back to me. And that's been beneficial. She sends notes from the meetings that she attends and that's been nice."

Another mentee stated:

"We share information back and forth... so I've used some of the tools, some of the educational pieces, some of the competency training forms that she has shared with us, and I've also utilized her as a resource."

Mentors felt that the informational support helped mentees gain confidence in their ability to address their challenges. One mentor shared,

"I, I really see that their confidence in what they're doing is, is really a boost for them. For us to say, yep, you're doing it right, you're doing exactly what you should be doing and your infection control plan is helping and you're doing you're on the right track, I think that's really beneficial to them -- that boost of confidence."

A mentee reflected similar sentiments:

"When we...were getting ready to do our first gray room, it was very, very beneficial to have her and be able to go through -- Okay, we've got this, and we've got that... did you consider this? And do you have that? And, you know, it was just nice to have, kind of a second brain."

Mentors shared that mentees were often

overwhelmed with information and stated that the guidelines from different agencies such as ICAP (Infection Control and Prevention), NE DHHS (Nebraska Department of Health and Human Services), and CMS were constantly changing and contradicted each other.

One mentor underscored;

"Frequently, more frequently than not, the target would move a bit, or the advice would change, and they really appreciated some breakdown of that or maybe a little bit of clarification."

Mentees concurred and stated that working with mentors helped them sort through a large amount of information that is often conflicting.

Building Relationships

Mentors indicated that providing technical support was crucial, and PiP was about building relationships with their mentees, providing emotional encouragement and support, and empathizing with and appreciating their mentees. They developed trust and mutual respect for their respective commitments to supporting the residents, family, and staff members in care facilities.

Several mentors emphasized that it was about relationships and;

"...not just about a program. While sharing documents were important, it really does come down to the people and relationships for me just building those and learning from them."

Another mentor shared a similar perspective;

"It was about building a relationship and a friendship with these people...even if it's just by email they know that somebody's listening and paying attention if they've got a question. I have had them actually get a hold of me at all hours of the day and night."

Developing a trusted partner to share information and confidentially was essential for building relationships. One mentor stated;

"Not having that conversation go anywhere and developing that trust and relationship for them to have an outlet and get some questions answered."

Expressing gratitude and thanks was a key factor in building relationships.

Mentors empathized with their mentees and felt that the stress of keeping their facilities safe and

complying with regulations was taking a toll on the mentees and their staff. One mentor wished that some support could be provided to the mentees in dealing with the stress. She expressed;

"...just how much they're feeling right now and how much pressure and how much stress and all that is on them right now, I could just really hear that on my phone call so, any, any help that they could use...would be most beneficial to everybody."

Another mentor shared similar sentiments;

"I have a few mentees crying on the phone for me because they're just so tired of all of the pressure and the requirements that they're having to meet and then having issues with testing and positives being false and then having to go back into Phase 1, and they're just really stressed."

Mentees felt that emotional support and encouragement were significant. Mentee:

"When I was so upset, he was there to calm me down. There have been a couple of times I've been pretty upset with things that have happened either through state survey process or with trying to figure out...how long staff need the whole staff process of where what I need to do and stuff like that. And he brought me down. Let me get it off my chest. And then he brought me back down to reality, and that was really nice."

Mentee:

"I think it's hard to replace that, that relationship quality that comes between the [mentor and mentee], or at least that I have with my mentor. Awesome!"

Mentee:

"It was just really nice to have that person that I could call and say. Okay, you know, this came up. This is what I'm thinking that we're going to put in place. What's your take on this? And it was just a very nice relationship."

Mentee:

"The underlying thing I agree with XX [name redacted] is that there was someone for you to talk to and to voice your concerns or frustrations and that that was so helpful. We all need that for our own mental well-being during this time of the pandemic."

One mentee stated:

"I could just let it all off my chest. he'll just listen to me, and some days I just need that, I just need someone that will listen and let me get it off my chest."

Mentee:

"For me, it was just nice. Someone cared and someone who's out there that I could talk to being like I said, Independent facility. It was just tough and it was nice that there was someone out there that would help me."

Mentee:

"In some respects, sort of a counseling. The relationship is well, for those times that I was extremely stressed or frustrated or, or what have you? It was nice to talk to somebody that could say, okay, now take a deep breath. And let's break this down and look at it and, you know, and go on from there."

Mentors empathized with the challenges of their mentees and appreciated their ingenuity and hard work to maintain the physical and mental well-being of the residents, families, and staff. One mentor stated;

"I remember one of the directors tell me, I think we're killing these people and she was talking about the residents with the social isolation, and it wasn't just the words, but it was the emotion behind the words, it was the frustration...at times she was so discouraged, so ready to quit."

Another mentor shared similar sentiments;

"many of my mentees felt like their residents were being treated like prisoners in the very beginning because they were locked up in their rooms and had no human contact except for the staff. That was really heartbreaking."

Also, mentors were grateful for the positive feedback they received from their mentees, and it helped strengthen their relationship with their mentees. Mentors indicated that they especially appreciated the *"thank you."* One mentor revealed a similar perspective and mentioned that she feels appreciated when her mentees *"express their gratitude for the program."* A mentor shared that his mentee told him;

"you know you are so amazing I don't know what I would do without you...!, I look forward to our call every day."

Overall, they felt that the *"mentees have been very receptive to our phone calls."*

Perceived Role of Mentor/Mentees

Mentors had varied perspectives on how they saw their role in providing support. Some of them saw their role as a coach while feeling that they served as a sounding board to each other. One mentor

stated that he saw his role as a coach as helping his mentees problem solve and work through issues they experienced, such as interpretation of the guidelines.

Another mentor explained her problem-solving role;

"kind of a back and forth like you know well what do you think are the positives on that, what do you think are the negatives on that, and just kind of helping them to go through [the issue]."

Other mentors stated that they saw their role as more of a *"supportive role than an active coaching role."* She stated that since a lot of the information was new and evolving, she felt that they were *"...kind of learning back and forth from each other."* A similar sentiment was shared by another mentor, and she indicated that it has been *"as much of a learning experience that is it has been helping them."*

Four mentors stated that they served as a sounding board;

"...listen to what they had to say and if there were periods of frustration...just hear them out and help them out with their questions."

One mentee reflected similar sentiments:

"I think for myself personally, my mentor was really the sounding board...It was just really nice to be able to visit with somebody that have some probably a little bit more or a lot more emergency preparedness, planning background than what? Also, a nursing background. And I know that she had filled several roles as a nurse."

Mentee:

"It's nice to have him to be able to bounce ideas off of... Like if they're not recreating the wheel and just getting those other ideas on how to do it. Right?"

Some mentors and mentees saw each other as friends and felt they would continue staying in touch even after the PiP program ended. Mentee:

"So he became a friend. You know, someone that quite honestly after the program...someone that I probably would very much so like to keep in touch with, I mean, because he helped me with more than just the covid pandemic."

Mentee:

"You know, even if the funding would have went away, he still would have helped on his own time. And I think that's awesome."

Indeed, several mentors stated that they hoped to maintain the relationship with their mentees after the program was over. Mentee:

"I still want to maintain those relationships and those friendships that are being built now so that's been really important."

Another mentor shared similar sentiments

"Well I've thought about that myself and I'm actually gonna let my mentees know that [when] the program has ended, that doesn't mean our relationship has ended so if you have any questions at any time you've got my email you've got my phone call me and I'll try to help you out."

Recommended Changes to the Program

Overall, mentors and mentees were delighted with the program. One mentor stated;

"I think the program was excellent. Whoever thought of it did a very, very good job. The mentees that I had were so appreciative of the program...kudos to you folks who put it together."

Mentee:

"Personally, I like everything there is about the program. I think everything's working. Honestly, I have nothing but good things to say about the whole experience. I wish it was something that could go on 100% of the time."

Another mentee stated:

"I don't want to think about the end [of the program]."

Suggestions for improvement of the program included mentee peer-mentoring/networking. Two mentors suggested to *"gather some of the mentees together"* since he felt they are *"experts on things like staff morale boosters or resident morale boosters."* One mentor felt that, *"allowing them to feed off each other and help each other would put them a little bit more in that helping role, and I think that always builds confidence."* Another mentor suggested to *"develop some sort of support organization,"* so they could assist each other.

Mentee:

"I personally feel would be very useful would be resourcing for, like, networking. So, we're like, if we had a continual group thread, or chat, like our HR has it, our facility management has it. We have places we can go to where facilities like ours and

people doing jobs like ours can voice and have this talk in between. So, during the times in between, we're gathering information. So, we might be able to see how other critical access hospitals are handling the situation. And then we might have more to bring back to XX [name of mentor redacted], after gathering that information from one another. So, I think that would be a great tool and a great resource."

The following are some other suggestions that mentors and mentee provided:

1. Include training/orientation of mentors via Zoom on mentorship and set expectations for the program.
2. Provide background information for each facility at the time of assignment to mentors, such as location and size, number of residents, nearest health department, COVID-19 spread in the county, etc.
3. Provide basic training for mentors on HR-related issues and Medicare and CMS survey requirements. One mentor explained that she did not expect to *"come out as HR professionals"* but felt that *"just the basics of HR would be helpful."*
4. Provide behavioral training and support for both mentors and mentees.

"If nothing else...we give the tools to the people we are mentoring to recognize changes in the behavioral or mental status in these folks."

Another mentor suggested: He suggested that they could;

"from time to time" spend a few minutes "...letting the mentors debrief to one another, because if was become pretty stressful, we have a lot on our plate."

5. Include formative evaluation with mentee feedback directly communicated to the PiP UNMC (University of Nebraska Medical Center) leadership team.

One mentor stated:

"...it'd be nice monthly to get that loop coming back to us and having that documented [through] an official channel so if we're doing great we know that [and] if there's issues that we need to resolve."

He suggested that a short evaluation survey could be sent out to all mentees from the PiP leadership-team directly to mentees, *"bypassing us [mentors]"*.

6. Vary the time of huddle meetings during the week. For example, *"having one may be on a Monday morning and maybe a Tuesday afternoon."*
7. Having more flexibility in accounting for time spent in providing support to mentees.

Alternative Programs

Mentors were asked about alternative programs should the PiP program get discontinued due to lack of funding. Several mentors provided suggestions:

1. The mentor stated that since all facilities were connected to the Leading Age Nebraska and the Nebraska Healthcare Association, she felt that both these agencies could be used to support mentees if the PiP Mentorship program ended.
2. Two mentors suggested using the healthcare coalitions – to send the information to the healthcare coalition coordinator, and *"forwarded on to their partners and their members."*
3. A *"hotline program"* that people can call when they are *"really up against the wall"* can also get the needed assistance. One suggestion was to sort through the different and sometimes conflicting guidelines from the different entities such as DHHS, ICAP, and the Governor's office and send daily emails to the facilities so they could use them.
4. Clearing house for info.

Mentee:

"It is so hard to keep up with what comes out from emergency preparedness. CMS, CDC, DHHS. If there was some ability for somebody to say, Here's everything that came out this week and it's all in chronological order and here is an easy way to find it all because when I go to CDC website or I go to CMS website, it's like going down numerous rabbit holes...if there was some way to cross reference the information that's out there and have a very easy link to it for facilities, for instance...I want the cohorting that the last cohorting information that CDC came out with it is so hard to find that information if you didn't save it somewhere. So if there was some type of a guide that says here's all of the information on cohorting and here's all the links for it. Here's all the information on PPE or extended use of PPE, and here's all the links for it. So it could be a quick guide to take people back and forth. They update those links so frequently that the average facility with one administrator or one nurse trying to watch all of this it's nearly impossible."

Mentee:

"Maybe kind of like that list serve that I had where there's a group of people from each company that could just send that, you know, here we're dealing with this and how are you doing it?.....and just getting those ideas back."

5. Template for policies

Mentee:

"Sample policies, just a basic sample policy to say, here's a policy to get started on with your testing plan. Here's a policy to get started on with your cohorting plan...you have to individualize it to each and every facility, but just a bones, bare bones, one to help somebody get started with, because I tell you the number of policies that I've done and the revisions to all of those policies that I have done since March is astronomical."

Mentee:

"I wish there was some process for, um, all of those groups to sit down and talk and come up with a concrete plan and then take it out to the facilities, with something in writing, some type of template or some type of a training program that would help them understand. And if everybody were on the same page, and that hasn't happened. And I think that's probably the most frustrating thing for facilities. So if there was something on that order from at a higher level..."

DISCUSSION

The impact of COVID-19 on the LTCF industry will reverberate for years, if not decades. In an industry that has seldom experienced a sea change, the time has come to apply systems thinking to operations in normal times and planning for future public health disasters. Some predict a mass exodus of long-term-care professionals, and others demand a better-coordinated response at the state level across the nation (Behrens & Naylor, 2020). Either way, shifts in the operational paradigm will be imperative. This study makes a case for the addition of systematic mentorship as an outcome through the improvement matrix of after-action reports.

A systematic review of mentorships was conducted in 2019 and demonstrated interesting findings that explain many of the successes illustrated through our focus group (Liao et al., 2020). Mentor capability was determined to influence participant

experiences. Characteristics such as approachability, solid knowledge base, good communication skills, and clinical expertise were all valuable (Liao et al., 2020). Recommendations for competitively selecting mentors and improving their capacity through training and education are all features of our mentorship program. Mentors were selected from existing relationships and daily (eventually becoming thrice weekly) huddles, provided ample opportunities for collective education, peer mentoring of mentors, and information updates in an ever-evolving situation. Despite these touchpoints, mentors expressed concerns over their orientation to the program and their mentees while admitting that they were able to compensate for these drawbacks. We would recommend a more systematic orientation be developed for onboard mentors that include building capacity for softer skills such as communication and psychological first aid. Training should be provided before mentors engage with mentees to ensure that they are subject matter experts in the discipline necessary at the time. Foundational knowledge of infection prevention and emergency preparedness is imperative in a pandemic. As antibiotic resistance becomes a more pressing problem in any healthcare setting, infection prevention expertise will be sought far and wide. Given the more transient staffing nature of the LTCF industry, the consistent presence of subject matter expertise in infection prevention and control will become a top priority in the future.

Rural facilities often operate in isolation, so mentorship programs fill that void more consistently than professional organizations or agencies tasked with oversight or expertise.

The concept of peer-to-peer connectivity was also a recommendation and varied between involvement by professional organizations and healthcare coalitions. In essence, the oversight was not as significant as the opportunity to share experiences. Mentees in our program expressed the desire to be better connected to their peers in the region. We recommend incorporating a peer-to-peer mechanism into future mentorship programs. Lifelines through mentors were genuinely appreciated in our program. However, most professionals welcome a chance to connect to peers experiencing the same crisis in public health emergencies or challenges with ever-evolving accreditation requirements.

Methodically matching mentors to mentees was also a recommendation from the systematic review (Liao et al., 2020). Our PiP program only had one occurrence where a mentor was replaced for a better match.

Fortunately, this occurred early in the program and emphasized early monitoring and intervention where needed.

Given that solutions for future planning should be based on lessons learned from previous crises, mentees in this program provided sound advice for measures that should be implemented without a formalized mentorship program. Consolidation of information seemed to be the most relevant. Chronological updates that highlighted the newest recommendations separate from previously provided were critical for most facilities. The time spent deciphering the latest updates became problematic in a world where guidance from expert agencies was evolving rapidly and confusing. Furthermore lastly, providing templates for policies and procedures (e.g., PPE, cohorting) would be a time-saving measure for an already overwhelmed facility.

The poignant testimony emerging from the programmatic evaluation of a project is proof that any investment in mentoring assistance to dedicated professionals managing LTCF provides significant returns. This program started as an idea borne out of a relatively isolated industry in crisis, then struggled for funding, but became a salvation for a few dozen facility representatives. This example serves as a national “*call to action*” for all facilities serving our aging and vulnerable populations. Build an infrastructure to provide valuable support for those who will dedicate their professional lives to protecting our vulnerable aging generation.

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Definitions and Measurement of Engagement in Persons with Dementia: A Scoping Review

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ABSTRACT

Creating meaningful engagement for a person with dementia is recognized as a non-pharmacological approach to enhancing their well-being and decreasing their agitation, anxiety, and depression. However, no standard definition of engagement exists. A scoping review was conducted to examine the current definitions of engagement in persons with dementia and the measurement of engagement. The literature search was conducted using CINAHL/EBSCO and PubMed for the years 2016-2021 using the search terms "dementia AND elderly AND engagement." A screening process was developed, with articles meeting inclusion criteria independently reviewed by at least two team members. A follow-up of publications of the key authors was conducted alongside a search of the gray literature. Congruent themes of the definitions were identified, and articles were grouped into thematic categories. The two major themes of engagement definitions: were social contact/interaction and response to

activity and/or stimuli, and two minor themes, meaningful/satisfying activity and program/activity attendance, were found in the literature. The measurement of engagement reflected the two major themes of definitions reviewed and was primarily captured through observation. Major components of the three observation-based scales were similar, capturing affect, attitude, and attention in various formats and degrees. A comprehensive definition, combining key aspects of the cited definitions developed by the researchers, follows the Emotional and/or behavioral response generated by introducing stimuli through social or activity-based interactions that are meaningful to the individual and create satisfaction. The current observational approach to capture engagement is impractical for clinical use as it is subjective and time-consuming. This scoping review reveals the need for objective technology-based tools that capture the holistic concept of engagement among persons with dementia.

KEYWORDS: Engagement; Dementia; Scoping Review; Definition of Engagement; Measurement of Engagement.

KEY PRACTITIONER MESSAGE

1. Engagement of persons with dementia has implications for daily functioning, holistic well-being, positive mental health, and cognitive ability.
2. A holistic definition of engagement is important if the outcomes of being engaged are going to have a meaningful effect on the person with dementia.
3. Developing an objective and unobtrusive engagement measurement for persons with dementia is essential to be clinically applicable.

INTRODUCTION

With the growth of the aging population and the rising incidence of dementia which represents Alzheimer's disease and related dementias (ADRD), it is vital to develop solutions that positively impact the quality of life of these individuals. One solution is interventions that improve engagement in meaningful activities (Kemp et al., 2021).

Kemp et al. (2021) reported that dementia is a progressive disease that decreases a person's ability to interact with the environment and results in a loss of interest in social activities, leading to social isolation and lower quality of life. Kemp also reported that when a person with dementia is engaged in meaningful activity, it slows or reduces some of the related cognitive symptoms providing more prolonged independence and increased quality of life. Creating opportunities for meaningful engagement is a promising non-pharmacological approach to enhancing the well-being of persons with dementia and has implications for improving their cognitive and physical function (Mansbach et al., 2017; Theurer et al., 2015). The engagement has been cited as improving the quality of life of those with ADRD (Dementia Action Alliance, 2016; Fazio et al., 2018).

Determining and providing activities and social interactions that engage persons with dementia has been identified as crucial for delivering person-centered care (Jonathan, 2017). The Person-Centered Care model recognizes that when a person is engaged in a meaningful activity, he or she interacts with his or her surroundings, resulting in increased life satisfaction and quality. Consequently, it is increasingly important to understand what activities the individual finds meaningful and in what instances an individual is being engaged. Similarly, the Need Driven Model recognizes engagement as an important variable for improving quality of life (Whall & Kolanowski, 2004). Engagement has also been identified as an important outcome for various other programs implemented in long-term care settings (Gaspar & Westberg, 2020; Westberg et al., 2017).

A recent literature review was conducted by Motealleha et al. (2019) in which they identified many different definitions of engagement, including (but not limited to): level of stimulation (active or passive), level of social interaction (communication and interaction between residents), level of financial incentive (volunteer or paid work), temporal

commitment (residents visited or talked about the garden), and/or type of activities. They also found that the measurement and intervention used for each definition of engagement differed (Motealleh et al., 2019). These methodological variations make it difficult to interpret the results for researchers and limit the generalizability in clinical practice.

Engagement has been the focus of outcomes for research and clinical programs, but no standard definition exists. This paper will present a scoping review to examine the current definitions of engagement in persons with dementia and how engagement is measured. These definitions and measurement approaches will be critically assessed to determine the components of engagement captured in the current measurement tools that could be applied to an objective solution for tracking engagement.

METHOD

Scoping reviews provide an approach to reviewing research evidence without needing to answer a discrete research question (Sucharew & Macaluso, 2019). In this study, a scoping review is defined as a research synthesis aimed at identifying, classifying, and understanding the existing body of literature (Munn et al., 2018). The focus of this scoping review is to determine the clinical definitions and measurement of the concepts of engagement limited to individuals residing in assisted living or nursing homes and is guided by the question, "What are the characteristics and components of measurements of the clinical concept of engagement for persons with dementia?"

Eligibility Criteria

Literature included in the scoping review included items available in the CINAHL/EBSCO and PUBMED databases published between 2016 and 2020, having a population of older adults with dementia, provided a definition of engagement (clinical or theoretical), published in the English language and when providing a clinical intervention, identified a tool or measurement of engagement.

Information Sources

Published articles were obtained through systematic searches of select databases using a Midwest urban university using the library's subscription services to standard healthcare databases. Supplemental

literature was investigated using the reference list from the published literature. Grey literature was obtained through an internet search using the Google search engine.

Search Strategy

The initial literature search was conducted in the summer of 2020 by a professional health sciences research librarian. The databases selected were CINAHL/EBSCO (nursing and allied health 1946 - present) and PubMed (subscription). The search was limited to 2016–2020 using the terms “*dementia AND elderly AND engagement*.” The search query includes terms selected by the authors to capture engagement as widely as possible while still limiting to clinical applications appropriate to those with dementia. After sorting for duplicates, 93 articles were obtained and exported to Endnote (Clarivate-EndNote, Philadelphia, Pennsylvania, USA) folders for the research team to review. PDF copies of the articles were downloaded from library sources and stored on a Google Drive cloud storage (Google, Mountain View, California, USA) for future access by the team.

The reference list of the most relevant articles was reviewed for additional publications. A second search was completed in September 2020 by the researchers using the public PubMed database sponsored by the National Library of Medicine (NCBI NLM) website (<https://pubmed.ncbi.nlm.nih.gov/>) to capture the most relevant publications and authors who had sustained research focus on the engagement of persons with dementia as identified in the original literature search. The search was completed using the terms dementia, engagement, and the author’s name. A sample of articles for each author group over their publication lifetime was reviewed for definitions of engagement. As a consequence of this review, researchers were able to identify sustainability or changes in the definition over time, as well as new references that cited the author’s sources. The author names used in this search were: Camp, Cohen-Mansfield, Goodenough, Kolanowski, Kang, Jones, Perugia, Snow, and Van Beek.

A third search was manually conducted in December 2020 using standard internet browsers and Google search services (<https://www.google.com>) to identify gray literature, including consumer evidence, white papers, unpublished thesis, dissertations, blogs, and professional conference proceedings that refer to a definition of engagement. The search

term “*engagement of those with dementia*” was used to get overall results. An intentional decision was made to only screen the first 200 entries (as sorted by Google for relevance) since most of the hits were duplicates of each other or the literature already collected from the first two searches, and it was unlikely to yield a host of new articles.

In addition, a google search was conducted using the same terms for the literature search to compare the definitions in the literature with definitions on websites. This search was done on two dates in January 2021. The sites on the first two screens of the search that were not published articles were reviewed for definitions of engagement and measurement instruments.

Screening Process

A screening process was used to determine the study’s relevance for inclusion in the scoping review. All studies focused on persons with dementia were included in the initial search to gather as comprehensive a collection of articles as possible. Only articles available in full text and the English language were included due to a lack of translation resources. When the same material was found in multiple published forms or more than one publication (epub, reprint in another journal, online before print, electronic article, print article, etc.), only the most current and complete version was used.

In the first step, citations and abstracts of the collection were reviewed, and any articles that included the concept of clinical engagement (in any definition prescribed by the original author) or a measurement tool that measured any element of engagement (as defined by the original author) were retained for further screening. The analysis did not include papers that described the engagement of non-clinical elements such as community resources, political campaigns, or financial systems.

All articles were initially reviewed by graduate assistants who completed a screening form and then submitted to the researchers for review. At least two team members independently reviewed articles; many were reviewed by three. When results did not agree, the team discussed the questionable articles in regularly scheduled meetings to determine if they should be included or excluded.

Based on the data collected in the screening form, articles that did not include the population of interest, dementia populations in senior living

facilities (assisted living, nursing home, skilled care, rehabilitation, etc.), were excluded. Additionally, articles were removed if the concept of engagement was focused on engaging staff rather than patient engagement with their surroundings.

The remaining articles were downloaded as full-text and reviewed using a data collection form including author, date, definition of engagement, measurement of engagement, characteristics of the measurement, and conceptual framework. Articles were excluded at this stage if they did not present a distinct definition of engagement that provided characteristics beyond physical presence in the same general space or simple interaction with something. The review data were compiled into a single Microsoft Excel 2013 (Microsoft Corporation, Redmond, WA) spreadsheet and shared with team members via Google Drive.

RESULTS

Engagement Definitions

The literature presents a continuum of definitions of engagement ranging from simply the interaction with an item or attending an activity to a more comprehensive conceptualization that explores the meaningfulness of an interaction. Congruent themes were identified, and articles were grouped into thematic categories. The two significant engagement themes were social contact/interaction and response to activity and/or stimuli, and two minor themes, meaningful/satisfying activity and program/activity attendance, were found in the literature. [Table-1](#) demonstrates the rate of engagement types with the number of articles found in the literature for each major theme, while [Table-2](#) summarizes the definitions of engagement found in the literature for each major theme.

Table-1. Number of Literature References Reviewed in Each Theme Category

Definition Theme Category	Number of Articles Reviewed
Social contact/ interaction	9
A Response to Activity and/or Stimuli	14
Program / activity attendance	1
Meaningful/ satisfying activity	2

Social Contact/Interaction Theme

This group of literature contained a coherent set of definitions focused on social contact and interaction as the main concepts defining engagement. These definitions contained a common theme of “*being social*” and, in most instances, used the Resident Assessment Instrument-Minimum Data Set (RAI-MDS) to define and measure engagement. The RAI-MDS measurement scale is part of a clinical assessment process required for a nursing home to be certified to receive Medicare or Medicaid funding. This standardized assessment is comprehensive and intended to determine the extent of each resident’s functional capacity. In addition, a series of questions address health needs and the ability for social engagement. The definition used in the RAI-MDS characterized engagement as the ability of the resident to take the initiative to participate in the opportunities for social activities offered by the nursing home, such as playing cards, playing games, participating in group exercise, watching tv, interacting with others 1:1, interacting with other in a group, interacting with robotic animals, interacting with planned activities, etc. (Freeman et al., [2017](#); Gerritsen et al., [2008](#); Lou et al., [2013](#); Serrani Azcurra, [2012](#); Tse et al., [2018](#); van Beek et al., [2011](#); Yoon & Kim, [2017](#); Zeisel et al., [2018](#)).

Ziesel et al. ([2018](#)) offer a similar definition of an engaging activity as an activity in which participants interact in a socially acceptable manner. This definition offered by Ziesel uses the term “*engaged*” as a defining characteristic of engagement and only addresses engaging activities, not the engagement of people with dementia. This lacks clarity but does specify that engagement contains a social context with qualitative meaning.

Response to Activity and/or Stimuli Theme

This group of literature contains a coherent set of definitions that indicate engagement was a response to a specific activity and/or stimuli. There were a variety of stated definitions, but all alluded to the same central concept of response without quantification of meaning. This definition theme was used generically when the engagement was an outcome measure of a specific intervention (items or program) or a model of care. The interventions varied in range from simple stimuli of handing an individual an object to a more complex activity such as the outcome of the Montessori program. The engagement was used as a secondary characterization of the response to an intervention, not as a primary definition for

a measure. Most of the time, the focus was on an individual rather than a group. Leone et al. (2012) described engagement as being involved or occupied with external stimuli, while Bailey et al. (2017) similarly stated that engagement was engagement with materials. In associated research, Lazar et al. (2016) did not formally define engagement but produced outcomes that captured involvement and interactions with an activity. This trend continues with recent research by Lucock et al. (2020), who indicated that any physical contact or orientation to an item is engagement.

It is important to note that this theme group contains several sets of literature composed by the same authors, providing a consistent definition across literature platforms. One set of articles utilized the definition of engagement introduced by Cohen-Mansfield et al. (2009) and is still commonly used today (Kemp et al., 2021).

Being so proliferative throughout the literature, this definition has stayed relatively consistent over the years. This definition represents engagement as the duration, level of attention, and attitude of a person while involved with an external stimulus. This definition expands upon earlier definitions by highlighting the context of length and attitude as essential parts of the conceptual definition. Other writers have used this term with slight modifications (Kang, 2012; Leone et al., 2012).

Another definition of engagement commonly seen in the literature addresses the outcomes of Montessori programming. The Montessori program has been used in a variety of research and clinical activities over the years and is most cited as using four types of engagement: constructive engagement, passive engagement, non-engagement, and other engagement. Skrajner et al. (2014), and Mbakile-Mahlanza et al. (2020), use the concept of

Table-2. Definitions of Engagement and Associated Measures for Each Theme Category in the Literature

	Select Reference(s)	Definition	Associated measurement
Theme Category: Social Contact/ Interaction	Freeman et al. (2017)	Ability to take advantage of opportunities for social interaction and to initiate actions that engage in the life of the home" along with "a requirement the resident has the opportunity to engage and must take action by participating in social activities."	RAI-MDS derived Index for Social Engagement (ISE)
	Gerritsen et al. (2008)		
	Lou et al. (2013)		
	Serrani Azcurra (2012)		
	Tse et al. (2018)		
	van Beek et al. (2011)		
	Yoon, J. Y., & Kim, H. (2017)		
	Ziesel et al. (2018)	"Engaging activity" is one in which participants are engaged with each other in a socially appropriate and/or altruistic manner.	Menorah Park Engagement Scale
Theme Category: A Response to Activity and/or Stimuli	Bailey et al. (2017)	Engagement with materials	No Measurement
	Lazar et al. (2016)	The engagement was not formally defined but captured with activity involvement and interactions	No Measurement
	Leone et al. (2012)	Being involved or occupied with external stimuli	Observational Measurement of Engagement (OME)
	Lucock et al. (2020)	Used definition of engagement by Raetz et al. (2013): any physical contact with the item or orientation to the item, depending on the typical use of an item	No Measurement
	Cohen-Mansfield et al. (2009)	The act of being occupied or involved with an external stimulus and includes the dimensions of duration, attention, and attitude	The Observational Measurement of Engagement Assessment (or an adaptation of the assessment)
	Cohen-Mansfield et al. (2010a), (2010b)		
Cohen-Mansfield et al. (2012)			
Kemp et al. (2021)			

engagement which involves interaction with stimuli generally located within the external environment.

Mbakile-Mahlanza et al. (2020) used the Montessori activities in a trial of dementia patients and stated that engagement involves interaction through activities. The activities were designed to engage a dementia patient's attention while promoting positive social interaction. A similar definition was presented in research by Skrajner et al. (2014) while working with dementia patients' engagement using the Montessori program, with engagement defined as the effect of providing meaningful activities to persons with dementia but not an individual's overall engagement.

A similar definition was presented in research by Skrajner et al. (2014) while working with dementia patients' engagement using the Montessori program, with engagement defined as the effect of providing meaningful activities to persons with dementia but not an individual's overall engagement.

A less common but more recently cited definition of engagement surfaced from a group of articles published by a team of researchers in Australia (Jones et al., 2015; Jones et al., 2018; Moyle et al., 2017). Their definition indicates that engagement is an emotional or behavioral expression or response during or following the introduction of an activity. This moves the focus of engagement to an individual's internal focus through emotion and behavior instead of externally focused through physical touch and observation and consisted of 5 dimensions - affective, visual, verbal, behavioral, and social. This definition contains individual meaning and subjectivity. One component of the measurement tool they developed includes a social category indicating group interaction, even though the definition indicates that the activity is individually experienced.

Two other minor themes appear in the literature but are not as widely utilized as the last two groups and include: Program/activity attendance and Meaningful/Satisfying activity.

Meaningful/Satisfying Activity Theme

This literature group contains a definition of engagement that includes whether the participant found the activity meaningful or satisfying. This introduces a spectrum of satisfaction as a proxy measure for engagement and assumes that only meaningful or satisfying activities will be engaging.

Perugia, van Berkel et al. (2018) introduced a

comprehensive definition of engagement that indicates that through active involvement with an activity, an individual experiences enjoyment, a more positive mood, and becomes more captivated by the activity. In addition, Perugia, Rodriguez-Martin, et al. (2018) introduced the quantity of movement as a measure of engagement and motivation. Through this involvement, the individual is less distracted and more inclined to work harder at the activity. Eggert et al. (2015) offered a similar definition of engagement which shows that the individual is involved, and this involvement was triggered by a meaningful activity and created outcomes for the participant that included being more energetic and in a positive mood. This definition is very subjective as it relies on self-report of meaning and assumes individuals have the mental capacity for analytic thought and self-awareness, although these characteristics may not be present in individuals who suffer from dementia.

Program/Activity Attendance Theme

This theme contains the simplest definition of engagement as *an individual's attendance at a program or activity*. Attendance is recorded, and engagement is assumed regardless of the content of the activity or level of interaction. There is no context of interaction with objects, people, or even attention to the activity. One study used this approach when Tak et al. (2015) looked at activity engagement in nursing home residents with dementia and measured engagement as an individual attending an activity. This categorization is mainly used when reporting on the effect of a program or activity being offered.

Measurement of Engagement

The measurement of engagement varied across a continuum similar to the definitions. The most straightforward measurement tool determined if an individual attended an activity, while most measurement scales required subjective researcher observation of the individual during a response to a stimulus or activity. One approach used technology instead of researcher observation.

Five tools were identified in the literature that capture engagement through observation: 1) Engagement of a Person with Dementia Scale (EPWDS); 2) Menorah Park Engagement Scale (MPES); 3) Observational Measurement of Engagement Scale (OMES); 4) RAI-MDS Derived Index for Social Engagement (ISE) and 5) RISE - Revised RAI-ISE scale.

Components of the Measurement Scales

The various components of engagement captured in the observational measurement scales were categorized as a type of interaction/involvement observed, and responsive aspects are outlined in [Table-3](#).

All five scales capture the interaction with others and/or activities to varying degrees. The types of interaction or involvement category components were primarily captured in the RAI-MDS Index for Social Engagement (ISE) and its revised version, the RISE. Social interaction is the focus of the items on this scale, including interaction with others and involvement with activities, but it is only a record of the interaction or involvement in the activity. It does not include the resident's response except for the one question, "positive response to others," on the RISE. The focus on social engagement differentiates this measure from the other measures reported in the literature.

The other three scales (EPWDS, MPES, and OME) capture engagement through observation and determine engagement for a variety of activities based on how responsive an individual is to a stimulus or activity. The components of the response captured are duration, attention, affect, and attitude and are used when a resident is participating in a psychosocial activity. It is important to note that even though the definition of engagement proposed by the developer of the EPWDS is "a response to an activity," the response incorporates two questions on social interaction in this measure. The MPES was developed to accompany the Montessori-based Dementia Program. The OME is based on response to a stimulus - generally the presentation of an item but was used by some authors to capture a more complex activity.

Duration is captured on two of the scales. The MPES has the observer code for each type of engagement observed (constructive, passive, etc.) into three categories (never seen,

Table-3. Components of Engagement in Observational Measurement Scales found in the Literature

	Types of interaction or involvement observed					Responsive Aspects of the observation captured				Types of engagement	Other components	Scoring
	Interaction with others	Involvement in facility activities	Involvement in/with planned or structured activities	Involvement in self-initiated activities	Varies based on target activity	Affective state	Duration	Attention	Attitude			
Engagement of a Person with Dementia Scale (Jones, Sung & Moyle, 2015)	Yes	No	No	No	Psycho-social activity	Yes	No	Yes	No	Affective Visual Verbal	Environment appropriate	Total score
Menorah Park Engagement Scale (Judge, Camp & Orsull-Jeras, 2000)	No	No	No	No	Yes	Yes	Yes	Yes	No	Social Constructive Passive Non-engagement Helped others Acted in-appropriately Refusing and/or leaving an activity	Duration of each type of engagement	
Observational Measurement of Engagement Assessment (Cohen-Mansfield, Dakheel-Ali & Marx, 2009)	No	No	Yes	No	Yes		Yes	Yes	Yes	No	No	No
RAI-MDS derived Index for Social Engagement (ISE) (Hawes et al., 1997)	Yes	Yes	Yes	Yes	No	No	No	No	No	No	Establishes own goals	0-6
RISE – revised RAI ISE (Gerritsen et al., 2008)	Yes	Yes	Yes	No	No	No	No	No	Positive response to others	No	Initiates interaction with others	0-6

seen less than ½ of the observation period, or greater than ½ of the period). Duration is captured on the OME in the amount of time engaged, with the time in seconds or minutes, depending on the study.

All three observation tools include attention level as a component, yet they use different coding systems. The EPWDS categorizes attention by visual, verbal, or behavioral attention, while the OBS codes attention into the categories of not attentive, somewhat attentive, or very attentive. The MPES classifies engagement based on attentiveness (constructive, passive, non-engaged, and refused).

All instruments ask the observer to capture the attitude and/or affect. The EPWDS captures affect as either positive or negative. The MPES includes affects as either pleasure, anxiety, or sadness. Attitude is coded on a five-point scale on the OME, ranging from very negative to very positive.

The literature also offered a technology approach to capture engagement that did not use a standard measurement scale. A recent study investigated the use of a wrist-worn accelerometer to capture engagement (Perugia, Rodríguez-Martín et al., 2018). The researchers found a significant correlation between the quantity of movement gauged with the accelerometer and the observed engagement of individuals with dementia during two activities (Perugia, Rodríguez-Martín et al., 2018). They also found that apathy and depression significantly negatively impact an individual's engagement (Perugia, Rodríguez-Martín et al., 2018). This measured gross movement of participants without concern for the quality of sensor signal or differentiation of fine motor movements.

Results of Grey Literature

The results of the google search of current websites that appeared using the key terms engagement and dementia provided a variety of sites. The sites represented key organizations that provide resources for persons with dementia or care for those individuals. Although all the sites noted the importance of engagement for those with dementia, none offered additional information about an engagement definition.

DISCUSSION

This scoping review was conducted to describe the current definitions and measures for engagement

among persons living with dementia. Engagement is an important concept for this population that is noted to influence their quality of life, yet it lacks a clear meaning and a variety of measures. These challenges are supported by Nazir (2021) in a webinar by the National Academies of Sciences, as he cites that problems focusing on improving the quality of care for nursing home residents are related to a lack of real-time data analytics and irrelevant metrics to measure resident status and outcomes. He continues that one pathway to enhancing the life quality of nursing home residents is to properly define the concepts and characteristics of resident populations to build appropriate measures and methods. Additionally, the National Academies of Science released an article outlining the imperative to address nursing home quality, including the engagement of residents, staff, and families (National Academies of Sciences, 2022).

Overview of Engagement

This scoping review of the engagement of persons living with dementia has identified a variety of definitions and measures of engagement. Two major engagement definitions were found in the literature: social contact/interaction and response to activity and/or stimuli, and two minor themes; meaningful/enjoyable activity and program/activity attendance. Social interaction was identified as a major theme of engagement in the definitions reviewed and primarily related to the readily available measurement data from the RAI-MDS with the social engagement subscale.

Overall, definitions that reflected the response/interaction to the activity theme were related to the purpose of the research - which was testing an intervention with engagement as an outcome. For example, in research that used the robot dog as an interactive activity, the definition of engagement was focused on interaction with the object. Research that defined engagement as a response to something typically looked at as a response to select aspects of a program, such as Montessori Inspired Lifestyle (Gaspar & Westberg, 2020). Definitions that included characteristics of meaningfulness and satisfaction provided the most holistic perspective of engagement by characterizing the emotions behind the words. Conversely, the characteristic of attendance at an activity, although commonly used in clinical situations, appears less prevalent in the research literature and lacks any of the specific characteristics explaining engagement.

The grey literature identifies the concept of engagement as critically relevant to produce positive outcomes, but there is no unified definition or measurement tool. The idea of engagement was presumed to be understood by the reader and not characterized in the grey literature.

Measurement of Engagement

The measurement of engagement reflected the two major themes of the definitions reviewed, social interactions and response to an activity/stimulus, which were captured through observation. As noted previously, the social engagement subscale of the RAI-MDS was the most frequently used measure as it exists on an established database. Staff members must complete this scale based on their observations over seven days, then summarize it on the scale.

The major components of the three observation-based scales, EPWDS, MPE, and OME, were similar in capturing affect, attitude, and attention in some formats and to various degrees; however, all three measures have limited focus on social interaction. The observation was focused on the response of the participant/subject to a specific activity to determine the meaningfulness of the activity for the individual (Jones et al., 2018), not to measure a unified definition of engagement. The research team conducted these observations, which were episodic and stimuli based.

Another aspect important to consider for research and clinical application unrelated to the engagement components captured on the measurement tools is the scoring. Two measures, the EPWDS and ISE, calculate a total engagement score. This contrasts with the MPES, which measures the duration of each type of engagement but does not produce a composite score for comparison. The five aspects of engagement measured in the OBS each have a distinct measuring unit, again not allowing for a total score that could be used to characterize a unified definition of engagement. A measure of an individual's overall engagement cannot be captured in the latter two scales. The scoring, even if a total score is calculated, only represents that level for the select period of observation time and does not capture the overall engagement. Perugia, Rodríguez-Martín, et al. (2018) reported a high correlation of the movement captured by a technology wristband tool with the activity in which the person was participating. This study provides insight into the possibility of these types of tools being able to offer greater insight into

the measurement of engagement in all populations by providing standardized, objective data to classify levels of engagement. Such tools would need to be designed to measure engagement characteristics defined by movement, location, and proximity. If a device can capture engagement activities through movement, location, and proximity, then the defined characteristics of engagement could be estimated more accurately.

Recommendations

There is a need to incorporate the critical aspects and characteristics of various definitions relevant to an outcome of enhanced quality of life for persons with dementia to achieve one coherent definition of engagement. These characteristics include emotional or behavioral expression or response during or following the introduction of the activity or social interaction and provide for satisfaction and/or meaning. With the inclusion of all these characteristics, the definition will capture the dimensions of engagement in multiple settings and holistically define the actions of the individual. By combining key aspects of the existing definitions, the researchers of this review suggest a comprehensive definition for engagement of individuals with dementia as *“emotional and behavioral responses generated by the introduction of stimuli through social or activity-based interactions that are meaningful to the individual and create satisfaction.”* This definition could be either positive or negative, but ideally, interventions should be designed to produce positive emotional/behavioral outcomes.

Current measurement tools do not capture all the characteristics of the unified engagement definition proposed by the researchers. A tool needs to be developed that captures a variety of characteristic data points to measure all the aspects of engagement, not just items of interest to a specific researcher. One solution to the measurement issues related to engagement is the development of a technology-based approach. The technology must be an objective measure that captures the data passively without interfering with daily activity. In addition to movement, wearable technology can easily capture time and proximity to inanimate objects and other people. Aspects captured through technology provide the foundation for a proxy measure of engagement that can be further enhanced with component and composite scoring, 24/7 measurement, and other features such as capturing voice responses and automatic measurement of the duration of activity interactions.

From a clinical perspective, capturing the engagement of a person with dementia is important. Staff members must determine stimuli that will engage an individual to provide individualized care. These stimuli captured in a resident's plan of care can be used to improve well-being and alleviate common neuropsychiatric symptoms that are detrimental to the individual, family, and staff. An engagement metric would capture changes in the level of engagement of a resident over time, informing staff and family. The level of engagement captured has the potential to serve as a proxy for quality of life, especially for those with dementia who cannot express their perception of meaningfulness. There would also be an opportunity to use the engagement metric as part of the evaluation plan of programs contributing to the cost analysis

Strengths and Limitations of this Scoping Review

This scoping review focused on the definition of engagement for persons living with dementia. The focus helped define the key terms used and guided the literature review, so articles that did not include "dementia" as a key term were not part of the review, thus potentially eliminating definitions that would have been relevant. Limitations in finding all the relevant literature to review stem from limited subscriptions to search databases, limitation on access to full texts of articles, and a lack of critical appraisal of each article's scientific strength and research rigor that would have been completed in a meta-analysis paper. A strength of the scoping review allowed grey literature and other non-traditional sources to be investigated to enhance the pool of sources to gather information. There is a lack of research on the clinical application of engagement measurement tools; for example, the RIA-MDS is included in the scoping review but focuses on residents of nursing homes who do not necessarily have a diagnosis of dementia.

CONCLUSION

Accurately measuring the engagement of a person with dementia and determining those activities and interactions that are engaging is beneficial for stakeholders to promote resident-centered care and enhanced quality of life. One problem is that there is currently no objective, automated, and simple way to measure engagement. The most recognized measurement scales to capture engagement use

observation. These observations are generally focused on the testing of an intervention and are not clinically feasible. The subjective nature of observation and the time-consuming nature of this activity make it impractical for longitudinal measurement of clinical engagement. The use of technology to capture engagement is a promising approach that would create clinical applicability to the use of engagement to facilitate the planning of activities individually, and the use of engagement as an outcome.

One must define and characterize how engagement has been used clinically in the area of dementia research before a technology-based measurement tool can be created. For example, does engagement mean one is present at an activity or that one has participated in said activity? Should engagement measurements require the physical touch of an item (such as a pet or toy) or just the presence in the proximity of the item?

Providing persons with dementia opportunities to engage in activities is important for their well-being, as reported in the research and gray literature. However, the literature has varied definitions of engagement for persons with dementia. A comprehensive definition combining the key aspects of the definitions in the literature proposed by the researchers is "*emotional and behavioral responses generated by the introduction of stimuli through social or activity-based interactions that are meaningful to the individual and create satisfaction.*"

This proposed definition may provide the basis for the future development of new measurement methods to better capture engagement in people with dementia and stimulate the development of a technology-based measurement solution.

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Journal Articles:

Lo, C. L., & Su, Z. Y. (2018). Developing multiple evaluation frameworks in an older adults care information system project: A case study of aging country. *Journal of Aging and Long-Term Care*, 1(1), 34-48. doi:10.5505/jaltc.2017.65375.

Edited Book:

Whitbourne, S. K. (Ed.) (2000). *Wiley Series on Adulthood and Aging. Psychopathology in Later Adulthood*. Hoboken, NJ, US: John Wiley & Sons Inc.

Book Section:

Bowen, C. E., Noack, M. G., & Staudinger, U. M. (2011). Aging in the Work Context. In K. W. Schaie & S. Willis (Eds.), *Handbook of the Psychology of Aging* (7th Ed.) (pp. 263-277). San Diego: Academic Press.



Web Page:

Borji, H. S. (2016, 25.07.2016). Global Economic Issues of an Aging Population. Retrieved from <http://www.investopedia.com/articles/investing/011216/4-global-economic-issues-aging-population.asp>.

Figures and Tables:

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Vision and Mission

The major goal of the Journal of Aging and Long-Term Care (JALTC) is to advance the scholarly contributions that address the theoretical, clinical and practical issues related to aging and long-term care. The JALTC, while making efforts to create care services for older people at the best quality available that are more humane, that pay special attention to people's dignity, aims from the perspective of the whole aging process- to discuss Social Care Insurance as a human right, to contribute care for older people to be transformed into an interdisciplinary field, to integrate care services for older people and gerontological concepts and to create more effective collaboration between them, to enhance the quality of care services for older people and the quality of life of caregivers from medical, psychological and sociological perspectives, to highlight the cultural factors in care for older people, to increase the potential of formal and informal care services, to provide wide and reachable gerontological education and training opportunities for caregivers, families and the older people.

Aims and Scope

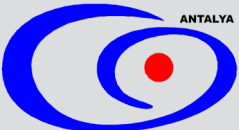
"National Association of Social and Applied Gerontology (NASAG)" has recently assumed responsibility for the planning and introduction of a new international journal, namely, the Journal of Aging and Long-Term Care (JALTC). With world societies facing rapid increases in their respective older populations, there is a need for new 21st century visions, practices, cultural sensitivities and evidenced-based policies that assist in balancing the tensions between informal and formal longterm care support and services as well as examining topics about aging.

The JALTC is being launched as the official journal of the NASAG. The preceding journal aims to foster new scholarship contributions that address theoretical, clinical and practical issues related to aging and long-term care. It is intended that the JALTC will be the first and foremost a multidisciplinary and interdisciplinary journal seeking to use research to build quality-based public policies for long-term health care for older people.

It is accepted that aging and long-term care is open to a diverse range of interpretations which in turn creates a differential set of implications for research, policy, and practice. As a consequence, the focus of the journal will be to include the full gamut of health, family, and social services that are available in the home and the wider community to assist those older people who have or are losing the capacity to fully care for themselves. The adoption of a broader view of aging and long term care allows for a continuum of care support and service systems that include home base family and nursing care, respite day care centers, hospital and hospice care, residential care, and rehabilitation services. It is also crucial to be aware that life circumstances can change suddenly and dramatically resulting in the need for transitional care arrangements requiring responsive, available, accessible, affordable and flexible health care service provision.

For further assistance and more detailed information about the JALTC and the publishing process, please do not hesitate to contact Editor-in-Chief of the JALTC via sending an e-mail: editor-in-chief@jaltc.net Editor-in-Chief: Emre SENOL-DURAK

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