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Perspective

A roadmap to develop dementia research capacity and capability in Pakistan: A model for low- and middle-income countries

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Abstract

Objective: To produce a strategic roadmap for supporting the development of dementia research in Pakistan.

Background: While global research strategies for dementia research already exist, none is tailored to the specific needs and challenges of low- and middle-income countries (LMIC) like Pakistan.

Methods: We undertook an iterative consensus process with lay and professional experts to develop a Theory of Change-based strategy for dementia research in Pakistan. This included Expert Reference Groups (ERGs), strategic planning techniques, a "research question" priority survey, and consultations with Key Opinion Leaders.

Results: We agreed on ten principles to guide dementia research in Pakistan, emphasizing pragmatic, resource sparing, real-world approaches to support people with dementia, both locally and internationally. Goals included capacity/capability building. Priority research topics included raising awareness and understanding of dementia, and improving quality of life.

Conclusion: This roadmap may be a model for other LMIC health ecosystems with emerging dementia research cultures.

1. Introduction

1.1. Context and impetus

About two-thirds of the nearly 50 million people with dementia (PwD) worldwide currently reside in low- and middle-income countries (LMICs) [1]. In South Asia alone, the number of PwD is likely to be over 9 million by 2030 [2]. In Pakistan, one of the most populous South Asian countries, services for older persons' health and social care are limited [3,4], and the infrastructure to support PwD and their care partners is even less developed, or, in many cases, nonexistent. Research capacity and capability for older person's health issues, as well as for noncommunicable diseases (NCD), is starting to emerge [5]; however, research for dementia still lags behind. Furthermore, stigma regarding the diagnosis and a lack of understanding of dementia as being outside of the normal aging process adds to the challenges in detection and care [6]. Family members, usually women, or informal and untrained care partners, are on the front-line of delivering dementia care in the home setting. This often places a significant burden on families and may have negative health, social, and economic implications. The "roadmap" outlined here establishes a blueprint to develop a research infrastructure for dementia, which is critical to addressing some of these challenges.

1.2. Why is dementia research important in Pakistan?

In a health economy with very little infrastructure for dementia care, and a low level of public awareness and understanding, it could be argued that the priority should be on service development rather than research. However, health research, concerned with discovering new information, awareness, and understanding, and providing a solid evidence base, is necessary to trigger changes in services, care pathways, and policies. Furthermore, if health budgets are limited, a more cost-effective strategy may be the prevention of disease and the optimal management of long-term conditions. Such an approach depends on evidence specific to the population in question; this necessitates a strong research infrastructure.

To date, no published randomized controlled trial (RCT) nor longitudinal cohort study for Alzheimer's disease or other dementias have been undertaken in Pakistan. Moreover, in spite of the rising prevalence and burden of dementia in South and Southeast Asia [7], only a handful of dementia-related RCTs has been completed in this region [8]. This constitutes fewer than 2% of all RCTs for these conditions.

Several factors have contributed to this relative neglect of dementia research, including the dearth of dementia training programs, research centers, and other support services, such as research registries, brain banks, and appropriate neuroimaging experience [8]. Moreover, the demographic distribution of the country, which has had a "youth bulge" [9], has directed health and medical research activity away from older people. Until relatively recently, the average life expectancy in Pakistan was low [10], rendering the proportion of people with age-related chronic conditions small compared to the more pressing issues of maternal and child health and infectious disease. However, lifespan is now increasing and is predicted to exceed age 70 by 2023 [11]. Already, an estimated 12.5 million older adults are already living in Pakistan [12]. Thus, there is a pressing need for policy, practice, and research, to focus more on the needs of older people, including dementia.

1.3. Models of research roadmaps

Recently, international dementia research strategies have been developed to target efforts to offset the current and future burden of dementia globally and within specific societies. A landmark was the 2013 G8 Dementia Summit, "Global Action Against Dementia," that led to the World Health Organization' (WHO) research question prioritization exercise [13,14]. Other initiatives include the United Kingdom's Alzheimer's Society's "Roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025" [15], the USA's "International Alzheimer's Disease Research Portfolio" [16,17], and the European Union's "Joint Program for Neurodegenerative Disease Research" [18].

1.4. Need for a specific roadmap

While the initiatives mentioned above have already triggered significant advances in dementia research (for example, in the UK, the proportion of PwD included in research has risen from fewer than 1% of PwD in 2012 to over 5.3% in 2015/16, [19] the situation in LMICs remains unchanged [3]. Furthermore, in the WHO-led dementia research prioritization exercise [15], only 10% of the participants were from middle-income countries. None was from countries categorized as "low" or "least" developed, notably South Asia. Another consideration is the significant unmet need of the diaspora population from LMICs. In the UK, for example, according to the 2011 consensus, South Asians comprise about 5% of the total population [20] and yet are

significantly under-represented within the National Health Service's memory or dementia services [21,22]. Furthermore, even if older South Asians do present to services, their condition is often significantly advanced, and care burden may already have escalated. Thus, significant challenges in diagnosis and care for this minority group exist, including the lack of cultural, education, and language-appropriate assessment tools and care pathways [23].

Our objective here is to provide a "roadmap" or dynamic strategy for how dementia research in Pakistan might develop over the next 5–15 years, considering: (1) research topic priorities; (2) short, medium and long-term goals; and (3) recommendations to achieve the goals. We have based our roadmap on the Theory of Change (ToC) as the theoretical framework [24,25] to provide a flexible approach to visualizing goals and setting milestones. ToC is an established mechanism guiding development work in LMICs.

2. Methods

2.1. Preparatory activity

As a first step, we convened a Roadmap Task Force (This group included: a clinical academic and a fellow in dementia research; a dementia third sector executive; a practicing neuropsychiatrist; a geriatric psychiatrists with experience working with migrant South Asians in the UK and Pakistan; professors of global mental health in the UK and Pakistan; a ToC methodologist; an LMIC research ethics expert; and dementia researchers from Pakistan. Three members of the group also had experience as dementia care partners.) of eleven stakeholders with experience in Pakistan's dementia and mental health research landscape. The Task Force had a series of virtual meetings over a six-week period to establish the strategic framework, approach and methods of the work.

Knowledge and experience elicitation from experts within a field may include a variety of methods, including interviews, workshops, expert conversations, scenarios, and decision-making tools [26,27]. Thus, to iteratively develop the roadmap, we adopted a hybrid of such methods, including Expert Reference Groups for consensus and decision making, a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis, a research theme prioritization exercise (based on a modified version of the WHO's 2016 prioritization exercise [15]), and 1:1 consultations with professional and lay expert stakeholders and key opinion leaders (KOLs).

2.2. Strategic framework for the roadmap

To guide our work, we applied "Theory of Change" (ToC), a type of causal pathway which provides a detailed and visual description of how and why an expected change may occur in a certain context/setting, and sets out milestones leading to desired goals (short-, medium-, and long-term), based on a shared vision [25,28]. Since dementia

research in Pakistan is still in its infancy, and many unknowns exist, ToC, often used in development work, is a good tool to iteratively update the roadmap, continuously monitor change, and adjust assumptions according to the changing conditions.

2.3. Participants

2.3.1. Expert reference group (ERG)

Professional and lay experts (The stakeholder group (ERG and 1:1 consultees) included the following lay and professional experts: Alzheimer's Pakistan (third sector) workers (n = 4); care partners (n = 6); care home manager, Karachi (n = 1); dementia clinicians (psychiatrist, neurologists, geriatricians: n = 7); psychologists with older adult experience (n = 4); dementia researchers (nurse; n = 1; assistant, n = 2; coordinators; n = 3); dementia clinical academics (n = 5); mental health academics (n = 4, all with global mental health expertise); global and national health policy experts (n = 2); dementia speech and language pathologist (n = 1).) (n = 47), identified through review of the literature, personal contacts, and "snowballing" and selected for their clinical, research, or policy expertise or personal experience in the area, were invited to attend one of three ERGs. Of those contacted, 40 (85%) responded. Experts attended either a face-to-face group meeting or attended via video link. For those unable to attend the group ERGs, we conducted 1:1 interviews regarding the same themes and objectives. We purposefully sought to include representation from across regions in Pakistan (Sindh, Punjab, Balochistan, Khyber Pakhtunkhwa), as well as internationally (UK, Australia, Canada, USA, Bangladesh, India, Nigeria, Iran, Ghana, and Kenya) to capture the diaspora experience, as well as complementary LMIC perspectives.

2.3.2. Research question priority-setting exercise

Using a similar recruitment method and representation as in the ERG's, we contacted 57 additional dementia or mental health professionals or researchers for an online survey.

2.3.3. Key opinion leaders (KOLs)

Our final group of participants was contacted to provide critical feedback on draft versions of the roadmap. KOLs were identified as people with experience and impact in national and/or global mental health and dementia, particularly with relevance to LMICs, such as Pakistan (see Acknowledgments).

2.4. Settings

The ERGs were held on separate days in Karachi (November 15, 2018), Lahore (November 17, 2018), and via video link (November 23, 2018). We conducted the survey online from the University of Manchester. The KOL interviews were conducted by phone, video link, or email.

Table 1
Outline of the ten principles to guide dementia research in Pakistan (in order of priority agreed by Pakistan Dementia Research Study Group)

Guiding principle for actions	Comment or explanation
1. People with dementia and their families are at the core of the research	• "Person-centered care" for dementia needs to be the foundation upon which all care and research for dementia in Pakistan is built; it is characterized by the recognition that the person with dementia has choices, is able to experience life and relationships and their previous life experiences and personality, with a focus on their strengths, is foremost [28]; • Patient and public involvement (PPI) [29] the partnership between patients and/or public and researchers, is crucial in helping to prioritize research questions, advise on meaningful outcomes, support the choice of appropriate and realistic study design and delivery, and assist with dissemination of findings; PPI is the natural extension of person-centered care; meaningful PPI should be incorporated in all dementia research in Pakistan from the first conceptualization of the research question to the final dissemination; • Cross-national PPI in mental health and dementia is starting to emerge, with approaches adapted to settings in LMICs [30].
2. Ethical research practice	• All dementia researchers require robust training in ethical practice (i.e., the UK's Good Clinical Practice training is a model), ideally with a focus on vulnerable adults and capacity assessments and obtaining consent to participate in research; • All dementia research requires full ethical approval from ethical review boards versed in research with older, potentially vulnerable adults who may lack capacity; • Transparency of protocols and data should be a goal, with consideration of storing data on publicly accessible data portals, such as the UK's Dementia Platform UK [31]
3. Quality control	• Researchers should obtain training in research methods, with a dementia focus, including quantitative and qualitative approaches, as necessary for their area of interest; • Training in appropriate research delivery methods, with dementia focus, including aspects of recruitment, working with care partners, undertaking research in different settings (i.e., home, clinic, care home, etc.), and "customer care"; • Quality control of data collection, transfer and storage methods with clear Data Management Plans part of all projects; • Systems should be established to internally and externally monitor or audit research.
4. Equity of access to research opportunities for stakeholders	• Gender equity should be prioritized; access to mental health care for women, particularly older women, has not been prioritized in Pakistan [32], and it is likely to be the same for access to research opportunities; researchers must be aware of the "triple jeopardy" of female sex, financial insecurity, and older age [33]. • Education and literacy inequalities in Pakistan are significant; dementia research often excludes those without basic literacy, thus designing research to ensure full inclusion of PwD and their families with all levels of literacy must be a priority; • Socioeconomic divisions in Pakistan are becoming exaggerated, and ensuring that people from all socioeconomic strata have access to dementia research opportunities must be a key consideration.
5. Pragmatic, cost-effective and resource sparing approaches	• Interventional trials with pragmatic designs and effectiveness goals should take priority over efficacy trials of potentially high-cost interventions requiring complex diagnostic procedures or disease stratification; • Research evaluating resource sparing approaches, such as "task shifting" for dementia diagnosis and care will be important; • Including health economic analyses in clinical and social care research will be important.
6. Impactful work that will make a measurable difference to those affected	• In the first phase, the focus of clinical and social care-based research for dementia should be on projects with proximal benefits for PwD and their families; • To ensure the best outcome for PwD and their families, "real world" studies with meaningful outcomes (i.e., "clinically meaningful" and meaningful to the stakeholders) will be key; this could involve inclusion of Patient/Care reported outcomes (PROs/CROs) [34–36]; • Implementation studies should be considered, particularly those who have interventions or approaches already demonstrated as being effective in other settings; • Follow-on studies from small scale feasibility or pilot studies should be encouraged to avoid the trap of repeated small scale studies which do not deliver definitive solutions to support PwD and their families; • Increasing the knowledge and skills of the dementia research workforce improvement science and implementation science methods will steer the focus to tangible and sustainable outcomes for the wellbeing of PwD and their families.
7. Capacity and capability building inherent in research programs/projects	• Models of research methods and delivery training in LMIC for NCD already exist [37] and could provide good models for dementia research; • New project proposals should include capacity and capability building as part of the overall project plan, with allocated funds, clear protocols and measurement and reporting of outcomes; • These efforts could lean on the developing science of capacity strengthening (i.e., The Capacity Research Unit at Liverpool School of Tropical Medicine) and follow important principles, such as (1) the articulation of "Research Capacity Strengthening Plan" which is aligned to the aspirations of the partnering organizations.

(*Continued*)

Table 1
Outline of the ten principles to guide dementia research in Pakistan (in order of priority agreed by Pakistan Dementia Research Study Group) (*Continued*)

Guiding principle for actions	Comment or explanation
8. Collaborative and supportive working among researchers, particularly across organizational or other boundaries ("stronger together")	• Dementia research is by nature complex and requires multidisciplinary input, thus sharing of expertise across a range of fields, particularly with researchers who have gained experience at centers of excellence internationally should be the standard; • Learning emerging from the new "science of collaboration" [27], which describes the conceptual basis, types, and motivations for partnerships and pros and cons of research collaborations should be incorporated; • All researchers should endeavor to create a culture of transparent and inclusive working practices from the outset of collaborations, using Memoranda of Understanding (MOU) if needed; • The focus should be on cultivating medium- and long-term relationships between and among individuals, research groups, and institutions with a conscious goal of breaking down silos and "empire-building" in the service of the greater goal of developing and delivering the research.
9. Partnering with established centers with an ethos of a "rooted partnership"	• All dementia research partnerships should agree on a model of what an "ideal partnership" should look like, i.e., A "rooted partnership" incorporating the four pillars of Co-creation; capacity-building; sustainability; and openness [38]; • An ideal partnership should result in a seamless blend of skills and expertise, including the established partner providing expertise and resources not available in the LMIC and the LMIC partner providing local clinical and other contextual knowledge; • Balance and fairness in contributions (financial, workforce, etc.) and outputs (authorship, attributions, etc.).
10. The wider Pakistani community of the international diaspora should be included.	• Bidirectional learning from the work done in Pakistan can translate to benefit the wider immigrant community of the Pakistani diaspora, including in high-income countries, and vice versa; • Comparative studies of local and migrant communities are important.

2.5. Procedures

2.5.1. Roadmap Taskforce premeeting

This involved agreement of broad outline by partners of the Roadmap Task Force (by teleconference, October 19, 2018).

2.5.2. Expert reference group meetings

Each group, lasting 90 minutes, was attended by up to eight stakeholders representing different professional and lay perspectives, and with experience of dementia care or research in Pakistan or with the wider Pakistani community. Prior the ERG's, participants to completed a premeeting questionnaire to guide the discussion of the ERG (see Table 1) and to participants' opinions on the ERG objectives, which were to: (1) agree on the principles of dementia research in a LMIC like Pakistan; (2) prioritize the methodological domains and scoring criteria for key research questions; (3) undertake a "situation analysis" using a SWOT approach; and (4) scope goals and actions regarding dementia research capacity and capability. This formed the basis for an initial draft of the ToC document.

Each ERG was introduced by the lead facilitator (IL) through a brief didactic presentation on the topic, using evidence derived from an ongoing systematic review of the literature. This provided a point of reference for the guided discussion among the experts and to ensure the objectives were understood. The facilitator then prompted discussion, including the SWOT analysis, by posing a set of key questions reflecting the objectives. Any examples of tacit knowledge that may have underlain suggested approaches were also probed. Outputs were captured by the facilitator and a scribe using field notes and audio recording. A summary of the ERG outputs was sent to participants for verification of accuracy and to enable further input of ideas or opinions.

2.5.3. Research topic prioritization exercise

To prioritize research topics relevant to dementia in Pakistan, we adapted Shah et al.'s [14] approach (based on the method developed by the Child Health and Nutrition Research Initiative) [39]. This resulted in a list of research topics, organized around seven domains (Prevention, identification, and reduction of risk. Quality of care for people with dementia and their carers. Delivery of care and services for people with dementia and their carers. Diagnosis, biomarker development, and disease monitoring. Pharmacological and nonpharmacological clinical–translational research. Public awareness and understanding. Physiology and progression of normal aging and disease pathogenesis.). We used these same seven domains, under which we included the top five specific research topics for each domain (total of 35), taken from the "long list" of Shah et al.'s [14] 59 research topics. To focus our prioritization exercise, we purposely chose not to include all 59 thematic avenues, and we collapsed two overlapping topics into one, resulting in 33 research topics. These were then sent to the 57 stakeholders as a survey conducted over a three-week period in 2018.

On the survey, respondents were asked to rate each research topic as "1" (agree), "0" (disagree), or "0.5" (unsure/do not know), for each of five scoring criteria. The scoring criteria adapted from Shah et al. [14] were in order of priority established by the ERG's feedback, which was (most to least important) potential to: (1) reduce the burden of dementia on people with the condition, care partners and society as a whole; (2) be translated into practical impacts

(i.e., practical applications, implementation of new or adapted knowledge); (3) achieve its stated outcome within a reasonable period of time; (4) impact PwD and their care partners in an equitable way (i.e., considering socioeconomic and demographic factors, particularly gender, education level and geography); and (5) potential for a conceptual breakthrough unique to Pakistan or other LMICs. The returned scores were analyzed by adding the scores of the five criteria for each research topic, resulting in a grand total score per topic, which was then converted into a percentage. This dichotomization was important to more clearly differentiate the priorities in a resource-scarce health economy, such as Pakistan.

2.5.4. Theory of change framework development

A ToC expert facilitated a day-long workshop (Sharjah, United Arab Emirates, December 5, 2018) for 12 dementia experts from Pakistan to develop a draft ToC strategy. Raw material collected from the three ERGs was collated, and through consensus discussions, goals (short-, intermediate- and long-term), assumptions, barriers, and facilitators, as well as other key aspects of a ToC strategy were agreed.

2.5.5. Key opinion leaders (KOLS) feedback on the draft ToC and 2nd draft revision

We conducted 1:1 interviews to gather feedback on the draft ToC document. KOL opinions were also sought regarding the principles and outcome of the SWOT analysis. Feedback was incorporated into the second draft document, which was then circulated to the core team and Roadmap Stakeholder Group for another set of comments, which were then assimilated into the final roadmap document.

3. Results

Here we outline the findings from each step of the iterative roadmap development process.

3.1. Principles to guide dementia research in Pakistan

Since the current dementia landscape in Pakistan is still research "light," there exists the opportunity to define, at the very earliest stages, a set of core principles to guide the conduct of dementia research to benefit all stakeholders. The ten key principles, agreed by consensus in the ERG and supported by the subsequent 1:1 consultations, are outlined in detail in Table 1. They are, in order of priority: (1) PwD and their families are at the core of the research; (2) ethical research practice; (3) quality control of research methods and delivery; (4) equity of access to research opportunities for all PwD and their families; (5) pragmatic, cost-effective and resource sparing approaches; (6) impactful work with meaningful outcomes that will make a measurable difference to those affected; (7) capacity and capability building inherent in the research programs/projects; (8) collaborative and supportive working amongst researchers,

particularly across organizational or other boundaries ("stronger together"); (9) international collaborations guided by the ethos of a "rooted partnership"; and (10) inclusion of the wider Pakistani community of the international diaspora.

3.2. Analysis of strengths, Weaknesses, Opportunities and Threats (SWOT)

A summary of the SWOT analysis, which emerged from the three ERGs is outlined in Table 2. The following themes are captured by the analysis:

3.2.1. Community awareness, knowledge and stigma

Recent qualitative work on understanding, beliefs, and treatment of dementia in Pakistan [40], revealed low levels of understanding and awareness about dementia in Pakistan. Stigma remains high, and negative and inaccurate beliefs about dementia are common. However, strengths and opportunities lie in the strong religious affiliations of Pakistani society as whole, and tapping into the religious network of society to raise awareness at local and national levels regarding dementia, and its risk factors may enhance the success of an awareness-raising campaign.

3.2.2. Human capital

An important asset within Pakistan is the significant human capital resulting from a high number of very educated young people in disciplines important for dementia research. Every year, Pakistan graduates approximately 4000 students in the fields of psychology, the health sciences, and over 4000 in medicine and other related disciplines [41]. Pakistan has 114 medical schools, health sciences colleges [41], and 108 departments of psychology and social sciences in Pakistan [42] that offer bachelor degrees in psychology with social sciences. It should be noted, however, that although the ERGs agreed that the human capital for creativity and cognitive abilities in young Pakistanis graduates is significant, the stock of competencies, knowledge, and skills relevant to problems of brain aging and dementia was low. The majority of the many health sciences programs mentioned above do not have a focus on ageing-related health problems, particularly brain health. However, some new programs, such as the Sussex Institute of NeuroPsychiatry in Islamabad, are developing. Thus, the challenge will to refocus aspects of the curriculum to include brain ageing-related issues and encourage participation by students in higher level study through Masters and Ph.D. programs.

The movement of medical professionals and health science-related graduates from South Asia to high-income countries (HICs), such as the UK, the USA, and Australia, has resulted in a number of high profile, highly trained national and international dementia research leaders of Pakistani origin working outside Pakistan. Harnessing the significant experience and expertise of such professionals and researchers represents an important opportunity for international collaboration, mentorship of younger or less

Table 2
Strengths, Weaknesses, Opportunities and Threats (SWOT) to developing dementia research in Pakistan

Strengths	Weaknesses
- English is the working language of clinicians and researchers, ensuring full access to the international literature as limited access can turn this into a weakness for not making it available to most of the clinicians; - Excellent network of medical schools and higher educational institutions producing high numbers of university-trained graduates in relevant fields (i.e., psychology, social sciences); - Willingness of the new generation medical and social care workforce (i.e., early career professionals) to engage with dementia as a subspeciality; - Strong family structures supporting home-based dementia care; - Well-established networks of religious clerics and people of high social status engaged in teaching and supporting the community.	- Poor public understanding and awareness of dementia and high levels of stigma, limiting help-seeking; - Minimal development of dementia research in the county; - Limited number of professionals engaged in dementia research and clinical work; - Limited development of clinical and social care infrastructure for people living with dementia; - Few diagnostic services for people at risk of dementia to create a referral base for dementia; - Limited public funding for diagnosis, treatment, and research in dementia; - Minimal mental health and dementia training in medical school; - Geriatric psychiatry is not a developed specialty in Pakistan. - Neuropsychiatry is not recognized and acknowledged as a separate entity by the psychiatrists and neurologists - Research culture does not prevail in the country - Due to the high prevalence of infant, child, and maternal, and infectious diseases, poverty, malnutrition, food insecurity, and other NCDs dementia is not given a priority in the national health policy - Lack of funding resources in the country and limited research training of faculty - Lack of trained personnel to diagnose and manage dementia - Lack of diagnostic tools and validated instruments in Urdu/local languages - Lack of local and international collaborations - Lack of repositories and registries
Opportunities	Threats
- Highly trained senior researchers in international centers of excellence with Pakistani heritage or links - Existence of an infrastructure for mental health research which may provide a springboard on which to undertake multicentered clinical studies for dementia (i.e., Pakistan Institute for Living and Learning; Institute of Psychiatry, Rawalpindi); - Strong links with dementia centers in other countries; - Growing number of international funding bodies interested in supporting dementia research in LMICs, particularly in partnership with economically strong countries; - Strong links with Pakistan expatriates trained in dementia research and clinical work, who live in Europe, Australia, and North America; - Alzheimer's Pakistan, which has links to Alzheimer's Disease International (ADI); - Flexibility in how medical practice is undertaken with a mix of public and private institutions. - Professional neurology and psychiatry societies in Pakistan - Trained neuropsychiatrist in Pakistan	- High level of social and medical unmet needs across several different areas rending dementia a low priority; "Research imperialism" leading to an imbalance in power among partners, especially if collaborating with high-income countries; "Ethical imperialism" leading to the inappropriate adoption of nonlocal standards of conduct for dementia research; - Hierarchical structures in academic and medical institutions leaving early career researchers less able to chart their own research trajectories nor always receive the appropriate credit for their work (i.e., authorship, promotion, etc.); - Ongoing movement of highly trained and talented individuals to overseas centers where career opportunities might be greater. - Unwillingness of local researchers to collaborate and/or share data - People not willing to donate brains post mortem due to religious and cultural beliefs

experienced researchers, and role modeling for those still in Pakistan. Moreover, the professional diaspora community might enable dementia-related research evidence developed in HICs to be relatively easily adopted into the Pakistani context, provided the appropriate cultural, educational, and language-related factors have been taken into consideration. Thus, there exist opportunities for mutually beneficial "brain exchanges" rather than a "brain drain."

3.2.3. Training and education

Psychiatry professional training in Pakistan has, to date, only led to registration in the General Psychiatry qualifica-

tion, which does not include dementia training. There has been a recent move to expand the training and registration process to include sub-specialties, such as child psychiatry, forensic psychiatry, and geriatric (or "old age") psychiatry. Since the training and education curriculum for the sub-specialty of geriatric psychiatry has yet to be developed, there is an important opportunity to also develop neuropsychiatry as a subspecialty to ensure that robust training in dementia research methods is included. Furthermore, offering opportunities for higher specialist trainees to complete meaningful dementia-related research, audit, or implementation science projects will be important. In neurology

specialty training programs, specific training in the prevention, diagnosis, and management of dementia is also not generally available. Finally, postgraduate training programs in geriatric medicine are yet to develop in Pakistan.

3.2.4. Infrastructure

Pakistan has a complex mix of private, public and third sector organizations that delivers health care, and this provides the opportunity for interested individuals or groups of individuals, to pursue a special interest, such as dementia-related practice or research. While such flexibility may be an advantage, it may be limited by the threat of poor quality control, lack of appropriate governance, and the possibility that vulnerable PwD and their families might be put at risk.

In spite of the paucity of health and social care services of PwD and their families in Pakistan, a few privately owned facilities provide models of care outside a family context. These generally have a previous or current religious affiliation (i.e., the Catholic Church) or are third sector organizations, notably Alzheimer's Pakistan [43]. Engaging such organizations in research endeavors may further their credibility with policymakers and also foster more bespoke programs for dementia. For example, in one care home in Karachi, Dar el Sekun, regular "vision camps" and "diabetes camps" are undertaken by peripatetic vision care and medical services. However, no "brain camps" or other services specific to dementia diagnosis or care have ever been offered (personal communication, July 2018). Indeed, it is not clear whether any of the few care homes in Pakistan are aware of the proportion of their residents who may have dementia.

Finally, there are a few examples of well-established, internationally supported third sector research organizations. For example, the Pakistan Institute of Living and Learning [44] and the Institute of Psychiatry Rawalpindi have been undertaking internationally funded high-quality mental health research in collaboration with local, national, and international university partners for several years. In the past 20 years, PILL has trained between 300–500 researchers in mental health research methodology and research study delivery and governance, both within the organization and for other institutions. Expanding the capacity and upskilling the team for dementia work would be the logical next step. Alzheimer's Pakistan [43] has also been involved in the research. For example, they have recently completed a collaborative project, "Understanding, beliefs and treatment of dementia in Pakistan" with the University of Southampton and Brighton and Sussex medical school, UK [40].

3.2.5. Societal and cultural aspects

Pakistan is relatively homogeneous in terms of religion (it is 97% Muslim), and this provides an important context through which to develop dementia care pathways, and, indirectly, dementia research opportunities. Religious leaders play an important part in community life, and there exist many opportunities for dementia research to engage with clerics or other influential individuals with social status. If they are included in the dementia care and/or research agenda, they can be an important access point for help-seeking, recruitment of potential participants, and enhancing general awareness of dementia and ageing-related brain conditions.

Within the domestic sphere, the family-centric structure of Pakistani communities is a marked strength for dementia care, creating opportunities to engage the wider family in the research agenda. However, a potential threat of close-knit family care structures is that PwD may be excluded from access to care or research as families may keep problems within the family circle and limit external help-seeking. Examples of dementia support groups and training and educational sessions for families and informal care partners of PwD are starting to develop [45], but initiatives, such as these need to be adopted at a national level and systematically evaluated. Recently, in collaboration with Alzheimer's Disease International, Alzheimer's Pakistan has launched a structured training program for caregivers [46].

3.2.6. Collaboration with high-income countries (HICs)

The opportunities for dementia research in collaboration with HICs are increasing as several HICs are incorporating research as part of their global development agendas, and dementia has been identified as an area of priority. However, inherent in HIC-LMIC collaborations is the threat of an imbalance in the relationship and the risk of "research imperialism" [47]. Due to unequal power at the outset, there exists the possibility of the dominant partner exploiting the vulnerability of LMIC researchers and institutions and adopting a paternalistic attitude. This may lead to inequalities in control over funding, recognition for the work, and workload. Conversely, the LMIC receiving partner may exploit the HIC through unrealistic expectations of responsibility for the success of the project. Other threats include "ethical imperialism" [47] by adopting "Western" research ethics principles by LMICs, which may have different norms of conduct. Nonetheless, with these caveats in mind, the potential to benefit from HIC-LMIC collaboration is high.

Finally, collaborating with HICs provides an opportunity to address some of the challenges in diagnosis, care, and support for immigrant Pakistani communities which exist even in these HICs. For example, in the UK, issues, such as stigma, high levels of comorbidity, late help-seeking, and lack of culturally and linguistically valid diagnostic and monitoring tools, all contribute to inequity in care for migrant communities [23].

3.3. Research question priority setting

Based on the WHO's priority-setting exercise [14], 33 research questions were extracted for our research question priority-setting exercise. The response rate to the survey was 79% (45/57). Respondents were clinicians (35%), researchers (17%) and academics (55%), with years of dementia research

Table 3
Prioritized research questions for dementia research in Pakistan, classified into domains

Domain and research question	Overall score (mean and percentage of survey respondents)
Public awareness and understanding	
Enhance awareness and understanding of dementia at a community or society-level	165 (73%)
Culture-specific aspects of dementia presentations	156 (69%)
Understanding cultural attitudes toward people with dementia,	154 (68%)
Investigate aspects impacting the quality of life and other outcomes of people with dementia and their care partners in different settings in Pakistan (i.e., rural vs. urban) and in Pakistani immigrant communities (i.e., internationally).	148 (65%)
Prevention, identification, and reduction of risk	
Common conditions of aging (i.e., vascular disease, hearing, vision) impact on dementia	155 (68%)
Improving knowledge, skills, and capacity of health and social care workforce for dementia	150 (66%)
Quality of care for people with dementia and their carers	
Family aspects of supporting people with dementia	178 (79%)
Best methods for training, educating and supporting care partners	166 (74%)
Evaluating community approaches to supporting people with dementia	157 (70%)
Delivery of care and services for people with dementia and their carers	
Finding the best interventions (medications and/or nonmedication, i.e., behavioral) for managing challenging behaviors in dementia (i.e., behavioral and psychological symptoms, BPSD),	152 (67%)
Improving knowledge, skills and capacity of health and social care workforce for dementia	150 (66%)
Developing nonpharmacological therapies which can be delivered by nonspecialists	155 (68%)
Diagnosis, biomarker development, and disease monitoring	0 (0%)
Pharmacological and nonpharmacological clinical–translational research	
Finding the best interventions (medications and/or nonmedication, i.e., behavioral) for managing challenging behaviors in dementia (i.e., behavioral and psychological symptoms, BPSD)	152 (67%)
Physiology and progression of normal aging and disease pathogenesis	0 (0%)

knowledge and/or experience, ranging from 1–35 years. About a third of respondents (33%) had over 10 years of professional experience in dementia or mental health research/clinical practice relevant to Pakistan or LMICs. The research topics, in order of priority based on the highest scores across the five rating criteria, are listed in Table 3.

The top 10 topics fell within the five domains of: (1) public awareness and understanding (4 topics); (2) prevention, identification, and reduction of risk (2 topics); (3) quality of care for PwD and their care partners (3 topics); (4) delivery of care and services for PwD and their care partners (3 topics); and (6) pharmacological and nonpharmacological clinical–translational research (1 topic). None of the top 10 topics fell within the remaining two domains of diagnosis, biomarker development and disease monitoring, and physiology and progression of normal aging and disease pathogenesis. The top 10 specific topics, in order of priority were (see Table 2): (1) family aspects of supporting PwD; (2) best methods for training, educating and supporting care partners; (3) enhancing awareness and understanding of dementia at a community or society-level; (4) evaluating community approaches to supporting PwD (i.e., integrated care, case management, day care, etc) across the life course of dementia; (5) culture-specific aspects of dementia; (6a) developing nonpharmacological therapies which can be delivered by nonspecialists (6b) common conditions of aging (i.e., vascular risk factor and hearing, vision remediation); that impact on dementia; (7) understanding cultural attitudes to-

ward PwD; (8) finding the best interventions (medications and/or nonmedication, i.e., behavioral) for managing challenging behaviors in dementia (i.e., behavioral and psychological symptoms, BPSD); (9) improving knowledge, skills and capacity of the health and social care workforce for dementia; and (10) investigating aspects affecting quality of life and other outcomes of PwD and their care partners in different settings in Pakistan (i.e., rural vs. urban) and in Pakistani immigrant communities (i.e., internationally). The two least prioritized topics were: (1) undertaking clinical trials of new potential disease-modifying therapies, particularly those which require biomarker verification (i.e., neuroimaging, CSF) for eligibility into the trials; and (2) identifying the underlying mechanisms of resilience to neurodegenerative disease-causing dementia at all stages.

Finally, two topics that were highly prioritized on the "burden reduction" and "practical impact" criteria only, were: (1) finding the best interventions for managing challenging behaviors in dementia; and (2) identifying strategies to support people in the advanced stage of dementia. Findings suggest that what may be considered as "biomedical initiatives" were rated as having the lowest priority. The highest priority was given to culturally-relevant family/community/social awareness, training, and care-related initiatives.

3.3.1. Strategic plan to reach the goals (Theory of Change)

Underpinned by the framework of ToC, we set out specific time-based goals with actions to achieve the goals

Table 4
Goals and actions to reach goals for developing dementia research infrastructure in Pakistan and for the wider Pakistani community

Specific goal	Actions to reach the goals
Immediate term (by 2019):	
Develop a model of change to support the Roadmap, based on Theory of Change (ToC) methodology	• Undertake a ToC exercise with stakeholders to develop a model of how dementia research may develop, based on learning and development
Scope of the depth and breadth of Dementia research completed or ongoing in Pakistan.	• Undertake a systematic review of existing dementia research in Pakistan with a view to linking in with global databases of ongoing research [48]
Short term: (1–5 years):	
Launch a **National Dementia Strategy** for Dementia in Pakistan	• WHO Global Action Plan aspires for 75% of countries to adopt a national strategy for dementia by 2025 [49]
Initiatives to **increase awareness** about dementia in rural, as well as urban settings employing a variety of methods	• Developing educational materials regarding brain health that are accessible to all sectors of the community, with particular consideration given to literacy issues
Utilize existing **community support** system to empower family and social support network of people with dementia	• Undertaking capacity building initiatives for family and community members of people with dementia to equip them with knowledge, tools, and strategies to deal with dementia by becoming the change agents from within communities.
Making culturally and linguistically relevant and representative screening and diagnostic tools available for timely dementia assessment and diagnosis	• Developing and adapting screening and diagnostic tools for people with dementia and their carers; • Formulating a comprehensive dementia assessment battery validated in Urdu and other local languages standardized on the Pakistani population.
Putting strong and continuous preventative measures in place	• Developing and introducing courses on brain health and dementia at higher education levels for psychologists, allied health and medical professionals; • Providing sensitization and awareness training about dementia in schools through innovative approaches, such as inter-generational projects.
Creation of a "**national asset map**" for existing pockets of dementia research identification of opportunities for upscaling of capacity and capability	• Undertaking a systematic literature search and scoping exercise of all dementia research conducted in Pakistan or related to the international Pakistani community in the past 10 years; • Scoping "hot spots" of dementia research activity or existing collaborations, locally and internationally; • Scoping areas of strength or activity in related disciplines: mental health research; chronic conditions work; social support for older people
Develop closer **collaborations** among researchers across organizational and regional boundaries within Pakistan	• Establishing a "dementia research portal" as a repository for research activities (project descriptions, protocols of ongoing research) and outputs (publications, presentations, impact activities, etc), hosted by a "neutral" location, such as the website of Alzheimer's Pakistan [43]to facilitate easy access especially to local researchers. • Establishing a network of active and potential dementia researchers with regular virtual meetings and an annual meeting tagged to an annual medical or social care meeting • Establishing a neuropsychiatry sub-group within the Pakistan Society of Neurology and/or the Pakistan Psychiatric Association.
Conscious fostering of research **collaborations with high-income countries** to take advantage of the increased funding for "global research"	• Fostering a mentorship scheme between dementia researchers in HIC and those in Pakistan to develop joint funding bids and access funding or training opportunities worldwide.
Pilot **registries** of people with dementia to test feasibility, acceptability, and ethical factors of maintaining data sets	• Encouraging clinicians, third sector organizations, and research centers to maintain ethically approved, anonymized data sets of people with dementia to understand aspects, such as pathways to care, comorbidities, neuropsychiatric symptoms, referral pattern, care resources, caregiver burden, and cost of care.
Develop and pilot **training in research methods** with relevance for dementia/neuroscience or link to existing clinical and social science research training schemes	• Engaging local researchers in academic/institutional settings or with research organizations to conduct dementia research projects and engage students/interns/psychology trainees for research projects.
Develop and pilot **training in gold standard research delivery methods** (i.e., quality control, ethical practice, data integrity, good clinical practice, etc)	• Collaborating with College of Physicians and Surgeons (CPSP) Pakistan to integrate this in CMEs for residents training [50].
Include a mandatory **research module** in training schemes for higher clinical specialty trainees (i.e., psychiatry, neurology, geriatrics)	• Leveraging dementia researcher networks would be a relevant place to develop, support and promote these activities in different regions of Pakistan.
Encourage inclusion of **dementia awareness, knowledge, and skills** in training schemes for nurses and allied health professionals	• Collaborating with major training institutes in different regions to undertake "train the trainer" schemes.

(Continued)

Table 4
Goals and actions to reach goals for developing dementia research infrastructure in Pakistan and for the wider Pakistani community (*Continued*)

Specific goal	Actions to reach the goals
Undertake **pilot and feasibility studies** on nonpharmacologic interventions for dementia, adapted for Pakistan	• Ongoing examples of small pilot/feasibility projects being undertaken with minimal funding include (1) adapted Cognitive Stimulation Therapy in dementia; For example, at their daycare center, ALZ PAK has been providing cognitive stimulation activities to PWD and also bringing young children once a week. (2) adapted Montessori intervention for PwD; (3) SENSE-Cog Asia: Hearing support for PwD in South Asia.
Develop collaborations with large-scale international projects, such as the '10/66 group (add ref); STRIDE (https://www.stride-dementia.org/)	• Reaching out actively to project leads to develop collaborations, share protocols, and align projects.
Medium term: (5–10 years):	
Establish a **research registry** of people with dementia for recruitment	• Collaborating with existing researchers in other disciplines or disease areas to bolt-on aspects of brain health or aging to existing registries or cohorts.
Develop a **longitudinal prospective** aging cohort	• Leveraging existing well-organized bodies with human capital for opportunities to capture and follow key health indices and risk factors relevant to dementia (example: England's "Whitehall Study" of civil servants followed over time [51].
	• Establishing collaborations with community and public health departments and institutes in different regions of Pakistan We can give examples of some existing cohorts in Pakistan
Develop **capacity to deliver pharmacologic clinical trials**, with a focus on cost-effective interventions	• Undertaking pilot studies of off-patent drugs with potential for re-purposing for dementia
Long term: (10–20 years):	
Establish centers of excellence for dementia research	• Supporting nascent efforts to develop by linking with stronger departments in their local universities or departments or across institutions.
Develop a wider capacity to deliver fully powered multicentered RCTs for pharmacological and nonpharmacological interventions for dementia at different stages of the condition or disease.	• Considering novel approaches for clinical trials that are shorter, lower cost, and suitable for the pragmatic trials of repurposed drugs already licensed for other conditions, i.e., adaptive trial designs.

(outlined in Table 4). Key assumptions included: (1) an emphasis on capacity and capability building goals, espoused by the ERGs and the expert consultations; (2) willingness of stakeholders to work cooperatively toward the goals to realize the vision; (3) potential for collaboration with HICs; and (4) willingness of policymakers to recognize dementia research as important. Barriers and facilitators were articulated through our SWOT exercise.

4. Discussion

Our vision was to outline a cost-effective, sustainable infrastructure to conduct meaningful, impactful dementia research in Pakistan, thereby yielding tangible outcomes to improve the lives of PwD and their families, both in Pakistan and in the wider international Pakistani community. This may be a model for complementary activity in other LMICs elsewhere. Through this Roadmap exercise, we have found that the opportunities for developing dementia research are plentiful and many strengths exist; however, the current activity is sparse and the challenges are clear. The most obvious potential lies in the human capital of a highly educated and increasingly skilled young workforce, which could be harnessed to move the field forward. The possibility to enlist relevant expertise and mentorship in established centers overseas is significant.

A key aspect of the Roadmap effort was to clearly lay out a set of principles upon which to develop a research infrastructure for dementia. Importantly, these principles are in no way intended to be restrictive, particularly with the emphasis on "real world," pragmatic research which is resource sparing and cost effective. It can be argued that this approach might stifle innovation or limit the chance of conceptual breakthroughs, thereby consigning the research community in Pakistan to undertaking adaptive or "me too" research. While this risk certainly exists, if the basic infrastructure for pragmatic dementia research in Pakistan is developed in a way that gains traction with the wider community of stakeholders, including policymakers, funders, and opinion leaders, then more remote research questions may better be addressed and gain funding support.

Key recommendations that have emerged from our roadmap exercise include the need to guard against imbalances in international collaboration. To do this, clear work plans, collaboration agreements and other Memoranda of Understanding (MOU) need to be established at the outset of any new research collaboration. This will ensure that the work is underpinned by a set of principles, including the notion of a "rooted partnership" outlined in Table 1. Family members as partners in the research endeavor will strengthen the outcomes for the PwD, as well as their families, and enhance the meaningfulness of the outcomes. The role of

community leaders, including religious leaders, can be crucial in raising awareness and understanding at the local community and national level.

Training and capacity development for dementia research is key. Other specialty areas, such as global cardiac health, have already identified significant unmet needs in the area of research and training for NCDs in LMICs [52]. To address this, the National Heart, Lung, and Blood Institute-United Health Collaborating Centers of Excellence initiative created a training subcommittee to conduct an intensive, mentored health-related research experience for early-stage investigators from the key centers around the world [44]. This model could be emulated for dementia research, and the publicly available materials from this and other training programs could be adapted. Moreover, with respect to the field of dementia, specific skills and attitudes are required when working with older people who may lack capacity, as well as issues related to research delivery methods, including recruitment, working collaboratively with care partners ("participant dyads"), fostering retention, ethical practice, and the use of outcome rating scales.

Finally, a limitation of the current roadmap is the lack of focus on primary care and task shifting of care and support responsibilities for PwD. Task shifting is particularly important in a setting, such as Pakistan, which has a marked vertical medical structure, dominated by doctors. Primary care is still developing in Pakistan, but ensuring that the dementia care and research agenda is part of this development will be important for the future.

RESEARCH IN CONTEXT

1 Systematic review: This work reflects the consensus opinion of expert stakeholder regarding capacity and capability building for dementia research in Pakistan.

2 Interpretation: This work provides a roadmap for other lower-and-middle income countries to develop strategies to progress a dementia research agenda, including understanding strengths, opportunities, weakness and threats, and prioritizing research questions. It is designed around a set of principles to guide the work and the research collaborations.

3 Future directions: The 'Roadmap' will form a nexus for developing dementia research collaborations nationally and internationally, and will provide direction for research activity.

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