



The role of imparts in delivering a holistic sickle cell service

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IMPARTS Screening

- The IMPARTS (Integrating Mental and Physical Health Research Training and Services) screening system was introduced within haematology clinics in March 2019.
- Given routinely to patients attending for an annual review or who are new to the service (e.g. transferred from a different hospital or transitioned from the paediatric service).

Questionnaires used

- The Patient Health Questionnaire-9 (PHQ-9)
- The Generalised Anxiety Disorder Scale (GAD-7)
- The IRT SMOKING questionnaire
- The Jenkins Sleep questionnaire (JSQ)
- The Work and Social Adjustment Scale (WSAS)
- Brief Pain inventory (BPI) for patients who answer that pain been an ongoing and significant problem in their life over the past three months
- Medication questionnaire (for patients currently prescribed Hydroxycarbamide or Exjade)

Why bother?

It is well established that when patients have co-morbid mental health problems, this:

- Results in poorer outcomes through direct physiological mechanisms, by decreasing adherence to treatment and by increasing unhealthy behaviour such as smoking, poor diet and lack of exercise;
- Predicts increased length of hospital stay, more outpatient visits, poorer quality of life, greater disability, increased admissions and health care costs, poorer concordance with treatments and poorer health outcomes;
- Predicts functioning better than medical variables do.

Screening in Clinic

- Patients are given an information sheet by a member of the nursing team upon arriving for their appointment;
- The information sheet explains the purpose of screening and invites them to complete the web-based questionnaire on the iPad;
- If the patient agrees to complete the screening, they will be given the iPad to complete the questionnaires prior to their consultation;
- Support is given to the patient to complete the screening as far as possible, particularly if they have sight impairment, physical disability, language or learning needs.

Honorary Assistant Psychologist

- Currently we are lucky to have U'mau Otuokon as an Honorary Assistant Psychologist who has played a vital role in:
 - ❖ Supporting patients to complete the questionnaires
 - ❖ Maintaining an electronic database of their scores
 - ❖ Liaising with the IMPARTS team and troubleshooting any technical problems

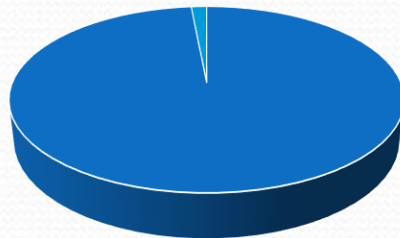
Screening Implementation



Participation

- 201 Patients screened March 2019 – March 2020
- 3 patients only declined participation (1.5%)

**King's Sickle Cell Service
IMPARTS Participation**
March 2019 - March 2020



■ Participated ■ Declined Participation

Anecdotal themes from patient conversations:

- Most patients were happy to have psychological and other impact/concerns addressed
- A substantial number of patients expressed the frustration they felt living with a very disruptive yet invisible disease; 'no one understands'
- Some patients felt psychological distress was not relevant to them but would participate anyway
- At times patients became notably emotional during screening sessions, occasionally ending in tears

PMI	Group	Type	Score	Description	Referral	Alert
	Sickle Cell KCH	SCMED				

Are you currently prescribed and taking Hydroxycarbamide or Exjade? 2 (No)

PMI	Group	Type	Score	Description	Referral	Alert
	Sickle Cell KCH	PHQ9	23 / 27	Probable Major Depression	Follow risk assessment guide; contact team psychologist if available, or liaison psychiatry for advice if needed. Offer urgent referral to team psychologist for direct work or liaison with mental health services	Suicidal Thoughts

1) Little interest or pleasure in doing things?	3 (Nearly every day)
2) Feeling down, depressed, or hopeless?	3 (Nearly every day)
3) Trouble falling or staying asleep, or sleeping too much?	3 (Nearly every day)
4) Feeling tired or having little energy?	3 (Nearly every day)
5) Poor appetite or overeating?	3 (Nearly every day)
6) Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	3 (Nearly every day)
7) Trouble concentrating on things, such as reading the newspaper or watching television?	1 (Several days)
8) Moving or speaking so slowly that other people have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	2 (More than half the days)
9) Over the last two weeks have you had thoughts that you would be better off dead or of hurting yourself in some way?	2 (More than half the days)
10) You have indicated that you have some of the problems on this questionnaire. How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Somewhat difficult

PMI	Group	Type	Score	Description	Referral	Alert
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Sickle Cell KCH GAD7

16 / 21

Significant levels of anxiety which would be worth exploring further

Suggest self-referral to IAPT or inform GP (and suggest they refer the patient to IAPT). Consider referral to team psychologist, if the psychological needs are closely related to the patient's medical condition

- | | |
|---|-----------------------------|
| 1) Feeling nervous, anxious or on edge? | 2 (More than half the days) |
| 2) Not being able to stop or control worrying? | 2 (More than half the days) |
| 3) Worrying too much about different things? | 3 (Nearly every day) |
| 4) Trouble relaxing? | 3 (Nearly every day) |
| 5) Being so restless that it is hard to sit still? | 1 (Several days) |
| 6) Becoming easily annoyed or irritable? | 3 (Nearly every day) |
| 7) Feeling afraid as if something awful might happen? | 2 (More than half the days) |

PMI	Group	Type	Score	Description	Referral	Alert
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Sickle Cell KCH

JENKINS

16 / 20

- | | |
|---|----------------|
| 1) Have trouble falling asleep? | 4 (15-21 days) |
| 2) Wake up several times a night? | 4 (15-21 days) |
| 3) Have trouble staying asleep (including waking too early)? | 4 (15-21 days) |
| 4) Wake up after your usual amount of sleep feeling tired and worn out? | 4 (15-21 days) |

PMI	Group	Type	Score	Description	Referral	Alert
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Sickle Cell KCH

WORKSOCIAL

37 / 40

Moderate to severe impairment

- | | |
|---|---|
| 1) Because of my illness my ability to go to work or attend school/college is impaired | 7 |
| 2) Because of my illness my home management is impaired (cleaning, shopping, cooking, child care, paying bills etc) | 8 |
| 3) Because of my illness my social and leisure activities are impaired (activities with other people, e.g. outings, visitors, parties etc) | 7 |
| 4) Because of my illness my private leisure activities are impaired (activities done alone, e.g. reading gardening, walking alone, sewing, etc) | 7 |
| 5) Because of my illness my ability to form and maintain relationships is impaired | 8 |

PMI	Group	Type	Score	Description	Referral	Alert
	Sickle Cell KCH	SMOKING				

Have you smoked more than 100 cigarettes (5 packets of cigarettes) in your lifetime? N (No)
 Do you currently smoke? N (No)

PMI	Group	Type	Score	Description	Referral	Alert
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	Sickle Cell KCH	SCBPI	110 / 110			
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Ask patient if severity and interference of pain is typical and representative of the last three months. If "yes" then consider discussion with team psychologist about referral to joint haematology and pain clinic appointment.

Has pain been an ongoing and significant problem in your life over the past three months?	1 (Yes)
Please rate your pain by picking the one number that best describes your pain at its WORST in the past week.	10
Please rate your pain by picking the one number that best describes your pain at its LEAST in the past week.	10
Please rate your pain by picking the one number that best describes your pain on the AVERAGE.	10
Please rate your pain by picking the one number that tells how much pain you have RIGHT NOW.	10
General Activity	10
Mood	10
Walking ability	10
Normal work (includes both outside the home and housework)	10
Relationships with other people	10
Sleep	10
Enjoyment of life	10

Remote Screening

- Patients are sent a link 24 hours prior to their appointment;
- Patients clicking the link will see an information summary which explains the purpose of screening and invites them to complete the web-based questionnaire;
- If the patient agrees to complete the screening, they will follow the link on the information summary to complete the screening;
- A central email account for the clinic will receive a notification that the patient has completed screening;
- Patients answering positively for suicidal ideation will see a pop-up screen which directs them to more immediate sources of help and support if they feel unable to keep themselves safe until their appointment.

Depression

- 52 out of 201 patients screened positive for probable Major Depression, a prevalence rate of 26% (based on a score of 10 and above out of 27 on the PHQ-9).
- This prevalence rate rises to 35% if an additional 19 patients are included who had milder symptoms of depression and scores between 5-9.



Anxiety

- 39 out of 201 patients screened positive for probable Generalised Anxiety Disorder, a prevalence rate of 19% (based on a score of 10 and above out of 21 on the GAD-7).
- This prevalence rate rises to 29% if an additional 19 patients are included who had elevated levels of anxiety and scores between 5-9.



Sleep disturbance

- 51 out of 201 patients had a high frequency of sleep disturbance, a prevalence rate of 25% (based on a score of 12 or more out of 20 on the JSQ).
- If using a lower cut off score of 5 and above, this would indicate 68% of patients had experienced poor sleep over the preceding month as compared to normal sleepers.



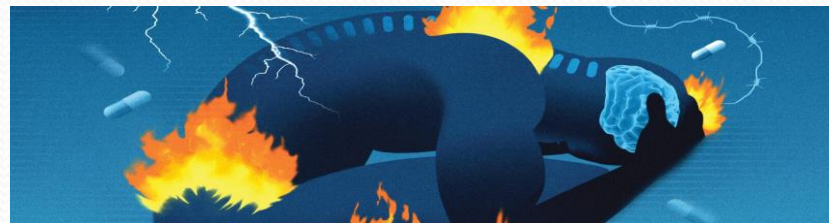
Functional Impairment

- 45 out of 201 patients rated the degree of impairment in their functioning due to their health condition as being in the moderately severe to severe range, a prevalence rate of 22% (based on a score of 21 or more out of 40 on the WSAS).
- This prevalence rate rises to 52% if those with moderate impairments are included (scores between 10-20 on the WSAS).



Pain

- 119 out of 201 said pain had been an ongoing and significant problem in their life over the past three months, a prevalence rate of 59%.
- Of these 119 patients, 52 said the pain had been in the moderate to severe range over the past week, a prevalence rate of 44% (based on mean scores of 5 and above on the BPI Severity scales), while 60 patients reported the interference of this pain on their life had been moderate to severe over the past week, a prevalence rate of 50% (based on mean scores of 5 and above on the BPI Interference scales).



Interpretations

- The data from this audit is in keeping with more recent findings that pain in adults with SCD is far more prevalent and severe than previous studies have portrayed (e.g. Smith et al. 2008).
- For patients with a BPI score of above 55 (moderate to severe pain), 57% also screened positive for probable Major Depression, while 42% screened positive for probable Generalised Anxiety Disorder.
- Depression and anxiety have been shown to be larger predictors of pain factors than disease phenotype, and result in increased frequency, intensity, distress and disruption due to pain (e.g. Levenson et al. 2008).

Patient Feedback



- *'Very good... covers questions I would have liked to talk about'*
- *"this [screening] is very good". Patient noted previous illness which was related to stress and identified the need to be more educated on how to manage their health*
- *Brief Pain Index is 'an insult... offensive... not appropriate.' Patient noted this as a common issue of discontent amongst other SCD sufferers. 'Patients and professionals should work in partnership to develop care' for SCD cohort'*
- *'this is too late... I needed this kind of assessment years ago when I was struggling. However, I enjoyed the questionnaire experience'*
- *'...glad ...this is what I am going through now'*

Staff Reflections

- *There is always a lot to learn from listening to patients as the range of psychological and lifestyle differences varies just as the expression of the physical illness varies.*
- *I was moved by patient vulnerability, inspired by their resilience and proud to be part of a service addressing this significant interaction of their whole health.*
- *IMPARTS highlights the significant impact of psychological distress in the lives of individuals living with sickle cell and thalassemia, and helps us strengthen the business case for expanding our psychology service by providing clear data on prevalence of depression, anxiety, sleep disorder etc. in our cohort.*
- *'IMPARTS has enabled us to begin a more holistic conversation with our service users and given the team a better understanding of some of the additional struggles that they face.'*
Consultant Haematologist



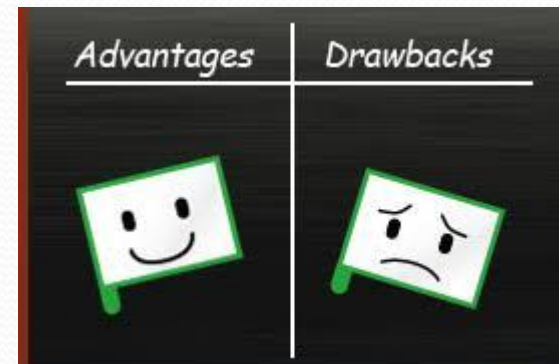
Additional Benefits

- IMPARTS data has been used within a business case for an additional psychologist.
- It helped identify the psychological needs within this patient group, but highlighted the fact existing psychology staffing levels were unable to meet this need fully.



Draw backs

- PHQ-9 – depression scores can be inflated by symptoms more attributable to the health condition (e.g. fatigue).
- Technical issues – infrequent.
- Accessibility of data – is held by the IMPARTS team and has to be accessed through them, and is not linked to individual patients.
- Patient fatigue.



1	A	B	C	D	E	F	G	H	I	J	K	L	
	Number	Name	Date	PHQ-9	GAD-7	Jenkins	WSAS	BPI	BPI S	BPI I	Action?	iPad Issues?	Feedback
9			18/07/2019	25	18	18	30	64			On caseload		!Multiple hig suicidal ideati
10			27/02/2020	25	18	20	37	94			Contact and offer appt		PHQ-9 Q9 = n
11			31/10/2019	23	16	16	34	110	10	10	Referred to perinatel		
12			28/11/2019	23	17	17	34	92	7.3	9	Declined Psych	Green iPad lost connection 1625 - 16	PHQ9- suicida
13			22/08/2019	22	19	17	35	100	9	9.1	Letter sent		significant. V
14			14/11/2019	22	21	20	20	90	6.3	9.3	On caseload	14.11.2019. Reporting ref email. About quest U.O. to C.E. and A.S. 19.11.2019,	About quest lot.'
15			21/03/2019	22	18	20	28	100	7.5	10	Letter sent		
16			03/10/2019	20	19	18	18	75	5.8	7.4	Letter sent		depression.
17			22/08/2019	19	15	12	38	73	5.8	7.1	Letter sent		posible tear
18			31/10/2019	19	13	16	22	73	5.3	7.4	On caseload		
19			11/07/2019	19	12	10	14	39	4.3	3.1	Letter sent	7944946855	
20			19/12/2019	18	14	8	29	82	6.5	8	Contact by phone		PHQ-9- suicida
21			08/08/2019	18	21	16	20	78	10	5.4	Letter sent		referral for P
22			22/08/2019	18	8	4	14	0	0	0	Letter sent		visibly low du
23			30/01/2020	18	2	12	30	98	8.5	9.1	On pain WL		
24			06/02/2020	18	2	7	16	40	3.3	3.9			
25			09/05/2019	18	1	4	20	0	0	0	Letter sent		
26			21/03/2019	17	2	10	33	65			Letter sent		
27			16/01/2020	17	2	12	14	0	0	0	Send letter		
28			12/12/2019	17	10	10	24	71	5.5	7	Offer Psy appt- ask Sara		PHQ9- Notes
29			26/09/2019	17	18	15	31	75	5.5	7.6	Letter sent		poss psycho
30			30/01/2020	17	10	6	37	82	5.5	8.6	Send letter		
31			02/01/2020	16	10	3	10	77	9.3	5.7	Send letter		*Pt visibly 'h
32			11/07/2019	16	0	0	30	82	6.5	8	Declined off of psych		
33			05/12/2019	16	2	12	18	58	5.8	5	Offer Psy appt	PHQ9- suicidal ideation.	
34			31/10/2019	15	15	3	18	69	6	6.4	Send letter		

Future developments

- Implement within the Transition clinic.
- Implement within the Joint sickle pain clinic.
- Use as an outcome measure.



Questions?

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