



Wilton Park

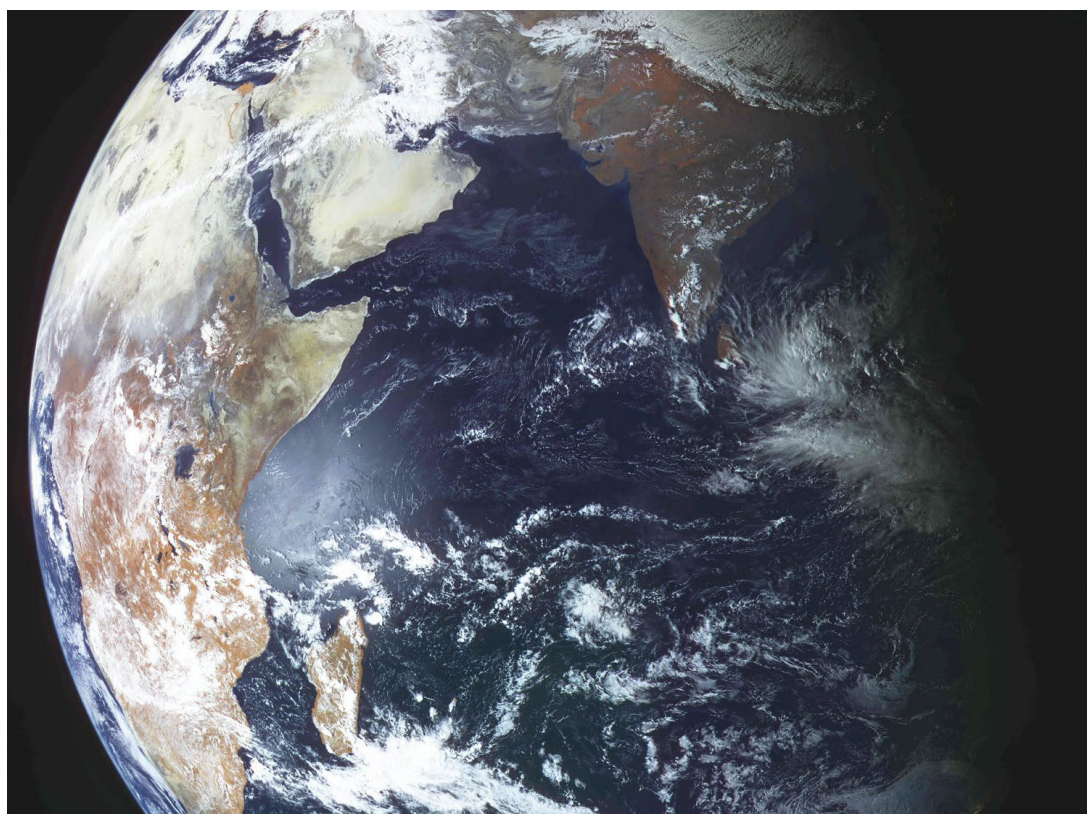


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Report

Reimagining global health: self-care interventions and implications for healthcare

Monday 10 – Wednesday 12 September 2018 | WP1639

In partnership with:





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In association with the WHO Department of Reproductive Health and Research (RHR), the Children's Investment Fund Foundation (CIFF) and the Defeat-NCD Partnership

Executive Summary

Self-care for health benefits is not new, but has steadily grown in importance in recent years with individuals increasingly accessing self-care interventions, services, products and information outside traditional health sectors. This growing movement towards self-care spans health promotion, disease prevention, and disease control and treatment.

Much of the recent increase in self-care is due to new technologies and systems of communications which can bring diagnostics, treatment, and healthcare information to millions of individuals around the world. Drugs, diagnostics and devices converge with advances in digital technologies and are rapidly making possible new configurations of self-care. These advances have the possibility of linking with more traditional forms of self-care which have been used by people, and with the social networks and techniques of self-care that are context specific and locally acceptable.

The World Health Organization (WHO) is developing normative guidance around self-care, including for sexual and reproductive health and rights (SRHR), bringing the multiplicity in form, purpose, and context of self-care within social, biomedical, and traditional care that hold great promise for improving coverage, reducing inequities, and enhancing user autonomy.

This Wilton Park thought-leadership dialogue, convened in partnership with WHO, CIFF and Defeat-NCD Partnership focused on self-care approaches which have the potential to change the way healthcare is imagined.

Key points

- Advances in digital health technologies and communications are facilitating a transition of healthcare from health professionals to individuals (self-care) in disease diagnostics, treatments, on-going chronic care and in health promotion.
- Self-care isn't new - rather it is a fundamental human endeavour; recognising existing forms of self-care and enhancing them with the new interventions is a way to optimise human health.

- As self-care interventions become more widely available, healthcare providers will need to be trained to better promote their use and uptake.
- Self-care could lead to increased inequities and vulnerabilities in situations where limited resources, unsustainable technological infrastructure and advanced age and debility where additional support and links to quality health systems beyond self-care is needed.
- Self-care interventions are expected to be key for future healthcare delivery and fit into the new priorities for the WHO which include advancing universal healthcare coverage, addressing health emergencies and promoting healthier populations.

Self-care: definition and potential

1. Self-care is what people do for themselves to establish and maintain health and to prevent and deal with illness. Different pillars of self-care include knowledge about mental wellbeing, physical activity, health eating, risk avoidance, good hygiene and the informed use of products and advice from a wide variety of health practitioners. (The Alma Ata Declaration of 1978¹ was grounded in the principles of participation, self-reliance, and the duty to participate).
2. Self-care is seen as part of a people-centred approach to an individual's care of their health and could be regarded as about the most profoundly human role of caring for oneself, for families and for those in ones' communities.
3. Self-care can be thought of as a deliberate self-initiated function within an individual's own control that they use to manage existing disease, control illness, create and maintain health. Self-care is therefore wider than medical interventions, and it incorporates both traditional practices and biomedicines. An expanded vision of self-care allows it to be a public health approach, not just an adjunct to clinical regimens. However, while some self-care practices can improve health and well/being, some may be neutral or harmful and should not be recommended.
4. Some fundamental questions pertaining to self-care are:
 - How can individuals who are engaged in self-care be helped to do it in the best way possible?
 - How to ensure that quality health information is available and accessible for different target audiences and for different health and wellbeing needs?
 - How can access to new forms of self-care be made most equitable?
 - What sort of data is needed to support new forms of self-care?
 - How can self-care interventions be used to improve some of the current health conditions in resource constrained settings?
 - How can user's experiences and knowledge be incorporated into normative guidance to better reflect their needs and priorities regarding self-care?
 - Is use of self-care driven by lack of access to health services or by preference?
 - What is the current and future role of the private sector and pharmacies in the movement towards enhanced forms of self-care interventions?
5. Like other services, access to self-care is not a given. Attention to human rights, ethics, legal and social accountability, gender, and literacy levels need to be considered to promote an individual's sense of agency, autonomy and well-being and avoid exacerbation of inequalities.

¹ http://www.who.int/publications/almaata_declaration_en.pdf?ua=1

6. Self-care could be a result of a rejection of medicine/biomedicine by some; it has the potential to provide more pathways and options towards health for themselves and those in their care. With the increasing burden of chronic and debilitating conditions like cancer and other long-term states of less than optimal health, self-care can play a role in palliative care in advanced stages of illness. As the locus of control within the medical encounter shifts towards a more people-centered approach to healthcare, new ethical configurations will emerge.

Trends in self-care interventions: Places of access I - digital health

7. Self-care interventions are accessed through a variety of means. Innovations being developed through different means are increasingly available globally and are one element driving the renewed interest in digital health.
8. Digital health goes beyond improving access to health information and services, enabling individuals to play a more active role in their health and wellbeing. With increased support for diagnosis and treatment, digital health is now part of the underlying infrastructure for delivery of good quality health services that are linked to health professionals or accessed independently.
9. Many digital applications can be used in conjunction with self-initiated health interventions. Digital systems are increasingly sophisticated and more personalised than they were in the past. There are many kinds of digital health applications available, for example those targeting reproductive and child health. There is also a myriad of screening and self testing technologies that can be used in conjunction with video instruction to teach self-care techniques (such as performing blood glucose monitoring) that can be repeated at home multiple times, thus, allowing users to learn at their own pace. Evidence of the effectiveness of these digital approaches is limited but growing. Technology can be one part of a larger intervention that may include healthcare providers and the support of family and friends.
10. A variety of differential diagnosis applications already exist. For instance, the example of Ada Health was shared during the meeting. These systems are being refined with the integration of artificial intelligence (AI) capabilities and they are increasingly linked to high quality research results published in peer-reviewed journals. These are probabilistic systems, originally developed for medical practitioners that use symptom databases that were subsequently fashioned into digital applications directly accessed by the general population. Digital applications can be used as an intermediary in the diagnostic process, aid in triaging acute cases of illnesses and/or injuries and connect with the results of self-testing tools. This connectivity can greatly increase the power of both the information and diagnostic systems.
11. Other examples of digital health self-care approaches include mental health diagnostics, services and self/group-care that can be linked and provide vital services such as suicide prevention and screening for sub-clinical mood disorders. Self-testing results for endemic diseases can be gathered along with information about occurrences and their locations during epidemics. Digital databases can provide a means for collating and collecting large quantities of health data that can be analysed and used to study many aspects of epidemic outbreaks and seasonally occurring illnesses.
12. For digital health applications to reach their full potential there are still many outstanding issues. These include limited access to technology by vulnerable and low resource populations, especially if this delivery format becomes part of the regular delivery system of health information and access to treatment modalities. There needs to be an objective analysis of how well does digitally communicated health information reach different populations? How easy is it to access? How effective a role it does it really play in improving health outcomes? Issues surrounding privacy in the digital realm as well as the ever-present misinformation on many topics are

fundamental topics that need be addressed. The quality of digital health applications needs to be ascertained, and the public needs a system of ensuring safety and effectiveness with respect to digital health applications. The added costs of rolling out and scaling up compared to current services needs to be factored in. Identifying the efficacy and efficiency of many of these technologies will be key.

13. In order to understand the mechanisms of self-care more research is needed on the processes, mechanisms and contexts of the use of self-care, especially relating to digital health. Better understanding of how people are currently using digital health apps, platforms and other components, what their goals are in relation to their current use of self-care and how this might change in the future.

Trends in self-care interventions: places of access II - pharmacies and the role of pharmacists

14. Pharmacies and pharmacists are expected to play an increasingly important role in the growing movement towards self-care. This is because pharmacies and pharmacists are at one of the critical hubs for delivering the best information possible to the public about many aspects of healthcare testing, diagnoses and biomedical treatment options.
15. Medications are the most widely used intervention in healthcare and importantly, adverse drug reactions (ADRs) are also a major cause of death. For instance, in the US, ADRs are the 3rd leading cause of death in the general population. As self-care is increasingly part of healthcare and medicines management, there must be a strong focus on safety.
16. With an expanded scope of practice, the legalities of working as a pharmacist will change. As roles and responsibilities shift among different practitioner groups, inter-professional communication will be of paramount importance.
17. The following recommendations are proposed as being essential to underpin and support the pharmacy profession in relation to their expanding role in supporting the self-care agenda:
 - **Government health teams need to include pharmacists at the policy making level.** Many health departments do not have pharmacists and are primarily medically lead. However, collaboration and multidisciplinary working are key to delivering successful healthcare and it is strongly recommended that this is reflected in the policy making process. In those health departments where pharmacists are employed, many are 2-3 grades below the policy making level. This is not helpful in getting the necessary legislation or policies in place to bring about the changes needed. This is especially so in Low and Middle-Income Countries (LMIC)s. In higher income countries there has been some success in more recent years, however there is still much to be done to restructure health systems.
 - **Better regulations of pharmacists, pharmacies and medicines is needed.** Many countries have some regulations; however many are inadequate and in some countries there are none. Access to medicines is important, but should not beat the cost of safety and efforts are needed to work together to improve this. Good governance is essential to deliver good healthcare and facilitate better self-care. Regulations need to establish standards of practice and training requirements, including continuing professional development, for all professionals including pharmacists. They also need to establish how and where medicines can be obtained safely. However, this is only part of the requirement as regulations on their own will not change practice if they are not enforced.

- **Workforce planning and training of pharmacists is the third element of delivering better self-care.** Pharmacists are well placed in communities to help deliver on the self-care agenda, but for this to be realised a well-trained workforce is needed promoting best standards. Whilst there has been an increase in the pharmacy workforce in the last decade, this has disproportionately occurred in high income countries. There is still a vast unmet need in LMICs in terms of both number of pharmacists, and access to training, to ensure a competent workforce.

Trends in self-care interventions: places of access III - vulnerable populations

18. People in conditions of vulnerability often use self-care as their primary form of healthcare. For many of the world's poor, traditional treatments given by non-biomedical practitioners and self-treatments using locally available substances have been the only recourse to curative medicine. Many people, have faith in their own traditions, medicines and practices and indeed, some of these interventions may well have some effective answers to their local health issues. Access to traditional health facilities may be impeded due to distance or socioeconomic conditions making self-care or traditional medicines a more attractive option.
19. In these situations, the question for increasing the effectiveness of self-care becomes one of respectfully integrating new forms of self-care with existing practices that have been deemed safe. There is also the work of identifying harmful forms of self-care in these and all communities and educating the public about better alternatives. Individuals living in low resource settings may well have good answers to healthcare needs and as new forms of biomedical self-care are introduced the emphasis should be on supporting and enhancing existing forms of self-care. More use of high technology approaches, such as digital health, may not be the answer in some settings and could result in more harm than good if the needed support systems are not in place.
20. Examples shared included the support for vulnerable populations in India where patient-driven approaches to self-care are ensuring TB treatment, through coupons and education, or supporting slum-dwellers in India where there may be hot-spots for HIV or TB.
21. Beyond individuals living permanently in conditions of instability, the world is facing an unprecedented number of refugees from wars, natural disasters and climate change. These groups of people, now numbering over 68 million, face compounding issues of such things as gender and religious based violence and little or no access to medical care in crisis settings. Self-care interventions are needed in these settings, perhaps even more than in stable situations. Oftentimes displacement is protracted, populations may spend years in refugee camps and or uncertain resettlement situations.

Self-care interventions: linking with healthcare policy

22. The process of (re)imagining the future of health by integrating and supporting what individuals are already doing in relation to their self-care, with technologies that are just being developed, can reinforce the commitment to promote the central role of people in their own health, linked to a functioning health sector where they can go to receive quality care if needed.
23. Healthcare policy which acknowledges and supports self-care can be developed at various levels and in differing ways (including prevention efforts) and on the ground, health-focused activities. Current debates promote an extension of service delivery beyond primary, secondary and tertiary, to include self-care as a fourth 'pre-primary' level. Integrating self-care into existing healthcare programmes, and building a strong

platform at the primary healthcare level could reduce health costs.

24. Governmental policies can encourage behaviour change, focusing on supporting prevention efforts for example, encouraging healthy life choices which can decrease conditions linked to diabetes, cancer, chronic respiratory problems or other chronic illnesses. Such support at the primary healthcare level can be very beneficial. However, evidence is needed of the effectiveness and cost savings of the current, and future, innovations in self-care that can tackle a wide array of health issues.
25. As governments develop policy and support approaches towards self-care an initial step is to understand what people are already doing in terms of their self-care. Policies will also need to be backed by sufficient funding.
26. Self-care approaches to healthcare will change how healthcare workers provide care. The role of those in charge of many aspects of healthcare, primarily medical doctors, may be challenged by new forms self-diagnostics and self-treatments for NCDs, communicable illnesses, and mental health. As health professionals integrate new technologies of self-care in the realms of testing, diagnostics, treatments and health maintenance into their practices, tasks will shift and issues of shifting costs and patterns of reimbursement will need to be dealt with.
27. The role of healthcare providers is concomitantly changing along with the increase in digital health systems. How acceptable is digital health to health practitioners at all levels? Do practitioners avail themselves of the best data possible via these systems and how do they view their patients' increasingly active role in their own self-care?
28. It is also noted that there are fundamental power issues around increasing the role of self-care within the accepted purview of health systems. As a shift occurs in the ability of individuals to take a more active role in their own health new ways of interacting with different kinds of health practitioners is expected to emerge. For example, new forms of self-care may ameliorate current situations where patients may feel they are treated in condescending and disrespectful ways.
29. The way that healthcare workers are trained will also need to change and curriculum upgrades of the medical and allied health education programmes needed. Changes will also be needed in practitioner licensure and legal responsibilities.
30. As an example, the role of pharmacists is changing and evolving in response to increased use of self-care diagnostic and treatment regimen. These changes are occurring at the level of policy, governmental regulations, and scope of practice and will, in different configurations, also occur in the other healthcare professions (MDs, RNs, Physician Assistants, and others).

Promoting public health – examples in practice

31. An example of government developing approaches to supporting self-care approaches, particularly in relation to promoting public health, is the UK's forthcoming mental health campaign Every Mind Matters. This campaign targets those who might not be looking for support by reframing mental health, and identifies that small shifts can make a big impact, with a non-medical, individual internet based approach. ²In the UK there is a great need for extending mental health service delivery. Programmes to support mental health can be delivered over the internet and be articulated with self-care health approaches. More research needs to be done to establish the evidence of this kind of mental health, self-care.
32. For programmes and approaches such as these to be accepted, used and successful, people's needs and abilities to obtain access to internet systems need to be established. Individual needs, once established can be listed and integrated into digital apps that provide medication and other kinds of reminders.

² <https://www.gov.uk/government/news/new-mental-health-campaign-launched-across-the-midlands>

33. Another example is that of Zimbabwe where an approach to support better prevention efforts is being taken to reduce the incidence of NCDs, for example diabetes. There is recognition of the different pillars that are needed to support self-care efforts, which go way beyond medication, to promote low-carbohydrate diets for example, and including involving such actors as urban planners. In these contexts also linking traditional self-care, which may lead to delayed diagnosis, with modern healthcare.
34. In such countries with low resources for health, or fragile health-care systems steps can be taken to support self-care approaches, whether through SRHR, NCDs or mental health. These are not new, but now being better acknowledged alongside biomedical approaches.

Self-care across the lifespan

Adolescent self-care: look good and feel good

35. Adolescent healthcare needs can be met with new forms of self-care. This group is particularly poised to take advantage of this kind of information and programmes. Developing good decision-making and confidence are essential at this stage of human development and many useful tools can be delivered digitally.
36. Policies need to be established that integrate notions of self-care into educational systems; teaching self-care as the norm from an early age will create a generation who are capable of using and understanding information provided via digital systems. Because adolescents are keenly aware of gender issues and peer group demands, an understanding of this context can enhance and support teen self-care programmes. Once engaged on their own terms, adolescents are seen as prime users of new forms of self-care.

(Re)productive age

37. As individuals move into their prime reproductive and monetarily productive years new forms of self-care can be implemented that will give them more control over sexual health, occupational health, and on-going healthy life style maintenance. Individuals of this age are able to engage in shared decision making with a variety of health practitioners and are key community leaders in using and exploiting fully the possibilities of new technologies related to self-care. Local organisations that focus on health and well-being need to also be engaged with this endeavour.

Older age

38. As individuals pass into older age and are faced with increasingly fragile and challenged bodies, new forms of self-care can be integrated in ways that are supportive and productive. However, as the older generations are less able to handle technologies, they may need special assistance, programmes and technologies especially designed with their needs in mind. As individuals lose their independence they may experience cognitive problems, physical decline and may have special needs as they deal with their ultimate mortality.
39. Individuals who are aging, and/or seriously declining for other pathological reasons, need to be monitored for the appropriateness of self-care approaches; changes in cognition and sight/hearing for example, may be rapid and render them incapable of using self-care delivered via digital platforms. Points of vulnerability such as retirement, loss of partners and other challenges that face the aging population need to be considered with respect to how much self-care can be utilised and how many of their needs must be met in other ways.

The economic and policy dimensions of self-care

40. It may be premature to focus on the financial and economic dimensions of self-care. Some governments will be attracted to self-care because it could save money, but for most that is not the primary aim of increasing self-care approaches and supporting them. Related experiences of self-care in operations within the fields of banking, insurance or airline booking are valid. Is that what is anticipated for health?

41. It was suggested that:

- The movement towards self-care should be part of a push to strengthen overall health systems.
- Self-care must be part of an overall health system, allowing those who can manage their health to do so, while focusing the health system on those who most need help.
- Self-care unifies development practitioners, with their focus on infectious diseases and maternal and child health, and developed country practitioners whose increasing focus is on NCDs, with much of Latin America and Asia now rapidly joining this camp.
- Self-care will largely fall into health promotion, diagnosis and treatment, including self-administered 3 D's – drugs, diagnostics, devices on one hand, and data-enabled-health-apps. Automatic data enabled drug administration is also on the horizon. If the self-care movement is to gain traction at the national and international policy level it was suggested that the focus on the initial 3 Ds (such as condoms) are not the focus lest this be seen as 'unsexy' and purely seeming to repackage old ideas.
- Data-enabled-health-apps would be best situated under the wider ambit of Big-Data/Artificial Intelligence/Machine Learning, for which there is unprecedented current interest and excitement.
- Self-care has the potential to further advance the health of those who can already manage their health well – the better educated and more affluent while not helping the excluded and marginalized sectors of the world's population, this needs to be acknowledged and dealt with as systems are developed.

Self-care products—challenges associated with their use and disposal

42. As dependence on hospital-based systems is reduced and people-centered care is enhanced, more services and products will be accessed and used by the lay person, and this will inevitably result in a significant rise in waste disposal of these products. Many products are made of plastics, and chemicals; medical waste is a danger now to workers, patients and communities. Over half of the global population are now at risk from unregulated and unsafe disposal of medical wastes.
43. A befouled environment is a human rights issue. Right of access to information, clean environment, safe working environment, life and health is threatened with open landfills and incineration of toxic materials. Water pollution from microplastic particles and other waste materials is a serious issue. There is also danger to the hundreds of thousands of individuals who make their livings scavenging in areas where things such as used needles, biohazards from testing and diagnostic equipment and emissions from the burning of medical packaging have serious environmental implications. We need urgent short-term solutions for these problems and also sustainable and effective long-term solutions.

Setting a framework for the future of healthcare: the proposed WHO guidelines

44. WHO acknowledges the need to develop normative guidance for the growing number of interventions available. The guidance being proposed, initially on SRHR, and building on existing guidelines will be people-centered and evidence-based. Establishing a research agenda will also be important to ensure recommendations and best practices are grounded in the best possible evidence.

45. A special supplement including the latest evidence and thinking around self-care interventions for SRHR and a conceptual framework for WHO normative guidance will be published in The BMJ in April 2019.

Summary

Self-care interventions are among the most exciting new prospects on the horizon for improving health and well-being, including for vulnerable populations. Advances in technology and in understanding existing forms of caring are the basis for moving forward with new and innovative programmes of self-care. With increased partnerships between communities, donors, programme managers, health workers, health technology developers, practitioners and health Ministries, multi-level interventions can be envisioned. This will lead to challenge to existing medical and healthcare provision, and change.

Self-care should be an integral part of the entire gamut of healthcare, from prevention through treatment and beyond. There is a great potential for integrating the concept of self-care into many aspects of an individual's life.

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