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ARC West Midlands News Blog

30 April 2021
At what point does self-care topple over into self-help? Self-care, narrowly interpreted, relates to a person taking responsibility for their own clinical care. Self-care is very widely used in diabetes where it is often reinforced by peer support. Self-help, by contrast, is interpreted to mean that steps are taken to empower disabled or disadvantaged people. While self-care and self-help might be distinct conceptually, the concepts may elide in practice. First, self-help programmes may include self-care elements. Second, both self-help and self-care programmes may include specific elements to provide psychological and social support. The figure below provides a conceptual map showing how four different elements (promoting self-care, providing psychological support, promoting a supportive social environment, and fostering economic development) can make a spectrum of activities. It is likely that these activities interact in such a way as to reinforce each other.

The global extension of ARC West Midlands is carrying out work on community support for people affected by leprosy. Like ARC WM itself, this work is supported by the NIHR. It is through this route that we became interested in self-help.

We are carrying out a prospective evaluation of a self-help intervention in Nepal, along with retrospective evaluations of the sustainability of self-help interventions in Nigeria, India and Nepal.

As part of the above work, we are reviewing self-help programmes more broadly. We have read the systematic review of economic self-help group programmes for woman’s empowerment by Brody and colleagues.[1] We have also reviewed work on micro-finance and tried to avail ourselves of the work of the Abdul Latif Jameel Poverty Action Lab.

The financial instruments that may be used within self-help programmes, are made up of one or more of the following three basic methods: savings groups, micro-credit, and cash transfers. Cash transfers may be conditional or unconditional. These financial instruments are often accompanied by some form of training intervention so that people can be more productive. Self-help is based around the formation of self-help groups – groups of people who are disadvantaged in some way are created and mentored by facilitators. Part of the theory is that these self-help groups are psychotropic.

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**A Conceptual Model of Different Support for Dis-advantaged People in Communities**

- **Self-care** (e.g., foot care in diabetes & leprosy)
- **Psychological support** (e.g., peer support/women’s groups)
- **Social support** (e.g., leadership/reducing stigma, street theatre)
- **Self-help/ economic advancement** (e.g., savings, syndicates, credit, transfers, training, provision seeds, or animal)
– they foster comradery, provide psychological support and enable people to share know-how. The facilitators are usually funded through an NGO, such as The Leprosy Mission, operating with support of local authorities.

Self-help interventions are usually evaluated in terms of economic advancement and psychosocial benefit. Economic advancement can be measured on the basis of income, expenditure and wealth (or some combination of these). Psychosocial effects can be measured at one or more of three levels: personal, community and political. If they are combined with self-care, then health outcomes should be included in the evaluation.

It turns out that micro-finance is less effective economically than generally claimed, and the larger and more rigorous the study, the smaller the effect of the intervention. It may be that the benefits of micro-finance are more psychosocial than strictly economic, avoiding the anxiety of having to take out more expensive loans from ‘sharks’.

Self-help groups that we work with in India are women only, while self-help groups in Nepal include both men and women. The jury is still out on whether women only or mixed gender groups are preferable. There is, however, some evidence that self-help does not reach the very poorest of the poor, despite them being the main target group. We have found some evidence that stigma may flow bi-directionally in self-help groups; suffering stigma does not preclude a negative attitude to people with other disabilities.

The self-help industry is vast; over 80 million women in India have taken part in some form of self-help intervention. The 2019 Nobel Prize in Economic Sciences was awarded to economists who have contributed to this science of development economics at grassroots levels, and who co-founded the Abdul Latif Jameel Poverty Action Lab.

Economic self-help groups funded by Leprosy Missions have broadened to include other conditions and very poor and marginalised people. Thus, healthcare and more general socio-economic care have merged. This integration of health and broader welfare is also epitomised in our ARC WM where we have programmes on school mental health, social prescribing, and the health and welfare of the work force. The health economics profession is recognising that a narrow focus on just ‘health’ is not sound, except perhaps in examining the more technical ends of care. That is why the ICE-CAP (ICEpop CAPability measure) is gaining popularity. In the case of leprosy, self-help and self-care could be particularly synergistic, since most people affected by leprosy are subsistence farmers. Farming is inimical to preventing and recovering from the foot ulcers that are a major feature of the disease. Economic empowerment and providing the skills to pursue sedentary occupations should therefore be of special value to people affected by the long-term neurological sequelae of the disease.

Reference:
Can Increasing Consultant Cover Improve Safety on the Labour Ward?

Sharon Morad (Consultant Obstetrician, Labour Ward Lead Obstetrician); Beck Taylor (Clinical Research Fellow and Honorary Consultant in Public Health); Sara Kenyon (Professor of Evidence Based Maternity Care)

In the March issue of the ARC WM News Blog our Director, Richard Lilford, discussed the need for researchers to “march to the beat of the policy drum,” and identify opportunities to evaluate large scale service interventions. [1] Consultant obstetrician and ARC WM collaborator, Dr Sharon Morad, approached the ARC WM Maternity theme with such an opportunity – to use routinely gathered data to assess the clinical impact of a recent local policy change, increasing consultant obstetric presence to 24/7 on the labour ward. In the majority of maternity units consultants are only physically present on the labour ward from 08:00–20:00, and on-call from home overnight, and, while recommended by the Royal College of Obstetrics and Gynaecology, only two large maternity units in the UK had implemented 24/7 consultant presence. Implementing workforce change in a substantial and costly way to improve maternity would be unlikely to be resourced by research funders. Similarly, robust evaluation was beyond the scope of the NHS. By working in partnership through the ARC model, clinicians and academics have delivered timely evidence regarding the importance of senior obstetrician presence.

Our study was based in one large unit with around 6,000 births each year, which introduced 24/7 consultant presence on labour ward.[2] Data from three years before and after the intervention was analysed, totalling 33,434 babies. This is the largest study exploring this intervention, and by using a time-series approach it is the most robust approach available for this sort of data.

We focused on a ‘composite’ group of important baby outcomes selected in consultation with the clinicians (intrapartum stillbirth, neonatal death, requirement for ‘cooling’, or admission to neonatal intensive care within three hours of...
The prevalence of the primary outcome increased by 0.65%, from 2.07% (359/17324) before 24/7 consultant presence, to 2.72% (438/16110, P < 0.001) after 24/7 consultant presence – this was consistent with an upward trend over time already well established before 24/7 consultant presence began (OR 1.09 p.a.; CI 1.04 to 1.13). Overall, there was no change in this trend associated with the transition to 24/7. However, in babies born ≥37 weeks gestation, who constitute >90% of births, the upward trend was reversed after implementation of 24/7 (OR 0.67 p.a.; CI 0.49 to 0.93; P = 0.017). No substantial differences were shown in other outcomes or subgroups.

The Ockendon report (page 19, section 4.61) recommends that ‘consultant obstetricians must be directly involved and lead in the management of all complex pregnancies and labour.’[3] In large units, women with complex pregnancies will frequently present out of hours. However, thus far there has been a lack of evidence supporting the benefit of consultant presence out of hours. The evidence provided by this study, from a unit that actually introduced consultant cover at night, would be of great benefit to other organisations that are considering their options for improving safety in their units, particularly in providing evidence when developing their business case for expanding consultant presence. The team is currently engaging with national policymakers and clinical leaders to ensure that this important new evidence reaches maternity services to guide decision making and practice to improve safety and outcomes for babies.

References:


I recently shared on social media this article from the New York Times about learning to listen to patient stories. The response was instructive, with a large number of my contacts firstly saying ‘how wonderful’, followed, invariably, by some comment about how it would be good to have such patient and public involvements here in the UK. When I replied that such initiatives do indeed occur here in the UK with public involvement in professional selection, clinical training, research and academia, the response was, most often, one of surprise. Having been involved with PPIE for a number of years, in various parts of the country, most recently here at ARC WM, I am disappointed that mine and many other public contributors are so little known outside the institutions that make use of our services. Obviously, changing this is a priority for the future.

Inevitably, my newly-illuminated social contacts next question is: why do you do it? This has, I suppose, changed over the years. I have been involved with patient advocacy for many years both as a nurse and volunteer, specifically during the AIDS pandemic of the eighties and nineties here in the UK. Yes, our current straits are not my first pandemic. The initial passion for having patients’ voices heard, and care crafted with the patient as equal partner (nothing about me without me) has never left me and, as a patient myself, that has only consolidated.

Joining ARC WM recently, the question came again, why do you want to do this? I realised that within this new pandemic my rationales had shifted. I see clearly the correlations that exist between the HIV pandemic and the COVID-19 pandemic. The “other” scapegoating

Tony Russell-Pattison, an ARC WM Contributor (Long-Term Conditions), shares personal reflections on what motivates him to be involved in research. Drawing on his experiences of public involvement during two pandemics, Tony shares his thoughts on why partnership working, with people from a range of backgrounds, is important now more than ever.
unleashing homophobia in the former pandemic and racism in both. The conspiracy theories leading to denial in whole populations soothed by the false notion that they are not at risk. The partnering of patients with researchers and clinicians for drug trials and vaccine development (the later still ongoing within both pandemics); the urgent need for intense health promotion to protect populations; the social and psychological management of multiple deaths and bereavements; and finally, coming to terms with living with the virus.

I realised that much excellent work, creative care models and relevant research existed from the HIV world that was applicable to the world where COVID-19 stalks, and that it would be a sad legacy for the many friends and loved ones who died of AIDS if these very hard-won insights were not championed again in this new pandemic. Things are different, of course, and it may be necessary, at times, to attempt the reinvention of some wheels. However, there are significant spokes available in the lived experience of the survivors of that first pandemic that can assist greatly. I think that is why I do it, in a nutshell.

ARC WM has allowed me to have input to COVID-19 research and other factors of health and social care, for which I am grateful. Maybe, if I can distil my motivating factors, I can use those insights to assist other members of the public and patients to identify their potential contributions to the expanding requirement of institutions and professions to have quality public input to facilitate excellence in partnership with our clinical and academic colleagues.

The motivations of public contributors for involvement can be as varied as the people themselves. Some speculation, however, is possible and it is useful to categorise them. A spectrum of rationales could be constructed from positive through neutral to negative in nature, as their base. Positive, the desire to “give something back” after receiving excellent care or benefiting from life changing research, the desire to make often painful experience count for something good. Neutral, the wish to utilise experience and advance knowledge for its own sake (although, arguably such altruism is very positive). Negative, the desire to improve standards, services, outcomes for others having received sub-optimum or poor/dangerous care (so that this will never happen to someone else).

Such speculation is interesting but validation, partnered research that distils and confirms/categorises the motivations of a group, such as the public contributors to ARC WM, would obviously be much better. Not merely for academic reasons but to provide insights to service providers and researchers (and public contributors) as to who else might share such motivations in their practice and enable them to invite such individuals to consider their own involvement. A benefit to the individuals themselves, as we contributors can attest, but also to the system as a whole. Public involvement needs a constantly renewed supply of the motivated public, perhaps this would help?
It goes without saying that, for all of us, the COVID-19 pandemic has presented a broad range of practical challenges. As someone whose professional role focuses on Public and Patient Involvement and Engagement (PPIE) in health and social care research, I have witnessed many examples in which the admirable efforts and adaptations of PPIE colleagues and public members that have allowed for PPIE activity to be sustained throughout this trying period.

Prior to March 2020, a large proportion of the duties undertaken by PPIE professionals were conducted in-person. Whether it be providing advice to a researcher, hosting public engagement events, or facilitating research-focussed workshops, face-to-face was the preferred setting. This is in large part down to the general perception that in-person interactions are more free-flowing and, arguably just as importantly, they provide a good opportunity to grab a brew to converse over!

It was unfathomable that this way of working would soon no longer be an option, but the need for social distancing meant that, for what we hoped would only be a short while, engagement activities had to be conducted remotely. Herein began many people’s first foray into remote engagement; and this venture into less familiar approaches raised a lot of questions. How could the vibe of in-person interactions be best replicated? What impact would the pandemic have on the ability of public members to engage in PPIE activities? Which people would benefit from remote engagement and who would be further disadvantaged? To name just a few...

Conversations with colleagues in the PPIE community led me to understand I wasn’t the only one who perceived this sudden change as a monumental challenge. Long-established ways of working had been swept away and the lack of familiarity conjured a feeling of being “lost at sea”. In response, the PPIE professional community engaged in a flurry of activity in which knowledge was shared through online workshops and informal working groups. Much of this new-found knowledge was used to swiftly determine what was deliverable in the short-medium term.

As we entered summer, it became apparent that the prospect of the return of in-person engagement activities within the calendar year was looking bleak. Though lockdown restrictions relaxed, the need to socially distance remained and so, that being the case, it became accepted...
that we would need to continue to conduct PPIE remotely until early 2021, at the very least.

Fast forward to present day and a significant amount of change has occurred within the PPIE sector. A wide array of approaches has been used to best-facilitate PPIE through this unusual period and, for the most part, PPIE professionals have regained some sense of control. All of this lends to me feeling that now is a good time for the entire PPIE community to reflect, extract learnings and share new-found knowledge.

The practice of disseminating information relating to PPIE through organised events is not new but, what is novel is the frequency with which such events are taking place online. Last month the Midlands Health Alliance coordinated a virtual event entitled “Beyond COVID-19: New Directions for Public Involvement in Health and Social Care Research in the Midlands”.

Over three days, members of the West Midlands PPIE community delivered sessions on a range of pertinent topics, including:

- **Public Partnerships: COVID learning and future directions – Q&A;** Zoey Gray (NIHR Centre for Engagement and Dissemination)
- **An introduction to patient and public involvement and engagement;** Laura Chapman (Birmingham), Tracy Gazeley (Coventry and Warwickshire) & PPIE contributors
- **Involving children and young people in research: Adapting to the virtual world;** Sian Lyons (Leicester), Kate Frost (Nottingham) & PPIE contributors
- **Impact – The art of counting bees;** Becky Pritchard (Leicester)
- **Approaches to co-production in health and social care;** Magdalena Skrybant (Birmingham) & Sophie Staniszewska (Warwick)
- **Creative approaches – From ticking the box to outside the box;** Becky Pritchard (Leicester)
- **Diversity and Inclusion: PPI with BAME communities;** Nani Patel (Leicester), Nasima Miah (Leicester) & PPIE contributors
- **Public co-applicants: Equal members of the research team;** Steven Blackburn (Keele) & PPIE contributors
- **Moving forward – Panel Q&A;** Margaret O’Hara, Liz Eglington, Andy Warren & Tony Kelly

The hard work of everyone involved in the programme was clear to see and these efforts culminated in a series of sessions that were highly engaging, informative, and thought-provoking. I was impressed to see that sessions were well-attended by audiences composed of PPIE professionals, researchers, and members of the public, and that speaker duties were equally shared between PPIE professionals and PPIE contributors, embodying the spirit of the event.

Personal highlights included seeing the concept and value of co-production in health and social care clearly laid out in a session facilitated by NIHR ARC WM colleagues Magdalena Skrybant and Sophie Staniszewska, and hearing Tony Kelly speak so eloquently about inequalities in the engagement of under-represented communities in health and social care research.

Reflecting back to the horrid “lost at sea” feeling that struck many PPIE professionals soon after the first lockdown, the emergence of events such as “Beyond COVID-19: New Directions for Public Involvement in Health Research” is a sign of the progress that has been made. Through study and experience, the PPIE community is now better able to answer many of the questions that stumped us back in March 2020 and I am a firm believer that continuing to share our knowledge and experiences is key to successfully charting a course for the future of PPIE in health and social care research.

Full video recordings of sessions from the event are available online at the Midlands Health Alliance website: midlandshealthalliance.org.uk/ppie-event.
I thank Prof Paramjit Gill for alerting me to this important study carried out in Dhaka and reported in the New England Journal of Medicine.[1]

Childhood undernutrition is a scandal in our age. It is associated with poor growth and reduced cognitive development, and the problem has only been exacerbated by the COVID-19 pandemic.

There is a strong correlation between undernutrition and both stunting and impaired neurological development. However, intervention trials show positive effects on stunting but not on cognitive outcomes.[2] Recently, your News Blog reported on an exception to this trend.[3] In this trial, carried out in west Africa, a nutritional intervention based on specific nutritional components important for brain development, showed a positive result on cognitive development.[4] So, one explanation for the mainly null results of previous nutritional interventions is that they did not include the relevant nutrients. Let’s call this the “nutrient hypothesis”. Another explanation for the null results is that the trial interventions were introduced too late and after the damage had been done; it may be necessary to prevent, rather than treat, malnutrition if intellectual damage is to be prevented. Let’s call this the “timing hypothesis”. The aforementioned article addresses the latter hypothesis, but in a very particular way.

It is known that malnutrition is associated with a disturbance in the intestinal microbiome. Moreover, when the microbiome of malnourished children was transferred to the gut of rodents, it led to reduced growth in the recipients. [5] Thus, there seems to be a regress in which malnutrition leads to a microbiome profile that potentiates the effects of the malnutrition. It is thought that this is protective in the short-term, by conserving energy, but at the cost of longer-term reduction in development. Indeed
it is already known that malnutrition in early life impedes muscle development and has long-term harmful effects on health, increasing the risk of hypertension and vascular disease.

To test what I have called the “timing hypothesis”, the study evaluated microbiota-directed complementary food against placebo in an RCT among children between 12 and 18 months of age; around the time of weaning.

The intervention improved growth, resulted in a more normal microbiological profile and changed the pattern of protein expression in the blood, in favour of mediators of skeletal growth and neurological development. Meanwhile, pro-inflammatory mediators were reduced.

This study involved only 123 participants who were all very intensely investigated. The ARC WM Director is joint chief investigator with Semira Manaseki-Holland on a study of weaning foods in rural and urban Mali. It would be interesting to build on the study and test, simultaneously, both of the above hypotheses. This would evaluate the dual hypothesis that most nutritional interventions have been too little, too late. That is to say, they have not used the optimal nutrients and were initiated too late in the development of malnutrition. A prophylactic intervention around the time of weaning with cognitive outcomes is surely a sensible next step.

References:


ARC WM Quiz

What is the Brier score?

email your answer to: ARCWM@warwick.ac.uk

Answer to previous quiz: James Harrison is credited with saving over 2 million babies thanks to donating his blood plasma over 1,100 times. Known as the Man with the Golden Arm, his blood plasma was contained strong and persistent antibodies that could be used to prevent Rhesus disease. Read more here.

Congratulations to Richard Grant and Alan Hargreaves who were first to answer correctly.
ARC West Midlands has a theme of work on child and adolescent mental health. So, an article in the Economist on divorce rates among parents whose first child was a girl versus those whose first child was a boy, caught my eye.[1]

It has long been known that the probability of divorce is higher when the first child is a girl, than when the first child is a boy. This article, based on a large study in the Netherlands and North America,[2] examined the effect of the age of the child at the time of divorce. The study replicated the well-known effect that divorce rates are higher for parents of a girl child. However, it found that this effect was observed only during the teenage years, peaking at the age of 15. The increased risk is large, at about 1.5 percentage points when averaged over the teenage years. Interview studies show that parents of teenage daughters quarrel more than those of teenage sons. They argue over the amount of freedom the child should have.

As to the personal and policy implications... the ARC WM Director is parent and grandparent of both boys and girls - he couldn’t possibly comment!

References:
During the 1960s and into the early 1970s the USA implemented and expanded a national food stamp programme, where households received booklets of coupons that could be exchanged for food (see our leading article on pages 1-2 for a discussion on similar support programmes). Over the years several papers have been published looking at various outcomes of this programme, finding, for example, associations with improved health outcomes in children,[1] and changes in diet (an increase in fruit consumption, yet lowering overall diet quality).[2]

A recent study in the Journal of Human Resources looked at the impact the programme had on crime.[3] The authors looked at criminal conviction data in North Carolina, together with variation in the roll-out of the food stamp programme, and found that availability of the programme in early childhood was associated with significant reductions in future criminal activity. For every year that the programme was available from conception to age 5, the likelihood of criminal conviction for a 24-year-old adult was reduced by 2.5%. This effect was more pronounced when considering violent and felony convictions, and also for non-white people (attributed to higher levels of participation in the food stamp programme). The authors were able to account for various possibilities, such as migration of criminals out of North Carolina, as the data for North Carolina specifically included individual county of birth, allowing them to generate conviction rates for birth month cohorts of individuals.

Further, the authors estimate that the benefits to society arising from the programme were greater than the cost of the programme itself.

References:
Latest News and Events

Celebrating Public Involvement: NIHR Blog Features Article on Public Co-applicant in RIGHT Leprosy Global Health Project

Regular readers will be aware that Richard Lilford, ARC WM Director, together with other members of the ARC WM team, work on international research projects, including projects in low- and middle-income countries.

We’re delighted to share this recent news blog article from NIHR, which showcases public involvement in one of the NIHR-funded projects: Transforming the Treatment and Prevention of Leprosy and Buruli ulcers in Low and Middle-Income Countries (LMICs).

In the article, Jayashree P Kunju, patient co-applicant, describes her personal journey from leprosy patient to supporting communities. Shaping the research project is an important step on Jayashree’s mission to improve the lives of communities affected by leprosy. She reflects on how she draws on her personal experiences to contribute to the research agenda and project delivery.

We’re delighted that NIHR have chosen to share this example of public involvement. It’s important that patients and the public are at the heart of research projects, and Jayashree’s blog highlights the valuable contributions that public contributors can bring.

To learn more about Community Involvement and Engagement in this project, please contact Magdalena Skrybant (m.t.skrybant@bham.ac.uk).

Relaunched NIHR Resources to Support PPIE

The updated NIHR resources to support patient and public involvement have now been relaunched. They can now be found on Learning for Involvement. In addition, some of the more ‘introductory’ resources have been embedded into the audience sections of the main NIHR website. For example, you can find information for researchers here, and for patients and the public here. The launch of the updated resources across both platforms is summarised in a showcase page on the NIHR website, which will be promoted over the next few weeks.

Congratulations

Congratulations to Domenico Giacco (ARC WM Integrated Care in Youth Mental Health theme) who has recently been appointed a member of the NIHR ARC Mental Health Implementation Network (MHIN) Executive Committee.

National NIHR ARC Newsletter

The April issue of the national NIHR ARC newsletter is now available online, with reports on why social workers are key to promoting physical activity for disabled people; how to identify barriers to improving clinical practice; and the keeping well at home campaign.

To subscribe to future issues, please visit: https://tinyurl.com/ARCsnewsletter.
Dr Alex Pollock, Senior Research Fellow, at the Nursing, Midwifery and Allied Health Professions Research Unit is giving a seminar at Warwick Evidence on **Tuesday 25 May, 11:00-12:00** over MS Teams.

Dr Pollock has particular expertise relating to systematic reviews of complex interventions, leading methodological work, completing and supporting systematic reviews across the Unit. She is an associate editor with the Cochrane Stroke Group and Coordinating Editor for Cochrane Stroke. Dr Pollock has an active interest in public involvement in research and has led and contributed to a number of research prioritisation projects, including three with the James Lind Alliance. She led the ACTIVE project, funded by Cochrane Training, aimed at supporting review authors have meaningful involvement of patients and the public in systematic reviews.

If you would like to join, please contact: Mitra Murray, Warwick Evidence Project Manager, warwickevidence@warwick.ac.uk

Questions are welcome in advance.

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### Postgraduate Research Opportunities

A number of postgraduate research opportunities are currently available within ARC WM:

- An MSc on *Reducing health inequalities through increased screening in people with intellectual disability* within our Youth Mental Health theme. Further details available at: [https://warwick.ac.uk/fac/sci/med/study/researchdegrees/howtoapply/hs](https://warwick.ac.uk/fac/sci/med/study/researchdegrees/howtoapply/hs).

- Two fully-funded, full time, three-year PhD studentships available from September 2021. Further details available at: [findphd.com/phds/program/nihr-applied-research-collaboration-west-midlands/?p4765](http://findphd.com/phds/program/nihr-applied-research-collaboration-west-midlands/?p4765)


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### Health Services Research UK Conference 2021

Registration is now open for this year’s Health Services Research UK Conference, which will take place online from **6-8 July 2021**.

A wide range of live plenaries, workshops and discussion groups are being offered across the three days, as well as over 150 research presentations that which will be accessible on demand.

Plenaries will include:

- **Long COVID: patient experience and the developing research agenda.**

  - Meeting future challenges for the NHS workforce.

  - Diversity and inclusion in health and care research.


For more information, and to register, please visit: [www.eventsforce.net/hsruk2021](http://www.eventsforce.net/hsruk2021).
Recent Publications


