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GLOBAL GROWTH IN UNPAID CARE - TOWARDS SUSTAINABILITY

- A. Author's name and affiliation with e-mail
- 1 Louise Oldridge Nottingham Trent University <u>louise.oldridge@ntu.ac.uk</u>
- 2 Mary Larkin The Open University mary.larkin@open.ac.uk
- B. Synonyms (if applicable)

Carers, caring, family carer, informal care, unpaid care, caregivers, caregiving, care workers

C. Definitions

The concept of 'carer' has been used since the 1980s. Although definitions have varied, a carer is now widely regarded as someone who provides unpaid care or support to a member (a friend or family member) of their own household, of other households or of the community who due to illness, disability, a mental health problem or an addiction cannot cope without their support (Carers Trust, 2015; International Labour Organisation, 2018).

Introduction

The 2030 Agenda for Sustainable Development of 2015, endorsed by the United Nations, details 17 Sustainable Development Goals (SDG). The purpose of these goals is to address global challenges faced by nation states, including inequality. The fifth goal (SDG 5) is, to 'achieve gender equality and empower all women and girls' and target 5.4 specifically calls for recognition and valuing of the significant amounts of unpaid care work carried out by women across the globe 'through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate', (United Nations, 2015).

SDG 5, and its emphasis on recognising women's unpaid care work is long awaited (United Nations, 2015). It follows years of debate and advocacy of both activists and feminist academics highlighting issues of care, social reproduction and seeking to conceptualise unpaid activities as work (Rao, 2018; Taylor, 2004). Global acknowledgement of unpaid care work first came in 1995 at the Fourth International Women's Conference in Beijing (Rao, 2018). This was later endorsed by Elson (2008) (cited in Rao, 2018: 741) who proposed the 'three Rs' framework, to 'reduce, recognize and redistribute' women's unpaid care work. However, the varied understandings and definitions of unpaid care across geographical and socio-cultural locations have implications for families, the state and the market, in accordance with different policy mechanisms (Rao, 2018). Despite moves towards the holistic

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recognition of unpaid care work in global discourse, women's care work continues to be taken for granted at a policy level (Rao, 2018).

The aim of this chapter is to review the feasibility of SDG 5 and the policy requirements needed in order to achieve it, at a global level, and challenges associated in so doing. The United Kingdom (UK), a nation state and founding member of the UN, will be used to illustrate some the issues raised. If transformative changes are not made in policy at both national and global level there is a risk that SDG 5 will not be achieved. Given their centrality, the chapter will start with an examination of the concepts of care and carer. It then moves on to review existing levels of unpaid care and their impact, globally and in the UK, with specific reference to women. This is followed by an exploration of existing policy and the requirements of global and national policy in order to address SDG 5 in relation to unpaid care work.

• Conceptualising care and carer

Fundamental to the realisation of SDG 5 is an understanding of what care is and what makes someone a carer. Caring is a fundamental part of many human relationships, and it can therefore be difficult to distinguish between normal activity and that which goes beyond this (Larkin and Milne, 2014). As indicated above, caring is a contested term; many definitions exist, shaped by a number of factors, such as family make-up, carers' individual characteristics, socio-economic and cultural contexts (Yeandle et al, 2017; International Labour Organisation, 2018). Yeandle et al, (2017) capture its essence when they so aptly state, 'care is both a public and a private concern; it affects family members and paid workers; it concerns labour and love; it involves intimate practices, technical skills and challenging tasks that must respect a care recipient's dignity and comply with externally determined quality standards; and it is delivered 'in the moment' but may be the product of a lifetime of interactions', (Yeandle et al, 2017: 9).

When formally recognised in the 1980s, it was very much a case that the provision of care was that of an activity of "doing care to' another' (Ray et al, 2009: 116 cited in Milne and Larkin, 2015: 4; Barnes, 2006). This was conceptualised by Parker (1981) as 'caring about' (Parker, 1981 cited in Barnes, 2006: 7) and focused on the provision of physical care assistance and also simply being with an individual for a period of time. Conceptualisation of care increased in sophistication with the distinction between 'caring about' and 'caring for'; as, 'carer and cared for are familiar with each other and the care is an integral part of the intimacy of the family.... 'caring for' can be "assumed from a relationship of 'caring about" (James, 1992: 490). Conceptually, 'caring about' described feelings of concern for another and 'caring

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for' was seen as involving the tasks associated with caring in the form of unpaid labour (Ungerson, 1983).

Similarly, the 1980s marked the introduction of use of the term 'carer'. Since then, the term has become part of public discourse and is now used extensively in social, healthcare and research. Whilst it is used to refer to unpaid/informal carers it is also linked to and confused with those who are paid for the care work which they provide (Lloyd, 2006; Molyneaux et al, 2011). An important difference to note between unpaid and paid care work is that paid care workers are professionals working in exchange for pay in a range of settings, including home and residential care and nursing homes (The care workers charity, 2019).

Although the emergence of the term 'carer' afforded recognition of the unpaid care work which women have been carrying out since time immemorial, there are those who question whether the term 'carer' continues to meet its original obligations (Molyneaux et al, 2011). In fact, some argue that the term carer has become bureaucratic and in doing so has turned 'what was a normal human experience into an unnecessarily complex phenomenon', (Foster, 2005 cited in Molyneaux et al, 2011: 422). Kev issues in seeking to theorise care have involved the identification of who is a carer, what care involves and the validity of 'carer' as a concept (Larkin and Milne, 2014). Indeed, not all individuals are comfortable with the term 'carer' as it may impact their pre-existing relationship (O'Connor, 2007). For women in particular, caring is often seen as part of their normal role and they can be concerned about being carers as this could introduce political disparity into the relationship, destroying the original mutuality of contribution with those being cared for (O'Connor, 2007; Molyneaux, 2011). Up to half of carers do not self-identify as such (Lloyd, 2006); often only by interacting with others, particularly at support groups or with professionals, do they come to see themselves as 'caregivers' (O'Connor, 2007). This is significant, as often it is only through self-identification as a carer that support systems and services can be examined, in relation to existing policies. Where individuals do not choose to formally identify, or consider themselves as carers, they risk exclusion from support mechanisms, including advice and information, which may have personal and financial implications (Carers UK, 2019). This is particularly important if carers have to stop working in paid employment due to their caring, while at the same time their caring is often not recognised or valued as a form of work, as this next section explores.

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• Conceptualising and valuing informal caring as unpaid work

Integral to SDG 5 is the recognition of women's unpaid care work (United Nations, 2015). Acknowledging unpaid care as a form of work, and the value it brings, is the second problematic issue in realising SDG 5. The notion of unpaid care being considered as a type of work has been the subject of much debate in recent years; a focus on paid employment as the only mode of work of value has been, and still is, prioritised within public discourse (Hirsch and Millar, 2004), with those not in paid employment being regarded as 'not working', and in this instance, informal caring not being recognised as contributing towards society (Glenn, 2000). Furthermore, historically, paid employment in the public sphere has been considered as a male domain where economically productive industrial labour was provided, whereas unpaid domestic activities were conducted in private, typically by women (Taylor, 2004). Such a dualistic approach has given value, and therefore precedence to revenue generating activities, consigning domestic activities to invisibility from study, and ultimately reducing our understanding of what counts as work (Taylor, 2004). As a result, informal care work has come to be considered as a commodity and the organisation of labour cannot simply be categorised into public and private work activities anymore because it undermines the significant work activities undertaken by carers (Parry et al, 2005).

Recent conceptualisations have moved beyond defining work on the basis of payment alone, with considerations being given to activities such as caring. For example, Taylor (2004: 38) depicts experiences of voluntary work, stating 'what constitutes an activity as work, as opposed to something else such as leisure, is not whether it is paid but whether it involves the provision of a service to others or the production of goods for the consumption of others', (Taylor, 2004: 38). She suggests that caring be considered as unpaid informal work and private domestic labour. Indeed, failure to account for unpaid care work discounts the many activities it often involves. This is illustrated in Vassilev et al,'s (2013:2) study in 'care and illness labour' which identified three types of work:

- *Illness (specific) work* referring to the taking, and measurement, of medication; understanding symptoms; and making appointments;
- *Everyday work* refers to tasks associated with keeping the house; occupational labour; support and management of diet and exercise, shopping and personal care;
- *Emotional work* refers to work related to providing comfort which includes health, well-being and companionship.

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Additionally, in failing to adopt a broader approach to 'work' and continuing to only value economic activity as work, many states within the United Nations routinely rely on the provision of informal care to meet the care needs of many dependent adults. This has resulted in many carers leaving paid employment to meet their caring responsibilities (Carmichael and Charles, 2003; Van Houtven et al, 2013), often with inadequate financial recompense (Carers UK, 2019a). Hence, failure to recognise women's continued unpaid care work is fueling the ongoing gender inequalities, which have led to the development of SDG 5.4, as explored in the following section.

• Care work – a global challenge

In order to address SDG 5, the importance of care work throughout the world must be recognised; the act of caring is not only fundamental to human existence, bringing with it a range of emotions, but also has implications for the distribution of resources in global contexts (Yeandle et al, 2017). Across the globe, demographic shifts have been witnessed, including increasing and ageing populations, with improved life expectancy of those with lifelong disabilities (International Labour Organisation, 2018). Changing family structures and shortcomings in social policies and public services, combined with a simultaneous rise in care dependencies, have led to a growth in demand for carers in all societies, even in countries with welfare state provision (International Labour Organisation, 2018). Global economies depend on unpaid care work, often using carers to address shortfalls in infrastructure and public spending (International Labour Organisation, 2018). Despite the increasing number of carers, and growing recognition of unpaid care as a form of work, it is not considered when calculating Gross Domestic Product (GDP) (International Labour Organisation, 2018). However, data collected from 64 countries in 2018 indicates that unpaid care work accounts for 9 per cent of global GDP (International Alliance of Carer Organisations, 2018).

Taking account of the different ways care and carers are conceptualised and varying activities which may or may not be classed as care, it is difficult to quantify unpaid care provision but the United Nations Economic Commission for Europe (2019) suggest that worldwide, unpaid carers cover between 70 to 95 per cent of all care requirements. As a result, nearly all adults will be unpaid carers at some point in their life. Furthermore, with an increasing demand for care, it is likely that individuals will have more than one caring role – for example, caring for parents and an adult child with disabilities (International Labour Organisation, 2018).

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If care requirements are not addressed, the existing gaps in provision and quality have the potential to create an unsustainable care crisis on a global scale, put a further burden on paid care workers (where in some countries supply of this labour is limited, rife with inequalities, with many migrant workers facing low pay and difficult working conditions) and fuel existing gender inequalities for women and girls (International Labour Organisation, 2018). Even health and social care needs in many middle and high income countries are unsustainable without carers (International Labour Organisation, 2018; Pickard 2008). The UK is used to illustrate this further in the following section.

• Informal care in the UK

In the UK, informal care provision has increased at a rate higher than population growth and the health and social care system is unsustainable without the care provided by family and friends. Successive governments adopting neoliberal ideologies have emphasised the importance of family as a mechanism of care and have continued to rely on informal care as a policy initiative (Gilbert and Powell, 2005); it is estimated that the provision of informal care of dependent adults now saves the state £132 billion per year (Carers UK, 2017). With an ageing population and increasing rates of disability, care needs are set to rise (Pickard, 2008; Heitmueller, 2007). Recent research (Carers UK., 2019a) suggests there could now be as many as 8.8 million carers in the UK, compared with 6.3 million recorded in the Census in 2011 (Office for National Statistics, 2013). Specifically, projections are that the population of those aged 85 or over, will increase to around 3.2 million by 2041. With less people in residential care, the numbers of elderly people owning their own home has increased whilst the supply of care from Social Services has decreased, shifting care from institutions into communities, presenting a number of challenges in managing and ownership of ongoing care needs (Stewart and MacIntyre, 2013; Heitmueller, 2007). In some cases, this has led to gaps in the provision of care, regarding who provides what support and when (Vassilev et al, 2013). In addition, changes to family make-up in the UK means that most informal carers are looking after spouses and/or parents (Heitmueller, 2007).

In the 2011 Census, 57.7 per cent of unpaid carers of adults in England and Wales were women, with the highest provision of unpaid care, at 23.5 per cent, being provided by women aged 50 – 64 (Office for National Statistics, 2013). It is estimated that in Britain, 56 per cent of women will have provided such informal care for 20 hours or more per week by the time they reach 65 (Hirst, 2002). Data shows that female informal carers are more likely to care for longer hours, and are more likely to be the main carer, than men (Carmichael and Charles, 2003).

The UK's continued reliance on carers sits alongside policies to increase employment rates of older workers to meet the needs of an ageing population (Kirton and Greene, 2016) and government

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objectives to encourage carers to remain in employment (Her Majesty's Government, 2010). As a result of these conflicting government policies, carers can face pressure to both remain active in the labour market until they are older, and to provide care. The significant impact of caring on individuals is wellestablished. Not only for carers in the UK but for all carers across the world as the next section explores.

• The impact of caring on individuals in the UK and beyond

As discussed earlier, often carers do not identify themselves as such because of their ongoing relationships and feel they are simply doing their familial duty. This in turn means they remain both unknown and invisible, making the effectiveness of targeted policies challenging and the impact of caring unknown. Additionally, carers are not a homogenous group and there is variation in their profiles across the globe, for example, differences in race, age, the relationship with those requiring care, hours and activities of care provided. As a result, an intersectional approach is needed to consider the impact of caring and to work and research with carers, particularly when examining their experiences.

Caring is reported to have a significant impact on people's lives, which needs to be addressed through policy in order to achieve SDG 5. Although, for some at times, it can be rewarding, caring for a significant length of time with little or no support can be highly challenging, unpredictable and disadvantage carers (especially over the longer term) in terms of wellbeing, financial circumstances, education, ability to maintain employment, and social life (Larkin and Milne, 2014). Furthermore, individuals may not have a choice about when they do in fact become carers; legal obligation or feeling a moral obligation, a dearth in formal arrangements or a lack of information about other options all play a part (United Nations Economic Commission for Europe, 2019). It should be noted that, while a global issue, expectations and notions of care are also influenced by culture and religious beliefs (Oldridge, 2018). Research has indicated that asking for help with caring could be seen to go against family relationships and is stigmatising (Seabrooke and Milne, 2004; O'Connor, 2007).

Despite nations such as the UK having national health services and provisions in place at local levels, across the globe, access to affordable, relevant and quality care services to support unpaid carers are lacking (United Nations Economic Commission for Europe, 2019). Where such provisions are offered there are often bureaucratic processes to follow to access support, with lack of coordination between different agencies (United Nations Economic Commission for Europe, 2019; Carers UK, 2019a). Assumptions can be made about carers having the ability to provide the required care with little training or support (United Nations Economic Commission for Europe, 2019; Oldridge, 2019), relying on skills acquired from other life and professional experiences.

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A number of specific negative consequences of caring have been evidenced internationally. The act of caring can lead to reduced amount of time for carers to focus on their own health, including exercise and diet, attending medical appointments, and can lead to the development or aggravation of existing physical and mental health concerns (Carers UK, 2016; Larkin and Milne, 2014; Purkis & Ceci 2015; Vlachantoni et al. 2013). The costs associated with caring alongside reduced ability to participate in the labour market and education can affect savings, pension contributions and increase debt. With the trajectory of many conditions requiring more care over time, and demands of caring increasing with age, carers can find themselves needing to reduce hours and responsibilities at work, leave work and/or take early retirement (Carers UK, 2017; Van Houtven et al. 2013). When and if carers do exit the labour market it can be hard to return either when caring ceases, or whilst caring, due to its often unpredictable nature. Those who do continue to work and care often find their career development negatively affected (Oldridge, 2019; International Labour Organisation, 2018; King & Pickard 2013). Hutton and Hirst (2000) reported that carers suffer worse working conditions than their colleagues. Caring and other responsibilities, in combination with potentially reduced incomes, can also leave little time or financial resources for socialising (Carers UK, 2014; Cronin et al. 2014; Larkin, Henwood and Milne, 2018).

At the time of writing (May 2020) it is impossible to ignore the global health pandemic and that many countries, including the UK, are in in lockdown due to Covid-19. Whilst this global crisis has focused attention on healthcare, and paid care workers, the impact on informal carers remains largely unrecognised. Available evidence to date in the UK shows that many are providing even more care - on average an additional 10 hours per week - with over half feeling overwhelmed and yet concerned about their own health and burnout. Carers are also very worried about falling ill themselves and the impact on the those for whom they care, particularly in the light of the reduction in, and closure of, local services (Carers UK, 2020).

Given the disproportionate number of women caring across the globe, it is important to examine the impact of caring on women in greater detail, in light of the specific challenges of SDG 5, as the next section goes on to do.

Global impact on women

Caring remains highly gendered; globally women care for an average of 3.2 times more hours per week than men (Health and Social Care Information Centre, 2010; International Alliance of Carer Organisations, 2018; International Labour Organisation, 2018). Indeed, recently the International Labour

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Organisation (2018) reported that girls and women are providing over three-quarters of the total amount of unpaid care across the world, impacting their ability to find and maintain quality employment, particularly when 'there are no accessible, affordable and quality care options offered by the State, the market or the non-profit sector', (ibid, 2018: 10). There is not a single country where there is an equal share of unpaid care work between genders. Furthermore, continued lack of recognition of unpaid care work has led to lower wages and working conditions for paid care workers, again an area where women and migrant workers are over-represented (International Labour Organisation, 2018). This is highlighted by the 'unpaid care work-paid work-paid care work circle' (International Labour Organisation, 2018: 11). Furthermore, it has been found that women report feeling a greater sense of burden, and pressure to cease employment to care and are less likely to seek out support services (Milne et al., 2012).

• Existing global care policies and unpaid care work

As demonstrated in the discussions so far in this chapter, it is essential that existing care policies are developed, in order to meet target 5.4, under SDG 5. This includes greater recognition of care and carers; valuing of unpaid care work, with policies designed to address the challenges and impact of caring, and offering greater support and redistribution of care work, moving towards sustainable care regimes.

The plight of unpaid carers has garnered more attention at a national level in many countries where policies intended to support carers and increase their rights have been introduced (Larkin and Milne, 2014). Care policies have been put in place by public governing bodies to assign appropriate resources to allow for recognition, reduction and redistribution of care work through investment of finances, time and services (International Labour Organisation, 2018). When designed well, they can redress care inequalities and focus on carers' rights and support, but their provision differs across the world according to demographic, social, economic and cultural contexts impacting how care is viewed and the economic ability of states at a national level to intervene (International Labour Organisation, 2018). Often interacting with other areas of policy, they can include a focus on welfare benefits, employment legislation, and direct care provision, for example (International Labour Organisation, 2018).

Despite these developments, even in countries with high-incomes, care policies fail to address the systematic barriers and persisting inequalities (International Labour Organisation, 2018). In some countries, there are significant gaps in care policy provision (particularly in Africa, Asia and the Pacific, and the Arab States) resulting in poor health and economic consequences for women with care

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responsibilities. Whilst more attention is offered to care policies in Latin America and the Caribbean, there are issues in accessing support (International Labour Organisation, 2018).

In light of SDG5 from the United Nations, subsection 5.4, the reality is that addressing gender inequalities relies upon addressing the scale of unpaid care work through the recognition, reduction and redistribution of unpaid care work between genders, families and nation states at a global and national level (International Labour Organisation, 2018). Changes in policy need to be made relating to additional provision of services to care for dependent adults, welfare benefits offered to those providing care, supporting infrastructure and labour regulations for paid care workers and those providing unpaid care work alongside formal employment. If enacted successfully, such policies have the potential to be transformative in nature, changing the lives of unpaid carers, typically women, and striving for greater gender equality (International Labour Organisation, 2018). Considerations and implications for global policy are now reviewed.

Implications for global policy

A challenge in realising SDG 5 is the world's care crisis. Unless solutions are found, there will be further decreases in care provided and persistence in gender inequality (International Labour Organisation, 2018), and additional pressure on unpaid carers, their health and wellbeing (United Nations Economic Commission for Europe, 2019). Discussions on sustainable care are taking place globally with recent conferences such as the Global Carework Summit (9-11 June 2019) held at the University of Toronto, Canada and the Sustainable Care International Conference (to be rescheduled after lockdown), Sheffield, UK. Key themes within the current discourse are global care inequalities and policies, transnational and intergenerational exchanges of care, care and neoliberalism, decent care work and conditions, the organising of care workers, carer wellbeing, the role of assistive technologies aimed at reducing care burdens and the right to receive and provide care.

Nations' policies define their approach to care, who it is offered by and their working conditions. For SDG 5 to succeed, it is imperative that that there is a greater focus on providing high quality care work offering 'recognition, reduction and redistribution of unpaid care work and promoting decent working conditions and representation for all care workers', (International Labour Organisation, 2018: 28). At a global level, policies must be in place to offer support to unpaid carers so that they are not forced to exit the labour market, for their health and wellbeing to suffer, or face poverty and social exclusion (United Nations Economic Commission for Europe, 2019). The International Labour Organisation's (2018)

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recent report provides global recognition that unpaid care work continues to be one of the main barriers to women's participation in the labour market, whilst at the same time, providing understanding that paid care work remains an important mode of employment at a global level, particularly for women. As a result, nations need to focus on an equal distribution of unpaid care work; the promotion of public funding and investment in providing quality care; decent work and policies for paid care workers; supporting unpaid care workers wishing to return to, or maintain, paid employment; and the revaluing and formalisation of paid care work (International Labour Organisation, 2018).

"Recognizing" unpaid care work involves bringing to an end society's habitual practice of taking it for granted and challenging the social norms and gender stereotypes that undervalue it and make it invisible in policy design and implementation. "Reducing" unpaid care work means shortening the time devoted to such work when it involves drudgery, primarily by improving infrastructure. "Redistributing" unpaid care work means changing its distribution between women and men, but also between households and society as a whole', (International Labour Organisation, 2018: 25).

A way forward, proposed by the International Labour Organisation (2018), is the development of transformative policies and decent care work, accompanied by the necessary doubling of investment in the care economy which they predict could result in a total of 475 million jobs by 2030, creating more employment opportunities for women, developing additional economic benefits. In order to achieve SDG 5 by 2030, such policies should be guided by the principles of 'gender-responsiveness and human rights; universality, adequacy and equity; overall and primary responsibility of the State; social dialogue and representation', in design, implementation and during evaluation (International Labour Organisation, 2018: 111). At a practical level, the United Nations Economic Commission for Europe (2019) suggest this involves: defining informal/unpaid care to acknowledge contributions and necessary support; generating awareness of the issues associated with long-term unpaid care and assessing carer needs, offering alternatives; offer training and guidance to unpaid carers; both increase care services in the community and make access to these easier; and offer security of income and social protection such as health care and pensions for unpaid carers. Furthermore, support must be offered for those carers who are combining formal employment and unpaid care work (United Nations Economic Commission for Europe, 2019). Failure to do so will lead to carers being forced to leave work, with organisations losing talent, tacit knowledge and productivity, and financial implications for carers (Grayson, 2017; Oldridge, 2019). Governments have a responsibility to ensure employment legislation addresses carer needs such as flexible working, and leave provisions (Grayson, 2017). Some measures are now being taken in nation states, such as the Economic and Social Research Council funded programme (2017 - 2021)

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Sustainable Care: connecting people and systems, which seeks to find sustainable solutions to the UK's 'crisis of care', for which the outcomes could also inform implementation of SDG 5 (Economic and Social Research Council, 2018).

<u>Conclusion</u>

Across the globe, changing demographics and reduced public spending have led to increased care requirements, often met by unpaid carers. The act of caring and associated labour is becoming increasingly recognised but remains undervalued and supported. While unpaid and not seen to contribute to GDP, it involves illness, everyday and emotional work, ultimately providing a service to those in need. Despite not always recognising themselves as carers, it is clear that women bear the greatest burden of care responsibilities across the globe. The challenging and unpredictable nature of caring affects the wellbeing, finances, education, labour market status and social life of carers, disproportionately affecting women. Calls for sustainable care have been made to help address persisting care inequalities as part of the United Nations' sustainable development goals. If SDG 5 is to be successfully realised, nation states need to take action in both policy and practice. Future policies need to be underpinned by a greater understanding of care, its underlying issues and impact on carers across the globe. There is a requirement for comprehensive state provision that recognises the plight of informal carers alongside paid care workers and redistributes women's unpaid care work through supporting infrastructure and offering additional care provisions, increased practical and financial welfare benefits, greater employment flexibility and regulations, and improved working conditions. The need for such policies is heightened by the current global Covid-19 crisis.

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