

Knowing about you: eliciting dimensions of personhood within tuberculosis care

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SUMMARY

BACKGROUND: Knowing someone with tuberculosis (TB) as a person, rather than defining them by their illness, is part of recognising their dignity and unique individuality, and a requirement for effective care.

OBJECTIVE: An adaptation of the Patient Dignity Question (PDQ) was formalised for persons receiving treatment for active TB or latent tuberculous infection (LTBI), and its impact was evaluated for both the person and health care providers (HCPs).

DESIGN: Individuals with active TB or LTBI receiving treatment in Winnipeg, MB, Canada, were asked the PDQ as part of routine care. Patients and HCPs were subsequently invited to evaluate the application of the PDQ.

RESULTS: Of the 58 participants who responded to the

PDQ, 97% felt both that it was important to ask about them as an individual, and that the PDQ should be asked of all patients, while 55% thought it made a difference to their care. Thirty-eight per cent of HCPs said they learned something new about their patient, and 31% said it influenced their sense of connectedness with and sense of empathy for patients, as well as their personal satisfaction in providing care.

CONCLUSION: Formalising a dignity question as part of person-centred care provides a mechanism to create a respectful environment that is caring of the most marginalised who carry the burden of TB.

KEY WORDS: personhood; dignity; quality of care; effective care; caring

A PROMINENT THEME among studies of the patient experience is the need to feel that patients are treated as unique persons, and that their humanity is expressed in their individuality or ‘personhood’.¹ To be known for who you are, rather than as an illness, is central to the concept of dignified care.² The World Health Organization endorsed the Patients’ Charter for Tuberculosis Care, which describes ‘the right to be treated with respect and dignity’ and ‘the right to quality health care in a dignified environment’.³ These rights are integral to effective health programmes for preventing and treating tuberculosis (TB).³

TB disproportionately affects disadvantaged persons experiencing social and economic hardship.^{4,5} Treatment of TB and latent tuberculous infection (LTBI) is a long and potentially difficult process in those already experiencing such challenges.^{6,7} Effective TB prevention, diagnosis and care require an

approach that puts the dignity and personhood of the individual at the centre of its work.

In Canada, the province of Manitoba has the highest incidence of TB. In 2014, TB incidence was 10.5 per 100 000 population compared to 4.4/100 000 for Canada as a whole.⁸ Winnipeg, the capital of the province, had a TB incidence of 8.1/100 000 in 2011.⁹ In the core inner city area, where a disproportionate number of the city’s socio-economically disadvantaged citizens live, TB incidence was 23.2/100 000: 65% of those with TB in Winnipeg in 2011 were foreign-born, and 23% were indigenous. These persons face discrimination, poverty, historical trauma, ongoing concerns about their security, language barriers and challenges to accessing education, employment and culturally appropriate health care.

Chochinov et al. developed and evaluated a patient dignity question (PDQ)—‘What do I need to know about you as a person to give you the best care

possible?’—in the context of in-patient palliative end-of-life care.¹ The response to the PDQ was systematically documented and recorded on patient charts, followed by an evaluation of patients, family and health care staff to determine the impact the PDQ had on patient care. Chochinov et al. concluded that the PDQ offered an effective and simple way of eliciting personhood, enhancing patient, family and health care staff satisfaction.

The Winnipeg Regional Health Authority (WRHA) Integrated TB Services (ITBS) implemented the PDQ as part of routine care by health care providers (HCPs) during out-patient TB/LTBI treatment. At follow-up, patients were asked for their perception of the PDQ, and whether they thought it influenced the course of their care. HCPs were also asked to share their perceptions and whether they believed the PDQ had any effect on their provision of care.

METHODS

TB/LTBI patient enrolment took place between 1 October 2015 and 31 January 2016. Persons with LTBI were enrolled from a community primary care clinic during routine clinical assessment, while persons with TB disease were enrolled during contact investigation work performed by WRHA public health nurses (PHNs) in Winnipeg, MB, Canada. PHNs meet with the person with TB disease soon after diagnosis at home or in hospital isolation to establish a relationship, and initiate contact investigation and develop plans for supporting the individual once they are living in the community. Inclusion criteria included persons newly diagnosed with TB or LTBI aged ≥ 18 years, able to give informed consent and residing in Winnipeg.

Meetings were held with HCPs at each site to formalise an approach to eliciting personhood. The purpose of the present study was to adapt and evaluate the Chochinov PDQ tool when used in a non-hospital-based, non-palliative out-patient population. The experience of care givers at both sites led to the development of two distinct wordings for the PDQ, adapted for each site. For the clinic providing care for LTBI, the question was worded as follows: ‘Is there anything more that you think we should know about you as a person that might help us to provide the best possible care for you?’ For those with active TB, the question posed by PHNs was ‘What else do I need to know about you to provide you with good care?’ The PDQ formed the basis of a brief conversation focusing on the patient ‘as a person’.

Enrolled patients were asked the PDQ as part of routine care. Answers to the PDQ were routinely recorded in the patient’s chart. After answering the PDQ, patients were asked if they would be willing to have their responses evaluated as part of the Dignity Project. Patients consenting to have their responses

Table 1 PDQ patient feedback survey evaluations (data collapsed across both study sites) ($n = 31$)

The PDQ ...	Individuals who responded yes <i>n</i> (%)
Is important to ask	30 (97)
Should be asked of all patients	30 (97)
Should be asked at different points in time	19 (61)
Made a difference to their care	17 (55)
Helped them share something new	16 (52)
Had an emotional effect on them	8 (26)

PDQ = patient dignity question.

included in the project were also invited to participate in an evaluation of the PDQ at the end of the project. Informed consent was obtained for both analyses of their responses to the PDQ and a follow-up evaluation regarding their perceived effect of the PDQ on themselves and their care. To reduce bias, the follow-up evaluation was performed by a HCP who was not involved in the patient’s care. Using a questionnaire modelled on that of Chochinov et al.,¹ the nurses administering the PDQ were also asked to provide their perception of the influence, if any, that the PDQ had on their experience of care. The nurses provided their responses anonymously, in written form; these were then delivered to the project manager (CL) in sealed envelopes. Patient and nurse PDQ evaluation responses were analysed by the project manager using a constant comparative analysis approach to help generate major themes and categories in the responses to the PDQ.

A pre-existing WRHA ITBS committee, with representation from the WRHA Aboriginal Health Programme and the Southern Chiefs Organization, served as the advisory committee. Indigenous representation was considered essential because of the large percentage of indigenous people with TB in this region. Research ethics approval was granted by the Research Ethics Board of the University of Manitoba, Winnipeg, MB, Canada.

RESULTS

During the enrolment period, 29 persons were seen in care by PHNs and 41 by primary care clinic care givers. Three persons seen by PHNs were excluded from further analysis: two did not have TB, and one was aged < 18 years. Of the remaining 67 persons who were asked the PDQ, 58 consented to have their responses included in the PDQ analysis and 40 consented to be contacted in follow-up. Nine could not subsequently be reached by the project team. A total of 31 participants were therefore included in the final PDQ evaluation component.

Table 1 lists responses to the participant evaluation. Ninety-seven per cent felt that it was important to ask people about who they were as a person and

Table 2 Effect of PDQ on health care providers (data collapsed across both study sites) ($n = 13$)

Survey question	Disagreed* <i>n</i> (%)	Neutral <i>n</i> (%)	Agreed† <i>n</i> (%)
Learned something new from PDQ	3 (23)	3 (23)	5 (38)
Was emotionally affected by PDQ	4 (31)	4 (31)	4 (31)
PDQ influenced attitude toward patient	2 (15)	5 (38)	4 (31)
PDQ influenced care toward patient	2 (15)	3 (23)	5 (38)
PDQ influenced respect toward patient	4 (31)	3 (23)	3 (23)
PDQ influenced empathy for patient	4 (31)	3 (23)	4 (31)
PDQ influenced connectedness to patient	3 (23)	3 (23)	4 (31)
PDQ influenced personal satisfaction providing patient care	3 (23)	3 (23)	5 (38)

* Slightly disagreed, disagreed or strongly disagreed.

† Slightly agreed, agreed or strongly agreed.

PDQ = patient dignity question.

that the PDQ should be asked of all patients. Twenty-six per cent said that the PDQ affected them emotionally. Fifty-five per cent said it made a difference to their care relationship, and 52% said the PDQ helped them to share something new about themselves. As the PDQ was asked at only one point in the patient's care, 61% thought it should also be asked at other points in their care.

Thirteen HCPs, all nurses, responded to a staff evaluation (Table 2). When asked for their general impressions of the PDQ, 11/13 HCPs generally felt the PDQ was helpful or a good place to begin building a relationship. All HCPs said they either would use a PDQ in their practice or already used a similar informal question as part of their routine professional practice. Thirty-eight per cent felt that the PDQ told them something new about their patient, and 38% said using the PDQ influenced their care. Only 23% felt it changed their respect for the patient, and 31% felt it influenced their sense of empathy for their patient; several indicated that they already demonstrated those qualities towards all their patients.

Responses to the PDQ

Significant common themes emerged from participant responses to the PDQ, including expressions of a strong sense of self, sharing fears around the stigma of TB, and expressing social and relational pressures around the impact of TB on their lives.

Expressing a strong sense of self

Participants described their deepest sense of self as a feeling of personal integrity, wholeness and value. Work was frequently mentioned as an important component of the sense of self.

I am working for my family. I love working in the hospital, providing care for the sick.

Participants indicated that they desired information about their care as a means of enhancing their sense of control, integrity and empowerment.

I really want to know where this came from so that I don't make anyone else go through this.

People also shared what gave them strength in their lives.

I am a religious person. I am Pentecostal.

Some individuals also described their doubts that posed a threat to their sense of self.

I am not 100% convinced that I have TB infection. I would like to repeat the Mantoux skin test because I don't believe it was really positive.

Sharing fears around the stigma of TB

Participants repeatedly described feelings of fear, anxiety, shame and frustration, highlighting the stigma associated with TB and of being overwhelmed by their diagnosis.

I am worried about other people finding out about my diagnosis.

Another expressed their fear in this way:

I am worried about my co-workers finding out I have TB. I am worried about spreading TB to them. I had surgery, and I am not sure what to tell them about it when they ask.

One participant expressed fear and anxiety about being in the health care system again, because of perceived prior racism and concerns about personal security.

I have had bad experiences with the health system because I am 'brown' (Aboriginal). My symptoms get ignored. MDs have suggested I have cirrhosis due to alcohol. I don't drink. I have lupus. I don't like male workers. I am uncomfortable with male staff.

Expressing social and relational pressures around the impact of TB on their lives

Many participants openly shared their sense of obligation to their families, their duty to their community and their personal desires, and wanted their HCP to know how much TB/LTBI had disrupted their lives.

I am a student full time and working part time so it helps that I can come for evening appointments.

One participant spoke of the conflict she was experiencing in her sense of duty to her husband. She was feeling fatigue as a side effect from the TB medication.

I am having a problem at home because my husband often wants to have sex, and I don't because I am too tired. He wants me to see a doctor because he thinks something is wrong with me. I can't talk to my doctor because he is a man.

Hospitalised participants with active TB were more likely to include concerns about their physical needs, their vulnerability at being removed from their community and families, and the boredom they encountered in hospital airborne isolation rooms. They also spoke about the financial burden of being ill. One participant said that she worried that her elderly grandmother would pass away while she was being treated in hospital. She spoke of her fear of being away from her children for such a long time (2 weeks in isolation in hospital). One participant expressed their need to be reunited with their family:

I want to return to (home country) as soon as possible to be with my family. Can you talk to the doctor about this?

DISCUSSION

People with health concerns want to be seen, heard and treated as unique individuals. This has been demonstrated in studies among those receiving care for cancer and those in palliative care.^{1,2} In this study, we demonstrate the same desire among those receiving out-patient care for TB or LTBI. This is a population for whom the TB diagnosis is often accompanied by stigma, marginalisation and shame, all of which can be a profound assault on the sense of self and personhood.

This pilot study was the first application of the PDQ in an out-patient non-end-of-life care setting in Winnipeg. Nearly 100% of participants indicated this was an important question for them, and felt it was one all patients should be asked. Over half indicated that it allowed them to share something new about themselves and believed it would affect their care. While only about one third of HCPs indicated that the PDQ influenced them in various ways, all HCPs indicated that the intent of the question, and the issues it broached, were critically important. For several, the PDQ was a reaffirmation of their own approach to health care, while for others it was seen as redundant to what they are already doing informally. Based on patient and HCP feedback, it is clear that matters related to personhood must become or remain part of the clinical discourse.

Participants shared information about their sense of self, their struggles with TB-associated stigma, and the major impact that TB had on their lives. Their words go to the core of their perception of themselves and their personhood, and speak to their desire to be seen as unique individuals, not defined solely based on their medical condition. Dignity implies that all persons have inherent worth and value.¹⁰ Dignity is associated with the 'flourishing of personhood',¹¹ and is essential to the condition of being human.¹² For those with TB/LTBI, cure requires adherence to treatment that may be long and potentially difficult.^{6,7} Adherence is not achieved by 'telling' the patient what to do. It requires an approach that allows the flourishing of personhood.¹³

The Patients' Charter for Tuberculosis Care requires that patients be treated with dignity.³ Standardising ways to allow patients to express their personhood, such as formally asking the PDQ, may be a good place to begin. The PDQ is not meant to replace, but rather to set in motion, or to supplement, genuine conversations pertaining to personhood. Attention should also be paid to how eliciting personhood and addressing dignity might influence treatment adherence and cure rates.¹⁴

There were important limitations to this study. About one quarter of the participants who consented to be approached later to evaluate the impact of the PDQ on their care could not be reached. We do not know if this was due to the fact that persons with TB from remote northern communities are difficult to reach once they have returned home. The timing of the administration of the PDQ evaluations may also have affected the results, as the time interval between asking the PDQ and the follow-up evaluation varied, ranging from 2 weeks to 4 months. For those individuals who participated in the evaluation component of the study within 2 weeks of having completed the initial PDQ, there may not have been enough time to experience its full effects on their care.

Further research questions were raised by this pilot study. Future studies should explore the optimum timing and frequency of addressing personhood in care using a PDQ. Future study of the PDQ in TB care should also explore the impact that addressing personhood has on LTBI treatment acceptance rates, TB/LTBI treatment completion rates, access to and use of social services, and patient satisfaction measures, for example, by using Accreditation Canada evaluation tools to measure satisfaction in care.¹⁵

CONCLUSION

Formalising a dignity question as part of person-centred care provides an opportunity for people to be seen as more than just an illness. It provides a mechanism to create a respectful environment that is

caring of the most marginalised individuals who carry the burden of TB.

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RESUME

CADRE : Considérer une personne atteinte de tuberculose (TB) comme une personne, plutôt que de la définir par sa maladie, fait partie de la reconnaissance de sa dignité et de son unique individualité, et constitue une nécessité pour une prise en charge efficace.

OBJECTIF : Une adaptation d'une question relative à la dignité des patients (PDQ) a été formalisée pour des personnes bénéficiant d'un traitement de TB active ou infection latente tuberculeuse (LTBI) et son impact a été évalué à la fois pour le patient et pour les prestataires de soins (HCP).

SCHEMA : On a posé la PDQ aux patients atteints de TB active ou LTBI, bénéficiant d'un traitement à Winnipeg, MB, Canada, dans le cadre de la prise en charge de routine. Les patients et les HCP ont ensuite été invités à évaluer l'application du PDQ.

RÉSULTATS : Des 58 participants qui ont répondu à la PDQ, 97% ont estimé qu'il était important de poser des questions aux patients en tant qu'individus et que la PDQ devrait être offert à tous les patients, et 55% ont pensé que cela avait un impact sur leur prise en charge. Ont affirmé 38% des HCP qu'ils avaient appris quelque chose de nouveau à propos de leur patient, et 31% ont dit que cela influençait leur liens avec les patients et leur empathie à leur égard, ainsi que leur satisfaction personnelle lors de leur prestation de soins.

CONCLUSION : Formaliser une PDQ comme un élément d'une prise en charge centrée sur la personne contribue à créer un environnement respectueux qui prend soin des personnes les plus marginalisées qui portent le fardeau de la TB.

RESUMEN

MARCO DE REFERENCIA: El hecho de percibir a alguien que sufre tuberculosis (TB) como una persona, en lugar de definirlo por su enfermedad, contribuye a reconocer su dignidad, su individualidad exclusiva y constituye una condición primordial de la atención eficaz.

OBJETIVO: Una adaptación de la pregunta sobre la dignidad del paciente (PDQ) se formalizó para personas que reciben tratamiento por TB activa o infección tuberculosa latente (LTBI) y se evaluó la repercusión que tuvo la formulación de la pregunta en la persona y también en los profesionales de salud (HCP).

MÉTODO: La PDQ se planteó en el marco de la atención corriente a las personas que recibían tratamiento por TB activa o LTBI en Winnipeg, MB, Canadá. Luego se invitó a los pacientes y a los HCP a que evaluaran la utilización de la PDQ.

RESULTADOS: De los 58 participantes que respondieron a la PDQ, el 97% consideró que era importante que les formularan preguntas personales y que la PDQ se debía plantear a todos los pacientes. El 50% de los participantes afirmó que la pregunta había modificado la atención recibida. El 38% de los HCP afirmó que había aprendido algo nuevo sobre sus pacientes, y el 31% consideró que la pregunta había transformado su sentimiento de vínculo y empatía con los pacientes y también su satisfacción personal con la prestación de servicios.

CONCLUSIÓN: El hecho de formalizar una PDQ como parte de la atención centrada en la persona ofrece un mecanismo que facilita la creación de un clima de respeto en la asistencia a las personas marginalizadas que soportan el peso de la TB.
