

Not just surveys and indicators: narratives capture what really matters for health system strengthening

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Health system strengthening remains elusive and challenging. Health systems in many countries in sub-Saharan Africa are frequently characterised as weak, with inadequate management and accountability mechanisms, and poor human and financial resources. Putting patients and staff at the heart of health systems is an essential step towards strengthening them. As one of the three pillars of quality in health care, understanding patient experiences is key to moving towards people-centred care. Yet patient experiences are not a singular concept. Patient narratives can convey individual experiences of illness and health care, which complement and augment epidemiological and public health evidence. These narratives, gathered with rigorous, interview-based research and shared with digital tools (audio and video), can generate persuasive evidence. This evidence has important potential for influencing policy and practice, and for supporting people-centred care, but has not been tested systematically in low-income countries. In the Kenyan context of newborn health, work under way is generating evidence to show the transformative potential of patient narratives.

People-centred health systems

Although the importance of health system strengthening is recognised, it remains elusive and challenging to achieve.¹ Recognition that health systems are complex and adaptive social systems is growing.² Putting people—both patients and health-care staff—at the heart of these systems is an essential step in the drive to strengthening them.³ The contemporary rhetoric of policy makers around the world includes making health systems more responsive to patient needs and preferences. The 2016 WHO Global Strategy on integrated, people-centred health services commits countries to developing responsive, people-centred care systems that have the potential to generate substantial benefits for the care and health of all people.⁴ The 2018 Lancet Global Health Commission on High-Quality Health Systems in the Sustainable Development Goals Era: time for a revolution positioned positive user experiences as essential components of high-quality health systems and called for more research on patient experiences.¹ However, too often the focus on making health systems people-centred is addressed by trying to use measurable indicators of patient experience, which might narrow the gaze of quality improvement.⁵ We argue that trying to reduce patient experience to a set of quantifiable indicators is an inadequate approach to capturing the complex and nuanced experiences of encounters with a health system that evolve over time, and provides insufficient understanding to realise the goal of people-centred care. We suggest that greater emphasis can and should be placed on the analysis of patient narratives of their health and illness, and that this form of evidence is, as yet, underused in informing policy and clinical practice in low-income settings.^{6,7} Specifically, we propose that patient narratives, gathered by the use of rigorous, interview-based research and shared with digital tools (eg, audio and video) can generate persuasive evidence with important potential for policy and practice impact.

Understanding and collecting patient experiences

Understanding what it is really like for patients to experience health, illness, and health care can show what is working well, what needs to change and how to go about making improvements along the care pathway, and can support advocacy for change and inform policy and practice.^{8,9} People-centred organisations, in which health-care professionals work collaboratively with the people that use their services and focus on patient experiences, have improved staff experience, staff morale, and staff retention, and have reduced lengths of hospital stays for patients.^{10,11}

A wide range of approaches exist for collecting, understanding, and—crucially—using patient experiences.¹² Duschinsky and Paddison provide a genealogy of a concept now important in contemporary health-care administration and policy in high-income settings such as the UK, in which patient experiences can encompass patient voice, patient choice, patient expertise, patient perspectives, patient authority, and patients as auditors.¹³ The authors describe a trend to assess patient experience through surveys as a means of quality assurance and tracking improvement. However, patient experience surveys (which are also widely conducted across low-income health systems) can only reveal so much and have been challenged as being tokenistic.¹⁴ As snapshots, they can tell us whether patients were, or were not, happy with their care, but they cannot provide in-depth insights into the reasons why.

There are many qualitative approaches to understanding patient experiences that can complement survey data or stand alone to generate valuable knowledge in contemporary health care. These qualitative approaches include methods designed to understand how people feel and behave in health-care settings, by use of ethnographic observations and interaction analysis, or methods designed to generate people's accounts of their experiences through in-depth

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Panel: Patient experiences and narratives**Patient experiences**

An umbrella term for people's experience of illness and health services, collected with various methods including structured survey questionnaires, focus groups, semistructured or structured interviews, patients' free accounts of their experiences (ie, narratives), or ethnography that observes patient pathways and deduces where problems occur.¹⁰ Patient experiences can also be viewed entirely independently of research through stories or online blogs.

Patient narratives

A method of collecting unstructured accounts of patients' health and illness. These narratives are powerful for revealing what is important to patients and for addressing the how and why questions, such as how a patient understands their illness or why they find taking their medication difficult.^{10,18}

Digital patient narratives

Through careful and rigorous analysis, these narratives can identify common themes and polyphonic perspectives within a health system. Digital narratives can be collected by use of interview-based research studies with a wide sample of participants from different backgrounds and locations to maximise variation. These narratives can be disseminated and shared through multiple impactful platforms (eg, DIPEX International) using the medium of digital audio or video narratives.¹⁹

For more on DIPEX International
see <https://www.dipexinternational.org>

interviews and focus groups. These approaches aim to uncover what is important to patients, which is a necessary precondition of people-centred care.^{15,16} Low-income and middle-income countries (LMICs) have a rich tradition of using these approaches, including Kenya (where we are from and work).¹⁷ However, we have found a particularly illuminating and flexible method to be the collection and (comparative) analysis of patient narratives for dissemination via digital platforms. The use of digital patient narratives can be seen as a subset of approaches for studying patient experiences, but is yet to be used extensively in low-income settings (see panel).

Collecting and using digital patient narratives to improve care

Narrative interviews (unstructured accounts of patients' health and illness) are an essential part of the toolkit for understanding and reporting experiences of health, illness, and health care. Rather than being dismissed as anecdotes, narratives can be used through deliberate incorporation into interventions to inform quantitative approaches, such as discrete choice experiments, and to develop and translate evidence-based policies.^{20,21} The approach of narrative interviewing seeks to get close to what is most important to respondents by encouraging an account that illuminates their own perspectives and

priorities, providing insights into their world of health and illness as opposed to the world view of medicine.¹⁸

Capturing patient experiences through narratives, although important, is not enough of an end itself. These experiences must be used to inform and improve health systems. Patient perspectives provide information and support to other patients and the public, and can also be used to stimulate health-care improvement, for example through the use of co-design approaches.²² We have found this process to be particularly powerful and effective when narratives are gathered and shared with audio or video, or both.

One example of how digital patient narratives are used is the DIPEX International collaboration that now includes 14 high-income and middle-income countries. This collaboration publishes its research on public-facing websites about people's experiences of health, illness, and care, which are all based on the same core qualitative research method, with narratives (collected with face-to-face interviews that are audio-recorded or video-recorded, or both) to understand patient experiences and prompt improvements to care.¹⁰ At the core of these studies is an ambition to represent voices in their plurality, which is achieved through interviewing a wide sample of participants from different backgrounds and locations, asking about experiences in an open-ended way that allows for unanticipated responses, and by interviewing people in their home or a non-clinical setting.²³ These interviews are disseminated on freely accessible websites with video and audio clips. They give a face and voice to the experiences, which can be transformational for service improvement, clinician education, or for the patients and public who access the platform. Alternatively, video and audio clips from the analysis can be used in co-design approaches²⁴ or interactive theatre workshops to learn from patient narrative research.²⁵ Insights from these studies have been used for health-care improvement in varied settings, ranging from chronic conditions such as diabetes, new and emerging illness such as COVID-19, intensive care, dementia, and illness in pregnancy and childbirth.^{26,27} Although time-consuming to collect and analyse, these narrative interviews provide widely transferable and important insights that can be used to set priorities and underpin the co-design of actionable health-care improvements.²⁶ With appropriate permission from the interviewee, these narratives can be analysed multiple times for different purposes,^{26,28} for example, through experience-based co-design (EBCD), a structured approach to co-designing health-care improvement. EBCD captures narrative experiences on video and produces catalyst films to stimulate health-care improvement suggestions.²⁴ This approach has been used in a broad range of studies for cancer and palliative care, and, for example, a study to understand and reduce noise in intensive care units, but is not widely used in low-income settings.^{24,29-31} Insights into the motivations of patients indicate that consenting to an interview that will create an online resource designed

to provide support and information to other patients and their families, as well as inform clinical practice, differs from consent for a conventional research interview.²³ Altruism and the opportunity to share experiences to improve care are often core motivators; the shared experience of living with an illness can offer potential for solidarity with peers.³²

What do patient narratives have to offer LMICs?

Although there is a rich evidence base of qualitative health services research and participatory action research in LMICs,^{19,31,33} the digital patient narrative approach has not been tested in a systematic way in health systems in these settings. However, evidence suggests that good clinical practice and policy can be enriched by the knowledge generated through small, in-depth studies using this approach.¹⁶ The stories generated by a narrative approach, supported by credible evidence, are persuasive forms of evidence for policy actors in complex systems.⁷ The combination of digital patient narratives—which are based on rigorous methods of sampling, data collection, and analysis—with the careful consideration of ethics could be transformational in motivating policy makers, front-line staff, regional and national managers, educators, and funders to make health system improvements.⁵

In Kenya, we are conducting a study that seeks to use narratives of mothers' experiences of preterm birth as a pathfinder study for using patient narratives, collected via video-recorded interviews, to improve care. Premature birth remains a global health priority. Improving the quality and access to care for these preterm newborns is essential, but progress is too slow.⁵ Narratives of mothers' experiences could have a role in stimulating ideas for improvement at national, regional, and local levels, and in informing training. Emerging insights might include knowledge and expectations of prematurity, experiences of caring for a premature newborn, and the challenges faced post-discharge, both practical (eg, accessing follow-up care) and socioeconomic (eg, social stigma and effects on employment). Implications for policy and practice include improved education in pregnancy about the possibility of premature birth for both the mother and her partner, their families, and communities, and the establishment of peer-support groups for mothers of preterm babies. These initiatives could be co-designed with mothers and health-care staff using EBCD.

Ethnographic work on neonatal intensive care units in Kenya highlights the key role that mothers and informal care givers have in providing care for sick newborns in hospitals, and their fears and challenges in engaging with medical and nursing staff.³⁴ The in-depth interviews collected as audio and video narratives in 2021–22 have captured key insights into the salient experiences of these mothers. The potential for sharing these video narratives on a public-facing website for wider access is being explored. But already, these experiences are being used to stimulate changes in health-care provision through

co-design of a self-reflection-based communications training intervention for neonatal nursing staff. This training seeks to empower participants to build safe and trusting relationships, provide patient-centred care, communicate and relate well with colleagues, build emotional competence, and take better care of their own health and wellbeing.³⁵ This initiative is important because little emphasis has been placed on trying to understand the experiences and perceptions of mothers of preterm babies in low-income settings, or the roles they have in health care, patient outcomes, and family wellbeing.

Staff narratives, which are often also collected as part of co-design for improvement, could also have a role in addressing staff stress and promoting mutual understanding.³⁶ Insights from England and South Africa suggest staff value participation in EBCD processes, the opportunities to share and learn from patient narratives, and access to the person behind the patient.³¹

Opportunities, risks, and barriers in LMICs

As much as capturing and sharing patient (and staff) narratives can be empowering and supportive, barriers, risks, and potential harms must be considered ethically and responsibly in all settings.³⁷

The risks involved in collecting, analysing, and sharing these narratives require supporting patients to feel comfortable to speak up without fear of repercussions if they raise sensitive issues or being victimised, mitigating the emotional effects of sharing difficult experiences, ensuring health professionals do not feel attacked by feedback, and paying close attention in designing samples to capture polyphonic and representative voices.²³ Other ethical concerns centre around how patient narratives might be shaped by experiences of weak health systems with poor financial and human resources.

Evidence from research on health systems' accountability and responsiveness in LMICs has highlighted commonly used approaches to gathering patient feedback, such as suggestion boxes, but participation in such activities can be compromised by inadequate feedback and little faith that suggestions will be acted upon, which is in turn influenced by organisational constraints and norms.^{38,39} Here, we would argue that opportunities exist for powerful and actionable insights. Narratives of patient experiences have much to offer and give focus to perspectives on quality of care, with the potential to suggest mitigations or inexpensive and simple solutions towards patient-centred care. Two examples of simple but compelling insights can be drawn from one author's (DO) doctoral research in Kenya.³⁴ First, narratives highlighted the positive power of peer support among mothers of preterm babies in neonatal intensive care units; such support can be inexpensively encouraged in practice. Second, mothers' narratives revealed how the design of hospitals, such as placing postnatal wards on different floors to neonatal intensive care units, can exacerbate physical separation of

mothers from their premature newborns. Novel approaches to using video-recorded patient narratives give a face and voice to the patients who experience these problems and can provide the catalyst for actionable improvements, engagement at multiple levels of the system (ie, government, county, and individual levels), and can encourage patient participation and confidence in sharing their experiences. A 2023 Viewpoint by English and colleagues described the paradox in which a system-level focus on quality measurement is often not linked to investments at the local level.⁵ Patient narratives offer a form of knowledge that could operate powerfully to stimulate improvements at all levels of health systems in LMICs.

Conclusion

Research on patient experiences is needed for health system strengthening, but this umbrella term has unrealised potential.¹ The core point of our argument is that research using patient narratives offers rich potential but is underused in LMICs. As a supplement to other approaches for collecting patient experiences (eg, focus groups, surveys, and other types of research in LMICs), rigorously collected and analysed patient narratives, disseminated publicly via digital stories, can be put to deliberate use in policy and training to build staff empathy, communication, and teamwork skills. These narratives have the potential for identifying improvements along the care pathway and for supporting people-centred care that can be transformative.²³

Patient narratives are a powerful form of knowledge that can illuminate and explain quandaries raised by biomedical, epidemiological, and clinical research. Bringing these different forms of knowledge together can inform and shape health care in ways that support access and outcomes. Narratives can be emancipatory, especially when voices of vulnerable populations have a chance to be heard. Narrative-based research is also a good investment—with appropriate permissions it can be used for secondary analysis and is a powerful asset in resource-restricted settings to stimulate co-designed improvements (eg, EBDCD) and in clinical teaching. In the Kenyan context of newborn health, using an in-depth study of mothers' experiences of preterm birth, we are seeking to generate evidence that will enable us to do just this. In the future, similar narrative approaches with front-line staff could contribute to health system strengthening alongside these family narratives. These approaches could build on, and complement, existing participatory and experiential learning approaches.²

Contributors

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Declaration of interests

ME is part of WHO Technical Working Groups (in an unpaid role) and an Advisory Group for the Wellcome Trust for a trial of oxygen therapy in African hospitals. All other authors declare no competing interests.

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