Illuminating the importance of adding patient knowledge to continual improvement in healthcare

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INTRODUCTION

The importance of involving patients in quality improvement (QI) is becoming increasingly evident in healthcare. 1 2  To achieve this, various approaches, such as codesign 7 and coproduction 4 are being introduced alongside different models and frameworks to improve the quality and safety of healthcare systems. Codesign describes a way of involving both patients and professionals in QI, focusing on the improvement of the experiences of healthcare services. 3 Coproduction refers to the interdependent work of patients and professionals to design, create, develop, deliver, assess and improve the relationships and actions contributing to patient and public health. 4 However, patient involvement and QI have, historically, mainly developed independently. The traditional way of working with improvements in healthcare has been for healthcare professionals to develop what they believe is best for the patients according to their professional knowledge only. 3 Yet, to achieve, preserve and improve patient and population health, relationships between the various stakeholders, patients and the public included, some kind of joint action should be involved. 5 There are synergies shown between professional knowledge, improvement knowledge and patient involvement in QI. 6 Thus, an integration of patient and professional knowledge in QI can offer sustainability to the coproduction of value for patients. So, how can this synergy be displayed and understood by patients and professionals alike?

Batalden and Stoltz 7 introduced a framework (figure 1) in which the components of professional knowledge and improvement knowledge were linked to enable continual improvement of healthcare.

Almost 20 years later, a model of healthcare service coproduction was proposed. 8 In coproduction, patients and professionals work together by sharing their respective knowledge, skills, resources and responsibility. 7 9 Patients are arguably as much experts in determining healthcare outcomes as are professionals, although with expertise in terms of lived experiences of direct care and of the healthcare system, and knowledge of their symptoms, individual resources and of the context of their lives. In this viewpoint, we argue for the importance of adding patients’ experiential knowledge as an equally significant component of the original Framework for the Continual Improvement of Healthcare. 7 We suggest a model for visualising how patient knowledge in healthcare QI may establish sustainable codesign and coproduction. If linked together, the three knowledge domains can enable continual and sustainable QI to better fit patient purposes and needs. The model may help healthcare organisations as well as patients and professionals to understand the importance of the integration.

THE THREE KNOWLEDGE DOMAINS

In the following, we give a brief description of the current knowledge domains in Batalden and Stoltz model 7 and a more in-depth description of patient knowledge that we argue needs to be added. We also propose how the new model can be visualised.

Improvement knowledge

Inspiration from the industrial quality movement reached healthcare in the 1980s. 7 9 Components highlighted by Batalden and Stoltz 7 are: Understanding variation, psychology, knowledge theory and system understanding. To understand variation means to find unwanted variation which is not related to coincidence, so that the understanding of this variation can be
used as a point of view in QI.10 Psychology refers to the importance of intrinsic factors in QI.11 Patients’ needs can be a neutral attractor that brings different professions together in QI.12 Knowledge theory in relation to improvement knowledge originated from conceptualistic pragmatic philosophy12 and is closely related to how individuals create meaning and transform that ability. This is an important aspect in many QI projects.12 System understanding has been explored during the past years and healthcare systems are often described as being complex and adaptive.13 When improving healthcare systems, system understanding is crucial.7

Professional knowledge
Professional knowledge, if joined with improvement knowledge, can contribute significantly to the transformation of healthcare services. Together, the two knowledge domains are argued to enable continual improvement.7 Professional knowledge includes knowledge of the subject (such as anatomy and microbiology), of the discipline (such as nursing and paediatrics) and of healthcare moral values (such as values of patients, families and providers, as well as contextual, social values). Recently, and following the service-dominant logic in healthcare argued by Batalden et al.,4 the necessity of a shift from the traditional, paternalistic model of education towards a coproduction model of education for professionals, is proposed.14

Batalden and Stoltz7 suggested that a combination of professional and improvement knowledge supporting QI in healthcare creates increased value for patients. In addition, they argued that continual improvement is expected to improve outcomes not only for patients (health), but also for system performance (care) and professional development (learning).

Patient knowledge
A striking observation in the early literature on improvement knowledge is the relative lack of patient perspective. Not that the patient is unmentioned, but quite a lot of the literature focuses more on operations than on the patient perspective.12 In figure 2, the extended linkage of knowledge, adding patient knowledge to the framework by Batalden and Stoltz,7 is visualised (figure 2).

The person’s perspective and lived experiences
Understanding each person’s unique story of being a patient, including values and resources, knowledge of their own life and experiences of their disease and care process, is the foundation of patient knowledge. Patients experience the complete patient journey (ie, care process) from a persons perspective, unlike professionals who only see parts and different activities in the process. Working together with the patient as an active partner and code-signer, with shared responsibility and decision-making, maximises the design of the individual care process and the whole system and its coordination.3 15 16 In addition, there are examples of better outcomes for patients when using patient involvement in QI.1 12 Outcomes of care processes improve with high level of patient involvement.1 Important actions include listening to and understanding

Figure 1 The linkage of knowledge required for continual improvement, from Batalden and Stoltz.7

Figure 2 The extended linkage of knowledge required for continual improvement, adapted from Batalden and Stoltz.7
The experiences, comments and ideas of patients and their next-of-kin in order to find new ways of working together.8 16 17 Patients’ knowledge from their own professional career can also often be a resource to QI.16

The whole picture of the patient journey
Professionals need to understand that in healthcare, which is a public service organisation, value is coproduced in a service process with the patient. To succeed in this, the patient’s unique knowledge of the services delivered and the care process experienced is crucial.16 17 Often it is only the patient who holds the complete picture of the patient journey. When professionals and patients interact and exchange knowledge about their needs, situation and life, common values are created and these can result in significant improvements.3 The essence of this approach is to understand what an illness means in the daily life for the person.15 To achieve this, a culture shift is required where patient knowledge is considered as equally important as professional knowledge. If not, outcomes will continue being created for the organisation only and the individual adaptation will be absent. This is an important prerequisite for high performance microsystems.3 12

THE LINKAGE OF THE THREE KNOWLEDGE DOMAINS
Batalden et al4 proposed a new way of thinking about the delivery model for healthcare, in which the predominant logic of healthcare producing goods is contrasted to the logic of healthcare producing services. In this model, patients and professionals interact as participants in the healthcare system within their community/society, equally contributing to the broader aim of good health for all. Coproduction at different levels is proposed, from the more basic face-to-face encounters and communication, to shared planning and shared implementation. However, coproduction is difficult to accomplish in clinical practice.17 This may be due to the fact that patient involvement can play out in several ways and at different levels of healthcare. One common way to involve patients is to consider each individual patient’s need to be involved in their own care and to ensure that the care delivered is person-centred.15 However, there are other ways. For example, patients can also be involved in the design of care and care journeys at the group level, which is the focus of our viewpoint.3 16 18 Further ways of involving patients can be by inclusion in, for example, steering groups, teaching and research.18

As well as being involved at different levels of healthcare, patients can be involved to varying degrees.19 Patients can be asked for their opinions or experiences, which is seen as a low degree of involvement. If patients are allowed to participate in, for example, improvement projects on the same premises as professionals, their involvement is considered to occur to a high degree. However, there are challenges. The term ‘patient involvement’ includes many aspects and issues that are not clearly understood by either patients or professionals20 and there is a relative lack of empirical evidence about how it might work in clinical practice.5 Furthermore, patients and professionals can experience multiple barriers to patient involvement, such as inadequate individual ability, negative attitudes, equality issues, communication failures, hierarchy structures, and structural, organisational barriers.17 Another issue to be aware of is tokenism. The risk of tokenism occurs, for example, when patients are used in the marketing of a QI project by being described as members, but in reality do not have the opportunity to be actively involved.21 Involving patients at different levels can be effective in many ways, but it is also difficult, demanding and has significant resource implications.22 Patients and professionals will need new competences, knowledge and skills, and healthcare organisations will need to provide the time, money and supportive systems23 necessary to coproduce its services.4 Some professionals who want to promote person-centredness and foster patient involvement find it challenging to be ‘coproducers’ and coach patients to coproduce. This is a role requiring skills and competences that are not part of their formal professional education.17 Our proposed extended model (figure 2) could probably be of practical use in education of professionals as it visualises the importance of the knowledge domains and how they, if combined, can strengthen a development of better care.

Patient involvement may also be complex and challenging due to the willingness and ability of patients and professionals to participate in joint improvement work.16 24 Therefore, the understanding of how patient knowledge, in addition to professional knowledge and improvement knowledge, supports QI is crucial. Patient involvement has considerable potential but, as mentioned, it can threaten the identity and status of professionals.16 However, it is also argued that active involvement of patients can play out as a mechanism for mobilising a move from profession-centric healthcare towards a more power-balanced situation.22 Healthcare organisations that choose to go down this road will face significant system and cultural shifts that include changing from patient engagement to patient partnership, from patient empowerment to collective empowerment, from patients being passionate champions to being part of the supportive systems, from considering parts to considering whole-ness (from healthcare to health) and from ‘doing for’ to ‘doing with’.25 This cultural change will have impact on the existing attitudes, values and assumptions.8

Putting our arguments together, we believe patients’ knowledge and experiences may help to combine care processes, simplify the complicated and focus on what is meaningful and important to achieve the best outcomes. Building QI on the complete picture of the patient journey based on patient knowledge can contribute towards a cohesive healthcare system including care in different care levels, for example, hospital and primary care. Thus, with patient knowledge added, the provision of care can be improved and the patients’ abilities to make
use of healthcare resources for life and health may subsequently increase.\textsuperscript{3,4,12} Understanding how patients engage with the organisation, how they rely on the services and how to best communicate with them, is paramount.

As patient knowledge develops as a resource to QI, we need to keep an eye on how it affects the other two knowledge domains. Here is still a lot to learn. Our experience is that adding patient knowledge has challenged and improved the professional knowledge domain regarding culture and skills for person-centred care and coproduction. In the aspect of improvement knowledge, there is still a need to learn from codesign approaches. Especially QI in which coproduction requires a design process.

CONCLUSION

We argue for the importance of linking patient knowledge to professional knowledge and improvement knowledge for developing improved outcomes for patients in healthcare. People with lived experiences as patients have a unique perspective on living with disease(s) and/or injury(ies) and the care journey, and should therefore be considered experts in their field. Their knowledge contributes to a holistic view of care processes, which in combination with professional knowledge and improvement knowledge can lead to sustainable coproduction in QI and improved outcomes for patients.

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