

WEBVTT

NOTE duration:"00:22:28"

NOTE recognizability:0.939

NOTE language:en-us

NOTE Confidence: 0.9219852

00:00:25.010 --> 00:00:26.886 Hello there, My name is Emily Morose.

NOTE Confidence: 0.9219852

00:00:26.890 --> 00:00:28.840 I'm a postdoctoral Fellow in the

NOTE Confidence: 0.9219852

00:00:28.840 --> 00:00:30.747 section of Geriatrics here at the

NOTE Confidence: 0.9219852

00:00:30.747 --> 00:00:32.556 Yale School of Medicine by training.

NOTE Confidence: 0.9219852

00:00:32.556 --> 00:00:33.968 I'm a developmental psychologist

NOTE Confidence: 0.9219852

00:00:33.968 --> 00:00:36.088 as well as a healthcare

NOTE Confidence: 0.9219852

00:00:36.088 --> 00:00:38.008 quality improvement researcher,

NOTE Confidence: 0.9219852

00:00:38.010 --> 00:00:39.234 and I'm excited to share my

NOTE Confidence: 0.9219852

00:00:39.234 --> 00:00:40.370 work with you all today.

NOTE Confidence: 0.9425346

00:00:42.420 --> 00:00:44.444 So I want to start by reminding the

NOTE Confidence: 0.9425346

00:00:44.444 --> 00:00:46.546 audience you probably know, just broadly,

NOTE Confidence: 0.9425346

00:00:46.546 --> 00:00:48.964 that care for individuals with chronic

NOTE Confidence: 0.9425346

00:00:48.964 --> 00:00:51.155 illnesses or functional needs relies

NOTE Confidence: 0.9425346

00:00:51.155 --> 00:00:53.355 currently on a multimillion person
NOTE Confidence: 0.9425346

00:00:53.355 --> 00:00:55.419 workforce of family caregivers.
NOTE Confidence: 0.9425346

00:00:55.420 --> 00:00:57.520 These caregivers contribute a wide range
NOTE Confidence: 0.9425346

00:00:57.520 --> 00:00:59.860 of support to their care recipient,
NOTE Confidence: 0.9425346

00:00:59.860 --> 00:01:01.548 including helping with activities
NOTE Confidence: 0.9425346

00:01:01.548 --> 00:01:03.848 of daily living, health planning,
NOTE Confidence: 0.9425346

00:01:03.848 --> 00:01:06.418 transportation, legal and medical system,
NOTE Confidence: 0.9425346

00:01:06.420 --> 00:01:09.018 navigation, emotional regulation,
NOTE Confidence: 0.9425346

00:01:09.018 --> 00:01:10.750 and companionship.
NOTE Confidence: 0.9425346

00:01:10.750 --> 00:01:13.067 Considering that wide range of support tasks,
NOTE Confidence: 0.9425346

00:01:13.070 --> 00:01:15.525 preparedness for caregivers is a
NOTE Confidence: 0.9425346

00:01:15.525 --> 00:01:17.974 major predictor of the functioning,
NOTE Confidence: 0.9425346

00:01:17.974 --> 00:01:18.950 psychological health,
NOTE Confidence: 0.9425346

00:01:18.950 --> 00:01:21.526 and quality of life of both the
NOTE Confidence: 0.9425346

00:01:21.526 --> 00:01:23.790 caregiver and their care recipient.
NOTE Confidence: 0.9425346

00:01:23.790 --> 00:01:26.830 However, few opportunities exist currently

NOTE Confidence: 0.9425346

00:01:26.830 --> 00:01:29.262 to bolster caregiver preparedness,

NOTE Confidence: 0.9425346

00:01:29.270 --> 00:01:31.274 and the interventions that do exist

NOTE Confidence: 0.9425346

00:01:31.274 --> 00:01:32.929 focus on providing caregivers with

NOTE Confidence: 0.9425346

00:01:32.929 --> 00:01:34.798 specific skills to address each of the

NOTE Confidence: 0.9425346

00:01:34.798 --> 00:01:37.018 types of support tasks that they may be

NOTE Confidence: 0.9425346

00:01:37.018 --> 00:01:40.120 engaging in with their care recipient.

NOTE Confidence: 0.9425346

00:01:40.120 --> 00:01:41.788 Because we're seeing a steady increase

NOTE Confidence: 0.9425346

00:01:41.788 --> 00:01:43.799 in our population of family caregivers,

NOTE Confidence: 0.9425346

00:01:43.800 --> 00:01:45.632 particularly those caregivers of

NOTE Confidence: 0.9425346

00:01:45.632 --> 00:01:47.922 close others living with Alzheimer's

NOTE Confidence: 0.9425346

00:01:47.922 --> 00:01:49.760 disease and related dementias,

NOTE Confidence: 0.9425346

00:01:49.760 --> 00:01:51.945 preparing caregivers for care roles

NOTE Confidence: 0.9425346

00:01:51.945 --> 00:01:54.840 has become a public health priority.

NOTE Confidence: 0.9425346

00:01:54.840 --> 00:01:55.462 So currently,

NOTE Confidence: 0.9425346

00:01:55.462 --> 00:01:57.017 one in five Americans provide

NOTE Confidence: 0.9425346

00:01:57.017 --> 00:01:58.719 care to a close other,
NOTE Confidence: 0.9425346

00:01:58.720 --> 00:02:00.848 including over 11,000,000 caregivers
NOTE Confidence: 0.9425346

00:02:00.848 --> 00:02:03.508 of persons living with dementia
NOTE Confidence: 0.9425346

00:02:03.508 --> 00:02:05.889 who provide over 16 billion
NOTE Confidence: 0.9425346

00:02:05.889 --> 00:02:08.104 hours of unpaid care annually.
NOTE Confidence: 0.9425346

00:02:08.110 --> 00:02:10.050 And this proportion is expected
NOTE Confidence: 0.9425346

00:02:10.050 --> 00:02:12.577 to increase over time as the
NOTE Confidence: 0.9425346

00:02:12.577 --> 00:02:14.629 prevalence of dementia increases.
NOTE Confidence: 0.9425346

00:02:14.630 --> 00:02:17.066 And caregiving for a person living
NOTE Confidence: 0.9425346

00:02:17.066 --> 00:02:19.204 with dementia is typically a
NOTE Confidence: 0.9425346

00:02:19.204 --> 00:02:20.988 multiyear experience where care
NOTE Confidence: 0.9425346

00:02:20.988 --> 00:02:23.218 partner symptoms worse worsen and
NOTE Confidence: 0.9425346

00:02:23.286 --> 00:02:25.350 their needs increase gradually.
NOTE Confidence: 0.9425346

00:02:25.350 --> 00:02:26.902 At the same time,
NOTE Confidence: 0.9425346

00:02:26.902 --> 00:02:28.454 public policies worldwide encourage
NOTE Confidence: 0.9425346

00:02:28.454 --> 00:02:30.365 family caregivers to do whatever they

NOTE Confidence: 0.9425346

00:02:30.365 --> 00:02:32.470 can to keep that care partner at home,

NOTE Confidence: 0.9425346

00:02:32.470 --> 00:02:34.680 supporting their daily needs while

NOTE Confidence: 0.9425346

00:02:34.680 --> 00:02:37.430 allowing them to age in place.

NOTE Confidence: 0.9425346

00:02:37.430 --> 00:02:40.085 This long care trajectory requires

NOTE Confidence: 0.9425346

00:02:40.085 --> 00:02:42.430 those caregivers to gain or or or.

NOTE Confidence: 0.9425346

00:02:42.430 --> 00:02:45.470 It can actually allow those caregivers

NOTE Confidence: 0.9425346

00:02:45.470 --> 00:02:47.430 to gain a variety of skills and

NOTE Confidence: 0.9425346

00:02:47.483 --> 00:02:49.347 pragmatic insights about caregiving.

NOTE Confidence: 0.9425346

00:02:49.350 --> 00:02:51.630 But it also increases the chances

NOTE Confidence: 0.9425346

00:02:51.630 --> 00:02:53.979 that those caregivers are going to

NOTE Confidence: 0.9425346

00:02:53.979 --> 00:02:55.869 take on a negative psychological

NOTE Confidence: 0.9425346

00:02:55.870 --> 00:02:57.710 consequences of those caregiving

NOTE Confidence: 0.9425346

00:02:57.710 --> 00:02:59.550 experiences that they've had.

NOTE Confidence: 0.9425346

00:02:59.550 --> 00:03:01.788 Some of those consequences include guilt,

NOTE Confidence: 0.9425346

00:03:01.790 --> 00:03:06.510 burnout, roll, strain, depression, etcetera.

NOTE Confidence: 0.9425346

00:03:06.510 --> 00:03:09.110 And not only are we seeing an increased
NOTE Confidence: 0.9425346

00:03:09.110 --> 00:03:10.790 reliance on caregivers in general,
NOTE Confidence: 0.9425346

00:03:10.790 --> 00:03:12.342 we're specifically seeing an
NOTE Confidence: 0.9425346

00:03:12.342 --> 00:03:14.282 increased reliance on people to
NOTE Confidence: 0.9425346

00:03:14.282 --> 00:03:16.637 be caregivers for more than one
NOTE Confidence: 0.9425346

00:03:16.637 --> 00:03:18.542 loved one across their adulthood.
NOTE Confidence: 0.9425346

00:03:18.550 --> 00:03:22.177 So these are who could be considered in our
NOTE Confidence: 0.9425346

00:03:22.177 --> 00:03:24.830 population to be experienced caregivers.
NOTE Confidence: 0.9425346

00:03:24.830 --> 00:03:26.498 There may be individuals listening in
NOTE Confidence: 0.9425346

00:03:26.498 --> 00:03:28.150 today who are experienced caregivers,
NOTE Confidence: 0.9425346

00:03:28.150 --> 00:03:30.558 so people who have cared for more than
NOTE Confidence: 0.9425346

00:03:30.558 --> 00:03:33.236 one person who's who has who has lived
NOTE Confidence: 0.9425346

00:03:33.236 --> 00:03:36.050 with a chronic illness and needed support.
NOTE Confidence: 0.9425346

00:03:36.050 --> 00:03:37.210 And as our population ages,
NOTE Confidence: 0.9425346

00:03:37.210 --> 00:03:39.190 it is inevitable that more individuals
NOTE Confidence: 0.9425346

00:03:39.190 --> 00:03:41.608 will need to act as caregivers more

NOTE Confidence: 0.9425346

00:03:41.608 --> 00:03:43.684 than once while they are healthy,

NOTE Confidence: 0.9425346

00:03:43.690 --> 00:03:44.078 healthy,

NOTE Confidence: 0.9425346

00:03:44.078 --> 00:03:46.406 and capable to act as caregivers.

NOTE Confidence: 0.9425346

00:03:46.410 --> 00:03:48.042 We don't have stellar data in

NOTE Confidence: 0.9425346

00:03:48.042 --> 00:03:49.570 the US showing these trends,

NOTE Confidence: 0.9425346

00:03:49.570 --> 00:03:52.162 but we do have evidence from Canada that

NOTE Confidence: 0.9425346

00:03:52.162 --> 00:03:54.714 shows that about 1/4 of older adult

NOTE Confidence: 0.9425346

00:03:54.714 --> 00:03:57.417 caregivers will report caring for more than

NOTE Confidence: 0.9425346

00:03:57.417 --> 00:03:59.799 one care partner across their adulthood.

NOTE Confidence: 0.9425346

00:03:59.800 --> 00:04:00.138 So,

NOTE Confidence: 0.9425346

00:04:00.138 --> 00:04:00.814 for example,

NOTE Confidence: 0.9425346

00:04:00.814 --> 00:04:03.180 these Canadian demographers who did the study

NOTE Confidence: 0.9426682

00:04:03.239 --> 00:04:04.591 and mapped caregiving trajectories

NOTE Confidence: 0.9426682

00:04:04.591 --> 00:04:07.038 found that there were a few different

NOTE Confidence: 0.9426682

00:04:07.038 --> 00:04:09.558 subgroups of who I would call experienced

NOTE Confidence: 0.9426682

00:04:09.558 --> 00:04:12.005 caregivers who had cared for more than
NOTE Confidence: 0.9426682

00:04:12.005 --> 00:04:14.078 one loved one in their adulthood.
NOTE Confidence: 0.9426682

00:04:14.078 --> 00:04:16.804 So, for example, one trajectory includes this
NOTE Confidence: 0.9426682

00:04:16.804 --> 00:04:20.160 idea of an intensive parent care trajectory,
NOTE Confidence: 0.9426682

00:04:20.160 --> 00:04:23.070 which involves caring for multiple
NOTE Confidence: 0.9426682

00:04:23.070 --> 00:04:25.398 caregiving episodes across adulthood,
NOTE Confidence: 0.9426682

00:04:25.400 --> 00:04:27.320 typically about two caregiving episodes,
NOTE Confidence: 0.9426682

00:04:27.320 --> 00:04:30.600 often starting with care for a parent and
NOTE Confidence: 0.9426682

00:04:30.600 --> 00:04:33.315 ultimately comprising over 10 years of
NOTE Confidence: 0.9426682

00:04:33.315 --> 00:04:35.139 caregiving responsibility in adulthood.
NOTE Confidence: 0.9426682

00:04:35.140 --> 00:04:36.196 Other caregiving trajectories,
NOTE Confidence: 0.9426682

00:04:36.196 --> 00:04:38.660 like the this idea of serial caregivers,
NOTE Confidence: 0.9426682

00:04:38.660 --> 00:04:40.900 involve even more caregiving roles
NOTE Confidence: 0.9426682

00:04:40.900 --> 00:04:42.980 beginning even earlier in adulthood.
NOTE Confidence: 0.9426682

00:04:42.980 --> 00:04:45.430 So this for example involves an average
NOTE Confidence: 0.9426682

00:04:45.430 --> 00:04:48.120 of three caregiving episodes and usually

NOTE Confidence: 0.9426682

00:04:48.120 --> 00:04:51.420 comprises over 30 years of caregiving

NOTE Confidence: 0.9426682

00:04:51.420 --> 00:04:53.779 support provided to loved ones.

NOTE Confidence: 0.9426682

00:04:53.780 --> 00:04:56.185 So despite an increased dependence

NOTE Confidence: 0.9426682

00:04:56.185 --> 00:04:57.628 on family caregivers,

NOTE Confidence: 0.9426682

00:04:57.630 --> 00:04:59.730 caregivers of persons living with

NOTE Confidence: 0.9426682

00:04:59.730 --> 00:05:01.830 dementia report low preparedness to

NOTE Confidence: 0.9426682

00:05:01.897 --> 00:05:04.237 engage in caregiving roles and really

NOTE Confidence: 0.9426682

00:05:04.237 --> 00:05:06.494 limited resources to fully prepare them

NOTE Confidence: 0.9426682

00:05:06.494 --> 00:05:09.030 for what will come in those care roles.

NOTE Confidence: 0.9426682

00:05:09.030 --> 00:05:11.530 And these limitations have measurable

NOTE Confidence: 0.9426682

00:05:11.530 --> 00:05:14.030 impacts on those care outcomes.

NOTE Confidence: 0.9426682

00:05:14.030 --> 00:05:16.125 Caregivers who report low preparedness

NOTE Confidence: 0.9426682

00:05:16.125 --> 00:05:18.710 also report worth worse mental health,

NOTE Confidence: 0.9426682

00:05:18.710 --> 00:05:20.386 worst decision making efficacy,

NOTE Confidence: 0.9426682

00:05:20.386 --> 00:05:22.900 higher role strain and higher likelihood

NOTE Confidence: 0.9426682

00:05:22.968 --> 00:05:24.484 of institutionalizing their care
NOTE Confidence: 0.9426682

00:05:24.484 --> 00:05:27.085 partner earlier on in the course of
NOTE Confidence: 0.9426682

00:05:27.085 --> 00:05:28.961 care as well as local lower quality
NOTE Confidence: 0.9426682

00:05:28.961 --> 00:05:31.400 of life for those care partners.
NOTE Confidence: 0.9426682

00:05:31.400 --> 00:05:34.174 And that's why recent recently national
NOTE Confidence: 0.9426682

00:05:34.174 --> 00:05:36.359 leadership groups like the IMPACT
NOTE Confidence: 0.9426682

00:05:36.359 --> 00:05:38.242 Collaboratory and the Alzheimer's
NOTE Confidence: 0.9426682

00:05:38.242 --> 00:05:40.278 Association have developed research
NOTE Confidence: 0.9426682

00:05:40.278 --> 00:05:42.823 agendas that include designing robust
NOTE Confidence: 0.9426682

00:05:42.884 --> 00:05:45.579 strategies to improve caregiver preparedness.
NOTE Confidence: 0.9426682

00:05:45.580 --> 00:05:47.547 And one way to prepare caregivers is
NOTE Confidence: 0.9426682

00:05:47.547 --> 00:05:49.122 to consider what previous experiences
NOTE Confidence: 0.9426682

00:05:49.122 --> 00:05:51.132 with caregiving that they have had
NOTE Confidence: 0.9426682

00:05:51.132 --> 00:05:53.223 and how that may impact their
NOTE Confidence: 0.9426682

00:05:53.223 --> 00:05:54.933 preparedness for current care roles.
NOTE Confidence: 0.9406779

00:05:57.110 --> 00:05:58.975 So this idea that experiences

NOTE Confidence: 0.9406779

00:05:58.975 --> 00:06:01.433 in former care roles can impact

NOTE Confidence: 0.9406779

00:06:01.433 --> 00:06:03.690 navigation or stressors and current

NOTE Confidence: 0.9406779

00:06:03.690 --> 00:06:05.790 care roles isn't a new idea.

NOTE Confidence: 0.9406779

00:06:05.790 --> 00:06:08.430 Back in the 1980s and 1990s,

NOTE Confidence: 0.9406779

00:06:08.430 --> 00:06:09.906 researchers described this What's

NOTE Confidence: 0.9406779

00:06:09.906 --> 00:06:12.612 on the screen is the stress process

NOTE Confidence: 0.9406779

00:06:12.612 --> 00:06:14.308 model of family caregiving,

NOTE Confidence: 0.9406779

00:06:14.310 --> 00:06:16.635 and they included caregiving history

NOTE Confidence: 0.9406779

00:06:16.635 --> 00:06:18.960 as a key background characteristic

NOTE Confidence: 0.9406779

00:06:19.029 --> 00:06:21.059 that predicts the presence and

NOTE Confidence: 0.9406779

00:06:21.059 --> 00:06:23.089 degree of primary and secondary

NOTE Confidence: 0.9406779

00:06:23.159 --> 00:06:25.793 stressors in current care roles and

NOTE Confidence: 0.9406779

00:06:25.793 --> 00:06:27.549 ultimately impacts outcomes for

NOTE Confidence: 0.9406779

00:06:27.550 --> 00:06:29.830 that caregiver and care recipient.

NOTE Confidence: 0.9406779

00:06:29.830 --> 00:06:30.829 Yet still today,

NOTE Confidence: 0.9406779

00:06:30.829 --> 00:06:32.650 even years later, decades later,
NOTE Confidence: 0.9406779

00:06:32.650 --> 00:06:35.520 we know very little about the compounding
NOTE Confidence: 0.9406779

00:06:35.520 --> 00:06:37.693 effects of multiple caregiving roles
NOTE Confidence: 0.9406779

00:06:37.693 --> 00:06:40.695 across adulthood in terms of outcomes for
NOTE Confidence: 0.9406779

00:06:40.695 --> 00:06:43.059 the caregiver and their care recipient.
NOTE Confidence: 0.9406779

00:06:43.060 --> 00:06:44.580 So in the present,
NOTE Confidence: 0.9406779

00:06:44.580 --> 00:06:45.340 many individuals,
NOTE Confidence: 0.9406779

00:06:45.340 --> 00:06:46.918 and it seems like particularly those
NOTE Confidence: 0.9406779

00:06:46.918 --> 00:06:48.540 who have never been caregivers,
NOTE Confidence: 0.9406779

00:06:48.540 --> 00:06:50.005 might assume that if you've
NOTE Confidence: 0.9406779

00:06:50.005 --> 00:06:51.177 been a caregiver before,
NOTE Confidence: 0.9406779

00:06:51.180 --> 00:06:53.854 that can offer you a cumulative advantage,
NOTE Confidence: 0.9406779

00:06:53.860 --> 00:06:55.276 meaning that it provides you with
NOTE Confidence: 0.9406779

00:06:55.276 --> 00:06:57.477 a leg up in your current care role.
NOTE Confidence: 0.9406779

00:06:57.480 --> 00:06:59.120 This is an optimistic perspective,
NOTE Confidence: 0.9406779

00:06:59.120 --> 00:07:00.500 and ideally it's a perspective

NOTE Confidence: 0.9406779

00:07:00.500 --> 00:07:01.880 that's at least partially true.

NOTE Confidence: 0.9406779

00:07:01.880 --> 00:07:04.582 It would be really great if caregiving

NOTE Confidence: 0.9406779

00:07:04.582 --> 00:07:06.922 experiences can fortify us or teach us

NOTE Confidence: 0.9406779

00:07:06.922 --> 00:07:09.040 or prepare us to be caregivers again.

NOTE Confidence: 0.9406779

00:07:09.040 --> 00:07:11.505 This might minimize stressors and

NOTE Confidence: 0.9406779

00:07:11.505 --> 00:07:13.856 bolster self perception because and

NOTE Confidence: 0.9406779

00:07:13.856 --> 00:07:15.736 ultimately means that the existing

NOTE Confidence: 0.9406779

00:07:15.736 --> 00:07:17.690 workforce of caregivers are becoming

NOTE Confidence: 0.9406779

00:07:17.690 --> 00:07:19.635 better equipped for these roles.

NOTE Confidence: 0.9406779

00:07:19.640 --> 00:07:21.308 However, as we'll discuss,

NOTE Confidence: 0.9406779

00:07:21.308 --> 00:07:23.393 I believe that this assumption

NOTE Confidence: 0.9406779

00:07:23.393 --> 00:07:25.578 neglects the decades of research we

NOTE Confidence: 0.9406779

00:07:25.578 --> 00:07:27.916 have showing that there are persisting

NOTE Confidence: 0.9406779

00:07:27.916 --> 00:07:30.756 negative ramifications of caregiving roles,

NOTE Confidence: 0.9406779

00:07:30.760 --> 00:07:32.790 which in some cases may lead to

NOTE Confidence: 0.9406779

00:07:32.790 --> 00:07:35.201 not a cumulative advantage but a
NOTE Confidence: 0.9406779

00:07:35.201 --> 00:07:37.165 cumulative disadvantage for those
NOTE Confidence: 0.9406779

00:07:37.165 --> 00:07:38.147 experienced caregivers.
NOTE Confidence: 0.9406779

00:07:38.150 --> 00:07:40.425 So in pursuing this line of inquiry
NOTE Confidence: 0.9406779

00:07:40.425 --> 00:07:41.534 about experienced caregivers,
NOTE Confidence: 0.9406779

00:07:41.534 --> 00:07:43.886 several big questions have come up
NOTE Confidence: 0.9406779

00:07:43.886 --> 00:07:47.200 for me and including what skills or
NOTE Confidence: 0.9406779

00:07:47.200 --> 00:07:49.224 insights or psychological resources
NOTE Confidence: 0.9406779

00:07:49.224 --> 00:07:51.267 transfer from prior care roles
NOTE Confidence: 0.9406779

00:07:51.267 --> 00:07:53.469 to inform or improve current or
NOTE Confidence: 0.9406779

00:07:53.542 --> 00:07:54.790 future care roles.
NOTE Confidence: 0.9406779

00:07:54.790 --> 00:07:57.460 When and how those things happen?
NOTE Confidence: 0.9406779

00:07:57.460 --> 00:07:59.224 What insights are psychological
NOTE Confidence: 0.9406779

00:07:59.224 --> 00:08:00.988 consequences persist from prior
NOTE Confidence: 0.9406779

00:08:00.988 --> 00:08:03.384 care roles in ways that might
NOTE Confidence: 0.9406779

00:08:03.384 --> 00:08:05.199 undermine the benefits or harm

NOTE Confidence: 0.9406779

00:08:05.199 --> 00:08:06.940 functioning in current care roles?

NOTE Confidence: 0.9406779

00:08:06.940 --> 00:08:09.300 And again, why and how?

NOTE Confidence: 0.9406779

00:08:09.300 --> 00:08:10.098 And finally,

NOTE Confidence: 0.9406779

00:08:10.098 --> 00:08:12.093 what support do those experienced

NOTE Confidence: 0.9406779

00:08:12.093 --> 00:08:14.026 caregivers need to perform and

NOTE Confidence: 0.9406779

00:08:14.026 --> 00:08:16.048 thrive in their current care roles

NOTE Confidence: 0.9406779

00:08:16.048 --> 00:08:18.079 and even in future care roles?

NOTE Confidence: 0.9406779

00:08:18.080 --> 00:08:19.856 So I want to ground these

NOTE Confidence: 0.9406779

00:08:19.856 --> 00:08:21.040 questions in an example.

NOTE Confidence: 0.9406779

00:08:21.040 --> 00:08:23.084 We can think of someone who could

NOTE Confidence: 0.9406779

00:08:23.084 --> 00:08:25.160 be described as a novice caregiver.

NOTE Confidence: 0.9406779

00:08:25.160 --> 00:08:28.240 He's begun providing support for his mom,

NOTE Confidence: 0.9406779

00:08:28.240 --> 00:08:31.096 but he hasn't been a caregiver outside

NOTE Confidence: 0.9406779

00:08:31.096 --> 00:08:33.238 of childcare before in his life.

NOTE Confidence: 0.9406779

00:08:33.240 --> 00:08:35.788 So he has really limited skills with

NOTE Confidence: 0.9406779

00:08:35.788 --> 00:08:37.360 navigating the healthcare system,
NOTE Confidence: 0.9406779

00:08:37.360 --> 00:08:38.924 having those difficult conversations
NOTE Confidence: 0.9406779

00:08:38.924 --> 00:08:40.879 about prognosis or goals of
NOTE Confidence: 0.9406779

00:08:40.879 --> 00:08:42.799 care access and care resources,
NOTE Confidence: 0.9406779

00:08:42.800 --> 00:08:44.320 or predicting his mom's needs.
NOTE Confidence: 0.9406779

00:08:44.320 --> 00:08:45.487 In other words,
NOTE Confidence: 0.9406779

00:08:45.487 --> 00:08:47.432 he's exhibiting low preparedness because
NOTE Confidence: 0.9406779

00:08:47.432 --> 00:08:49.958 he doesn't have those caregiving skills.
NOTE Confidence: 0.9406779

00:08:49.960 --> 00:08:50.840 For him.
NOTE Confidence: 0.9406779

00:08:50.840 --> 00:08:53.920 A skill based intervention might be helpful,
NOTE Confidence: 0.9406779

00:08:53.920 --> 00:08:55.936 but the second person is caring
NOTE Confidence: 0.9406779

00:08:55.936 --> 00:08:57.919 for her husband and has also
NOTE Confidence: 0.9406779

00:08:57.919 --> 00:08:59.914 cared for her dad in the past.
NOTE Confidence: 0.9406779

00:08:59.920 --> 00:09:01.069 Although care experiences
NOTE Confidence: 0.9406779

00:09:01.069 --> 00:09:02.984 are different in many ways,
NOTE Confidence: 0.9406779

00:09:02.990 --> 00:09:05.321 she has picked up on skills in the past

NOTE Confidence: 0.9406779

00:09:05.321 --> 00:09:07.830 that are applicable to her caregiving now.

NOTE Confidence: 0.9319963

00:09:07.830 --> 00:09:10.250 She's also formed personal narratives

NOTE Confidence: 0.9319963

00:09:10.250 --> 00:09:12.670 about what caregiving looks like,

NOTE Confidence: 0.9319963

00:09:12.670 --> 00:09:13.870 how it should be done,

NOTE Confidence: 0.9319963

00:09:13.870 --> 00:09:15.870 and how good she is at doing it.

NOTE Confidence: 0.9319963

00:09:15.870 --> 00:09:17.662 So depending on the skills she's picked

NOTE Confidence: 0.9319963

00:09:17.662 --> 00:09:19.708 up and the narratives she's formed,

NOTE Confidence: 0.9319963

00:09:19.710 --> 00:09:21.168 she may feel fully prepared for

NOTE Confidence: 0.9319963

00:09:21.168 --> 00:09:22.829 it to care for her husband,

NOTE Confidence: 0.9319963

00:09:22.830 --> 00:09:25.287 or she may not. But if not,

NOTE Confidence: 0.9319963

00:09:25.290 --> 00:09:27.375 a skill based intervention might

NOTE Confidence: 0.9319963

00:09:27.375 --> 00:09:29.043 offer some additional support.

NOTE Confidence: 0.9319963

00:09:29.050 --> 00:09:31.576 But this caregiver might need other

NOTE Confidence: 0.9319963

00:09:31.576 --> 00:09:34.195 types of preparedness support that are

NOTE Confidence: 0.9319963

00:09:34.195 --> 00:09:36.370 not currently available to caregivers.

NOTE Confidence: 0.94943446

00:09:38.850 --> 00:09:41.210 So specifically in situations where
NOTE Confidence: 0.94943446

00:09:41.210 --> 00:09:43.014 experienced caregivers have really
NOTE Confidence: 0.94943446

00:09:43.014 --> 00:09:45.269 negative or complex narratives about
NOTE Confidence: 0.94943446

00:09:45.269 --> 00:09:47.479 their prior caregiving experiences,
NOTE Confidence: 0.94943446

00:09:47.480 --> 00:09:49.185 they might need specific support
NOTE Confidence: 0.94943446

00:09:49.185 --> 00:09:50.890 that goes beyond offering skill
NOTE Confidence: 0.94943446

00:09:50.947 --> 00:09:52.677 based training to instead address
NOTE Confidence: 0.94943446

00:09:52.677 --> 00:09:54.769 their worry about their ability to
NOTE Confidence: 0.94943446

00:09:54.769 --> 00:09:56.279 perform in the caregiving role.
NOTE Confidence: 0.9387881

00:09:58.840 --> 00:10:00.976 So, you know, considering all of
NOTE Confidence: 0.9387881

00:10:00.976 --> 00:10:03.071 this context and all these examples
NOTE Confidence: 0.9387881

00:10:03.071 --> 00:10:05.372 of of of how novice and experienced
NOTE Confidence: 0.9387881

00:10:05.372 --> 00:10:07.556 caregivers might might differ in the
NOTE Confidence: 0.9387881

00:10:07.556 --> 00:10:09.204 support resources that they need,
NOTE Confidence: 0.9387881

00:10:09.204 --> 00:10:11.895 a research team from the Yale School of
NOTE Confidence: 0.9387881

00:10:11.895 --> 00:10:14.304 Medicine and Public Health came together

NOTE Confidence: 0.9387881

00:10:14.304 --> 00:10:17.316 to explore this qualitatively in a

NOTE Confidence: 0.9387881

00:10:17.316 --> 00:10:20.659 sample of midlife former caregivers.

NOTE Confidence: 0.9387881

00:10:20.660 --> 00:10:22.430 And again, these were former caregivers

NOTE Confidence: 0.9387881

00:10:22.430 --> 00:10:24.909 of parents who had recently died following

NOTE Confidence: 0.9387881

00:10:24.909 --> 00:10:26.979 advanced Alzheimer's disease or dementia.

NOTE Confidence: 0.9387881

00:10:26.980 --> 00:10:29.472 And what our team had found is

NOTE Confidence: 0.9387881

00:10:29.472 --> 00:10:31.131 that former caregivers describe

NOTE Confidence: 0.9387881

00:10:31.131 --> 00:10:33.203 preparedness for future caregiving

NOTE Confidence: 0.9387881

00:10:33.203 --> 00:10:36.255 as involving several domains that are

NOTE Confidence: 0.9387881

00:10:36.255 --> 00:10:38.619 influenced by their prior care roles.

NOTE Confidence: 0.9387881

00:10:38.620 --> 00:10:40.060 So specifically looking at

NOTE Confidence: 0.9387881

00:10:40.060 --> 00:10:41.500 the light blue boxes,

NOTE Confidence: 0.9387881

00:10:41.500 --> 00:10:43.984 all former caregivers described that prior

NOTE Confidence: 0.9387881

00:10:43.984 --> 00:10:47.007 care roles taught them specific skills or

NOTE Confidence: 0.9387881

00:10:47.007 --> 00:10:49.172 pragmatic insights that could contribute

NOTE Confidence: 0.9387881

00:10:49.172 --> 00:10:52.338 to their preparedness for future care roles.

NOTE Confidence: 0.9387881

00:10:52.340 --> 00:10:53.057 And so again,

NOTE Confidence: 0.9387881

00:10:53.057 --> 00:10:54.491 we kind of categorize them into

NOTE Confidence: 0.9387881

00:10:54.491 --> 00:10:55.817 these three boxes of skills.

NOTE Confidence: 0.9387881

00:10:55.820 --> 00:10:57.818 First in terms of self conduct,

NOTE Confidence: 0.9387881

00:10:57.820 --> 00:11:00.058 so these are things like self-care,

NOTE Confidence: 0.9387881

00:11:00.060 --> 00:11:00.557 emotion,

NOTE Confidence: 0.9387881

00:11:00.557 --> 00:11:03.042 regulation or resilience and other

NOTE Confidence: 0.9387881

00:11:03.042 --> 00:11:05.030 psychological resources that some

NOTE Confidence: 0.9387881

00:11:05.095 --> 00:11:07.339 caregivers had developed and felt that

NOTE Confidence: 0.9387881

00:11:07.339 --> 00:11:10.260 they could tap into in future care roles.

NOTE Confidence: 0.9387881

00:11:10.260 --> 00:11:12.934 Next, we were we developed a category

NOTE Confidence: 0.9387881

00:11:12.934 --> 00:11:15.379 of skills in care navigation.

NOTE Confidence: 0.9387881

00:11:15.380 --> 00:11:17.340 So this involves coordinating Dr.

NOTE Confidence: 0.9387881

00:11:17.340 --> 00:11:20.160 visits, overseeing finances,

NOTE Confidence: 0.9387881

00:11:20.160 --> 00:11:22.700 hiring and managing formal care support,

NOTE Confidence: 0.9387881

00:11:22.700 --> 00:11:23.012 etcetera.

NOTE Confidence: 0.9387881

00:11:23.012 --> 00:11:23.636 And finally,

NOTE Confidence: 0.9387881

00:11:23.636 --> 00:11:26.240 we found a domain in terms of skills

NOTE Confidence: 0.9387881

00:11:26.240 --> 00:11:28.040 relating to relating with your

NOTE Confidence: 0.9387881

00:11:28.040 --> 00:11:30.140 care partner that care recipient.

NOTE Confidence: 0.9387881

00:11:30.140 --> 00:11:30.485 I'm.

NOTE Confidence: 0.9387881

00:11:30.485 --> 00:11:31.865 So this involves interpersonal

NOTE Confidence: 0.9387881

00:11:31.865 --> 00:11:33.590 skills for maintaining a strong

NOTE Confidence: 0.9387881

00:11:33.642 --> 00:11:35.467 positive relationship even when a

NOTE Confidence: 0.9387881

00:11:35.467 --> 00:11:36.927 care partner's personality changes

NOTE Confidence: 0.9387881

00:11:36.927 --> 00:11:38.738 or they become more dependent,

NOTE Confidence: 0.9387881

00:11:38.740 --> 00:11:41.834 which is really common in this Alzheimer's

NOTE Confidence: 0.9387881

00:11:41.834 --> 00:11:44.569 disease and dementia disease trajectory.

NOTE Confidence: 0.9387881

00:11:44.570 --> 00:11:46.712 So zooming out from those light blue

NOTE Confidence: 0.9387881

00:11:46.712 --> 00:11:48.210 boxes when caregivers described,

NOTE Confidence: 0.9387881

00:11:48.210 --> 00:11:49.558 while caregivers described those
NOTE Confidence: 0.9387881

00:11:49.558 --> 00:11:51.580 really critical skills that they had
NOTE Confidence: 0.9387881

00:11:51.629 --> 00:11:53.285 learned in those prior care roles,
NOTE Confidence: 0.9387881

00:11:53.290 --> 00:11:55.666 they also described the value of
NOTE Confidence: 0.9387881

00:11:55.666 --> 00:11:57.250 having developed confidence or
NOTE Confidence: 0.9387881

00:11:57.316 --> 00:11:59.201 belief in their personal ability
NOTE Confidence: 0.9387881

00:11:59.201 --> 00:12:01.530 to handle their future care roles.
NOTE Confidence: 0.9387881

00:12:01.530 --> 00:12:03.441 And I'm going to describe what confidence
NOTE Confidence: 0.9387881

00:12:03.441 --> 00:12:05.130 looks like more in just a minute.
NOTE Confidence: 0.9387881

00:12:05.130 --> 00:12:05.752 But finally,
NOTE Confidence: 0.9387881

00:12:05.752 --> 00:12:07.618 we know from previous research that
NOTE Confidence: 0.9387881

00:12:07.618 --> 00:12:09.248 one's ability to address activities
NOTE Confidence: 0.9387881

00:12:09.248 --> 00:12:10.843 of daily living like bathing,
NOTE Confidence: 0.9387881

00:12:10.850 --> 00:12:11.642 feeding, transporting,
NOTE Confidence: 0.9387881

00:12:11.642 --> 00:12:14.414 and dressing a care partner is also
NOTE Confidence: 0.9387881

00:12:14.414 --> 00:12:16.450 important for success and care roles.

NOTE Confidence: 0.9387881

00:12:16.450 --> 00:12:18.770 Caregivers didn't describe having gained

NOTE Confidence: 0.9387881

00:12:18.770 --> 00:12:21.586 any specific ability to perform these

NOTE Confidence: 0.9387881

00:12:21.586 --> 00:12:24.066 activities through prior care roles.

NOTE Confidence: 0.9387881

00:12:24.070 --> 00:12:24.734 It kind of appears,

NOTE Confidence: 0.9387881

00:12:24.734 --> 00:12:25.066 you know,

NOTE Confidence: 0.9387881

00:12:25.070 --> 00:12:26.990 in terms of our qualitative study

NOTE Confidence: 0.9387881

00:12:26.990 --> 00:12:28.591 that caregivers either feel like

NOTE Confidence: 0.9387881

00:12:28.591 --> 00:12:30.460 they had or did not have the

NOTE Confidence: 0.9387881

00:12:30.460 --> 00:12:31.839 physical strength or psychological

NOTE Confidence: 0.9387881

00:12:31.839 --> 00:12:33.411 wherewithal or other resources

NOTE Confidence: 0.9387881

00:12:33.411 --> 00:12:34.983 to handle those activities.

NOTE Confidence: 0.9387881

00:12:34.990 --> 00:12:36.712 Prior care roles don't really add

NOTE Confidence: 0.9387881

00:12:36.712 --> 00:12:38.430 or subtract from those abilities.

NOTE Confidence: 0.93713427

00:12:43.200 --> 00:12:45.036 So coming back to caregiving confidence,

NOTE Confidence: 0.93713427

00:12:45.040 --> 00:12:47.336 this is what I considered to be the

NOTE Confidence: 0.93713427

00:12:47.336 --> 00:12:49.205 crucial finding from this work broadly,
NOTE Confidence: 0.93713427

00:12:49.205 --> 00:12:51.430 although all caregivers described again
NOTE Confidence: 0.93713427

00:12:51.430 --> 00:12:54.260 having learned those skills from those light
NOTE Confidence: 0.93713427

00:12:54.260 --> 00:12:56.556 blue block boxes on the previous slide,
NOTE Confidence: 0.93713427

00:12:56.560 --> 00:12:58.468 their confidence varied really
NOTE Confidence: 0.93713427

00:12:58.468 --> 00:13:00.853 widely and we categorize confidence
NOTE Confidence: 0.93713427

00:13:00.853 --> 00:13:03.198 in these four different ways.
NOTE Confidence: 0.93713427

00:13:03.200 --> 00:13:07.072 So first we found a category of sustained
NOTE Confidence: 0.93713427

00:13:07.072 --> 00:13:08.781 confidence where caregivers described
NOTE Confidence: 0.93713427

00:13:08.781 --> 00:13:11.223 that because of previous care rules
NOTE Confidence: 0.93713427

00:13:11.223 --> 00:13:13.415 that they had had even earlier in
NOTE Confidence: 0.93713427

00:13:13.415 --> 00:13:15.600 life or because of caring professions,
NOTE Confidence: 0.93713427

00:13:15.600 --> 00:13:17.160 often health professions,
NOTE Confidence: 0.93713427

00:13:17.160 --> 00:13:18.555 they already had the sustained
NOTE Confidence: 0.93713427

00:13:18.555 --> 00:13:20.457 confidence to be able to be a
NOTE Confidence: 0.93713427

00:13:20.457 --> 00:13:22.032 caregiver as many times as it took.

NOTE Confidence: 0.93713427

00:13:22.040 --> 00:13:24.609 They sort of tapped back into this

NOTE Confidence: 0.93713427

00:13:24.609 --> 00:13:27.308 profession or sort of trade as a caregiver.

NOTE Confidence: 0.93713427

00:13:27.308 --> 00:13:29.390 And so this participant shared with

NOTE Confidence: 0.93713427

00:13:29.451 --> 00:13:31.460 us that I went into patient mode.

NOTE Confidence: 0.93713427

00:13:31.460 --> 00:13:32.117 I think, well,

NOTE Confidence: 0.93713427

00:13:32.117 --> 00:13:33.650 caring for what caring for my dad

NOTE Confidence: 0.93713427

00:13:33.698 --> 00:13:35.522 showed me was that even though I don't

NOTE Confidence: 0.93713427

00:13:35.522 --> 00:13:36.939 practice at the bedside anymore,

NOTE Confidence: 0.93713427

00:13:36.940 --> 00:13:39.094 there's still something that is at

NOTE Confidence: 0.93713427

00:13:39.094 --> 00:13:41.967 the core of who I am and what I do.

NOTE Confidence: 0.93713427

00:13:41.970 --> 00:13:44.070 Caregivers in some cases also

NOTE Confidence: 0.93713427

00:13:44.070 --> 00:13:45.330 described boosted confidence.

NOTE Confidence: 0.93713427

00:13:45.330 --> 00:13:47.570 And this was the category that encapsulated

NOTE Confidence: 0.93713427

00:13:47.570 --> 00:13:49.330 those people who felt like yes,

NOTE Confidence: 0.93713427

00:13:49.330 --> 00:13:51.090 because of my previous caregiving

NOTE Confidence: 0.93713427

00:13:51.090 --> 00:13:53.659 experience for my parent who who had

NOTE Confidence: 0.93713427

00:13:53.659 --> 00:13:55.524 recently died after advanced dementia,

NOTE Confidence: 0.93713427

00:13:55.530 --> 00:13:57.130 I now feel more prepared.

NOTE Confidence: 0.93713427

00:13:57.130 --> 00:13:58.490 I have this boosted confidence.

NOTE Confidence: 0.93713427

00:13:58.490 --> 00:14:01.010 I feel more able to be a caregiver again,

NOTE Confidence: 0.93713427

00:14:01.010 --> 00:14:02.635 and I'm actually looking forward

NOTE Confidence: 0.93713427

00:14:02.635 --> 00:14:03.610 to the opportunity.

NOTE Confidence: 0.93713427

00:14:03.610 --> 00:14:05.339 And so this caregiver said if I

NOTE Confidence: 0.93713427

00:14:05.339 --> 00:14:07.407 had to take care of somebody else,

NOTE Confidence: 0.93713427

00:14:07.410 --> 00:14:08.890 I would absolutely do it.

NOTE Confidence: 0.93713427

00:14:08.890 --> 00:14:10.450 I don't want somebody else to do it.

NOTE Confidence: 0.93713427

00:14:10.450 --> 00:14:11.290 I want to do it.

NOTE Confidence: 0.93713427

00:14:11.290 --> 00:14:12.986 I want to make the decisions and it

NOTE Confidence: 0.93713427

00:14:12.986 --> 00:14:14.592 was really interesting to hear this

NOTE Confidence: 0.93713427

00:14:14.592 --> 00:14:16.284 from a participant who had described

NOTE Confidence: 0.93713427

00:14:16.333 --> 00:14:17.911 previously never thinking that he would

NOTE Confidence: 0.93713427

00:14:17.911 --> 00:14:21.130 be a caregiver or a good caregiver.

NOTE Confidence: 0.93713427

00:14:21.130 --> 00:14:21.558 Next,

NOTE Confidence: 0.93713427

00:14:21.558 --> 00:14:23.698 we saw these individuals who

NOTE Confidence: 0.93713427

00:14:23.698 --> 00:14:24.982 describe restricted confidence.

NOTE Confidence: 0.93713427

00:14:24.990 --> 00:14:26.886 These were people who said I

NOTE Confidence: 0.93713427

00:14:26.886 --> 00:14:27.750 could be a caregiver.

NOTE Confidence: 0.93713427

00:14:27.750 --> 00:14:27.960 Again,

NOTE Confidence: 0.93713427

00:14:27.960 --> 00:14:29.430 I think that I have the ability,

NOTE Confidence: 0.93713427

00:14:29.430 --> 00:14:31.104 but I have some qualifiers or

NOTE Confidence: 0.93713427

00:14:31.104 --> 00:14:33.013 caveats about what I would want it

NOTE Confidence: 0.93713427

00:14:33.013 --> 00:14:35.070 to look the next like the next time.

NOTE Confidence: 0.93713427

00:14:35.070 --> 00:14:35.500 For example,

NOTE Confidence: 0.93713427

00:14:35.500 --> 00:14:37.791 I might not be able to do it if it

NOTE Confidence: 0.93713427

00:14:37.791 --> 00:14:39.590 was a different type of family member,

NOTE Confidence: 0.93713427

00:14:39.590 --> 00:14:41.750 say a sibling or a spouse,

NOTE Confidence: 0.93713427

00:14:41.750 --> 00:14:43.630 even though I did it for my parents.

NOTE Confidence: 0.93713427

00:14:43.630 --> 00:14:45.790 Or I was able to do it for my mom,

NOTE Confidence: 0.93713427

00:14:45.790 --> 00:14:47.194 but I'm not really sure about

NOTE Confidence: 0.93713427

00:14:47.194 --> 00:14:48.390 doing it for my dad.

NOTE Confidence: 0.93713427

00:14:48.390 --> 00:14:50.790 And so these were people who had those

NOTE Confidence: 0.93713427

00:14:50.790 --> 00:14:52.528 qualifiers or were sort of reluctant

NOTE Confidence: 0.93713427

00:14:52.528 --> 00:14:56.164 to to envision really stepping into

NOTE Confidence: 0.93713427

00:14:56.164 --> 00:14:57.652 a caregiving role in the future.

NOTE Confidence: 0.93713427

00:14:57.660 --> 00:14:58.818 So for example,

NOTE Confidence: 0.93713427

00:14:58.818 --> 00:14:59.976 this participant said,

NOTE Confidence: 0.93713427

00:14:59.980 --> 00:15:01.816 I definitely did learn some things.

NOTE Confidence: 0.93713427

00:15:01.820 --> 00:15:03.700 I also got very depressed.

NOTE Confidence: 0.93713427

00:15:03.700 --> 00:15:05.744 If I had to do it, would I do it?

NOTE Confidence: 0.93713427

00:15:05.744 --> 00:15:06.617 Probably I would,

NOTE Confidence: 0.93713427

00:15:06.620 --> 00:15:08.780 because that's the kind of person I am.

NOTE Confidence: 0.93713427

00:15:08.780 --> 00:15:09.860 But God, I don't really,

NOTE Confidence: 0.93713427

00:15:09.860 --> 00:15:11.172 I really don't want to have to go

NOTE Confidence: 0.93713427

00:15:11.172 --> 00:15:12.180 through that again emotionally.

NOTE Confidence: 0.93713427

00:15:12.180 --> 00:15:13.380 So she certainly says, oh,

NOTE Confidence: 0.93713427

00:15:13.380 --> 00:15:14.220 I think I could do it,

NOTE Confidence: 0.93713427

00:15:14.220 --> 00:15:16.236 but I do have these reservations

NOTE Confidence: 0.93713427

00:15:16.236 --> 00:15:17.580 because it was very

NOTE Confidence: 0.9348204

00:15:17.645 --> 00:15:19.068 challenging. And importantly,

NOTE Confidence: 0.9348204

00:15:19.068 --> 00:15:21.336 we found this fourth group of caregivers

NOTE Confidence: 0.9348204

00:15:21.336 --> 00:15:23.260 who described impeded confidence.

NOTE Confidence: 0.9348204

00:15:23.260 --> 00:15:24.835 These were individuals who were

NOTE Confidence: 0.9348204

00:15:24.835 --> 00:15:27.003 highly resistant to the idea of being

NOTE Confidence: 0.9348204

00:15:27.003 --> 00:15:28.617 a caregiver again in the future,

NOTE Confidence: 0.9348204

00:15:28.620 --> 00:15:30.420 even if they could picture somebody

NOTE Confidence: 0.9348204

00:15:30.420 --> 00:15:32.159 who they would likely have to

NOTE Confidence: 0.9348204

00:15:32.159 --> 00:15:33.617 care for again in the future.

NOTE Confidence: 0.9348204

00:15:33.620 --> 00:15:35.978 And so this participant had told us it hurts.

NOTE Confidence: 0.9348204

00:15:35.980 --> 00:15:37.936 When you find out you're naive,

NOTE Confidence: 0.9348204

00:15:37.940 --> 00:15:40.196 I feel like it's so damaging that you

NOTE Confidence: 0.9348204

00:15:40.196 --> 00:15:42.667 can't do it properly for somebody else.

NOTE Confidence: 0.9348204

00:15:42.670 --> 00:15:44.782 And so this person is really

NOTE Confidence: 0.9348204

00:15:44.782 --> 00:15:46.706 articulating this idea of, you know,

NOTE Confidence: 0.9348204

00:15:46.706 --> 00:15:48.770 I have this perception of myself as someone

NOTE Confidence: 0.9348204

00:15:48.827 --> 00:15:50.827 who was too naive in the caregiving role.

NOTE Confidence: 0.9348204

00:15:50.830 --> 00:15:52.526 And I'm really so damaged by that experience

NOTE Confidence: 0.9348204

00:15:52.526 --> 00:15:54.293 that I don't believe that I could be

NOTE Confidence: 0.9348204

00:15:54.293 --> 00:15:55.788 a good caregiver again in the future.

NOTE Confidence: 0.9347110333333333

00:15:59.070 --> 00:16:01.790 Importantly, for caregivers who had

NOTE Confidence: 0.9347110333333333

00:16:01.790 --> 00:16:03.966 restricted or impeded confidence,

NOTE Confidence: 0.9347110333333333

00:16:03.970 --> 00:16:05.785 even having learned important skills

NOTE Confidence: 0.9347110333333333

00:16:05.785 --> 00:16:08.393 from prior care roles appears to be

NOTE Confidence: 0.9347110333333333

00:16:08.393 --> 00:16:09.865 insufficient for their perceived

NOTE Confidence: 0.9347110333333333
00:16:09.865 --> 00:16:11.730 preparedness for future care roles,
NOTE Confidence: 0.9347110333333333
00:16:11.730 --> 00:16:13.529 as described by this caregiver who said,
NOTE Confidence: 0.9347110333333333
00:16:13.530 --> 00:16:15.645 I think I have more tools in my arsenal
NOTE Confidence: 0.9347110333333333
00:16:15.645 --> 00:16:17.567 to try to do things if I had to,
NOTE Confidence: 0.9347110333333333
00:16:17.570 --> 00:16:19.432 but I don't think I have any
NOTE Confidence: 0.9347110333333333
00:16:19.432 --> 00:16:21.203 level of certainty that I would be
NOTE Confidence: 0.9347110333333333
00:16:21.203 --> 00:16:23.020 able to deal with it any better.
NOTE Confidence: 0.9347110333333333
00:16:23.020 --> 00:16:24.915 And also, skills and confidence
NOTE Confidence: 0.9347110333333333
00:16:24.915 --> 00:16:26.810 for future care experiences were
NOTE Confidence: 0.9347110333333333
00:16:26.873 --> 00:16:28.973 shaped by those personal narratives
NOTE Confidence: 0.9347110333333333
00:16:28.973 --> 00:16:30.653 that caregivers had developed
NOTE Confidence: 0.9347110333333333
00:16:30.653 --> 00:16:32.857 about their prior care experiences.
NOTE Confidence: 0.9347110333333333
00:16:32.860 --> 00:16:33.842 So specifically,
NOTE Confidence: 0.9347110333333333
00:16:33.842 --> 00:16:35.806 multiple caregivers described similar
NOTE Confidence: 0.9347110333333333
00:16:35.806 --> 00:16:38.529 events from their prior care roles
NOTE Confidence: 0.9347110333333333

00:16:38.529 --> 00:16:40.605 but narrated them in ways that
NOTE Confidence: 0.9347110333333333

00:16:40.605 --> 00:16:42.734 emphasized or deemphasized their own
NOTE Confidence: 0.9347110333333333

00:16:42.734 --> 00:16:45.014 competence or aptitude or insights,
NOTE Confidence: 0.9347110333333333

00:16:45.020 --> 00:16:47.720 which influenced their their sense
NOTE Confidence: 0.9347110333333333

00:16:47.720 --> 00:16:49.340 of preparedness for.
NOTE Confidence: 0.9347110333333333

00:16:49.340 --> 00:16:50.480 So for example,
NOTE Confidence: 0.9347110333333333

00:16:50.480 --> 00:16:52.380 2 caregivers both described learning
NOTE Confidence: 0.9347110333333333

00:16:52.380 --> 00:16:54.842 that they were too committed to
NOTE Confidence: 0.9347110333333333

00:16:54.842 --> 00:16:56.368 caregiving without support from others
NOTE Confidence: 0.9347110333333333

00:16:56.368 --> 00:16:58.020 they weren't willing to take on help,
NOTE Confidence: 0.9347110333333333

00:16:58.020 --> 00:17:00.095 which is a typical caregiving
NOTE Confidence: 0.9347110333333333

00:17:00.095 --> 00:17:01.340 issue caregiver issue.
NOTE Confidence: 0.9347110333333333

00:17:01.340 --> 00:17:03.660 They want to try to do it all by themselves.
NOTE Confidence: 0.9347110333333333

00:17:03.660 --> 00:17:06.984 And these caregivers described that these
NOTE Confidence: 0.9347110333333333

00:17:06.984 --> 00:17:09.300 insights affected them in different ways.
NOTE Confidence: 0.9347110333333333

00:17:09.300 --> 00:17:12.170 So one participant said, here's my line,

NOTE Confidence: 0.9347110333333333
00:17:12.170 --> 00:17:13.682 as long as there's somebody there
NOTE Confidence: 0.9347110333333333
00:17:13.682 --> 00:17:14.690 who can help you,
NOTE Confidence: 0.9347110333333333
00:17:14.690 --> 00:17:16.489 I have the knowledge and I know
NOTE Confidence: 0.9347110333333333
00:17:16.489 --> 00:17:17.570 what limitations I have,
NOTE Confidence: 0.9347110333333333
00:17:17.570 --> 00:17:18.666 so I'm better prepared.
NOTE Confidence: 0.9347110333333333
00:17:18.666 --> 00:17:20.036 So this person basically describes
NOTE Confidence: 0.9347110333333333
00:17:20.036 --> 00:17:21.449 having learned from her mistakes,
NOTE Confidence: 0.9347110333333333
00:17:21.450 --> 00:17:24.048 not not having taken on that,
NOTE Confidence: 0.9347110333333333
00:17:24.050 --> 00:17:25.335 that support earlier on in
NOTE Confidence: 0.9347110333333333
00:17:25.335 --> 00:17:26.363 her prior care role.
NOTE Confidence: 0.9347110333333333
00:17:26.370 --> 00:17:27.990 She now feels more prepared
NOTE Confidence: 0.9347110333333333
00:17:27.990 --> 00:17:29.286 because she's learned that.
NOTE Confidence: 0.9347110333333333
00:17:29.290 --> 00:17:30.514 But in contrast, again,
NOTE Confidence: 0.9347110333333333
00:17:30.514 --> 00:17:32.350 thinking about a different way that
NOTE Confidence: 0.9347110333333333
00:17:32.402 --> 00:17:34.010 the same narrative can be told,
NOTE Confidence: 0.9347110333333333

00:17:34.010 --> 00:17:35.178 another participant said that
NOTE Confidence: 0.9347110333333333

00:17:35.178 --> 00:17:36.930 was a mistake that I made,
NOTE Confidence: 0.9347110333333333

00:17:36.930 --> 00:17:39.050 not figuring out how to get more help.
NOTE Confidence: 0.9347110333333333

00:17:39.050 --> 00:17:40.660 I regret that I didn't.
NOTE Confidence: 0.9347110333333333

00:17:40.660 --> 00:17:41.620 You want to be a caregiver?
NOTE Confidence: 0.9347110333333333

00:17:41.620 --> 00:17:43.615 No, that's not something that I'm doing.
NOTE Confidence: 0.9347110333333333

00:17:43.620 --> 00:17:45.500 I can't emotionally handle it.
NOTE Confidence: 0.9347110333333333

00:17:45.500 --> 00:17:47.236 So this is a person who also
NOTE Confidence: 0.9347110333333333

00:17:47.236 --> 00:17:49.056 learned that they had made a mistake
NOTE Confidence: 0.9347110333333333

00:17:49.056 --> 00:17:50.580 and not taking on more help.
NOTE Confidence: 0.9347110333333333

00:17:50.580 --> 00:17:51.892 But in this case,
NOTE Confidence: 0.9347110333333333

00:17:51.892 --> 00:17:53.860 this is a caregiver who said,
NOTE Confidence: 0.9347110333333333

00:17:53.860 --> 00:17:55.732 I've learned that I'm not able to do that.
NOTE Confidence: 0.9347110333333333

00:17:55.740 --> 00:17:57.329 I've learned that it's not something that
NOTE Confidence: 0.9347110333333333

00:17:57.329 --> 00:17:58.859 I can emotionally handle in the future,
NOTE Confidence: 0.94338304

00:18:01.460 --> 00:18:02.790 so I want to wrap up with

NOTE Confidence: 0.94338304

00:18:02.790 --> 00:18:03.779 a few takeaways for you.

NOTE Confidence: 0.94338304

00:18:03.780 --> 00:18:05.980 Also, this study really provided

NOTE Confidence: 0.94338304

00:18:05.980 --> 00:18:07.528 very critical information to

NOTE Confidence: 0.94338304

00:18:07.528 --> 00:18:09.463 inform next steps in research

NOTE Confidence: 0.94338304

00:18:09.463 --> 00:18:11.540 but also in clinical practice.

NOTE Confidence: 0.94338304

00:18:11.540 --> 00:18:14.074 So first take away point is that

NOTE Confidence: 0.94338304

00:18:14.074 --> 00:18:16.275 preparedness for caregivers in a dementia

NOTE Confidence: 0.94338304

00:18:16.275 --> 00:18:18.375 care context often involves not just

NOTE Confidence: 0.94338304

00:18:18.375 --> 00:18:20.540 gaining skills or pragmatic insights,

NOTE Confidence: 0.94338304

00:18:20.540 --> 00:18:23.000 but also gaining and maintaining

NOTE Confidence: 0.94338304

00:18:23.000 --> 00:18:25.460 confidence in one's care ability.

NOTE Confidence: 0.94338304

00:18:25.460 --> 00:18:27.204 Multiple caregivers described that

NOTE Confidence: 0.94338304

00:18:27.204 --> 00:18:29.384 there was no clinical screening

NOTE Confidence: 0.94338304

00:18:29.384 --> 00:18:31.910 tool or practices in the clinical

NOTE Confidence: 0.94338304

00:18:31.910 --> 00:18:33.935 setting to address their preparedness

NOTE Confidence: 0.94338304

00:18:34.003 --> 00:18:35.538 early in their care role,
NOTE Confidence: 0.94338304

00:18:35.540 --> 00:18:37.946 and they consistently called for tools
NOTE Confidence: 0.94338304

00:18:37.946 --> 00:18:40.144 to prompt discussion with providers
NOTE Confidence: 0.94338304

00:18:40.144 --> 00:18:42.260 about their preparedness earlier
NOTE Confidence: 0.94338304

00:18:42.260 --> 00:18:44.376 in their caregiving trajectories.
NOTE Confidence: 0.94338304

00:18:44.380 --> 00:18:45.144 In addition,
NOTE Confidence: 0.94338304

00:18:45.144 --> 00:18:47.054 expecting that prior care roles
NOTE Confidence: 0.94338304

00:18:47.054 --> 00:18:48.574 and caregivers necessarily boost
NOTE Confidence: 0.94338304

00:18:48.574 --> 00:18:50.159 their preparedness just by nature
NOTE Confidence: 0.94338304

00:18:50.159 --> 00:18:52.026 of exposing them to the care
NOTE Confidence: 0.94338304

00:18:52.026 --> 00:18:53.371 situations that they could engage
NOTE Confidence: 0.94338304

00:18:53.371 --> 00:18:55.892 in is a flawed expectation and might
NOTE Confidence: 0.94338304

00:18:55.892 --> 00:18:58.032 be harmful for multiple reasons.
NOTE Confidence: 0.94338304

00:18:58.040 --> 00:18:58.704 So specifically,
NOTE Confidence: 0.94338304

00:18:58.704 --> 00:19:00.364 this expectation can lead to
NOTE Confidence: 0.94338304

00:19:00.364 --> 00:19:02.597 a focus on preparing not only

NOTE Confidence: 0.94338304

00:19:02.597 --> 00:19:04.157 novice caregivers or sorry,

NOTE Confidence: 0.94338304

00:19:04.160 --> 00:19:06.358 a focus on preparing only novice caregivers,

NOTE Confidence: 0.94338304

00:19:06.360 --> 00:19:07.980 leaving those experienced caregivers

NOTE Confidence: 0.94338304

00:19:07.980 --> 00:19:10.410 with few resources that are tailored

NOTE Confidence: 0.94338304

00:19:10.468 --> 00:19:12.526 to them because we just expect that

NOTE Confidence: 0.94338304

00:19:12.526 --> 00:19:14.518 they already know what they're doing.

NOTE Confidence: 0.94338304

00:19:14.520 --> 00:19:16.185 This expectation can also harm

NOTE Confidence: 0.94338304

00:19:16.185 --> 00:19:17.850 caregivers who feel pressure to

NOTE Confidence: 0.94338304

00:19:17.908 --> 00:19:19.714 be professionals or pros in their

NOTE Confidence: 0.94338304

00:19:19.714 --> 00:19:21.389 new care roles because they've

NOTE Confidence: 0.94338304

00:19:21.389 --> 00:19:22.637 been caregivers before,

NOTE Confidence: 0.94338304

00:19:22.640 --> 00:19:24.176 but who really don't feel adequately

NOTE Confidence: 0.94338304

00:19:24.176 --> 00:19:26.047 equipped and and don't know how to

NOTE Confidence: 0.94338304

00:19:26.047 --> 00:19:27.107 articulate that dissonance between

NOTE Confidence: 0.94338304

00:19:27.107 --> 00:19:28.783 what they feel like they should be

NOTE Confidence: 0.94338304

00:19:28.783 --> 00:19:30.620 and what they feel like they are.

NOTE Confidence: 0.94338304

00:19:30.620 --> 00:19:31.780 And finally,

NOTE Confidence: 0.94338304

00:19:31.780 --> 00:19:34.300 these findings revealed a subset

NOTE Confidence: 0.94338304

00:19:34.300 --> 00:19:36.640 of former caregivers who really did

NOTE Confidence: 0.94338304

00:19:36.640 --> 00:19:38.420 maintain personal narratives that

NOTE Confidence: 0.94338304

00:19:38.420 --> 00:19:40.755 perpetuated a sense of incompetency,

NOTE Confidence: 0.94338304

00:19:40.760 --> 00:19:42.848 diminishing their confidence and

NOTE Confidence: 0.94338304

00:19:42.848 --> 00:19:44.414 threatening their preparedness

NOTE Confidence: 0.94338304

00:19:44.414 --> 00:19:46.450 for future care roles.

NOTE Confidence: 0.94338304

00:19:46.450 --> 00:19:48.180 This is concerning given that

NOTE Confidence: 0.94338304

00:19:48.180 --> 00:19:50.327 participants were in midlife and the

NOTE Confidence: 0.94338304

00:19:50.327 --> 00:19:52.469 majority of the participants in this

NOTE Confidence: 0.94338304

00:19:52.469 --> 00:19:54.233 study anticipated being caregivers to

NOTE Confidence: 0.94338304

00:19:54.233 --> 00:19:56.445 family or close others in the future.

NOTE Confidence: 0.94338304

00:19:56.450 --> 00:19:56.850 Currently,

NOTE Confidence: 0.94338304

00:19:56.850 --> 00:19:59.250 there are no interventions that exist

NOTE Confidence: 0.94338304

00:19:59.250 --> 00:20:01.305 to support experienced caregivers and

NOTE Confidence: 0.94338304

00:20:01.305 --> 00:20:03.280 support their preparedness on multiple

NOTE Confidence: 0.94338304

00:20:03.280 --> 00:20:05.369 levels for their new care roles.

NOTE Confidence: 0.94338304

00:20:05.370 --> 00:20:07.476 And so we need to do more and better.

NOTE Confidence: 0.94338304

00:20:07.480 --> 00:20:08.460 But in the meantime,

NOTE Confidence: 0.94338304

00:20:08.460 --> 00:20:09.930 as we conduct that additional research

NOTE Confidence: 0.94338304

00:20:09.974 --> 00:20:11.642 and think about ways to intervene

NOTE Confidence: 0.94338304

00:20:11.642 --> 00:20:12.754 for these experienced caregivers,

NOTE Confidence: 0.94338304

00:20:12.760 --> 00:20:14.890 there are some takeaways specific

NOTE Confidence: 0.94338304

00:20:14.890 --> 00:20:17.840 to the clinical setting.

NOTE Confidence: 0.94338304

00:20:17.840 --> 00:20:19.936 The first take away that I just want

NOTE Confidence: 0.94338304

00:20:19.936 --> 00:20:22.053 to briefly emphasize is that it's

NOTE Confidence: 0.94338304

00:20:22.053 --> 00:20:23.973 important to empower caregivers by

NOTE Confidence: 0.94338304

00:20:23.973 --> 00:20:25.372 emphasizing their competency and

NOTE Confidence: 0.94338304

00:20:25.372 --> 00:20:27.591 that this might have a ripple effect

NOTE Confidence: 0.94338304

00:20:27.600 --> 00:20:29.120 where you can boost caregivers
NOTE Confidence: 0.94338304

00:20:29.120 --> 00:20:31.404 confidence in one care role and it
NOTE Confidence: 0.94338304

00:20:31.404 --> 00:20:33.184 could actually translate to positive
NOTE Confidence: 0.94338304

00:20:33.184 --> 00:20:35.199 outcomes across multiple caregiving roles.
NOTE Confidence: 0.94338304

00:20:35.200 --> 00:20:36.820 If a caregiver feels competent
NOTE Confidence: 0.94338304

00:20:36.820 --> 00:20:38.440 or in one care role,
NOTE Confidence: 0.94338304

00:20:38.440 --> 00:20:40.127 they might also take that with them
NOTE Confidence: 0.94338304

00:20:40.127 --> 00:20:42.177 in the form of a narrative they've
NOTE Confidence: 0.94338304

00:20:42.177 --> 00:20:43.767 they've developed about themselves as
NOTE Confidence: 0.94338304

00:20:43.767 --> 00:20:46.040 a caregiver into subsequent care roles.
NOTE Confidence: 0.94338304

00:20:46.040 --> 00:20:47.930 So there really is that important
NOTE Confidence: 0.94338304

00:20:47.930 --> 00:20:49.477 ripple effect to consider when
NOTE Confidence: 0.94338304

00:20:49.477 --> 00:20:52.020 we work with caregivers.
NOTE Confidence: 0.94338304

00:20:52.020 --> 00:20:52.325 Also,
NOTE Confidence: 0.94338304

00:20:52.325 --> 00:20:53.545 when considering a patient's
NOTE Confidence: 0.94338304

00:20:53.545 --> 00:20:54.460 care support network,

NOTE Confidence: 0.94338304

00:20:54.460 --> 00:20:56.620 it's critical to understand that their

NOTE Confidence: 0.94338304

00:20:56.620 --> 00:20:58.325 caregivers do have often caregiving

NOTE Confidence: 0.94338304

00:20:58.325 --> 00:21:00.372 histories that really shape the way

NOTE Confidence: 0.94338304

00:21:00.372 --> 00:21:02.374 that they're entering this new care role.

NOTE Confidence: 0.9371253

00:21:02.380 --> 00:21:04.361 And so not to think about caregivers

NOTE Confidence: 0.9371253

00:21:04.361 --> 00:21:06.181 coming into the clinic as a blank

NOTE Confidence: 0.9371253

00:21:06.181 --> 00:21:07.940 slate or sort of open to learn,

NOTE Confidence: 0.9371253

00:21:07.940 --> 00:21:10.180 but that they might also bring those

NOTE Confidence: 0.9371253

00:21:10.180 --> 00:21:12.076 narratives and those histories with them

NOTE Confidence: 0.9371253

00:21:12.076 --> 00:21:14.471 that can shape the way that they engage

NOTE Confidence: 0.9371253

00:21:14.471 --> 00:21:16.815 with you and and and with their patient.

NOTE Confidence: 0.9371253

00:21:16.820 --> 00:21:17.928 And finally, you know,

NOTE Confidence: 0.9371253

00:21:17.928 --> 00:21:19.929 one of the important takeaways from this

NOTE Confidence: 0.9371253

00:21:19.929 --> 00:21:21.903 is that we could simply ask caregivers

NOTE Confidence: 0.9371253

00:21:21.903 --> 00:21:23.220 during clinical encounters really

NOTE Confidence: 0.9371253

00:21:23.220 --> 00:21:24.965 simple questions about whether they've

NOTE Confidence: 0.9371253

00:21:24.965 --> 00:21:27.356 been a caregiver before and and just

NOTE Confidence: 0.9371253

00:21:27.356 --> 00:21:29.740 briefly to describe what was that like.

NOTE Confidence: 0.9371253

00:21:29.740 --> 00:21:31.742 And this might be able to reveal

NOTE Confidence: 0.9371253

00:21:31.742 --> 00:21:32.600 important information about

NOTE Confidence: 0.9371253

00:21:32.651 --> 00:21:33.938 the caregivers experiences,

NOTE Confidence: 0.9371253

00:21:33.940 --> 00:21:35.896 their fears and their support needs,

NOTE Confidence: 0.9371253

00:21:35.900 --> 00:21:38.700 allowing clinicians to more easily

NOTE Confidence: 0.9371253

00:21:38.700 --> 00:21:40.468 connect caregivers to resources or

NOTE Confidence: 0.9371253

00:21:40.468 --> 00:21:42.686 even just to consider how that patient

NOTE Confidence: 0.9371253

00:21:42.686 --> 00:21:44.774 might need additional support at home.

NOTE Confidence: 0.9378196

00:21:46.840 --> 00:21:49.257 So I just want to end off with providing

NOTE Confidence: 0.9378196

00:21:49.257 --> 00:21:50.765 some additional opportunities to

NOTE Confidence: 0.9378196

00:21:50.765 --> 00:21:53.030 learn about this work, this research,

NOTE Confidence: 0.9378196

00:21:53.030 --> 00:21:54.905 The qualitative study that I

NOTE Confidence: 0.9378196

00:21:54.905 --> 00:21:56.285 described during this presentation

NOTE Confidence: 0.9378196

00:21:56.285 --> 00:21:58.295 was published in the Journal of

NOTE Confidence: 0.9378196

00:21:58.295 --> 00:22:00.199 the American Geriatric Society.

NOTE Confidence: 0.9378196

00:22:00.200 --> 00:22:03.640 And also I recently went on as a

NOTE Confidence: 0.9378196

00:22:03.640 --> 00:22:05.440 guest for a podcast called Doing

NOTE Confidence: 0.9378196

00:22:05.440 --> 00:22:07.719 It Best with Elder Care Success.

NOTE Confidence: 0.9378196

00:22:07.720 --> 00:22:09.844 That podcast episode was about the

NOTE Confidence: 0.9378196

00:22:09.844 --> 00:22:11.586 idea of experienced caregivers and

NOTE Confidence: 0.9378196

00:22:11.586 --> 00:22:13.218 how we can better support them.

NOTE Confidence: 0.9378196

00:22:13.220 --> 00:22:14.684 So if you were interested in

NOTE Confidence: 0.9378196

00:22:14.684 --> 00:22:16.253 listening to that talk with the

NOTE Confidence: 0.9378196

00:22:16.253 --> 00:22:17.337 wonderful host Nancy May,

NOTE Confidence: 0.9378196

00:22:17.340 --> 00:22:19.698 you can go ahead and scan that QR code

NOTE Confidence: 0.9378196

00:22:19.698 --> 00:22:22.258 or just look up that podcast on any

NOTE Confidence: 0.9378196

00:22:22.258 --> 00:22:24.500 platform that you listen to podcasts.

NOTE Confidence: 0.9378196

00:22:24.500 --> 00:22:26.372 Thank you so much for your

NOTE Confidence: 0.9378196

00:22:26.372 --> 00:22:28.000 attention today to this talk.