

Centring rights-based access to self-care interventions

Laura Ferguson ^a, Manjulaa Narasimhan^b

a Associate Professor of Population and Public Health Sciences, Director of Research, USC Institute on Inequalities in Global Health, University of Southern California, Los Angeles, USA. *Correspondence:* laura.ferguson@med.usc.edu

b Scientist, Department of Sexual and Reproductive Health and Research, World Health Organization, includes the UNDP/UNFPA/UNICEF/WHO/World Bank Special Programme of Research, Development and Research Training in Human Reproduction – HRP, Geneva, Switzerland

Introduction

Ensuring sexual and reproductive health and rights (SRHR) is fundamental to the success of the Sustainable Development Goals and a range of other global commitments. As such, innovations that can help promote SRHR, including self-care interventions, offer exciting opportunities to improve health and rights simultaneously. While self-care is not new conceptually, the growing number of evidence-based technologies, medicines and products that can be accessed outside of the formal health sector point to the role lay people play as active participants in their own health care.¹ The introduction, use and uptake of self-care interventions for sexual and reproductive health (SRH) is a paradigm shift in health care delivery, bridging people and communities with primary health care services. Exploring human rights and gender equality considerations can help determine how self-care interventions can contribute to advancing SRH outcomes, particularly for underserved populations.² With due attention to local contexts, countries can also leverage these interventions to reach more people with quality, accessible, affordable, acceptable and equitable services.³ Understanding the user, the health system and the environment, is consequently key to ensuring that quality self-care interventions for SRH are more readily available without adding financial or emotional burden to individuals and communities.

The World Health Organization (WHO) has recently developed global normative guidance on self-care interventions for health and well-being.⁴ The WHO recommends self-care interventions as additional options to facility-based care, and therefore complementary to the health

system rather than a replacement for it. Action on the guideline recommendations requires a strategy that is informed by evidence, appropriate to the local context, and responsive to the needs and rights of individuals and communities as well as the health system. In providing such additional options and expanding choice, there is an underused opportunity to improve and increase quality health coverage for all.

The SRHM themed issue “Self-Care Interventions and Rights-Based Access” was designed to provide a space for community groups and experts, researchers, policymakers, implementers, donors, advocates and activists to share examples of successes and challenges and explore strategies for introducing and scaling-up access to self-care interventions for SRH with a specific focus on the needs and rights of underserved individuals and populations.

The issue opened for submissions in 2020, a year after publication of the first edition of the WHO global normative guideline on self-care interventions in June 2019 and as the world struggled to face the COVID-19 pandemic. To support overstretched health systems, there was an unprecedented acknowledgement of the role of individuals and communities in reducing the transmission of the virus, related mortality and morbidities, and protecting their own health through a range of self-care actions such as washing hands, physical distancing, and managing mild symptoms for COVID 19, and other health conditions. The WHO guidance to countries to maintain essential SRH services during COVID-19 subsequently prioritised a range of self-care interventions.⁵ The rapid increase in availability and uptake of self-care interventions during the COVID-19 outbreak may entirely change

healthcare delivery as this pandemic recedes. However, the pandemic also drew attention to the egregious inequalities that affect people’s health, pushing many to use self-care interventions due to lack of access to facility-based care, further underscoring the need for attention to rights in any health intervention.

In this editorial, we reflect on some of the notable findings from this themed issue, and on the prospects for ensuring that the introduction and uptake of self-care interventions for SRH, include equity, human rights, gender equality and social determinants of health as central to their implementation. Structured in alignment with our call for papers, we examine the themes of safeguards to enhance access to self-care intervention, regulatory and policy frameworks, community-led strategies, the right to information, and the right to privacy and accountability. Finally, we highlight some research gaps and directions for future work.

This themed issue

This issue includes 16 peer-reviewed articles, encompassing a mix of qualitative research (*n* = 5), quantitative research (*n* = 2), mixed methods research (*n* = 2), commentaries (*n* = 4) and reviews (*n* = 3). A number of these papers took a global perspective, including the three systematic literature reviews, one paper on attention to law, human rights and gender in the implementation of self-care interventions, one paper on social accountability, and one paper on findings from a global values and preferences survey about self-care interventions.

This issue includes five papers relevant to abortion, all of which come from the Latin America region. While interesting to read together, each paper is very different. They cover the provision of abortion through telehealth in different places and through different lenses, in-person and virtual abortion accompaniment models, and the challenges of self-managed abortion in the humanitarian setting of Venezuela. Most country-specific papers covering topics other than abortion reported on research in sub-Saharan Africa.

The table illustrates the breakdown of topics covered by key components of SRHR⁶ as well as a “general” category for non-topic-specific papers, and the geographical distribution of papers.

SRHR component	Number of papers	Region(s)
Fertility and contraception	3	Global (1); Africa (2)
Infertility	0	-
Antenatal care/ Childbirth/Postnatal care	0	-
Safe abortion/Post abortion care	5	Latin America
Sexual health and well-being	1	Global
Sexually transmitted infections including HIV	0	-
Comprehensive sexuality education	1	Africa
Cancers of the reproductive system	1	South Asia
Gender-based violence including violence against women	0	-
General	5	Global

There are no papers specifically addressing fertility, and no articles are included specific to HIV or other STIs. Given the numerous examples of access to self-care interventions for HIV, such as HIV self-testing, or for fertility, this may reflect the continued siloes between the SRHR, maternal and child health, and STI/HIV fields. Overall, and perhaps unsurprisingly, there is more attention to reproductive health than to sexual health. Both the systematic reviews on gender-affirming hormone therapy and lubricants, which encompass elements of sexual health and well-being, report on a limited evidence base and highlight important areas for additional research.

There was also a dearth of studies from high-income countries and only one from Asia. This suggests that implementation of self-care interventions may have started earlier in Africa and Latin America. If this is the case, it will be important to understand why this has occurred and how best other regions might be supported to engage with self-care interventions.

Despite explicitly requesting submissions in the form of analytical reviews such as historical, political or legal analyses, and rights-based narratives and critical perspectives from authors across disciplines, none were received.

With attention to marginalised, underserved populations as a cross-cutting issue, the call for papers for this themed issue sought to elicit papers to help understand how work across different elements of the self-care ecosystem has adopted human rights as a framework. An overview of how the papers in the themed issue respond to each of these elements is presented below.

Safeguards to enhance access

Overall, there is relatively little attention to the broader context within which self-care interventions for SRHR are delivered or any safeguarding to promote access and, as a result, limited understanding of the extent to which and the ways in which context matters. The importance of linkage to the health system and the valuable role of health workers were highlighted across many of the articles in this issue, and additional attention to how this might best be achieved would be useful.^{7–10} Logie and colleagues noted that the preferred location for accessing self-care interventions varied by the type of self-care intervention, with most respondents preferring to access them either from a doctor or at a pharmacy.⁷ The need for choice in where, how and from whom to access self-care interventions was repeatedly underscored.

The review by Ferguson and colleagues found insufficient and non-systematic attention to laws and policies, human rights and issues relating to gender in the context of self-care interventions globally. Self-care interventions require not only access to quality health services but also a conducive environment in which they might be carried out outside the health system, which requires a nuanced understanding of these broader societal structures and dynamics. By allowing (some) women and girls to circumvent gender barriers to accessing health care, a focus on self-care interventions can reduce the motivation for health programmes and policies to challenge restrictive gender norms. At the same time, the research notes that safe use of resources for contraception, abortion or HIV testing relies on privacy; women who are not able to maintain privacy face risk of

backlash from partners or other household members.⁸ The potential negative impact of patriarchal societies in which women may have low autonomy with regard to SRH and may be at risk of violence was noted by Obare and Burke.^{11,12}

Hémono and colleagues describe how systematic consideration of human rights principles in their pilot study on provision of a digital self-care intervention on family planning and reproductive health for adolescents in Rwanda strengthened the final intervention, including safeguards for access. While they found high levels of access to information through their digital intervention, actual purchase of self-care products through the online shop was much lower, illustrating the need to ensure clear pathways between access to information and uptake of services.¹³

All of the studies included in Kennedy and colleagues' systematic review on self-administration of gender-affirming hormone therapy relate to non-prescribed use outside of the formal health system. While it is important that transgender people can access gender-affirming hormone therapy in a setting in which they are comfortable, it is also key that the quality of the products being used is monitored, that appropriate information on dosing and side effects is available, and that health system and peer support is available if desired. Trans-friendly health services should be another source of gender-affirming hormones for self-administration to provide choice in points of access and level of support. Yet, shortages of skilled health workers, a lack of appropriate services, stigma and discrimination, and a restrictive policy environment were all identified as barriers to accessing gender-affirming hormones within health services. Most of the studies in the systematic review on the use of lubricants focused on acceptability of lubricant use, but some studies also noted challenges with their accessibility.¹⁴

Regulatory and policy frameworks

Ortiz and colleagues highlight regulatory impediments to the provision of telehealth abortion even in a permissive legal environment, underscoring the need to look not only at the content of laws themselves, but how these are translated into actions that facilitate access to care.¹⁵ The pathways to reform of obstructive laws, as well as to the implementation of supportive laws to promote uptake of self-care interventions for

SRHR and good SRH outcomes, warrant additional exploration.^{8,15}

Community-led strategies

Bercu and colleagues describe a model of “feminist collective-facilitated self-care intervention for in-person later abortion accompaniment in Latin America”, which “challenges the idea that self care means solo care”. Embracing the strength of the women’s movements in the study countries and the importance of social support central to their cultures, the authors highlight the importance of leveraging these dynamics within the context of self-care interventions.¹⁶ The four papers on abortion in non-humanitarian settings in Latin America all draw on the strength of the feminist movement and situate their work as a means to address inequalities and expand human rights, working around restrictions imposed by the law.^{15–18} In the paper about safe abortion within the humanitarian context in Venezuela, medical abortion is described as “an act of resistance to reproductive injustice”.¹⁹

While other studies include some attention to community participation in determining the acceptability of self-care interventions, this degree of community leadership is not seen in any of the non-abortion-related papers. This raises important questions about community leadership in the design and implementation of self-care interventions and how best to build on community strengths in other types of self-care interventions for SRHR and in other geographical settings.

Right to information

Many of the papers in this themed issue draw attention to the critical role of access to accurate, easy-to-understand information relating to self-care interventions and SRHR more broadly. Key myths persist relating to the lack of effectiveness of certain interventions as well as potential side effects that will need to be dispelled for people to trust some self-care interventions. In the context of emergency contraception in Ghana and Zambia, Kalamar and colleagues describe the need for support from the health system to ensure that information is available and accessible, particularly with regard to safety.⁹

In their commentary, Corneliess and colleagues emphasise the importance of implementers catering for clients with all levels of education. Noting

that there may be a tendency to withhold self-care interventions (particularly self-injectable contraception) from women with little or no education, they underscore the need to design information materials at appropriate literacy levels, to take the time to help women understand the intervention, and to provide the necessary support to ensure understanding and ability to use the intervention.²⁰

Access to the internet and a certain degree of digital literacy is noted as a pre-requisite for some self-care interventions including telehealth and online purchase of commodities. Ortiz and colleagues, in their commentary on abortion services provided via telehealth in Colombia, note that 60% of Colombia’s poorest lack internet access, with women facing particular challenges around access and digital literacy.¹⁵ Shrestha and colleagues found that women of lower socio-economic status in Nepal had lower digital literacy and were reluctant to consider online purchasing of HPV self-sampling kits.¹⁰

Right to privacy

In a global survey of values and preferences in relation to self-care interventions, Logie and colleagues found that privacy, confidentiality and accessibility were more important considerations in the use of self-care interventions than empowerment.⁷ Privacy was also found to be important to women using telehealth abortion services in Chile.¹⁸ The need to ensure privacy in self-care interventions is underscored by the findings of one of the papers in Burke and colleagues’ review of reproductive empowerment and self-care in family planning, which found that a client-facing digital technology intervention inadvertently increased experiences of physical violence.¹² Just as with other self-care interventions, digital interventions must be tailored to local context, attentive to possible unintended impacts, and with appropriate safeguards in place.

Accountability

In their paper on social accountability, the only paper in this collection on accountability, Kibira and colleagues note that “we cannot automatically assume that self-care interventions will be suited to addressing structural discrimination”, highlighting the need for accountability mechanisms. They draw attention to how solidarity

among health service users is key to collective action and social accountability, questioning if this might be lost in the use of self-care interventions and underscoring the need for community mobilisation for accountability in self-care. They also draw attention to the importance of accountability for the financial burden of self-care interventions and of ensuring that this is not transferred from the health system to individual clients.²¹

Looking to the future

In line with the call for papers, most articles in this themed issue draw on the WHO's definition of self-care interventions. It will be important to further explore what self-care means to different people and how these understandings may vary by location and stakeholder. Very few of the papers in this issue specifically studied digital health interventions as a form of self-care intervention, perhaps because digital health interventions are sometimes, but not always, positioned as self-care interventions. This begs the questions: how do digital interventions affect how self-care interventions are defined, and who makes decisions within that space that might have broader ramifications for self-care interventions? Further, how might we recognise the value of each of these different types of interventions, acknowledging their differences as well as potential synergies? A historical analysis of self-care interventions for SRHR might also yield useful lessons for current efforts, including those relating to digital health interventions.

Despite the call for papers for this themed issue being very focused on underserved populations, there are surprisingly few papers that specifically discuss particular population groups. There is a total absence of empirical papers focusing on lesbian, gay, bisexual, transgender or queer people, people living with HIV, people with disabilities, people in prisons and other closed settings, and indigenous people. All of these groups, and particularly people who might belong to more than one of these groups, might benefit from self-care interventions. But the challenges they might face in accessing these interventions and the ways in which the interventions are made available for them might be different from self-care interventions designed for the general population. A few of the papers in this themed issue note as a limitation that their sample is relatively well educated

or not of low socio-economic status, with Larrea and colleagues noting that access is mediated by resources. It may not be appropriate to extrapolate findings to these other population groups, leaving a gap in understanding.

There is a need for empirical studies into the offer of a range of self-care interventions for SRHR to diverse populations. Current studies usually focus on a single intervention and a single population, which limits understanding of the broader systems that can support the provision of self-care interventions, including laws, policies, health system structures and approaches to understanding gender and other social norms affecting acceptability. Additional research is needed to better understand the broader environment within which self-care interventions are implemented, how it can affect implementation, and how it might usefully be strengthened to better support the delivery of these interventions.

Linked to this, the power dynamics around self-care interventions for SRHR remain under-explored. How do these interventions take away or give power? It would be useful to unpack notions of how self-care interventions are linked to agency in sexual and reproductive decision-making. Understanding gender roles, norms and dynamics seems central to designing self-care interventions for SRHR that are acceptable and safe, and will require in-depth qualitative assessment across a variety of settings. Overall, there was a lack of manuscripts that contained an intentional analysis of potential gender-related negative consequences as well as opportunities in accessing self-care interventions for SRHR. While further research is needed in this area, this also points to the need to embed safeguarding in the promotion, use and uptake of self-care interventions for SRHR to ensure the rights of individuals to act upon informed health decisions. Particular attention to sexual health is needed as, compared to reproductive health, this receives very little attention.

Some of the papers from Latin America explored the important role that the feminist movement plays to support access to self-managed abortion, which could provide a framework for exploring other community-based strategies relevant to self-care interventions for SRHR. How do the capacity and cohesiveness of civil society and communities influence the availability of appropriate self-care interventions for SRHR? And how does this vary by intervention,

population and/or setting? What are the support systems that can help marginalised groups access self-care interventions?

We would welcome submissions on any of these topics and populations to our open issue at any time.

Conclusion

This collection of papers provides insight into some examples of current implementation of self-care interventions for SRHR. However, there is a need for more research to inform evidence-based implementation guidance to support equitable access to self-care interventions for SRHR, as shown by important gaps in implementation and current knowledge. While people's resilience and ability to self-manage health are increasingly acknowledged and indeed counted upon by health systems and health workers, as shown during the COVID-19 pandemic, there is a need for balance between health systems-based and people-centred approaches to the availability of self-care interventions. This will expand SRH choices, promote acceptability and offer

important opportunities to accelerate universal health coverage.

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ORCID

Laura Ferguson  <http://orcid.org/0000-0002-1340-793X>

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